Progressing from discretionary to obligatory evaluation practice to improve access and use of health information interfaces for all

Understanding the pragmatic complexities facing non-specialised development teams

By

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DEDICATION

For my family,

My wonderful husband, Damian,

My beautiful children, Brydee and Angus,

My Mum and sister Tracey,

And for Dad and Jo ….

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SUMMARY

Introduction:

Access and use of digital health interventions have become a critical factor in the transition to patient-centred models of care. Characteristics shaping an individual's online interactions are also those influencing barriers to using and understanding health information. Evaluations of usability and accessibility are considered crucial developer activities. Considered intrinsically burdensome, complex, and costly, evaluations have become discretionary to the process. Consequently, assumptions of universal Internet access and technical competency levels drive interface design leading to increased digital, social and health exclusion. My significant original contribution to knowledge within this thesis was improving scholarship and awareness of real-world evaluation practice during health information resource development. Contextualised to palliative care, the studies reflect those evaluations could improve interface design to ensure that carers and patients understand information to assist decision-making when facing a non-curable life-limiting condition.

Primary study question:

Does comprehensive and structured evaluation of usability and accessibility when undertaken during development identify interface areas that could improve user experience?

What is known already:

Consumers are driving the need to personalise their health management. Online health information lies crucially on the intersection between consumers need for information, abilities to understand information and potential improvements in health outcomes. Socio-cultural characteristics interplay across all factors influencing digital equity, competency, and technological acceptance. These characteristics affect literacy and health literacy levels, directly impacting on abilities to make informed health decisions. Improving digital readiness levels can increase confidence and the ability to assess information trustworthiness. Usability and accessibility evaluations are critical to user-centred design (UCD) but are not readily employed nor reported within health resource development. Team structures, usability experience, funding levels, participants and process management are all likely factors influencing the likelihood of evaluations being undertaken. Delegation of responsibility for evaluations is unresolved between development teams and commissioning funders.

Main findings:

Evaluation outcomes are not readily reported within peer-reviewed literature and cannot be used as an evidentiary source supporting novice developers' evaluation practice. Developer uncertainty and their unawareness of the implications of usability errors on interface accessibility across reiterations limit their ability to design usable experiences for all end-users. Inherent barriers to evaluations include previous usability and development experience and capacity to access participants. Attempts to diversify usability samples to include individuals from hard-to-reach groups facing barriers to online health information is problematic and may require in-person strategies rather than reliance on electronic messaging. Experiential digital capabilities appear to be reflective within measures of digital health literacy (DHL) in those choosing to interact remotely with usability evaluation methods, whereas socio-cultural/economic factors influence DHL in reluctant individuals engaging online. DHL stratification produced performance and behaviour variations, complicating participant selection. Responsibility for ensuring evaluations are employed needs to be considered by commissioning funders to ensure resource interfaces provide meaningful experiences for all users.

Conclusion:

Through identifying deficiencies and barriers within the development of health information resources, strategies can improve the normalisation of evaluation practice within processes by clearly articulating the roles, expectations and responsibilities of participants, developers, evaluators, and commissioning funders. Structured evaluation practice improved interface designs for end-users of palliative care resources to create a meaningful information experience.

DECLARATION

I certify that this thesis:

1. Does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university,
2. The research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. To the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed **Amanda M Adams**

Date 10th NOVEMBER 2021

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PUBLICATIONS AND CONFERENCE PRESENTATIONS FROM PHD STUDIES

Peer-reviewed articles

Adams A, Miller-Lewis L, Tieman J. 2021. Usability testing of a palliative care information resource - outcomes from a formative evaluation of The CarerHelp Toolkit. Informatics for Health and Social Care (*under review*).

Adams A, Miller-Lewis L, Tieman J. 2021. Learning Designers as expert evaluators in usability evaluations: Understanding their potential contribution to improving online health information resources. International Journal of Human-Computer Studies (*under review).*

Adams A, Miller-Lewis L, Tieman J. 2021. The role of digital health literacy in enabling diversified usability evaluation feedback to improve health interface use: a remotely moderated multi-method study. BMJ Open (*under review*).

Non-peer reviewed articles

Adams A. Balancing audience diversity and health information resource design. Blog. CareSearch Palliative Perspectives. Published August 13, 2020.

Adams A. Usability evaluation and online palliative care information resources. Blog. CareSearch Palliative Perspectives. Published July 16, 2019.

Conference and formal research presentations

Adams A. Applying usability and accessibility evaluations to shape user-centred health interfaces – Identifying barriers to practice and exploring the influence of end-user characteristics on evaluation outcomes. Presented at the Research Centre for Palliative Care, Death and Dying, 16th February 2021, Flinders University, Adelaide South Australia.

Adams A. None, one or some - is the usability testing method all we need when developing and evaluating health information interfaces? Presented at the Australian Institute of Digital Health Summit. 25th November 2020, Adelaide, Australia.

Adams A. Developers and Usability Testing – The Holy Grail or a Herring in Disguise? Presented at the Research Centre for Palliative Care, Death and Dying, 28th March 2020, Flinders University, Adelaide South Australia.

Adams A. Can usability testing be all we need when developing and evaluating health information resources under pressure? Presented at the Flinders University Digital Health Research Centre. 15th September 2020, Tonsley Precinct, Adelaide, South Australia.

ACRONYMS AND ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACM	Association for Computer Machinery
ADII	Australian Digital Inclusion Index
AHRQ	Agency for Healthcare Research and Quality (US)
AIHW	Australian Institute for Health and Welfare
ATSI	Aboriginal and Torres Strait Islander peoples
ADHA	Australian Digital Health Agency
ANOVA	Analysis of variance
CALD	Culturally and linguistically diverse communities
CCS	Closed card sort
CDSS	Clinical decision support system
CIHR	Canadian Institutes of Health Research
the Commonwealth	Australian Government (federal)
COVID-19	Corona virus (SARS-CoV-2 virus)
DHL	Digital health literacy
DHLI	Digital Health Literacy Instrument
DTA	Digital Transformation Agency
eHR	Electronic health record
eHEALS	Electronic Health Literacy Scale
e-Health	Electronic health
EMR	Electronic medical record
ESL	English as a second language
F2F	Face to face interaction
GP	General Practitioner
HC	Health consumers
HCA	Hierarchical cluster analysis
HCD	Human-centred design approach
HCI	Human computer interaction

HCP	Healthcare Professionals
HHS	US Government Health and Human Services
HL	Health literacy
HM	Horizontal menu
H-MR	Hierarchical Multiple regression
HTML	HyperText Markup Language
IEEE	Institute of Electrical and Electronics Engineers
IRSAD	Index of Relative Socio-economic Advantage and Disadvantage
ISO	International Standards Organisation
IT	Information technology
IXD	Interaction design
LD	Learning Designer (analogous to Instructional Designer, Educational Designer, Educational Technologist)
LM	Left menu
LMS	Learning management system
m-Health	Mobile health
M	Mean
myGOV	Australian Government's national health and social service digital platform
myHR	Australian Government's personal health record digital platform
NBN	Australian National Broadband Network
NICE	National Institute for Health Care Excellence (UK)
OECD	Organization for Economic Cooperation and Development
OHT	Online health toolkit
PHR	Personal health record
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SCAS	Short Computer Anxiety Scale
SD	Standard deviation
SDOH	Social determinants of health
SEIFA	Socio-Economic Indexes for Areas
SEQ	Single Ease Question
SUS	System Usability Scale
UCD	User-Centred Design approach

UE	Usability evaluation
UEM	Usability Evaluation Method
URL	Uniform Resource Locator
USERS	Humans
UX	User Experience
VAD	Voluntary assisted dying
VS	Versus
W3C	World Wide Web Consortium
WAI	Web Accessibility Initiative
WCAG	Web Content Accessibility Guidelines
WDMHC	Web Development Model for Healthcare Consumers

THESIS TERMS DEFINED

Non-specialised development team

Research within this thesis focuses on the work of multidisciplinary project teams commonly within academic settings funded to translate research or evidence into online websites, toolkits, apps, or devices. These will be referred to as 'non-specialised development teams'. It is important to acknowledge that being non-specialised does not infer non-expert; instead, expertise is concentrated in areas other than development or evaluation. Non-specialised teams have a complicated relationship with technical experts engaged with the project to undertake the digital build. Further complicating both the process and evaluation within interdisciplinary practice is the ability to apply user-centred approaches within academic research settings..

Technical experts

For the purpose of this thesis, the 'technical experts' are those professionals typically involved in developing into the online environment without embedded UX proficiencies or a dedicated UX team. These could be (or a group with a combination of): software programmers or developers, information architects, front-end or back-end developers or web designers.

User interface

Descriptions of the *interface* within this thesis include all aspects of physical, graphical, and communicative interactions with the system, device, platform, or software. Interfaces include information in many forms, and of crucial importance is how these are designed for end-users to find, access, and use features to complete a task. The thesis research focuses on website and online toolkit interfaces contextualised to palliative care information.

End-users

End-users are *humans* who use interfaces through intended or unintentional interactions and are defined by their relationship to the information being sought. 'End-user' will be synonymous with *user or person* within this thesis.

CHAPTER 1 - DESIGNING HEALTH INFORMATION INTERFACES FOR ALL – IDENTIFYING THE LAYERS OF COMPLEXITY

This chapter introduces the research undertaken within this PhD thesis describing the complex digital health landscape and explaining the essential need for evaluation practice within development processes.

1 AN INTRODUCTION TO THE THESIS RESEARCH

1.1 CHAPTER INTRODUCTION

The Internet has revolutionised how individuals construct their personal, professional and community relationships. Enabled by networked technologies, digitally included individuals[1] are connected and empowered by their increased feelings of personal autonomy,[2] freedom, influence, and security influencing beneficial interactions across all life domains, including work, politics, education, media, advocacy, and health. It is the last domain that is central to this thesis. The interconnectivity between health services, systems, and information is a recognised mechanism to support universal and equitable access to health services whilst improving systems' efficiency and sustainability to provide affordable care.[3] Digital health interventions such as electronic health records, telehealth, health and social service platforms, websites, mobile applications (apps) or electronic booking sites are offered up as a panacea[4] to a fragmented health environment by overcoming access and information access inconsistencies between health services or health systems providing care.[4-6]

The arrival of the COVID-19 pandemic in Australia in early 2020 has highlighted deficiencies in developing and evaluating these health interventions, which are key themes of this thesis. Not limited to the COVIDSafe mobile app,[7,8] online health information[9] and resources should have been invaluable in strengthening and promoting health messages around disease prevention, diagnosis, and management by increasing reach and engagement with '*all* Australians'. Pragmatically, failures in understanding how population diversity influences successful access, use and comprehension of health information resulted in the development of some online artefacts that performed less than optimally and were inaccessible. Arguably, development teams expended substantial amounts of taxpayer money for a limited return on investment. Presumptions of universal Internet access and the belief that 'everyone is online' can drive design and development, erroneously leading to a lack of crucial evaluations that could have identified and resolved fundamental issues prior to release.

Simply posing the following question during early design stages could have informed and shaped these resources very differently: '*So, how does someone access this important health information if a person:*

- *Has no access to devices and/or no or limited access to broadband,*
- *Has limited technical skills or lacks previous experience using the Internet and technologies,*
- *Has trouble reading English,*
- *Has low levels of general literacy or health literacy,*
- *Is older,*
- *Is living with a condition that impacts interactions online?'*

Considerations of the needs and requirements of all users could have improved engagement and interactions with health information and actively included vulnerable and digitally excluded groups within our community who regularly face barriers to access and use. Evaluations could have led to decreased anxiety and improved health outcomes for these individuals and groups and have improved the user experience of the information for the broader Australian population.

COVID-19 is but one high profile recent example. Governments and policymakers are aware of groups within the Australian communities who regularly cannot access or use the health information, platforms, or systems commissioned to support their health care.[10-12] While developers acknowledge that designing an interface for everyone to use successfully is nearly impossible,[13,14] applications of specific approaches can produce universal and inclusive interfaces usable by 'most', including digitally excluded individuals.[15] These approaches require robust development processes, experienced developers and evaluation methodologies that provide a mechanism to generate feedback to inform modifications specific to the intended users' needs, requirements, and abilities. Unfortunately, when both development and evaluation practices are poorly applied, interface design is less than optimal and affects end-user adoption,[16] trust,[17] and meaningful use[16] of the resource.

Given the importance of evaluations of use and access to interface quality, this thesis will explore pragmatic factors that influence the likelihood of structured evaluations undertaken during the development of health interfaces. The studies undertaken focussed on aspects of the development process, content, and user characteristics impacting real-world evaluation practice in non-specialised development teams. The following section provides an overview of the layered complexity of evaluation practice when developing health information resources for all, including approaches to evaluations, development processes, the diverse socio-cultural health context, and policies driving the need for designing interfaces for all.

1.2 INTRODUCTION - SETTING THE SCENE

Evaluations are considered crucial activities to assess the access, impact and effectiveness of online products and resources to their intended audiences.[18] However, the voluntary nature of evaluation practice can lead to ambiguity concerning the frequency, rigour and impact these activities have on improving users' interface. This thesis proposes an alternate stance - one of essentialism and obligation between the development team and commissioning funders of online health information resources. Underpinned by key concepts of evaluations, methodologies, and how these activities 'fit in' to processes during online health information resource development. Discussion within this chapter will now focus on the two essential factors influencing an individual's access, effectiveness and efficiency of use, and levels of satisfaction experienced when interacting with online interfaces - accessibility and usability.

1.3 EVALUATING INTERFACE ACCESSIBILITY

Measures of interface accessibility are directly related to identifying and resolving issues that impact those individuals who live with a disability or a condition or illness that impedes their sensory perception of the interface.[19] For many people living with disabilities, the Internet has been reported to improve quality of life, particularly in areas of enriching communication with friends or families,[20] participation in social networking including online support groups or groups with members having similar disabilities,[21] enhancing a sense of self-independence and determination and providing, access to services,[22,23] and information.[24,25] Successful interactions require adopting and acquiring technological devices, assistive (or adaptive) technology or haptic device-specific to their disability[26] and the technical capability to incorporate these into their online setup.[21] Whilst additional features are available pre-programmed in-site or embedded within interface skins[27] augmenting information display, there is still a need for screen readers, voice input or speech synthesisers, on-screen keyboards, pointing devices and alternative keyboards for those living with physical, motor, or psychological disability or illness.

Individuals living with a disability are not the only Internet users facing accessibility issues. For example, older people also experience difficulties and barriers to accessing information online[28] due to the natural deterioration of functional, visual[29] or cognitive decline with age.[24,30] They share a need for assistive technology or augmentation of the user interface (UI) to improve access to the information on the screen. Arguably, evaluating and reiterating interfaces for accessibility will assist those requiring assistive technologies, augmentation of information on screens, and improve the use and access for *all users* regardless of temporal or situation impairments or level of disability.[31,32]

Accessibility evaluation commonly involves conformance testing,[26] using either automated software tools (such as online services, applications, plug-ins or extensions for authoring tools) or web to browsers.[33] These applications identify issues when comparing features of the interface against the W3C/WCAG standards.[34] Web Content Accessibility Guidelines (WCAG 2.1) are a set of stable technical standards for developing accessible online content, organised under four principles: robust, operable, perceivable, and understandable (Appendix 1.1). WCAG are measured at three levels of conformance (A, AA and AAA). Developers can assess their resources for accessibility errors using automated onboard tools to reiterate structures, features, or information within the interface to resolve individuals' problems using assistive or adaptive devices. However, successful interactions are not just mediated by levels of accessibility. The ability for users to achieve their intended goals during visits to online resources are interceded by degrees of usability defined by the relationship between the functional components of the interface and expectations, experience, and digital capabilities.

1.4 USABILITY AND USER EXPERIENCE (UX)

Interactions between end-users and interfaces have increased in complexity due to device diversity and the connectivity of the Internet.[35] This has forced a re-conceptualisation of how usage[A] is evaluated in practice. Traditionally, usability focused on the product-centred quality attributes[37] of the interface. Synchronously with the rise of the Internet and the invention of novel devices, software, and platforms,[38] has moved to a broader definition perceiving the quality of use as an experience with a purpose applied within a real-world scenario.[39] More recently, the interdependence of usability and interface design have been duly accepted, and their relationship to end-users, their interactions, and how users experience using technology[40] established conceptually as 'User Experience' (UX). This neoteric shift from a unidimensional understanding of usability to a broader conceptualisation of experience draws from the acceptance of users behaving as 'actors' within the real-world[36,41] - each interaction's level of success or failure is shaped by an individual's cultural and social factors.[42] These factors inform past experiences, levels of digital capability, and access to technology. Therefore, a user's

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[A] Usability and UX share many commonalities including pragmatic aspects of usability in context with interaction, epistemologies and underlying theories supporting overlapping and complementary evaluation methodologies, an observed methodological shift from quantitative to qualitative approaches has been noted.[36]

experience is informed by all behaviours, physiological and psychological responses, achievements, beliefs, perceptions, emotions, and preferences that happen before, during interactions, and after using the online interface.[43] Where, "*the experience with even simple artifacts doesn't happen in a vacuum but, rather, in dynamic relationship with other people, places and objects. Additionally, the quality of people's experience changes over time and it is influenced by variations in these multiple contextual factors.*"[44(p424)]

For developers, understanding how users experience information within the interface provides a dualistic mechanism to evaluate user interactions' hedonistic qualities[B] and pragmatic aspects. Hedonistic elements are psychological reactions measured at a visceral or reflective level.[48,49] This assessment encompasses emotional feelings of possession, beauty, self-expression, challenge and stimulation or identification through personification[50,51] along with positive interactive experiences such as aspects of engagement or happiness.[48,52,53] Pragmatic elements of the UI contribute to the overall usability of the product. A resultant measure from an intent to improve human performance, information experience and perception of satisfaction within the interface. Components contributing to the overall measure of interface usability are reliability, flexibility, goal completion, satisfaction, learnability, memorability, effectiveness, and efficiency.[18,52,54,55] Section 3.4 of this thesis provides a pragmatic definition of usability applied to research studies undertaken within the body of research that defines a contemporary understanding of real-world usability evaluation practice.

Considered a component of UX, usability shares many evaluation methodologies and strategies with UX research, applied to generate and interpret user feedback to reiterate interfaces. Notably, whilst temporally coupled during evaluation, there is a point of demarcation[45,46] or divergence between UX and usability approaches at the point of assessing a user's satisfaction with their experience using the interface. Usability, unlike UX, considers a single, quantitative measure of satisfaction as a reflection of the cognitive consummation of the interactive experience.[56] This is unlike UX which considers satisfaction as a series of measures accounting for psychological factors influencing the accumulation of user satisfaction.[45] Contrary to

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[B] In context of the research approach within this thesis, Hassenzahl's premise[45,46] of two types of attributes that contribute to interaction, 1) practical aspects of interaction (pragmatics) and 2) hedonistic factors that concern largely identification or stimulation of the user will be accepted. This model concedes that both hedonistic and pragmatic attributes are present in all digital products unevenly, with distribution weighted on the objective and situation of use, for example, there may be requirements where there is a greater need to accomplish tasks, whereby pragmatic attributes will outweigh hedonic attributes such as pleasure or beauty and vice versa.[47]

assessing accessibility, evaluating usability is comparatively complicated, time-consuming[57] and requires both expertise to undertake assessments and interpret the feedback to generate meaningful interfaces for end-users. One of the complexities of undertaking usability evaluation for development teams is selecting and applying the appropriate evaluation method[58] to generate the correct type of feedback[55] to inform reiteration at specific stages of development – the choice is not always straightforward.

1.4.1 METHODS TO MEASURE USABILITY

Usability Evaluation Methods (UEM) are defined as a "*procedure which is composed of a set of well-defined activities for collecting usage data related to end-user interaction with an online product and how the specific properties of the product contribute to a degree of usability.*"[59(p2)] Development teams choose specific methods to employ within the development process based on the product's objective,[55,60] though the choice is often constrained by budgetary factors, resources available, evaluation expertise, types of feedback required or interface features to be interrogated.[61,62]

The rationale is to select appropriate evaluation methods to assess usability formatively during the formative design/development phase, alternatively (or subsequently) measure the extent to which usability objectives have been attained through summative evaluation.[63] Evaluators are required for both formative and summative evaluation methods,[64] however, the objective of the evaluation differs between the two. Formative feedback rapidly informs the reiteration of interface design involving small numbers of experts or users, ideally over several time points over the development stage. Results from formative evaluations are rarely formally presented; instead, are used to inform the development team of the issues or problems within the interface. Summative evaluations involve large numbers of participants to generate data to assess inferential differences between designs or measure effectiveness, usage, or impact on the interface on the user.[65-67] These commonly occur post-production, and methods employ a quantitative approach, demonstrating adoption, implementation, scalability and sustainability of the interface[68] by statistically significant data.[69,70] In a health context, this may be assessed as a change in behaviour or clinical practice to improve patient care and outcomes.[71] Data is typically presented within formal reports to support critical funding or purchasing decision-making by external bodies.

UEM can also be analytical or empirical, and this can be critical when availability or access to potential evaluators limit the proficiency of evaluations within the development process. While access to participants can directly affect the methodological approach, it should not preclude evaluations being undertaken. Expert evaluators can fill the void left by end-users, who employ analytical UEM to assess the interface's overall performance or attributes[72] measured against heuristics (rules) or guidelines.[73] User-based and inspection empirical UEM[74] focus on the pragmatic usability issues faced by representative end-users interacting within scenarios contextualised within actual use of the interface.

Usability methodologies are further differentiated by generation then interpretation of qualitative and quantitative data.[75] Formative UEM interpret the user's experience of information through the generation of qualitative data. Developers invite narratives, comments, and commentary informing the strength and weaknesses of designs.[76,77] Although time-intensive, results are neither widely generalisable nor powerful enough to support statistical significance in any observed differences.[76] However, qualitative methodologies generate rich and in-depth feedback describing issues or problems in context to real-life use. Alternatively, evaluation methods having a quantitative approach to measurements are commonly undertaken during the summative phase and undertaken on final or stable versions of the resource (as illustrated in Figure 1.1).

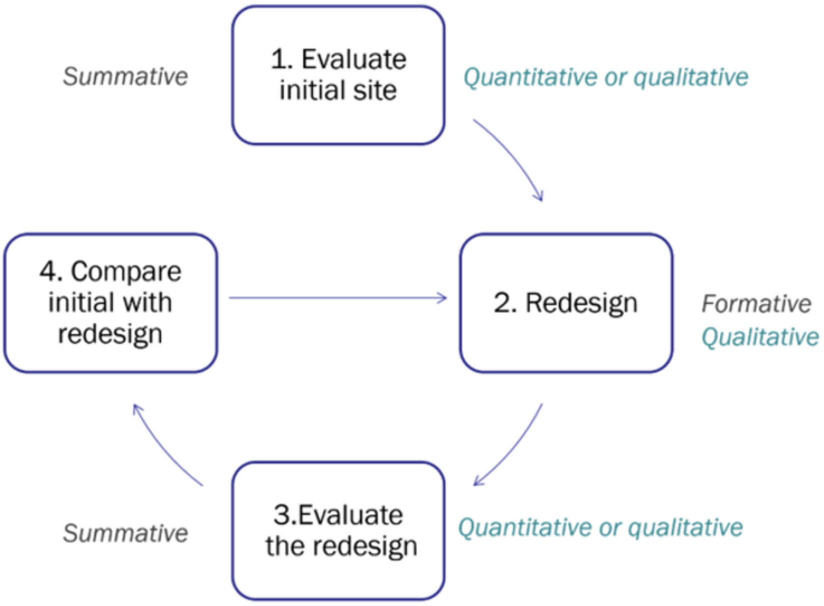

Figure 1.1. Usability Evaluation Method and iterative design cycle of online information resources[76]

[Budiu R. Quantitative vs. qualitative usability testing [Webpage]. NN/g Nielsen and Norman Group; 2017. (cited September 21, 2021). Available from: https://www.nngroup.com/articles/quant-vs-qual/. Figure reproduced with permission from Nielsen Norman Group https://www.nngroup.com/copyright-and-reprint-info/].

In summary, selecting the evaluation method is critical to generate the most appropriate feedback that will inform improvements to the interface - considered a temporal snapshot of the usability issues or problems at a single point within the development and as identified by a specific group of evaluators. UEM selection requires conceptual awareness of usability specificities,[75] nuances of methodologies and approaches, - to some degree previous practical experience. Whilst undertaking a single UEM within the development process should be a typical approach, usability practice recommends the application of multiple UEM during a product cycle to which barriers difficulties and barriers abound (clarified subsequently) for even the most experienced of teams. There is inherent power in applying multiple methods to uncover converging or diverging issues for users[78] compared with the "*methodolatry*"[79] of a single UEM, narrowing the scope of feedback. Applying multiple UEM (in approach or data generation) elicits multi-dimensional feedback, highlighting general and niche problems, and increasing credibility and persuasiveness of arguments to funders.[78]

1.4.2 THE STRENGTH OF TRIANGULATION

Employing both quantitative and qualitative methods to evaluate usability (and UX) allows developers to triangulate the identification of errors through exploiting strengths whilst covering perceived weaknesses[C] across and between approaches.[82] Combining both types of methodologies may improve the validity, relevance, specificity, sensitivity, diagnostic power, quality, and reliability of results.[82-84] For development teams working within health settings, triangulation or mixed-method research in usability practice mirrors similar approaches

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[C] The tension between the qualitative and quantitative 'camps' within the usability and UX fields are inherited from engineering and psychology approaches from within the HCI domain.[56] Researchers from a design-based approach to UX speculate the need to employ qualitative methods to evaluate within interactive systems.[80] Holistic researchers advocate a need to apply qualitative research methods to provide further insights and enrich the information that is absent from using quantitative measures only.[56] Qualitative measures allow researchers to explore the relationship between *"what we do and what we think or feel."*[56(p5)] Alternatively, researchers working within the reductionist, model-based view of user experience express a need to apply rigorous quantitative methods to provide accurate measures of cause and effect relationships between components of the system interfaces and user characteristics in larger groups of end-users.[81]

developed as a research paradigm where combinations of qualitative and quantitative research methods are applied in sequence or concurrently to elicit data.[85,86] Multilevel and complex feedback is generated using quantitative and qualitative methods applied in a between-method or within-method approach[78] similar to those observed with a statistical approach to ANOVAs.[87,88] Assessing usability using triangulation, therefore, can occur between or within:

1. Research methods
2. Facilitators
3. Observers
4. User-groups
5. Geographical location, and
6. Quantitative-qualitative approaches.

For development teams to generate qualitative or quantitative data to inform reiterations of the interface requires 'humans' involved in the process, either behaving as evaluators or users within evaluation approaches. Teams commonly face adversity when identifying and recruiting representatives of a diverse audience engaged with the process and available to participate in evaluations.

1.4.3 HUMANS ARE CHALLENGING

Individuals (*humans* compared to machines) provide feedback specific to their recruited role within the evaluation approach, whether behaving as an end-user or an evaluator. Evaluators provide feedback primarily as an expert in technology or subject matter or, in the case of heuristic experts,[89] both. Developers can consider expert feedback from two complementary viewpoints: an expert in their field and a 'user' who has expertise in a specialised area.[90,91] The latter can provide developers with a differing perspective to those behaving as representative end-users only. Participation by representatives from end-user groups is key to ensuring interfaces meet end-user needs and requirements to verify that information is comprehendible, and the interface is functional. Crucially, feedback generated can enhance interfaces so end-users can successfully achieve their task as assessed by usability measures of efficiency, error identification, and satisfaction.[54] Qualitative activities may involve end-users participating in inquiry-based activities such as focus groups or stakeholder interviews informing content or direction, or during development or post-implementation stages.

Conversely, end-users provide quantitative data through personal responses in surveys and questionnaires or through behavioural data describing movements within the interface contributing to analytical data retrieved from the platform or server. In real-world development processes, the ability for developers to articulate the user characteristics required for individuals to be *typical* of the user seeking this information and “a representative” of the diversity of their user group at the outset is difficult. Unfortunately, the investment in time and resources to identify willing participants who reflect this user type is further confounded by the challenges of managing resource-heavy processes within time-constrained development/evaluation approaches.

It is essential to recognise at this juncture the divergence between specific and generalised resources influencing both the definition and recruitment of the ‘typical’ user-archetype for usability evaluation. Typical end-users for specialised resources are tightly bound to the products’ environment or context of use. Commonalities between individuals may be a profession, medical condition, or illness (environment of use) or within a workplace (setting of use) relating to the developed product's content. End-users for these types of resources are confined to easily identifiable groups within the community, perhaps simplifying recruitment for developers[92] (except in groups where ethical considerations are required to access individuals within health services or settings). Generalised resources have a ‘casual’ relationship between archetypal characteristics of environment and setting, with a tauter connection to content available to a broader user base within the populations - albeit with similar diversity and availability complications. Generalised resources are for use by all community members, and in theory, interactions should not be limited by age, education level, gender, socioeconomic status, occupation, geographical location, or technical experience.

Pragmatically, recruiting appropriate samples for usability evaluations is problematic, especially for developers who are conscious of the need to diversify groups to truly represent the community whose interactions are shaped by their life experiences and technological abilities. These interactions, in turn, are shaped by an individual’s socio-cultural and socio-demographic characteristics. Individuals who are most likely to volunteer to be recruited for evaluations are technologically-savvy,[93-95] having a previous experience that alleviates potential apprehension, fear or mistrust of technology,[96] and sufficient literacy to understand the context, language, and content resource associated with experimental protocols.[93,97] Intentionally or inadvertently excluding end-users with diverse characteristics produces an arguably 'skewed' sample inappropriately being seen to represent the general population.

Therefore, the resource interface is at risk of being unusable by not identifying relevant problems or issues that could hinder accessing or understanding information for many who do not fit the 'typical' user-archetypes evaluation volunteers - especially those from groups within underserved or hard-to-reach communities. Conceivably, interface designs could be bolstered to support inclusive audiences if researchers could conceptualise universal typography of representative users from the general population. When recruited for usability evaluations, a universal user type could diversify the sample to truly reflect the general population's diversity, improving evaluation practice by streamlining recruitment and increasing the opportunity to produce inclusive interfaces for all users. Practically, recruitment of participants is time-consuming[92], adding further stressors to a design and development process, which could make evaluations an 'only if we have time activity' within the product cycle.[92]

1.5 'SQUEEZING' EVALUATIONS INTO DEVELOPMENT PROCESSES

Usability evaluation is multifaceted; generating meaningful feedback requires developers to rigorously apply practical and theoretical knowledge to plan, recruit, undertake, interpret, and analyse data to revise interfaces to improve user's effectiveness, efficiency, and satisfaction through the reiteration of the interface. Usability and accessibility evaluations are typically integrated within an overarching development approach, conceivably adding to an already intricate, time-constrained, and rapidly moving process driven by project milestones, agreed on deliverables and hard release date.

In an ideal world, development teams should deploy the user-centred[D] design (UCD) approach to guide development, especially when the online product or service is designed for an individual, group, or community to use.[99,100] By using the UCD approach, the artefact should be highly usable and accessible whilst avoiding adverse effects on health, safety, and performance.[98] This essentially requires 'user' engagement throughout all project phases: discovery/investigation (user context and requirements), design/development and evaluation.

[D] Standard ISO/IEC9241-210:2018 recognises in practice, and the term 'user' is applied synonymously with 'humans' as the stakeholder in this process.[98]

The key to this sequential approach from conceptualisation through evaluation and release is the iterative nature of the UCD. A series of timepoints for evaluation generates feedback within all stages and provides a rich source of information regarding users' potential behaviour interacting with designed information in 'real-world' scenarios.

As illustrated in Figure 1.2, the predetermined sequence of activities provides opportunities to undertake usability evaluations, generate feedback and reiterate the interface at multiple time points across the cycle.

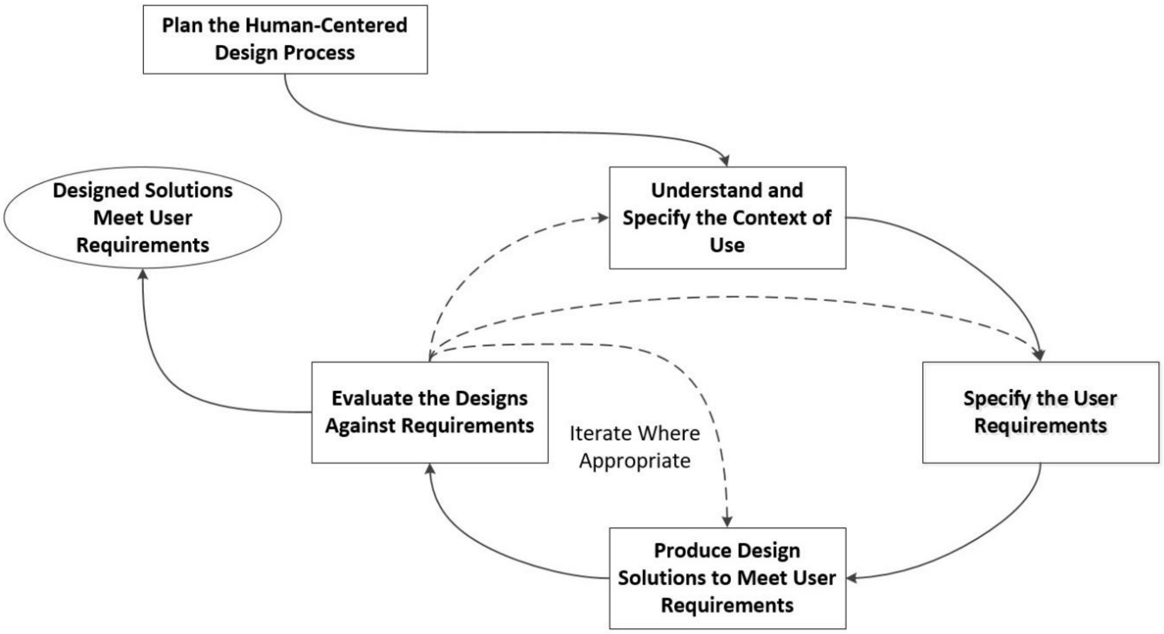

Figure 1.2: The User (human) -Centred Design Process[101]

[Harte R, Glynn L, Rodríguez-Molinero A, et al. A human-centred design methodology to enhance the usability, human factors, and user experience of connected health systems: a three-phase methodology. JMIR Hum Factors. 2017;4(1):e8. CC License https://creativecommons.org/licenses/by/4.0/. Image not modified].

As established previously, the practical decisions on which UEM to deploy, choice of prototype to evaluate, what stage of the cycle should evaluation be applied, and who is required to undertake this assessment are all interwoven within web development practice. For well-rehearsed, experienced, and well-resourced development teams, this would be familiar territory with overall project direction maintained using web development management strategies (such as agile[102-105] and variants thereof[103,106]).

Conversely, for non-specialised web teams, which may be limited economically and structurally constrained without specialist staff, difficulties in applying UCD are foreseeable. Such teams may not even recognise the value of usability evaluations and may not have the expertise to select, document and assess usability and accessibility evaluations diminishing the new resource's potential value.

Any real-world disparity between the gold standard UCD and pragmatic approach to evaluations could have significant implications for health information access and use for health consumers and health professionals. Given the systematic changes and assumptions of consumer engagement or capability in the current Australian health environment, this remains a significant issue to address.

1.6 TECHNO-PANACEA AND ASSUMPTIONS OF ACCESS AND USE

For an ageing population with an increasing prevalence of chronic conditions and illnesses, the Internet has become a critical factor in transitioning the consumer model of care towards patient-centredness[107] and efficiency.[108] Rising costs of sustaining publicly funded health systems, with escalating treatment costs and decreasing health budgets, has forced movement of the state-supported burden of care to individuals.[109] Becoming reliant on an individual's increased understanding, capacity, confidence in decision-making and awareness of health, diseases, options for treatment, symptoms, and behaviours.[110] Known as 'patient-centred care', the emergence of this self-care or self-management model has coincided with the advent of the Internet seeing *"shifts in policy priorities to the self-management of long-term conditions and the centrality of the informed, expert user."*[111(p1)] Furthermore, in making decisions about their health, which increases self-care capabilities,[111-113] Powell further argues that current health policies seek to realise expert user empowerment through "*harnessing technology to provide greater choice and control,*"[111(p1),] providing a sense of comfort and confidence[114] in approaching medical professionals [E]. In concordance with this new approach to care comes the need to access health services and systems that are also rapidly shifting into the online environment; this is not limited

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[E] Importantly, patient-centred care approach and patient empowerment are self-limiting, inherently restrained by crucial factors in creating the 'informed expert user' persona who fully engages with both the online environment and health information to better inform their care.

to publicly-funded systems reciprocated across non-government and corporate services providers. Consequently, consumers must access, understand, navigate, use, and interpret the information provided across different interfaces mediating interactions between platforms, software, applications, and websites to participate fully in their online health management. Many of these are gateways or portals to a nexus of vital health services supporting access to care, funds, personal health records, electronic prescriptions, healthcare appointments and vaccination records.

Digital health is proposed to be a "techno-panacea,"[4] a solution to improve health services, increase system enablers, and expand engagement with all communities through the Internet's reach for Commonwealth and State Governments. The Australian Digital Health Agency[115] has invested in digital health interventions within clinical care, encouraging the adoption of telehealth and telemedicine, personal electronic health records and across services to improve data privacy and security. The objective of this venture is twofold. 1) To enhance care provision, reducing patient burden through timely access to accurate and shared data between services. 2) To empower patients by encouraging self-care and health management.

Many patients elect to self-monitor (or co-monitor in partnership with their healthcare professional) their conditions by using wearable devices or connecting with mobile health (m-Health) apps.[116] Consumers can also choose to engage with health information websites and m-Health platforms actively. Access and use of interventions funded for one's self-care, or information for health management, prevention and promotion are initiated by individuals and are self-driven by personal need or motivations. Therefore, interactions are shaped by everyone's physical access to broadband and factors influencing successful interactions, including their abilities to use technology, their socio-cultural background, previous experience using digital interfaces, or adoption or avoidance levels with the online environment. For many groups and individuals within our communities, these factors become barriers to seeking, using, and understanding health information to improve decision-making for themselves or their families.

Developers who design and create interfaces for public-facing resources are assumptive of the context, environment, and capabilities of the humans (users) at the centre of the design. Developer-centric assumptions[117] frame interface designs towards end-users who are more likely to be similar to the developer[118] (generally young, Caucasian, tech-savvy, device-agnostic, wealthy and well-educated) than the actual end-user will be attempting to use these resources.[119] Developers tend to overestimate the population's ability to use technology, devices, tablets, mobile phones or associated peripherals.[120,121] There are also presumptions in the equivalency between connectivity and informed or efficient use of interfaces[21] that influence beliefs of a universal level of access and use within the broader population. Some aspects of the current digital landscape are separate from this process and should edify evaluation practice when developing online health interventions - inequitable access and disparate digital skills and health literacy within the general population.

1.7 ONLINE PARTICIPATION AS A PRODUCT OF THE DIGITAL DIVIDE

Digital participation requires the use of devices, software, or applications on the Internet to access information and trust placed in this technology.[96] Equivocally grounded within two environment and situational divisions, implicit access to the Internet[122,123] and limitations in interacting online to participate fully in one's health management.[123] Globally, access to the Internet and digitalisation of interactions, both economically and socially[124] have been considered the global drivers supporting critical reform agendas[125] where fair and equitable universal access to the Internet is ensuring disadvantaged or marginalised groups within society have an opportunity to assert their rights, to be heard or to improve their situations.[124] For some countries, access to the Internet is both a human and legal right.[126,127] Increasing access can improve experiences at an individual and societal level[F] and further reduce 'digital inclusion discrimination' faced universally by those over 65 being denied the ability to make independent decisions about their lives[G]. Factors include lack of physical and economic means to access the Internet (ability to connect equipment or afford broadband service), high levels of anxiety and insecurity due to low confidence or abilities to engage safely or successfully with the online environment.[129,131]

At this juncture, it is essential to identify two crucial concepts impacting the ability of communities to access and use the Internet to benefit health outcomes successfully. Firstly, the digital divide reveals the disparity between those with and without access to the digital environment and the ability to afford and establish connectivity of associated technologies.[132-134]

[F] For example: allowing communities to achieve financial security,[125] overcoming existing inequalities through improved access to health care,[125,128] advance gender equality through education[129] and for persons living with a disability, increase levels of inclusion across all aspects of life.[124]

[G] Exclusion remains despite ratification of UN Convention on the Rights of Persons with Disabilities,[129] and development of Commonwealth Disability Discrimination Act 1992[130] by the Australian Government.

Secondly, digital inclusion later extends this concept of the existing division by focusing on the interplay between technology and the Internet on positive outcomes across all components of society[10] whilst acknowledging the pervasive nature of technology influencing every dimension of life - seemingly to promote rapid digitalisation of every aspect affecting our social, economic, and behavioural norms.

Walton[127(p9.2)] suggests "*in many ways being connected – being digitally included – is ceasing to be an 'opt-in' or 'opt-out' choice if one wants to avoid disadvantage*" and noting "*there is simply more to lose from digital exclusion than there has been before.*" Issues of affordability of the Internet or devices, ability to physically connect devices, concerns over privacy or security of interactions and confidence or experience in operating technology disproportionately impacts the inclusion of specific groups living within the Australian community. Digital inclusion follows economic and social contours.[10] Populations profoundly affected include low-income households (below $35,000 per year),[129] individuals without fixed broadband access (mobile phone-only users), individuals aged 65 and over,[135] and those who did not complete secondary school education.[10,H] Aboriginal and Torres Strait Islander populations (ATSI), culturally and linguistically diverse communities (CALD), and individuals living with a disability.[129] are all less likely to be digitally included than other members of the Australian population.[10] Notably, intermittent or poor Internet coverage due to inferior, poorly maintained infrastructure or complete lack of communication technology can also exclude geographically isolated rural or remote populations from being digital citizens.[10,129,136]

Importantly, two and a half million Australians are not regularly online[10,108]; and hence are likely to be excluded from accessing or using online health interventions. Experiences of digital exclusion can arise from personal circumstances, socio-cultural background, previous life experiences, and have ambivalent feelings towards the Internet and technology.[137,138] Individuals also may have attitudes that technologies cannot offer control over their circumstances. They may also have inherent difficulties maintaining currency of knowledge and skills to address the continually changing technological environment.[10] Significantly, the divide between those who can or cannot gain access within audiences can complicate requirements for successful

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[H] ADII[10] is an empirical composite index of digital inclusion within Australia which has been calculated across three dimensions (access, affordability, and ability) from population data principally from the Australian Bureau of Statistics' (ABS) biennial Household Use of Information Technology (HUIT) survey.

interfaces that encourage and support interactions for those who are less skilled or technologically savvy. Diversity occurs across community groups and within groups in those audiences who are digital natives, technological adopters, cautious or intermittent users and technologically adverse individuals,[139] which generally reflect varying levels of technical abilities.

1.7.1 IT IS NOT JUST ABOUT INTERNET ACCESS

Being technologically successful requires 'the person' to behave as an 'expert user' requiring functional literacy and digital skills. There is an expectation for users to find and identify high quality and trustworthy resources with concurrent ability to read, understand and comprehend information before integrating this into their decision-making processes. An individual's level of digital readiness[139] at the level of operating interfaces requires the digital skills to interact, the capacity to trust in the information online, their belief to safeguard personal information and level of digital competency to undertake online tasks successfully.[140]

Digital competency[141] is the critical understanding of how devices or computers work. Familiarity with using different essential programs and peripherals is a crucial component of both digital literacy and competency,[141-143] and can increase confidence, engagement, including perceptions of relevance, safety, and motivation of being online.[10] All these factors interact to influence access, ability, and willingness to engage with information and services. In the real world, there are challenges to these assumptions. Generalist online audiences are likely to have a moderate to high number of reluctant [I] or cautious interactors,[139] who are not digital-ready and have low digital competency levels[144] – their skills may be limited to a single explicit criterion in a single function within the interface.[144, J] To overestimate capabilities or assume digital equity places development teams at risk of producing over-complicated, ineffective, unusable, or inaccessible interfaces for the intended core audience.

In a health context, these explicit skills are essential to achieve 'information empowerment'; there are apparent flaws in applying this to the expectations of how an individual will use

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[I] Horrigan[139] suggests following '*groups*' are evident in the sample (% population, gender, ethnicity, age, income level, education level): '*Unprepared* (14%, women, aged 50 or older, Low income households and low levels of formal education)', '*Traditional Learners* (5%, women, minorities, aged 50 or older, low income households', '*Reluctant* (33%, Men, aged 50 or older, low income households and low levels of formal education', '*Cautious Clickers* (31%, aged 30's and 40's higher income households, some college experience)' and '*Digitally Ready* (17%, aged 30's and 40's, higher income households, higher education levels)'.

[J] These groups share common characteristics being people aged over 50, belong to a minority group (ethnicity), low levels of formal education and low-income households.[139]

technology within a person-centred care model. For example, chronically ill patient populations (or those living with a life-limiting illness) cohorts are identified as potentially benefitting from online or digital support across clinical care areas, self-care, and health promotion prevention information or interventions online.[9] Pragmatically, these individuals are more likely to be older, less technically skilled, be adverse or anxious using technology, and have limited access to the Internet [K]. One could argue that successful interactions would be unlikely given the numerous barriers to use. This situation is not limited to chronic illness groups. Realistically, various Australian community groups of end-users also experience clusters of obstacles to successful online interactions. For example, those who are older (late adopters or avoiders of technology) or have little experience using the Internet or digital devices and technology (CALD including migrants, refugees) face immediate hurdles to undertaking successful interactions with current consumer-facing Government digital health interventions. Individuals from these groups require significant assistance provided by family, friends, or enablers to master the basic operations of devices even before initiating the interaction with the health interface.

1.7.2 SOCIO-CULTURAL CHARACTERISTICS AS ENABLERS OF INTERACTIVE SUCCESS

There is a recognised relationship between socio-demographic factors, adaptation to the digital environment and the ongoing implications for society[139] in a rapidly changing technological landscape. Socio-cultural demographic characteristics interplay across all aspects of digital equity and access, digital competency, acceptance, or avoidance of technology. Furthermore, these are the same characteristics[L] that impact literacy and health literacy levels influencing the comprehension or understanding of information to inform health decisions (presented diagrammatically in Figure 1.3).

However, life experiences, circumstances and inquiry-context impact each person's interactions differently depending on the context and environment of use. Health literacy is a combination of "*the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.*"[154(p2)]

[K] However, it is recognised for many older patients, that their primary source of health information remains with healthcare professionals[145] although this varied with socio-demographic or health factors and health literacy.[146-149]

[L] Internationally, these same characteristics that act to digitally exclude groups within multicultural[128,136,150-152] and mono-cultural populations [153] reported as aged, income and education (as indicators of socioeconomic inequality.[135]

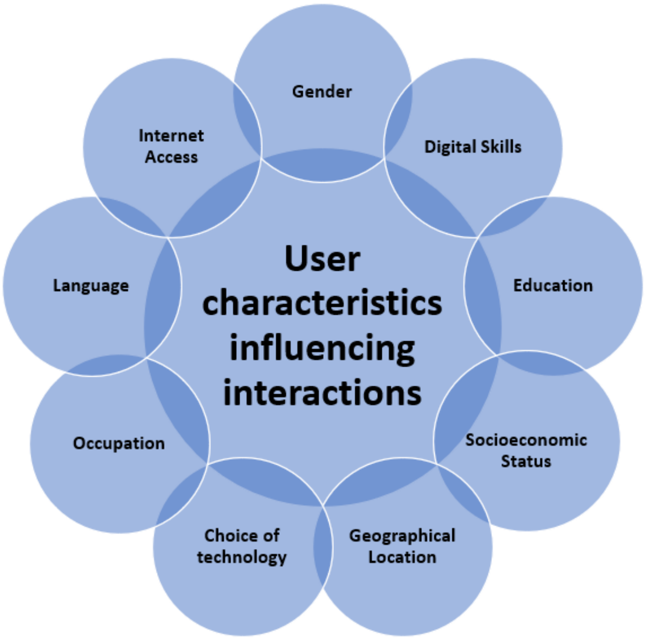

Figure 1.3: Diagrammatic representation of the overlapping socio-demographic and cultural factors contributing to end-users interactions online

It applies *to* both an individual and within health system environments,[154] policies, staff, infrastructure, processes, materials, and relationships impact the interaction between systems and patients. Low health literacy levels affect an individuals' ability to determine the level of trustworthiness or quality of information sources[155-157] and impact the aptitude to make informed decisions about their health when presented with high-quality, relevant information.[158-160] Low levels of general literacy compound and exacerbate this circumstance to comprehend an overwhelming volume of health information requiring individuals to expend large amounts of cognitive effort, time, and energy to locate relevant sources and sift through and evaluate an immense, often unverified online health information.[161] This is perhaps a ‘perfect storm’ for some community groups within the general population impacted by multiple factors that impede their ability and access to online health information. Factors (determinants) such as age, socioeconomic status, gender, education level, occupation, presence of disabilities, and geographic location are cumulative, impacting the direct affordability of broadband, access to technology, health literacy, attitudes, and acceptance of digital devices and digital skills to operate these successfully. Combined with systems and policies that keenly demand interaction with online information resources whilst actively disregarding barriers to access and use, one could advocate that this is a glaring omission of care as part of governance.

1.7.3 CHARACTERISTICS REFLECTIVE OF THE SOCIAL DETERMINANTS OF HEALTH

Levels of wealth,[162] access to employment or education, quality of living conditions, and community safety levels[162,163] profoundly drive the determinants that influence health, including health-related attitudes, beliefs, knowledge, and behaviours.[164] These social determinants of health (SDOH) also shape levels of engagement and successful interactions with digital health interventions encouraging self-care to promote health or disease prevention. For some community groups, the association between SDOH and health literacy has been established within the literature.[164] Associations have been identified in the disparities in access to health services,[165,166] and disease management.[162] This relationship was also reportedly evident in older people as late adopters to technology compared to younger, more tech-savvy populations.[167-169]

Analogous patterns of factors are emerging for other sub-populations experiencing digital inequity and exclusion at the intersection of multiple socio-cultural or environmental conditions that mediate this circumstance. For many who live with a disability, affordability of assistive devices[21,170] and the need to continually upgrade to the 'latest version' to maintain compatibility[171] influence levels of inclusion - compounded by low socioeconomic status, especially when 45% of persons living with a disability are living below the poverty line in Australia.[19,172]

There are expected low health literacy levels for individuals from CALD communities, newly arrived migrants, and refugees due to deficient or limited English.[173,174] Health literacy levels can be exacerbated by limited employment opportunities, social exclusion[136] and regional or rural resettlement, increasing the difficulties in navigating a new culture[175] and integrating with health services or accessing online health information.[175,176] The overlap in social determinants decreases health literacy, influences the ability to determine information's trustworthiness to address health queries, and increases the risk of exposure to inaccurate or online falsehoods.[32,112,161,168,177] The relationship between these SDOH and digital inclusion is an emerging research area with Internet connectivity, digital health literacy and digital competencies described as "*super social determinants of health*"[178(p1)] as this addresses all other factors influencing health outcomes.[178] Given these factors also shape online interactions when recognised in context with the digital divide and the current push to digitalise health experiences. It is essential to acknowledge the significance of building and designing interfaces for all and the role and responsibility of health professionals, development teams, usability experts and funders in enabling this.

1.8 POLICY, AGENCY, AND STRATEGIES TO IMPROVE DIGITAL SERVICES AND SKILLS

The Australian Government (the Commonwealth) is not naïve to the digital divide, nor the complications driven by digital inequities and digital readiness. The Commonwealth has developed strategies to address inadequacies in infrastructure and broadband affordability to improve general and health literacies and increase digital readiness through a generalist and targeted population approach. Local governments support community-specific initiatives to build language proficiency, online self-efficacy, confidence, and functional digital competencies for actively excluded groups from fully participating in aspects of their lives requiring online interactions.

The Commonwealth's twin agencies, Digital Transformation Agency (DTA)[179] and Australian Digital Health Agency (ADHA),[180] are tasked to direct and support agencies, departments, and organisations to upgrade existing or create new platforms, software, or technologies [M] to integrate across the digitised health system. For this strategy[115] to succeed, both providers and the digital enablers (systems) are needed to empower consumers to improve their health by improving access to clinical care, supporting self-care and self-management of conditions or illness, and engaging with health promotion or disease prevention information. To foster these connections, the Commonwealth has established guidelines and resources to assist developers (development teams) to encourage utilisation of user-centred approaches to design and development; to consider user needs and context of use to influence "*decision making, … supporting improved prioritisation and user experience.*"[115(p19)]

Funding and evidential guidance focus on intermediatory development teams designing and building software, platforms, dashboards, and mobile interfaces to integrate with the Commonwealth primary health systems, such as the electronic health records (eHR), telehealth and telemedicine suites and appointment booking programs. There is a failure to recognise

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[M] ADHA examples include improvements to personal electronic health record system, integration of telehealth into primary care, use of electronic prescription services, and other health technologies with express intent of improving outcomes, quality, and safety of healthcare.

equivalence and the critical role in fulfilling patient empowerment between *systems* and *information resources* (including '*the content*' wherein). Online health information is a crucial repository for guidance providing both a knowledge-based and a mediator of social supports within a like-minded community of users. In 2020, three-quarters of Australians had used the Internet to investigate a health issue, including older Australians (69% of those over 65 years) and 77% of individuals would like their doctors to recommend health information websites.[108] On examination of the information provided within the Agency's website,[180] there is a discrepancy between the level of financial support and practical guidance available for developers of online health information resources compared to those creating or integrating services or systems.

One could argue that this erroneous support does not increase meaningful interactions by those community groups who would benefit most from inclusive design, usability evaluations, accessibility compliance and a development process to support the process. There is a noted absence of 'online health information' within the umbrella definition of digital health interventions within the ADHA's formal strategies " *… range of technologies that can be used to treat patients and collect and share a person's health information, including mobile health and applications, electronic health records, telehealth and telemedicine, wearable devices, robotics and artificial intelligence.*"[108,N] Concerningly, there is an inference that online health content is not seen as a valued or investment-worthy digital product contributing to the increased awareness and knowledge to support health decisions within the community members.

Lack of recognition, funding, guidance, and practice recommendations increases the risk of losing individuals through the digital health strategy's cracks. Poor evaluation (or an absence of usability and accessibility) can render interfaces useless, primarily if intended audiences' requirements, needs, abilities and context of use are assumed or not considered during development. Interestingly, although the ADHA states, "*adoption will be accelerated by providing best practice design principles and guidelines to improve usability and user experience.*"[115(p47)] Notably, there are no recommendations for usability evaluation or usability testing within the thirteen Digital Service Standards.[181] Using the previous example of chronic illness sub-populations, consider the online health interactions of this group living with diabetes.

[N] Examples of digital health interventions include 'My Health Record, fitness trackers, smartwatches, sleep trackers, wellness applications, SMS reminders via mobile messaging, electronic discharge summaries, electronic prescribing, secure messaging, voice interfaces, medical drones, paperless hospitals, implanted microchips, robotic nurse assistants.[108]

Pragmatically, this group would comprise many older individuals living with comorbidities, with socio-demographic user characteristics influencing low health literacy levels and reluctant Internet users.

Figure 1.4 illustrates the imbalance between user-driven requirements for online health information driven by the increased need to manage and monitor their chronic condition (as illustrated by the time spent on health activities). This is compared with the relatively small investment within the development scope and support of health information interfaces within the current health service-centric interventions[182] by the ADHA.

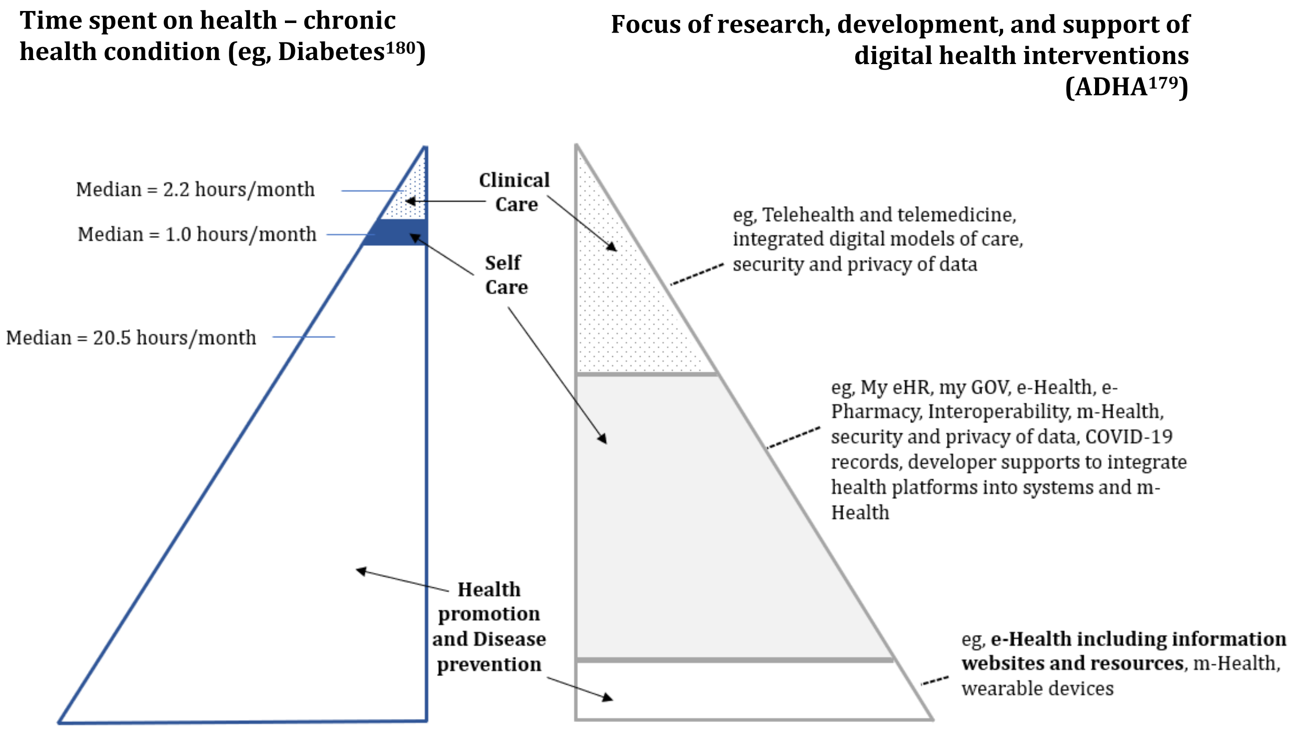

Figure 1.4. The imbalance between time spent on health for sub-population of Australian diabetics[183] and the focus of ADHA digital health interventions detailed within 'the Strategy'[115] (Figure adapted from Rowlands, Protheroe and McElhinney[184])

[Figure adapted from the image within the PowerPoint Presentation, Rowlands G, Protheroe J, McElhinney E. Digital health literacy. [Internet]. Geneva, Switzerland: World Health Organisation. Slide 8. (Accessed 2021 March 21). Available from: https://www.who.int/global-coordination-mechanism/activities/working-groups/17-s5-rowlands.pdf].

Arguably, extending patients and consumers' needs and requirements for health information across all disease and chronic illness states would require the ADHA to support developers to design universal and inclusive interfaces. The current approach to improving the digital health experience is focussed on a generalised systems approach,[182] which places the development of health information interfaces on the outer compared to other interventions. These interfaces require a contextualised strategy for development that acknowledges that an individual's health and medical information-seeking behaviour are tightly bound to their surrounding context.[185] The increased adoption of online health information by consumers as complementary to clinician advice [186] in combination with limited health literacy as a barrier to information seeking,[187] access and use of health interfaces should be of concern for the Commonwealth. As the content and the design of the interface are inherently related to meaningful experiences to access information to support health decision-making,[188] evaluation practice should no longer be discretionary in development processes, especially given the potential health outcomes for those who are vulnerable, digitally, or socially excluded or are from culturally diverse groups.

1.9 BARRIERS TO EVALUATION PRACTICE FOR DEVELOPERS

For end-users, interactions are considered successful if the intended goal is achieved when human action compels a response from the system using the UI as the mediator between the human and the device.[189,190] Ensuring the interface is usable and accessible should be the cornerstone of all evaluation activities undertaken by developers of resources; not undertaking evaluations has associated risks to the user and the development team. In a system sense, poor usability of clinical interfaces such as intranets, eHR and e-pharmacy can ultimately lead to increased risk[117] and prevalence of medical errors and fatalities within care settings.[191]For health consumers, health information resources that are unusable or inaccessible may be equally as dire. If the content is confusing, navigation is complicated, or interaction is frustratingly complex, misinterpret information found, leave the resource without resolution only to find less trustworthy information on other sites or opt-out of information-seeking altogether. Each option is likely to compound stress, increase hopelessness and agitation, and expose consumers to potentially untrustworthy information.

Anecdotally, commentary from usability engineering practitioners has bemoaned an increased prevalence of non-usable or inaccessible resources currently being produced by corporates,[192] Government, and not-for-profit organisations.[193] Health information websites were not excluded from this observation. A systematic review identified only three health websites from a cohort of information websites whose development teams described evaluation methodologies within the peer-reviewed literature.[194]

Development teams have a pragmatic understanding of usability and accessibility; that is, '*there is a need to check the resource to ensure that users can find, use and comprehend information within the design produced'.* This acceptance does not reflect the importance and cruciality that, when deployed, evaluations can significantly improve the user experience of interfaces in context with the diversity of user characteristics, digital inclusiveness, and the current digital agenda[O]. There is awareness of all of the components that drive the need for usability and accessibility evaluations to be undertaken (digital transformation agenda, digital exclusion, social and cultural factors, literacy and health literacy, digital readiness) and the implications for health outcomes. Therefore, the pressing requisite is to understand '*how developers know what works within their interfaces if end-users are not asked, and ultimately, who is responsible for ensuring evaluations are undertaken?'*.

One could reason that perhaps a lack of guidance or information could be a factor. However, it is conceded that development teams do not design and build in isolation and can access freely available guidelines and resources[193] to support evaluation practice, including international standards[98,195,][P], research-based resources[196,197] and countless websites offering advice. Therefore, the question remains why health information resources are often left unevaluated, designed on developer assumptions of how end-users interact, and/or created as interfaces for users who are typically like themselves.[117] A major factor that possibly contributes to relatively poor evaluation practice within health information resources is team composition, a structure that no longer reflects the traditional web development team when building into the web required specialised professionals each responsible for a component of the process[198] - which includes usability evaluation. Health information resources are currently more likely to be developed by groups whose speciality may be in one area of the development process (e.g.,

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[O] As stated within key objectives within ADHA's 'The Strategy' and outlined within the DTA website.

[P] International Standards Organisation (ISO) offer standards supporting international adoption of a consensus view of usability and UX. ISO/IEC9241-210:2019[195] defines user experience as a "*person's perception and responses resulting from the use and/or anticipated use of a product, system or service" and is a "consequence of brand image, presentation, functionality, system performance, interactive behaviour and assistive capabilities of the interactive system, the user 's internal and physical state resulting from prior experiences, attitudes, skills and personality, and the context of use*."

content development) but due to lack of resources or specialist personnel, team members are required to generalise their skills across components of the process which they may not have experience or knowledge to undertake this practice successfully.

Non-specialised teams and their process or practice are therefore of profound interest to the research within this thesis as their levels of development and evaluation expertise could:

- Influence the likelihood of evaluations being undertaken during development
- Affect application of guidelines or standards limiting the quality of evaluations
- Assist in ensuring appropriate representation in content development and end-user identification
- Explore universal and inclusive interface options for generalist audiences
- Determine the rigour of UEM employed
- Impact meaningful reiteration of the interface from findings of assessments
- Have implications for health outcomes for those in the community who face barriers to accessing and using online health information.

Non-specialised development teams and their current process and evaluation practice lends further discussion to evaluation accountability, sources and types of support required to improve their outcomes. Specifically, there is the role the commissioning funder (the Commonwealth) must play in ensuring usability and accessibility evaluation practice become essential components of typical development approaches for health information websites and resources.

1.10 DEFINING RESEARCH WITHIN THIS THESIS

The Internet provides healthcare consumers with information that increases opportunities to self-manage or self-diagnose conditions, to locate, question and publicly debate health recommendations or policy.[199] Most importantly, consumers drive the need to personalise their health management by accessing the information on various platforms to inform their decision-making on individualised healthcare concerns.[200] Access to electronic health information requires literacy on behalf of the user, both in understanding (a capacity to search, locate, understand, appraise and apply knowledge to solve a health problem[99]), and digital readiness, described as the level of experience in using digital tools to perform different tasks on the Internet and the ability to determine the extent of trustworthiness of the information.[139,201] Many developers and researchers consider evaluation as cost and time restrictive[202]; however, by choosing to invest in assessments applying evidence-based methods to conceptual models including measures of learnability, the efficiency of use, errors or issues and memorability[203,204] provides opportunities to garner valuable feedback for iterative design modification to improve accessibility and usability. This is critically important for online health information as this medium lies crucially on the intersection between the consumers need for health information, the ability to access and understand the information being provided, and potential improvements in health for the individual or the person they may be caring for.

Discussion within this thesis will draw on two aspects of interface design, universal and inclusive design as a possible mechanism to enhance and improve UX of health UI. Both encourage consideration of the diversity of end-users abilities. Inclusive design focusses on features that increase interactive participation for those who are typically excluded from interactions and moves beyond accessibility[205]. Universal or "*everyone interfaces*"[207] are designed to be easy to use and accommodate as broad audiences through flexibility without specialised or adaptative requirements and allowing for individual preferences.[13,208,Q] As such, universal designs could offer solutions to development teams when evaluating and designing for heterogenous abilities within the audience[206] of generalist health interfaces. It is not possible within this thesis to discuss interactive design; however, it is important to note that design, development and evaluation of user needs, or requirements of use has become an integral mediator of meaningful interactions to improve health outcomes.[209] These can only occur if developers consider divergence in users' abilities, health literacy, environments and background shaping their information experience.

1.10.1 WHY PALLIATIVE CARE?

The thesis research concentrates on how development teams can optimise their UI through evaluations to support universal access and use of information by a wide range of end-users. As the Research Centre supported this PhD for Palliative Care, Death and Dying, there were opportunities to evaluate palliative care interfaces already developed or being developed by CareSearch and their partner organisations. Research within this thesis is therefore, contextualised to palliative care - a family-centred care approach supporting quality of life for

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[Q] An example of universal design is 'dark mode' that is currently used within UI of websites and apps.

those living with a life-limiting illness and providing help for carers and families during the illness and bereavement.[210-212]

The universality of death, and the need to find online palliative care information across the life course, do not follow socioeconomic or cultural boundaries and span the digital divide. The ability *for everyone* to access, use and understand *online palliative care information* is influenced by successful interactions with the UI as facilitated by easy-to-use design, and the ability for 'people' to find and use the information provided – as influenced by their socio-demographic characteristics, technological abilities, and previous life experiences. Evaluations can consider these factors during development to improve UX of palliative care interfaces for all.

Therefore, palliative care gave context to the processes and participant selection, to observations, interactions, measures, feedback, interpretation, and implications from the evaluation research undertaken across the PhD. By understanding the challenges of developing online palliative care resources for diverse audiences, the outcomes from this PhD can inform recommendations for palliative care development teams, their evaluation practice and UI designs. These findings have broader implications for evaluations within interdisciplinary development processes of information resources within other health and medical domains.

1.10.2 THE SCOPE AND LIMITATIONS OF THESIS RESEARCH

The scope and limitations of the research within this thesis are defined within the following context. The thesis research will explore the factors, barriers and aspects of development that impact evaluation practice to understand complications, constraints, and mediators of improving UI usability and accessibility during typical processes undertaken by cross-[4,213,214] and interdisciplinary project teams.[106,215-217] Development processes will primarily focus on those attuned to conceptualising, designing, and building static health interfaces within the online environment. These resources whose structure and function are constrained by HTML code. All end-users view the same static version of the UI, with the content manually updated by developers.

Development of m-Health, dynamic websites and wearable devices UI are acknowledged as sharing aspects of the process, interaction design, UX and usability as static interfaces due to the UCD within the development approach. However, the need to integrate into a rapid, interconnective environment has seen a shift toward development within an human-computer interaction (HCI) environment and increased involvement of software programmers. This re-positioning has encouraged the development of these interfaces to become increasingly flexible and iterative. Processes to develop these types of health interfaces are beyond the scope of this thesis.

UI discussed herein provide *health information* to end-users – being health consumers and Healthcare Professionals (HCP) – and all descriptions within this thesis relate to health information UI unless otherwise stated. As previously discussed, palliative care is the subject domain of the interfaces examined in detail. Palliative care focusses the content, context, and environment of use for end-users involved in evaluations. There is one area of the thesis research whose scope of findings is not limited to types of interfaces, technology or development processes employed. Identification, recruitment, and participation of end-users and people within the evaluation process are key to all UCD approaches. Research findings and implications for evaluation practice are applicable for teams, processes, health or medical domains, healthcare settings and type of audiences to improve health UI for all.

1.10.3 SIGNIFICANCE OF THIS RESEARCH

The significant original contribution to knowledge that research within this thesis will contribute is threefold:

1. Adding evidence to the low number of systematic and well-documented studies determining the value of evaluation methodologies on online healthcare resources, particularly on the emerging format of online toolkits. These studies will investigate the current industry practice of undertaking and reporting evaluation outcomes in formal and informal literature. To expand the understanding of the role of various formative evaluation methods that should be undertaken within development approaches to create high quality, relevant and contextualised online health information resources. Whilst the findings are generalisable to the development and evaluation of resources for the broader health domain, the research and subsequent studies are contextualised to palliative care and reflect the diversity of patients and carers requiring information often during the most stressful period of their lives. Palliative care is provided to patients when faced with a non-curable life-limiting condition, illness, or disease, and it is delivered across the life course. Therefore, the ability to access palliative care online information extends over cultural/social boundaries, across socioeconomic divides,

traverses age and gender, into areas of geographical isolation or into communities where face-to-face (F2F) healthcare services are limited.

2. Research outcomes will also improve how developers of palliative care information resources can design and evaluate interfaces to ensure that all users can find and understand the information provided to assist with decision-making for loved ones at the end of their lives.
3. The studies will also contribute to knowledge gaps in describing health and digital health literacy levels within a cohort of the Australian population and how these characteristics could influence health information interface designs through usability evaluations. Whilst this research has wide-ranging implications for health policymakers, commissioning funders and development teams, findings can inform emerging "*critical digital health studies,*"[4(p2)] focussing on evaluations of digital health technologies and their impacts on outcomes for individuals, communities, and society.

1.10.4 OBJECTIVES OF RESEARCH WITHIN THIS THESIS

This thesis aims to assess the role of usability and accessibility evaluations undertaken during the development of online health information resources and determine their influence on user experience access and value.

The secondary aims of this thesis are to:

1. Identify methods of evaluation currently being undertaken by developers of online health toolkits and discuss the quality of the method reported within the published literature that contributes to users' usability and accessibility.

2. Determine if applying a structured evaluation approach could encourage iterative improvements of online health toolkits' developmental prototypes by identifying and reporting issues during usability testing. Can this model improve the end-user experience of access, understandability, and satisfaction with the implemented product?

3. Investigate how relationships between specific user characteristics and levels of digital readiness affect access and usability of an online palliative care information resource and if these factors influence the types of issues or problems identified during the application of different usability evaluation classes.

1.10.5 PRIMARY AND SECONDARY RESEARCH QUESTIONS

The primary research question that will be explored within this body of research is:

> *'Does comprehensive and structured evaluation of usability and accessibility when undertaken during development identify interface areas that could improve user experience?'*

Secondary research questions for studies within this thesis are as follows:

RQ1: How do researchers report usability evaluation methodology and outcomes in the peer-reviewed literature, and can this evidence support the project team development practice in building online health toolkit interfaces?

RQ2: Are descriptions of OHT development and evaluations reported within peer-reviewed literature a true reflection of real-world practice by development teams as explored by 'live OHT' interface design?

RQ3: Does a comprehensive, structured evaluation approach, when applied within a real-world development process, increase the likelihood of undertaking usability evaluations, and can a formal approach inform the multidisciplinary team's reiteration of the OHT interface?

RQ4: Which survey modality, paper-based or digital (online), as an engagement approach provides access to digitally excluded or technically disengaged individuals living within the community to participate in usability evaluations of health interface?

RQ5: What are the associations between respondents' mode of survey return and their socio-cultural demographics, online behaviours, and levels of health literacy?

RQ6: How do digital health literacy levels influence usability evaluations' outcomes and the implications for interface design when designing for everyone?

1.11 HOW THIS THESIS IS STRUCTURED

This body of work was undertaken considering three interplaying factors influencing successful usability and accessibility evaluation practice for developers of online health information resources. Five independent studies were conducted, with methods, results and outcomes presented in separate chapters and findings concerning each study's objectives and research questions discussed within each. Outcomes from each study are then discussed in context to the primary thesis research question objectives within Chapter 9 and includes an overarching analysis and exploratory discourse on the implications and recommendations for developers to improve the use and access of resources developed. The thesis structure is summarised and presented in Figure 1.5.

This chapter established the complex digital landscape where online health services and health information intersect. Therefore, it is essential to explore the development and evaluation approaches supporting the development and design of health resource interfaces given digital inequities and disparities in digital competencies within the general population. The next chapter explores the research-based standards, approaches, and frameworks that help health information development teams assess usability, accessibility and promote efficient development processes. Accessibility WCAG/WAI guidelines,[171] US Government Human Health Services (HHS) research-based usability guidelines[197] (www.usability.gov), Web Development Model for Healthcare Consumers (WDMHC)[218] are presented; the UCD process has previously been described in 1.1.7 of the current chapter.

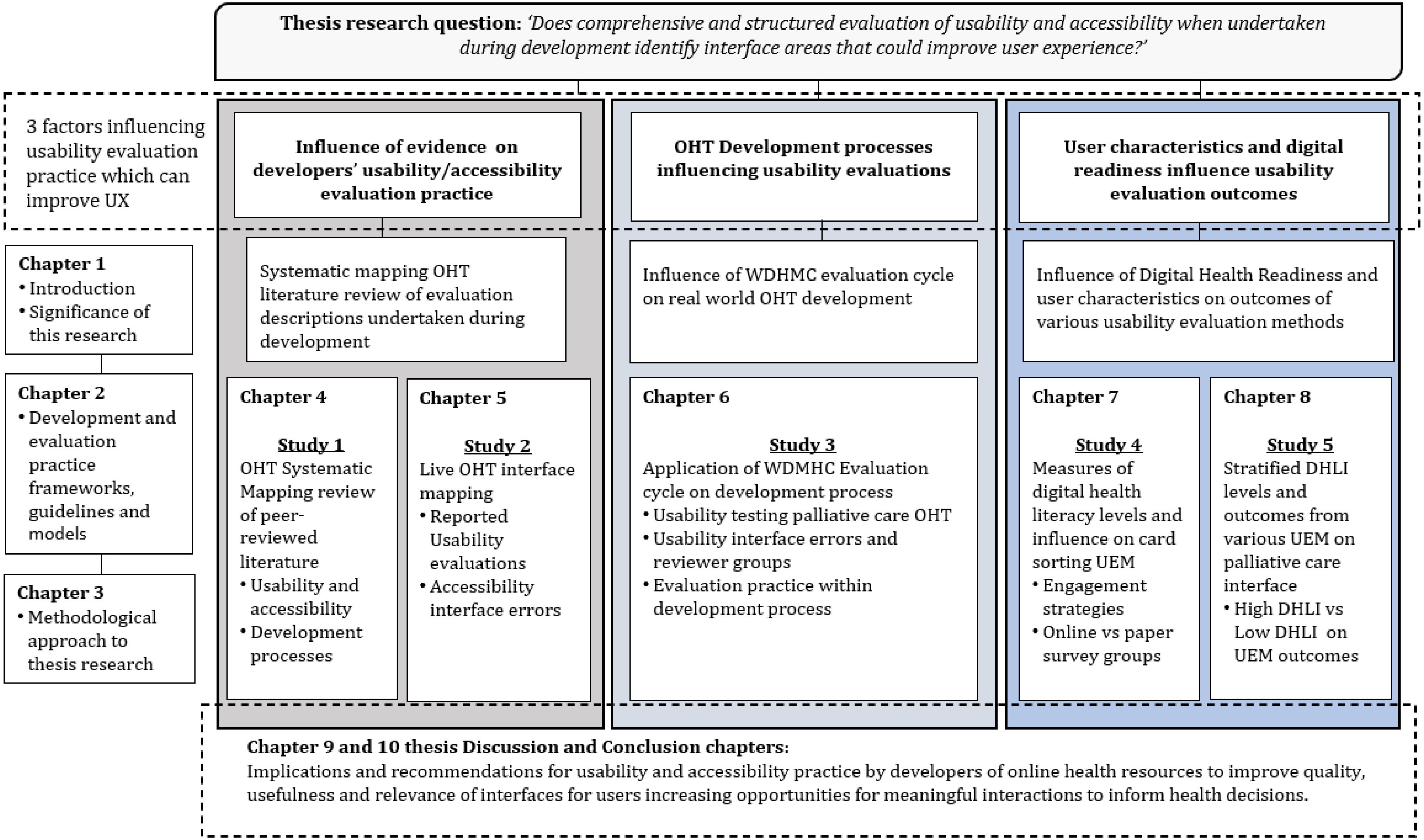


Figure 1.5. Schematic diagram of this theses structure with supporting studies and chapters

CHAPTER 2 - GUIDELINES, MODELS AND FRAMEWORKS SUPPORTING DEVELOPMENT AND EVALUATION PRACTICE

Chapter 2 outlines the development and evaluation guidelines, frameworks and models applied to thesis research. Practitioner guidance can support a user-centred design approach to the development and evaluation of interfaces.

2 PRACTICE GUIDELINES, MODELS AND FRAMEWORKS

2.1 CHAPTER INTRODUCTION

Guidelines, frameworks, and models are referred to, inferenced, or applied within the context of research within this thesis. Four key sources of evaluation practice guidance supporting the development of online health information resources in the 'real world' applied within this thesis:

1. User-Centred Design (UCD) Approach (section 1.5)
2. WCAG/WAI accessibility compliance ratings
3. Research-based usability guidelines (US Government Human Health Services (HHS) guidelines usability.gov)
4. WDMHC Web development model for health care consumers

As the User-Centred Design (UCD) approach was previously described, this chapter will introduce the WCAG/WAI accessibility compliance ratings, Research-based usability guidelines and Web Development Model for Healthcare Consumers (WDMHC).

2.2 WEB CONTENT ACCESSIBILITY GUIDELINES (WCAG) – MEASURE OF COMPLIANCE

Whilst accessibility is global (reflecting economic, political, societal) conditions[219]and unambiguous in definition, perspectives on the relationship of individuals to have the ability to participate fully in the world are described in three dimensions,[220] that is access to:

a) Physical environment
b) Information
c) Services.

For developers, evaluation of accessibility involves measuring compliance against guidelines describing UIs' design and functional features that facilitate those who experience difficulties interacting with the Internet. As accessibility is legislated within anti-discrimination law,[130] the extent that online resources comply with their legal obligations is measurable against criteria found within Web Content Accessibility Guidelines[171] as developed by Web Accessibility Initiative (WAI)/World Wide Web Consortium (W3C). Web Content Accessibility Guidelines (WCAG 2.1) are stable technical standards for developing accessible online content, organised under four principles with 17 guidelines having success criteria measured at three levels of conformance (A, AA, and AAA). Non-compliance is seen as the greatest issue across all Internet segments, including e-government,[221] e-commerce[222] and reports of 98% of all websites on the Internet being non-accessible[219] or non-compliant to A-Level.[223] These high rates of non-compliance relative to standards are attributed to developers' lack of knowledge or limited resources for the design and evaluation of information sources.[222]

2.3 HHS RESEARCH-BASED USABILITY GUIDELINES

Besides usability as a quality factor of interest, developers and their team prioritise a combination of other factors to focus on during development, including time-to-market, scalability, and maintainability (or longevity) of the product.[54,224] Usability can be investigated, measured, reported, and repeated for new iterative versions developed during pre- or post-release periods using specific methods to interrogate different user interaction aspects with the online resource or product. Various models, guidelines and frameworks have been conceptualised from research within HCI, usability engineering, computer information science, and psychology to support development teams to build helpful online resources. Whilst this diversity enriches the scope of evidence available to developers, freely accessible evidence-based resources are non-prescriptive[193] and effectively lack key information.[197] Furthermore, the quality of the guidance hidden behind paywalls of corporate and commercial entities (who encourage outsourcing of usability evaluations) is relatively unknown. There are no qualms with companies commercialising usability practice, but here highlights an issue for naïve practitioners on availability and sources of high-quality, evidence-based guidance if budget and previous development experience are lacking.

Unlike accessibility, usability guidelines do not have any legal ramifications associated with non-compliance. Improved usability of an online resource has ‘economic’ downstream effects on user engagement, enhancing economic buy-in, increasing analytics and metrics to demonstrate value and use of resources for funding bodies, and building shares in social media presence to amplify visibility in the digital marketplace. The usability goal is to ensure resources can provide every opportunity for the user to achieve the online resource's intended objective, presumably to increase knowledge, change behaviours or complete a task successfully. There are research-based usability guidelines collated from many fields that can contribute to understanding user interaction and the Internet, including recommendations for a standard user, those living with disabilities[225,226] or those of mature age[227-230] experiencing difficulties using interfaces, systems, or platforms. US Government of Health and Human Services (HHS) developed the Research-Based Web Design and Usability Guidelines,[197] (www.usability.gov), providing a comprehensive database of recommendations supported by research-based evidence.[196] usability.gov guidelines are freely available, support the UCD principle, and guide developers throughout the product development process. The development of these guidelines was through collaborative discussions between experts and web designers through an iterative process with each of the critical factors having ratings of evidence strength (based on both strengths of research evidence and level of importance placed on them by experts). usability.gov website provides 209 usability guidelines (including accessibility) across 18 different website designs and development (refer to Appendix 2.1 for a summary of topics and strength of evidence ratings).

2.4 THE WEB DEVELOPMENT MODEL FOR HEALTH CARE CONSUMERS (WDMHC)

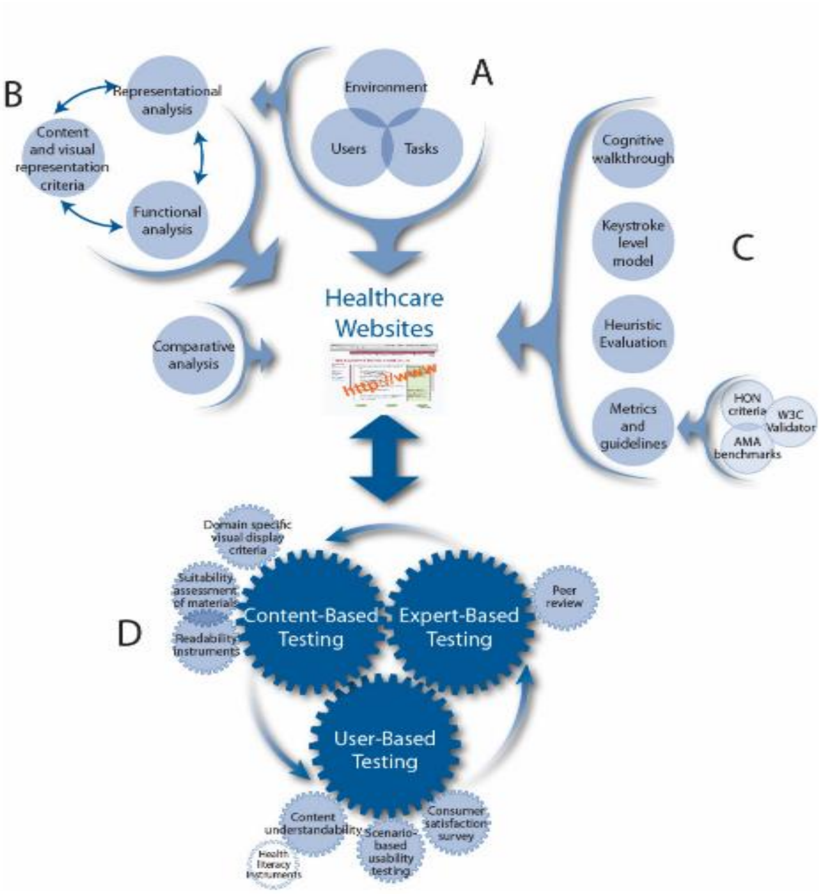
This validated model, Website Development Model for Healthcare Consumer (WDMHC) is underpinned by the UCD approach. The WDMHC was developed by Johnson and Turley[218] in response to the relative scarcity of a formalised approach encompassing research-based evaluations across all aspects of the online health website development process. Aspects include user requirements, content development, considerations for conceptual translation of the paper-based design into a virtual format, and prototype evaluation using different UEM class methodologies. Importantly, WDMHC encourages interactive features that depend heavily on end-users perceptions of interface usability, levels of success accessing and understanding information within the resource. Whilst this model provides a structured development approach to follow, for some researchers, the complexity and inherent timeliness required found that this could exclude its use within projects of limited scope, personnel, and funding.[231]

WDMHC framework consists of four phases with multiple steps in each (presented in Figure 2.1):

A. User, Task and Environment analysis – user characteristics, the environment of use and task identification
B. Functional and Representative analysis – how content is represented on the website, including visual and graphical representation, relationships between information elements and flow, design of information architecture and comparison to other websites
C. Inspection Method Application – methods to identify major conceptual or design flaws including heuristic evaluation, keystroke modelling, cognitive walkthroughs and

applying benchmarking (such as HONcode [post-release accreditation of content reliability and credibility provided by Health on the Net Foundation] and W3C compliance)

D. Expert, Content and User Testing – evaluation methods using various groups including usability testing with intended users, use of domain experts and analysis of content for readability and understandability



E.

Figure 2.1 Johnson and Turley[218] Website Development Model for Healthcare Consumers (WDMHC)

[Johnson CM, Turley JP. A new approach to building web-based interfaces for healthcare consumers. electronic Journal of Health Informatics. 2007;2(2):e2. CC License https://creativecommons.org/licenses/by/4.0/. Image not modified].

This framework has been applied previously to supporting design (or re-design) and development of health care websites,[231] a social media resource centre for emphysema patients[232] and design of a web-based health information database and call centre.[233]

2.5 MAPPING DOMAINS AND CONCEPTS OF GUIDELINES

Comparison of domains and concepts found within the UCD approach (discussed in section 1.5), development guidelines derived from the Research-Based Web Design and Usability Guidelines (usability.gov) website (section 2.3), and elements described in the WDMHC framework were mapped to identify disparities that would indicate any disadvantage for developers to employ one approach, model, or framework over another. In Appendix 2.2, all domains were represented equally across all three evidence resources, including all 18 chapters usability.gov site found to either overlap or complement phases, although the disparity between evaluation approaches is acknowledged.

WDMHC framework provides a comprehensive list of evaluation activities across the three domains (user, content, and expert). HHS guidelines recommend heuristic evaluation within the expert domain and suggest less complicated task-scenario testing as the preferred method for usability testing within the user domain. The usability.gov website also has no specific chapter dedicated to evaluation methods. Instead, this is diffusely scattered within the descriptions of producing written information for the Internet. Therefore, postulating the application of either HHS guidelines (usability.gov) or deployment of WDMHC framework during the development of online health information resources would provide similar, comprehensive recommendations to develop a meaningful and valuable artefact. A proposed caveat to this statement is that undertaking appropriate usability evaluation methods and conducting rigorous, objective evaluation protocols and the ability to interpret outcomes may depend on developer experience, development team structure or available resources *if* the HHS guidelines are of limited assistance in this domain. Working within this context also highlights the nature of compromise between the end-users' needs, system constraints, design specifications, and time frame balanced within the chosen framework for development.

Chapter 3 will outline the comprehensive approach to research undertaken within this thesis by presenting theoretical perspectives, epistemological knowledge, research framework explaining how information technology facilitates practice, scholarship, and research. Lastly, a description of the accepted pragmatic definition of usability as applied to research within this thesis.

CHAPTER 3 - THE METHODOLOGICAL APPROACH TO THESIS RESEARCH – EPISTEMOLOGY, RESEARCH FRAMEWORK AND THE DEFINITION OF PRAGMATIC USABILITY

This chapter presents the pragmatic methodological approach to research undertaken within this thesis. In addition, a theoretical model as a framework to support the studies is described, and a pragmatic definition of usability is given, one that underpins the understanding of the relationship between usability, accessibility, and user experience in this research context.

3 THE METHODOLOGICAL APPROACH TO THESIS RESEARCH

3.1 CHAPTER INTRODUCTION

This chapter describes the different approaches to research that has been undertaken within this PhD. Crotty's research framework[234] presents the ontology, epistemology, theoretical perspective, and specific methodologies applied within this PhD. The rationale for utilising Shanks' Model of the Information Services discipline[235] as a foundation of this research program are described concerning usability scholarship. Further, Nielsen's usability definition[236] is refined to provide a pragmatic understanding of usability applied to research within this thesis. Finally, an outline of the studies and their relationship to research questions and each other is offered.

3.2 EPISTEMOLOGY

The research approach within this thesis is described using Crotty's framework[234] of ontology, epistemology, theoretical perspective, and specific methodologies applied. An ontological approach to research undertaken within this body of work is based on the understandings that humans construct individual meanings as they interact with the world,[234] and we as researchers accept that there are both singular and multi-realities at play.[85] Experimentation is a method to explore various perspectives of a single phenomenon. As the design of these studies examines aspects of usability and UX, there is an acceptance that one cannot accept a complete, verifiable, and validated view of the interaction between human users and a machine's interface. This research attempts to understand both the tangible aspects of interface structure and the emotional consequence of interactions trying to make sense of the relationship by observing and quantifying other people's experiences instead of basing decisions on our assumptions of how people engage with information. Precariously balanced between reductionist and essentialist views exploring usability aspects of the interface and interaction, this research uses finite measures specifically contextualised to use whilst inviting aspects of holistic evaluation by considering satisfaction measures, a construct of emotion relating to functional features within the interface. Although usability evaluation is deductive, the observations and measures initiated can only expand implications for a specific homogenous group of users involved in testing. Therefore, how other diverse groups of end-users encounter the phenomena cannot be predicted based on these findings.

Instead, like design research, the work undertaken within this thesis is abductive, where we as researchers would explore the possible solution to a problem determining its resolution.[237] Abductive reasoning encompasses the concept of incompleteness in either evidence generated or explanation provided and proceeds to the likeliest solution based on the information available.[238] Usability evaluations are unlikely to yield the same complete set of data on each occasion that the same method is applied; variation in the user or prototype generates a different 'set' of data. Each 'set' generated is distinctive and unique to each person, incomplete even when analysed in combination. It may provide a solution that could solve issues for this user type but may not assist other users with different characteristics.

A pragmatic view is reflected within this thesis, undertaken in a practical "*what works, using diverse approaches and valuing both objective and subjective knowledge.*"[239(p43)] Both quantitative and qualitative methodologies were applied as a *within*-study approach. This design is not unusual for user research in both UX and usability fields as this provides a precise but intricate process to view interface issues from multiple perspectives allowing for triangulation of the findings and interpreting the analysis to propose a solution. This thesis's work addresses a single proposition using independent studies, each applying a different lens to explore the role of undertaking usability and accessibility evaluation to improve the end-user experience when developing online health information resources. In addressing approach-based questions, this body of research seeks to explore the impact of usability evaluation on the development process as a source of evidence for practice and as a methodology - to elicit feedback from humans in an open and exploratory manner which is supported by this epistemology given that experience is subjective, contextualised, and individualised.

This work explores evaluation as applied in practice, outcomes examining the motives and circumstances to poor practice compliance and consequences for users and developers. Evaluations combine qualitative methods, including think-aloud, expert review and structured interviews, and quantitative methods such as questionnaires, card sorting, and performance-based activities. Grounded in the real-world practicalities of evaluation practice, this approach provides a theoretical perspective, best described as a pragmatic approach to understanding[85] this research. An exploratory methodology is open to surprising study outcomes,[240] has components that encourage reflections on experience from a personal view and contextualised for users lived experiences and background, whilst also undertaking measures that seek to define and quantify these reactions. Analysis of this data depends on the type of methods used. Statistical analysis was applied to determine the significance, frequency, and distribution of quantitative data such as error counts, performance measures of task-related activities, and hierarchical cluster analysis of card sorting data. Qualitative data is analysed using a bottom-up approach, similar to grounded theory,[241] where error descriptions are generated from verbal expressions to construct a comprehensive catalogue of interface features acting as a barrier to successful interface use in a contextualised activity across users.

3.3 THESIS RESEARCH FRAMEWORK - MODEL OF THE DISCIPLINE OF INFORMATION SYSTEMS

The Model of the Discipline of Information Systems was the framework to structure the research within this thesis, describing relationships between research, practice, and scholarship in context to information systems within the higher education sector. First published by Shanks, Arnott and Rouse,[235] this model demonstrates the continuous interchange between scholarship and research activities in professional disciplines focused on improving practice where information technology is considered an enabler for this exchange. Shanks model (illustrated in Figure 3.1) defines scholarship as "*the process of systematising existing knowledge relevant for a discipline.*"[235(p4)] The scholarship attained is by reviewing literature in information systems and other related disciplines to generate novel or revised theories derived from previous research or theories, not from data.

The scholarship also requires professionals to be cognisant of research and knowledge generated in the reference disciplines (including psychology, computer science, economics, management) whilst research is concerned with generating new knowledge, contributing theories or hypotheses to reframe a professional's education. Practitioners can contribute equally to research and scholarship as these opinions or narratives are considered different from research as they are not grounded in the systematic analysis of data. It is important to note that although this research is not being undertaken within an organisational setting, Buckingham et al.[242] suggests that 'organisation' is transferrable to a societal discourse (such as information is) as "*a system which assembles, stores, processes and delivers information relevant to an organisation (or society) in such a way that the information is accessible and useful to those who wish to use it.*"[242(p18)]

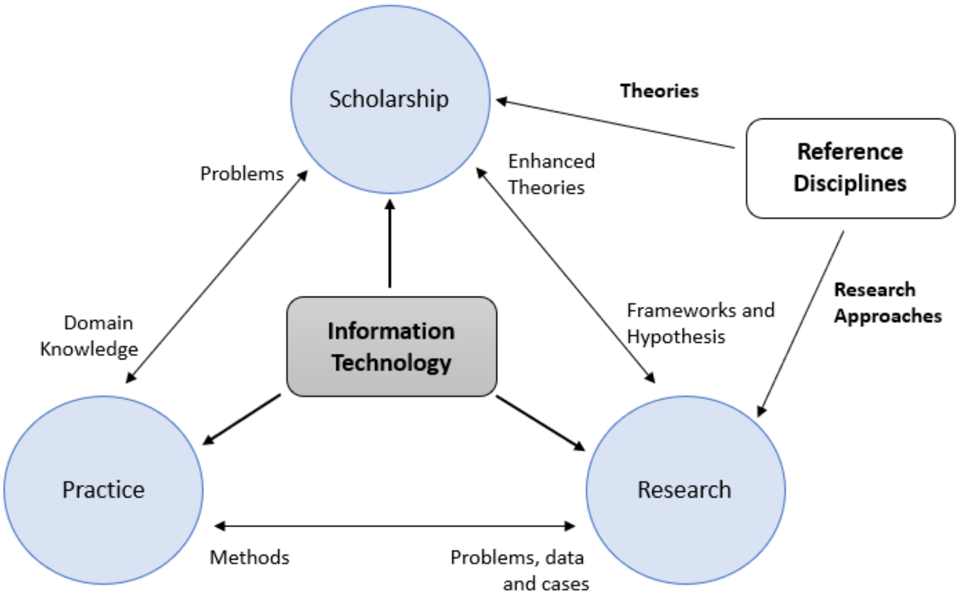


Figure 3.1 A Model for the Discipline of Information Systems (Shanks Arnott and Rouse[235](p4))

[G, Arnott D, Rouse A. A review of approaches to research and scholarship in information systems. Systems (Working paper series). 1993; Information Technology p.2-15. Figure recreated with permission of the author.]

Practitioners can learn through commercialised learning programs or free educational courses and network to exchange social or formal ideas to improve their professional development. The field of UX/usability perhaps can be considered a camaraderie of practitioners who have created a nebulous online support network out of necessity due to inter-professional relationships between within-team (internal) and external contractors contributing to the development and evaluation of online products. In a health information context, non-specialised development teams are multi-disciplinary, inter-disciplinary and trans-academic groups managed by core project personnel. This variation in skills and experience speaks directly to the need to support evaluations when this core expertise is missing or limited within teams.

Studies within this body of work explore evaluation through the lens of usability or user experience practice with an outlook on the difficulties that novice or inexperienced project staff face when working with collaborators undertaking online build and release of online health information resources. Exploring aspects of scholarship, such as finding, assimilating, and assembling learnings from all relevant reference disciplines, from peer-review literature to building practical understanding, when combined with scientific knowledge, can improve a shift from theory to practice.[243] Marcilly and Peute[244] suggest developing an evidence base for usability practice has stalled, with research outcomes from studies not focussing on reporting the conditions, application, and findings from usability evaluations.

There are limitations on exploring applications of UEM in the real world; researchers often report only single studies describing case studies with no follow-up research to corroborate findings,[89] inferences drawn from mathematical models[245,246] or studies that describe the underlying cognitive processes of the applied method on users. As with Shanks' proposition, usability research is considered crucial for generating new processes and usability practice methods. It is common to find new validated usability methods to complement new technologies, devices, software, or developed hardware. Through pioneering usability engineers, usability and UX research have been the foundation for developing international standards and informed practice by integrating theories, methodologies, and technical aspects from related disciplines, including HCI, psychology, interaction design, industrial design, and software engineering. As findings from this thesis will contribute to understandings of real-world evaluation practice during the development of health information resources. There are implications across three levels of scholarship where evidence, knowledge and practical recommendations are applied within and across the process, which can fill the scholarship gap. Dissemination of outcomes will be focussed on the level of:

1. Health systems and commissioning bodies – funding, resources and responsibility for usability and accessibility evaluations of health interfaces.
2. Project teams, usability and UX practitioners – increase the practical knowledge base and provide recommendations to improve practice.
3. Academic – improve the evidence base for usability practice within under-resourced development processes undertaken by non-specialised web development teams.

3.4 PRAGMATIC DEFINITION OF USABILITY APPLIED WITHIN THIS THESIS

Within this thesis, UX is acknowledged as the umbrella in which usability is one of many facets of investigation shaping current understandings of human-computer interaction. Research within this thesis will focus on a pragmatic, *tangible* measure of usability. Although not the focus, UX provides contextualisation to findings illuminating cultural and social elements that shape a user's 'baggage'[247] determining success or failure of each interaction within the real world.

Factors influencing usability as defined within Nielsen's Model of Acceptability[236] (Figure 3.2) are accepted as the elements contributing to an overall measure of 'utility', as a function of the system to complete an objective of the system, and 'usability' (how easily users can use the functionality of the system), utility and components of 'usefulness'.

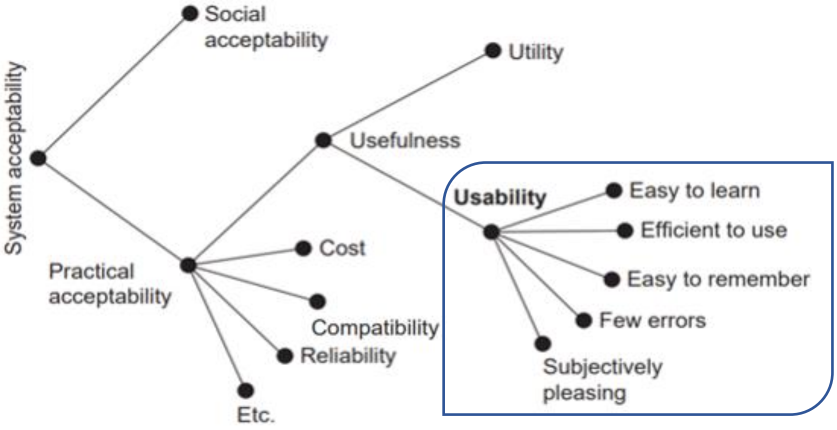


Figure 3.2 The accepted definition of usability within this thesis described by Nielsen's Model of System Acceptability Nielsen 1993[236(p25)]

[Figure is reprinted from Usability Engineering, Nielsen, J. Page 25. Copyright (1993), with permission from Elsevier. Image not modified.]

Operationally, this pragmatic usability assessment is measured across tangible concepts of learnability, ease and efficiency of use, memorability, and satisfaction[236] within real-life scenarios and environments of use.[39] The studies in this thesis will not attempt to analyse complexities of psychological attributes of satisfaction based on the reliance of human judgement on their previous experiences[248,249] characterised within UX research, instead subjectively eliciting user feedback levels of a single measure of satisfaction (as an indication of pleasurable use) by employing various psychometrically validated scales.

3.5 OUTLINE OF STUDIES WITHIN THIS THESIS

Five studies were conducted, each independently evaluating usability and accessibility contextualised to online health information resource development. The first study reviewed peer-reviewed literature using a systematic method to retrieve articles describing evaluation as a component of their online health toolkits (OHT), OHT being a relatively novel type of health resource that offers a validated approach to translate knowledge to inform health and to change practice or a prescribed behaviour.[250] This systematic mapping review focussed on usability and accessibility evaluation as reported within the literature, using literature databases as a proxy to explore current evaluation practice undertaken by project teams. A second study applied automated accessibility evaluation software to explore errors within 'live OHT interfaces' (retrieved from the Internet) as described in the mapping review literature in Study 1. This exploratory study provided an opportunity to examine how development teams employed evaluations during OHT development and how these processes shaped interface designs and error prevalence identified within post-release versions of the resources.

The third study within this thesis focussed on how process influences evaluation practice within the development process of a palliative care OHT, an exploratory study determining if a systematic evaluation approach during development could improve the user experience of the post-release interface and to identify barriers or difficulties to project team usability evaluation practice in the 'real world'. Of particular interest was a trade-off between complexity, inconvenience, recruitment issues and costs of undertaking rigorous usability evaluation with valuable feedback gained by engaging with human evaluators (both end-users and experts). Application of both quantitative and qualitative UEM was required to generate a complete 'picture' of interface errors used to generate a usability report or triangulate sources and types of errors identified by different reviewer groups.

The fourth study investigates the engagement and recruitment of end-users who are not typical user archetypes involved in usability evaluations. These individuals regularly faced barriers to successful use and access to online health information from within the community due to life circumstances and experiences that are the basis for interactive behaviours online. Community groups were invited to participate in a survey and online UEM using alternate recruitment strategies, creating two cohorts, one group completing surveys online and one group who returned via paper. These survey results were the basis for the stratification of participants within the final study of this thesis. Study 5 explored how individuals' socio-demographic factors and digital readiness levels as differentiated by digital health literacy levels influence interaction behaviours within a formal UEM of a palliative care website. Figure 3.3 presents a flow chart of the studies and their relationships with the research questions underpinning this series of studies.

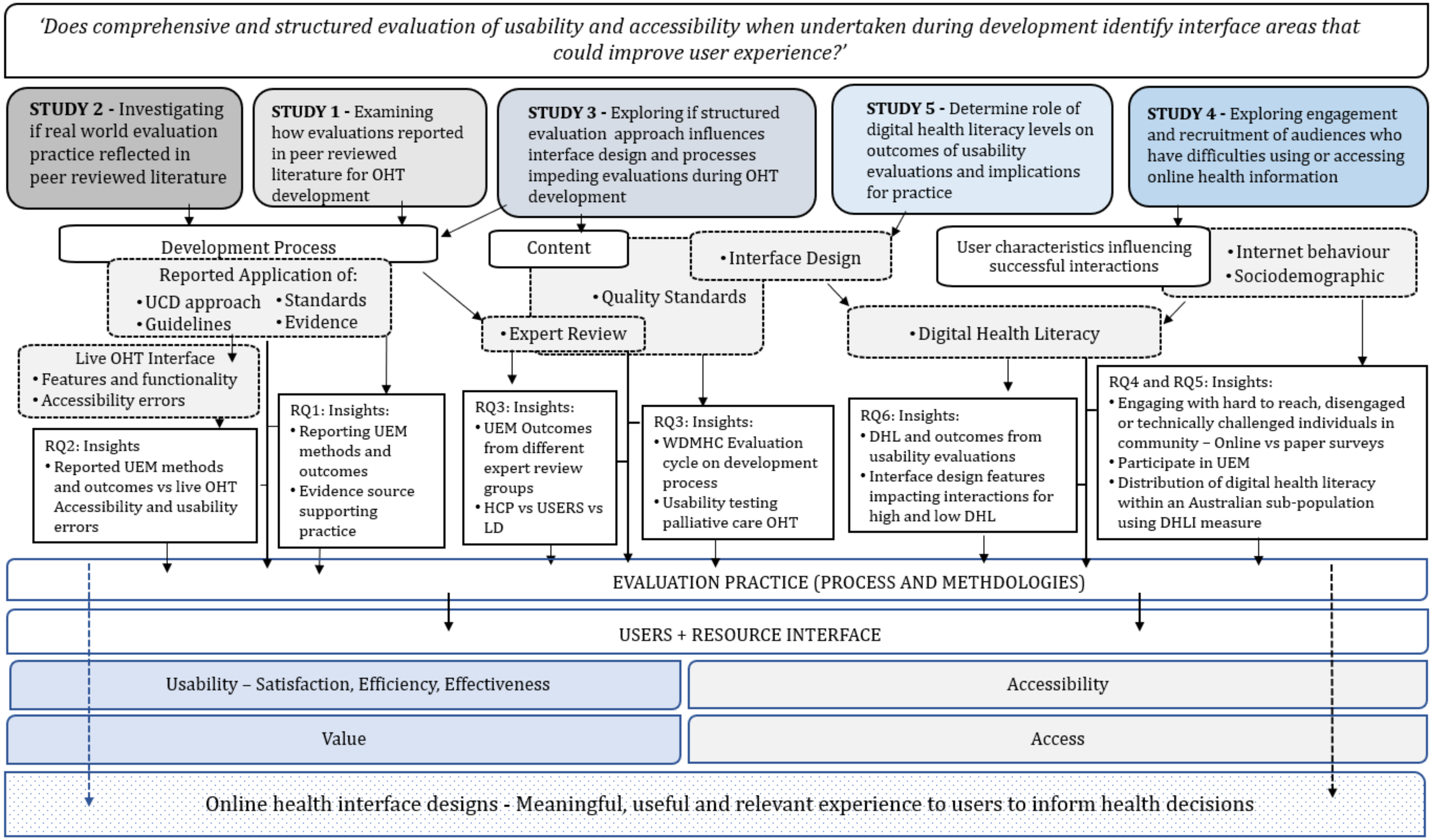


Figure 3.3 Overview of studies and intended insights across three processes, information design (content) and user characteristics impacting evaluation practice within development processes

CHAPTER 4 – EXPLORING APPLICABILITY OF THE PEER REVIEWED LITERATURE AS AN EVIDENCE BASE SUPPORTING EVALUATION PRACTICE WITHIN PRAGMATIC DEVELOPMENT PROCESSES

Chapter 4 presents the first research study within this PhD, investigating how researchers describe evaluation within the peer-reviewed literature. This chapter explores the current evaluation practice of development teams producing online health toolkits mapped within the peer-reviewed literature. The study examines if the peer-reviewed literature could offer evidence to support pragmatic evaluation practice by these teams within their development processes.

4 STUDY 1. A SYSTEMATIC MAPPING REVIEW OF THE LITERATURE – DESCRIPTIONS OF EVALUATION PRACTICE WITHIN PRAGMATIC DEVELOPMENT OF ONLINE HEALTH TOOLKITS

4.1 CHAPTER INTRODUCTION

This thesis's introduction has explored the complex environment that drives and shapes interactions between health consumers and online health information resources. Regardless of structure or level of prior experience, development teams play the central role in producing usable, relevant, and accessible health information resources balancing the wants of commissioning funders and the needs of end-users who are the intended audience. Therefore, evaluation of usability and accessibility is critical to ensure that both parties will be satisfied and crucially ensure interfaces are accessible, understandable, and functional for all end-users regardless of their socio-demographic characteristics, technological abilities, or previous life experiences.

Through the published literature, the study will explore current evaluation practice in context to development processes for online health information resources, focusing on current evaluation practice trends reported within the development of online health toolkits (OHT). OHT are an emerging online resource type that, although there is no accepted definition within the current literature,[251] have embedded multifaceted knowledge translation strategies that utilise high-quality research evidence to foster outcomes focussed on changing behaviours or practice.[252] Users are guided by their needs based on their levels of pre-existing knowledge and experiential learnings.[253] End-users engage with the toolkit's independent elements ('instruments') in a non-prescribed or non-systematic approach.[252] A contrast to traditional education courses where instruction is directed, knowledge is scaffolded, and sequential completion of activities are consequently linked to learning outcomes. Combining multi-formatted activities, divergent learners, and an online approach can maximise end-user engagement and learning opportunities but further complicate interface design at content levels (understandability and comprehension), interaction (functionality and navigation), and access. Therefore, evaluation is a critical activity within the development process for project teams when translating information for use across diverse learning activities or their health-derived instruments by heterogenous users. Evaluating levels of usability and accessibility can primarily assist end-users to interact successfully with the toolkit to change a health behaviour, increase their health knowledge or to improve practice in a health setting. The value of the peer-reviewed literature as an evidence base to inform usability or accessibility evaluations is unknown in real world development teams who are:

- non-specialised or non-traditional in structure, or
- naïve to content development or translation process, or
- not familiar in requirements to develop into the online environment, or
- inexperienced in undertaking UEM to assess interfaces, including interpreting feedback to inform interface improvements.

4.2 BACKGROUND AND RATIONALE

As described previously, user experience (UX) is an emerging field of research, practice and concept design that evolved in parallel with new technologies, software, and platforms. UX considers the relationship between the interaction of the user with design factors within the interface. UX is said to balance both the pragmatics (or holistic) aspects of usability: reliability, flexibility, goal completion satisfaction, learnability, memorability, effectiveness, and efficiency),[52] and satisfaction with hedonistic features of the interface.

In developing online health information resources, employing interaction design (IXD) within a UCD approach can enrich developers understandings of end-users perspectives, goals and experiences to improve interface engagement, function and aesthetics.[254] By applying design principles, developers can exemplify interactions between users and the interface,[255] particularly those factors that are critical in interaction design: labels, visual representations, relationships between physical objects or space and the online product, media that changes with time and behaviour and emotions.[255]

4.2.1 USABILITY KNOWLEDGE AND PRACTICAL GUIDANCE

As previously established, there is evidence of an intrinsic relationship between usability/UX research and practice.[256] In attempting to understand difficulties that non-specialist development teams encounter when finding information to inform processes, there is a need to explore the environment of practice, the status of scientific and practical knowledge, relationship to research and the role of standardised guidance in development.

Shanks et al.[235] acknowledge the interchange between research, practice, and scholarship information. It could be described as fraught and complicated, especially for novice or inexperienced project staff when implementing usability methodologies or applying understanding to interpret findings and reiterate designs. Development teams often have limited scholarship. These individuals are not usability nor UX professionals and do not have existing networks, knowledge or expertise that can support their application of the appropriate design or evaluation methods to the interface built. They do not have a professional relationship with knowledge, research findings, guidelines, or standards. Pragmatically, these teams would rely on established guidelines or sources of research evidence to assimilate these findings into customised practical knowledge or understandings to inform practice. In many development teams, there would be a reliance on contracted web design expertise, software programmers, or information architects to direct practice instead of prior knowledge from within the generalist team structure.[198]

Firstly, there is a need to address the understanding, knowledge, and practical expertise that associated computer scientists, information engineers, and programmers bring to the 'table'. As 'usability' was initially borne out of computer sciences, the concept of usability is not foreign to practising information technology specialists. However, the practice of undertaking rigorous usability evaluations and interpretation of the findings to produce a useable, desirable, and aesthetically pleasant artefact is notably absent. Ferré et al.[257] propose inherent difficulties for programming professionals to understand the role of usability in development, compounded by terminology and confusion over their role in the process. For example, a view commonly held is that programmers are solely responsible for system design, a belief that system design is independent of interface usability and that there is a need for a usability team to "*make it usable by designing a nice set of controls, adding the right colour combination, and using the right font.*"[257(p23)] Instead, this is not the case; system and interface interaction are the core of designing and will ultimately influence how end-users can successfully use the interface. Therefore, if collaborating computer engineers or programmers are involved in the development process, there is a high likelihood that their interpretation of usability is different from other team members. Language, terminology, understanding and interpretation design factors may be misinterpreted, or if responsibility for UX design lies with these professionals, the resultant product may have limited generalisable usability. However, it may also lack hedonistic qualities that drive engagement.

Secondly, the ability to search, find and use research-based findings or practice-driven instruction for usability or UX is difficult for developers for many reasons. Due to the referenced disciplines' multidisciplinary structure, knowledge to inform practice is not necessarily immediately translatable to usability and UX practice. Crucially, freely accessible high quality, contextualised resources are lacking. Practical information and accompanying expertise have been monetarised as commercial products to be on-sold.

There is a difference between scientific knowledge and practical knowledge, resulting in a theory-practice gap.[243] This gap is consequential and is unlikely to be filled by practitioners' experiences in the field as developers are quite removed from professional education and advice from practitioner networks due to a lack of qualifying credentials. According to Shanks et al.,[235] this leaves research as the remaining source for knowledge supporting usability for inexperienced developers. At this juncture, it is essential to discuss research as evidence and be discussed analogously to the definition and role that evidence has in influencing usability evaluation practice.

4.2.2 WHAT IS 'USABILITY EVIDENCE' AND HOW DOES IT INFORM PRACTICE

As with other disciplines, evidence is founded on data generated from research. For usability and UX practice, this information provides support, credibility, and confidence during iterative cycles of evaluation and re-design.[258] Usability evidence-based practice, therefore, is defined as "*the conscientious, explicit and judicious use of current best evidence in making decisions in the design of interactive systems in health care by applying usability engineering and usability design principles that have proven their value in practice*."[259(p131)] Like other disciplines, this places an impetus on applying research data as the primary tool shaping decision-making - moving away from common sense to derivative judgements based on supporting facts.[260] Marcilly et al.[244] refers to evidence-based methods (and processes) and usability design principles influencing interface appearance, interaction, and behaviours to drive evidence-based practice in usability evaluations. Evidence-based practice is knowledge-based, requiring contextual adaptation of existing evidence to the health information technology (HIT) evaluated through the practitioner's expertise (Figure 4.1).

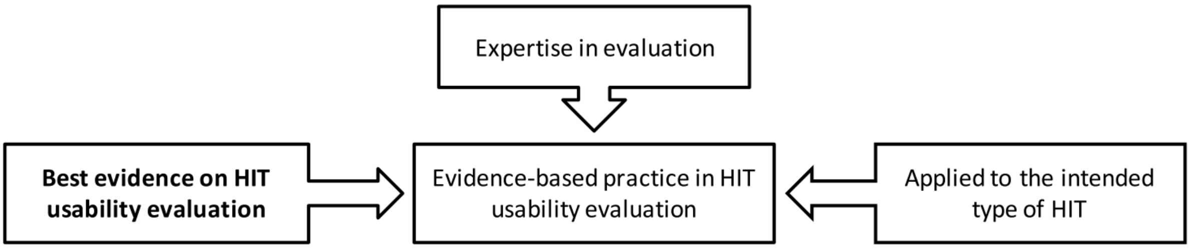


Figure 4.1 Schematic representation of how evidence-based usability knowledge feeds practice[244]

[Marcilly R, Peute L. How to reach evidence-based usability evaluation methods. Studies in health technology and informatics. 2017;234:211-6. CC License https://creativecommons.org/licenses/by/4.0/. Image not modified].

Therefore, evidence-based usability and UX practice require data from research that practitioners (or developers) need to adapt to suit their needs, including considerations of the type of resource, type of evaluation method, type of data required to demonstrate problems or issues and the stage of development where the evaluation method will be required. Developers seek to identify valid and reliable evidence[258] from UEMs in unbiased studies applying a user-centred approach. Research also has a role in demonstrating the value of usability within the development and in offering proof that some UEM in context has no value to interface reiteration.

4.2.3 TWO TYPES OF EVIDENCE

4.2.3.1 Standards

It has been challenging to develop universal development standards for design and processes due to diversity in industry, technologies, and content of the products.[261] The objective of international standards is to ensure compatibility, safety, and consistency across international borders. Examples of these standards are ISO9241-210 and ISO9241-11 relating to applying the UCD approach and design of the UI. Bevan[262] suggests that whilst these can support sound practice, they are difficult for practitioners to use in everyday practice. A more user-friendly and approachable set of guidelines are the freely accessible HHS Research-based Usability Guidelines (www.usability.gov), described in section 2.3, which are more comprehensive and accessible than the equivalent ISO standards. In an Australian context, there are no guidelines nor compliance standards that support practice, including any offering from the Commonwealth or

State governments impressing the minimum requirements to ensure usability and accessibility needs of resources can service the task or activity as required by the Australian public.

4.2.3.2 Research-based evidence – Peer-reviewed literature

A primary source of research-based evidence, especially for non-specialised project teams and inexperienced developers from an academic background, would be found within the in peer-reviewed literature (such as research articles, conference proceedings and digital theses) or within commercial online usability research series (either freely available or distributed via pay-per-view). This body of published literature should offer reliable and validated reports of research methodologies, rationale, findings, and outcomes data describing the development and evaluation processes undertaken during digital technologies production. Reporting how, when, and why usability or accessibility evaluations are conducted and what resulted provides an immediate source of evidence to support practice whilst demonstrating the value of the method to the UI produced. Researchers have observed this 'evidence' is not immediately translatable to practice, attributed to either context specificity (technology, content or environment of use) and/or a lack of *"complete and precise descriptions of the methods applied (e.g., type of method, profile and number of participants and/or evaluators, material, scenario, and heuristics used) and of the results obtained (e.g. only a small set of usability issues is reported)."*[244(p213)]

Marcilly and Peute[244] argue that this is the fault of the researcher for not fully disclosing rationale, methods, findings and outcomes, but scientific journals are complicit for allowing incomplete descriptions published without demanding completeness as seen in other fields of research or disciplines. Realistically, supposing standards are too difficult to understand or apply in practice. In that case, there is no local government support available, the expertise of the technical advisors is not sufficient to lead to acceptable design options, and access to usability guidance is either too general, not available for commercial reasons or incomplete - how will development teams manage. In short, *'If developers of online health information sources are inexperienced, unsure on what process or evaluation should be undertaken and when these should be applied, where are they going to find reliable research-based evidence to support their practice needs?'.*

The answer is perhaps demarcated between accessibility and usability. For accessibility, cognisance of WCAG (described in section 2.2), application of these standards within practice and a recognition of their importance to improving accessibility are reflected in advocacy for education by expert developers who work within the public domain (rather than academia, NGOs or private companies), are technically proficient and who are "in the trenches"[263(p119)] evaluating interfaces with users.[263] This perceived disparity in the adoption of WCAG within practice, firstly delineated by funding source, could be driven by the legal ramifications for public institutions if non-compliant and by the ready availability of assessment against expectation. Secondly, for developers interacting with users, WCAG could add value to the process and improve the end-product.[264] For usability, application of the HHS guidelines from usability.gov site or research models or frameworks is not reported conspicuously and not discernible within the literature. This question remains pertinent for professionals from academic or other disciplines and even for experienced developers or usability practitioners (who may have completed evaluations previously) facing new or emerging platforms, software, designs, content, user groups or devices. Instead, requiring the application of different evaluation methodologies may have situational changes that could impact processes such as using co-design or participatory processes, having unfamiliar management or development team structure and alternate funding arrangements.

4.2.4 USABILITY EVALUATION REPORTED WITHIN THE PEER-REVIEWED LITERATURE

Usability is a critical factor in the development process of all online systems, programmes, software, applications and platforms,[265] as failure to address identified failures or issues can impact UX and result in failure to complete tasks, boredom or frustration and in the case of medical devices or software, increase risks to patient safety through human error.[55] To not include usability or conduct inadequate usability evaluations within the online resource development process, and developers risk rendering a product less than optimally usable.[266,267] Business ramifications include costly redevelopment or redesign and the loss of brand acceptability or customer buy-in. Implications also impact the UX across all online environment areas, including e-Health, e-commerce, e-government, m-Health and devices, e-information, e-medical and e-learning.

4.2.4.1 Websites and learning platforms UEM

Researchers widely acknowledge that there is often limited expertise available, especially within non-specialised development teams, to conduct robust and rigorous evaluation protocols, interpret and apply results to iterative versions of the resource of evaluation outcomes.[197,218,268,269] A search of the formal literature has identified a scarcity of published material describing types of UEMs currently being utilised during the development of websites.

Primary foci of those retrieved discuss a critical analysis of shortcomings of evaluation methods,[61,270-272] statistical relevance and reliability of a UEM,[273-276] conjecture on the choice of method for specific contexts or objectives,[55,89,270,277-280] and descriptions of new evaluation methods, models, or frameworks.[218,233,245,266,269,281,282]

A systematic review of website UEM undertaken by Fernandez et al.[59] identified an increased interest in usability evaluations (number of publications). The authors highlighted that those deficits reflect poorly on the protocols conducted by developers. Only 10% of studies reviewed conducted formative qualitative UEMs during the pre-implementation phase of development which involves user-based testing. There were experimental design issues, lack of validation for UEMs conducted, over-reporting of usability issues, and scarce application of the test-retest iterative evaluation. Hence, 185 of the 206 (90%) studies in their review reported summative analytical UEMs at the point of implementation or final design before release. For learning platforms, the software's perceived usability can affect both the student's learning experience and the effectiveness[R] of the online course to influence learning.[287] The level of experience of these development teams was not ascertained within this systematic review, and therefore, there is an unknown level of previous usability or development experience within the development teams of these websites.

4.2.4.2 Mobile applications UEM

There are few articles published describing UEM undertaken during the development of mobile applications[289] for smartphones and tablets,[290] even though the forecasted number of mobile devices per capita is predicted to reach 1.4 billion.[265] A review of published literature has identified expert focus groups, interviews, questionnaires[289] and observational studies most frequently utilised when evaluating mobile applications.[265] A systematic review of mental health apps identified 42 studies that reported how these resources are applied in practice. Inal et al.[291] found usability was the intention in 21 articles, with the remainder split between feasibility and acceptability studies, with the majority reporting summative evaluations of prototypes or mature versions of the interface. A meta-analysis of 100 published studies describing UEMs in

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[R] Learning management systems (LMS) are integrated into websites, usability is related to function of the system and learner objectives which influences the interaction.[283,284] The most common usability evaluations undertaken when testing LMS are task related, as a measure of success or failure,[283] usage metric analysis as a measure of satisfaction[285] or heuristic expert inspection ignoring measures of effectiveness.[286] Studies also report that developers are reluctant to employ either complimentary UEMs improving outcomes across multiple levels of interaction[287] or accessibility,[286] methods that are attuned to multidisciplinary aspects of LMS and supported education resources[285] including qualitative usability evaluations involving users.[288]

the development of mobile applications and interfaces found 31 different usability criteria investigated, including the three essentials associated with general usability standard [ISO 9241:210(2018)[98]]; efficiency, effectiveness, and satisfaction.[292] Only 2% of studies measured dimensions of accessibility which is surprising due to the uptake and proliferation of applications or programmes available on a mobile platform, improving everyday life qualities for disabled or vulnerable users.

4.2.4.3 Electronic health records and electronic medical records UEM

For manufacturers of online electronic health record (eHR) software, the United States National Institute of Standards and Technology has developed guidelines promoting user-centred design and usability evaluations that focus on improving safety through the severity of risk approach to address identified usability issues.[293,294] Ellsworth et al.[295] completed a systematic review of the literature focusing on developing eHR software and systems that identified a relatively low number of valid scientific UEMs reported within the literature (120 eligible articles from a possible 4,800 identified). This paucity in literature was due to poor reporting, lack of usability experts to interpret outcomes and overall inconsistencies in the method's design and practical application. Surveys and think-aloud techniques were the most utilised (37% and 19%, respectively), with most usability evaluations conducted during or after the system's implementation and very few conducted early in the development cycle. Literature review of the development of interface design for electronic Medical Records (eMR) and eHR systems by Zahabi, Kaber and Swangnetr[296] suggested common violations to Nielsen and Molich's usability heuristics[297] across the studies reported in the literature, including inconsistency in design features, increased load on cognitive processing, inefficient use of language, presentation of information and error notification or prevention[S]. Further, a review of the literature describing personal health record (PHR) systems in Tasmania (Australia), Showell, Cummings and Turner[299] recognised invisibility of socially disadvantaged groups within development processes with HCP labelling these individuals as 'non-adopters' of PHR systems reflecting lack of access, low technological skills, low digital health literacy and poor education. Authors highlight the

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[S] Studies have found that usability evaluations of clinical decision support system software (CDSS) are rarely reported in the literature and are insulated from standard usability practice that are common in other health information systems or applications.[298] Post implementation evaluations in form of controlled trials are conducted and reported to measure effectiveness of the system on patient outcomes or to determine change in clinical practice, but there is limited literature describing formative, qualitative, multi-method evaluations undertaken during development of these systems to determine usefulness, utility, efficiency or safety.

importance of including socio-disadvantaged populations within truly representative samples during PHR UCD approaches to improve access and use for community members who have poorer health outcomes who interact with these health systems regularly.

4.2.5 ONLINE HEALTH TOOLKITS AS AN EMERGING INFORMATION RESOURCE

The Agency for Healthcare Research and Quality (AHRQ) defines a toolkit as "*a collection of related information, resources, or tools that together can guide users to develop a plan or organize efforts to follow evidence-based recommendations or meet evidence-based specific practice standards*."[252(p1)] Embedded tools within the toolkit are "*instruments*" that assist the end-users to complete specific tasks. These activities contribute to an evidence-based recommendation or standard,[300] and could be surveys, quizzes, podcasts, multimedia clips, online modules, or checklists.[252] Supporting knowledge translation strategies provides an advantage of online toolkits over static, unidimensional online resources that often engage users to provide information or re-direction to other sources and not necessarily promote further learnings or change behaviours. For online resources with a diverse user archetype, an online toolkit can provide multi-formatted activities that can support different learning styles recognised in formal education settings. Instructors are encouraged to design materials to engage with divergent learners to maximise engagement and learning opportunities. Usability is recognised as a key component of toolkit development by the AHRQ, producing a 'Usability Toolkit Checklist' within the Toolkit guidance document[300] buried within their website (www.AHRQ.gov). This checklist offers only assurance that usability should be a consideration during development and not a specific 'how to' undertake usability evaluation guide.

4.2.5.1 OHT evaluation in the literature

The inception of online toolkits is relatively new within the online information environment, and there are very few formal reviews or studies describing UEM applications during the development of this specific resource type. Barac et al.[250] published a scoping review of online health and healthcare toolkits to describe knowledge translation strategies employed relative to overall goals of the resource (could be to change practice or behaviour, disseminate information or build awareness) in a selected audience such as HCP, consumers, organisations, and policymakers. Developers of 31 toolkits had performed some form of evaluation of the strategies employed within the toolkits (31%), and 70% of this referenced evidence base for content included. Further to this study, Yamada et al.[252] completed a systematic review evaluating the effectiveness of toolkits facilitating implementation as a knowledge translation approach to support integrating evidence into clinical practice to change practice and improve patient outcomes. There has been no review of developers' current practice to the choice, application of, and outcomes from UEMs utilised in OHT production to date in the literature.

4.3 SIGNIFICANCE OF THIS STUDY

End-users engaging with OHTs have an opportunity to self-regulate learning. While being a delineated learning activity program, users can access these resources when an information need arises, at their convenience and without physical limitations of being involved with a formal learning program or environment. In theory, OHT are a perfect solution for the virtually connected user to improve knowledge, change practice or behaviour, and improve health outcomes personally or professionally. In real-world scenarios, physical, social, economic, technological, and scholastic limitations influence how, when and if a user can successfully access or use these resources.

With the ready adoption of digital and online tools within both consumer facing[301] and professional resources by developers to improve knowledge, increase self-management of health and facilitate behaviour change. The employment of usability and accessibility evaluations becomes crucial to ensure that these are 'fit for purpose' across a diverse range of users. Therefore, this systematic mapping review will explore the importance of development and research teams assessing usability by examining peer-reviewed literature as an in-proxy reflection of real-world practice. As discussed previously, there has been some literature published on the usability and accessibility evaluation methods undertaken by developers for other online types of health resources or software; however there has been no formal review of UEM applied to online toolkits. Peer-reviewed publications provide an essential methodological resource for developers or researchers undertaking similar development processes. By providing accurate, descriptive, and systematic narratives on applied UEM, interface modifications can significantly benefit all end-users. This review study will further identify methodological and reporting gaps within the online health toolkit literature and examine relationships between the development and evaluation of toolkits and whether usability or accessibility evaluation methods can improve the resource interface for the intended users.

4.4 RESEARCH QUESTION AND STUDY OBJECTIVES

RSQ1: How do researchers report usability evaluation methodology and outcomes in the peer-reviewed literature, and can this evidence support the project team development practice in building online health toolkit interfaces?

4.4.1 STUDY OBJECTIVES

1. Systematically identify and map the quality and comprehensiveness of published reports of OHT development processes and evaluation methods applied within.
2. Identify and quantify the frequency of UEM class and type undertaken at the different stages of OHT development.
3. Explore the use of standards for accessibility and usability to inform iterative changes in the development and implementation of OHT.
4. Examine the peer-reviewed literature to determine the extent of feedback generated from evaluations informing single or multiple iterative improvements during OHT development.
5. Investigate the relationship between the source of reported funding for studies and the evaluation of usability and accessibility undertaken during OHT development.

4.5 STUDY DESIGN

Figure 4.2 presents a schematic representation of this mapping review study. Methodology for systematic mapping review is described in detail within section 4.6 and includes search string development, data variables mapped from the literature and statistical analysis of data collected. Findings extracted from identified papers are presented in section 4.7, and section 4.8 explores both the current state of usability evaluation practice and if the application of UEM demonstrates an improvement of online health toolkit interfaces as described within the literature.

4.6 METHOD

The systematic mapping review was conducted to identify and comprehensively map the use of UEM for OHTs and to summarise the current information through an unbiased, systematic process that does not attempt to apply a formal assessment of quality to the extracted data.[59,77,302,303] Typically undertaken within the computer science field,[305] this methodology was chosen over types of reviews (such as systematic or scoping) as the objective was to identify gaps or changes in evaluation practice within the literature. Mapping review methods provide the scope to systematically examine all aspects of reported information without the need to synthesise nor apply critical analysis of the extracted data.[302] The study protocol was designed considering guidelines and protocols of other mapping review studies within the computer science field, including Casteleyn, Garrig'os and Maz'on,[304] Fernandez, Insfran, and Abrahão,[59] Petersen, Vakkalanka and Kuzniarz,[305] and Budgen et al.[306]

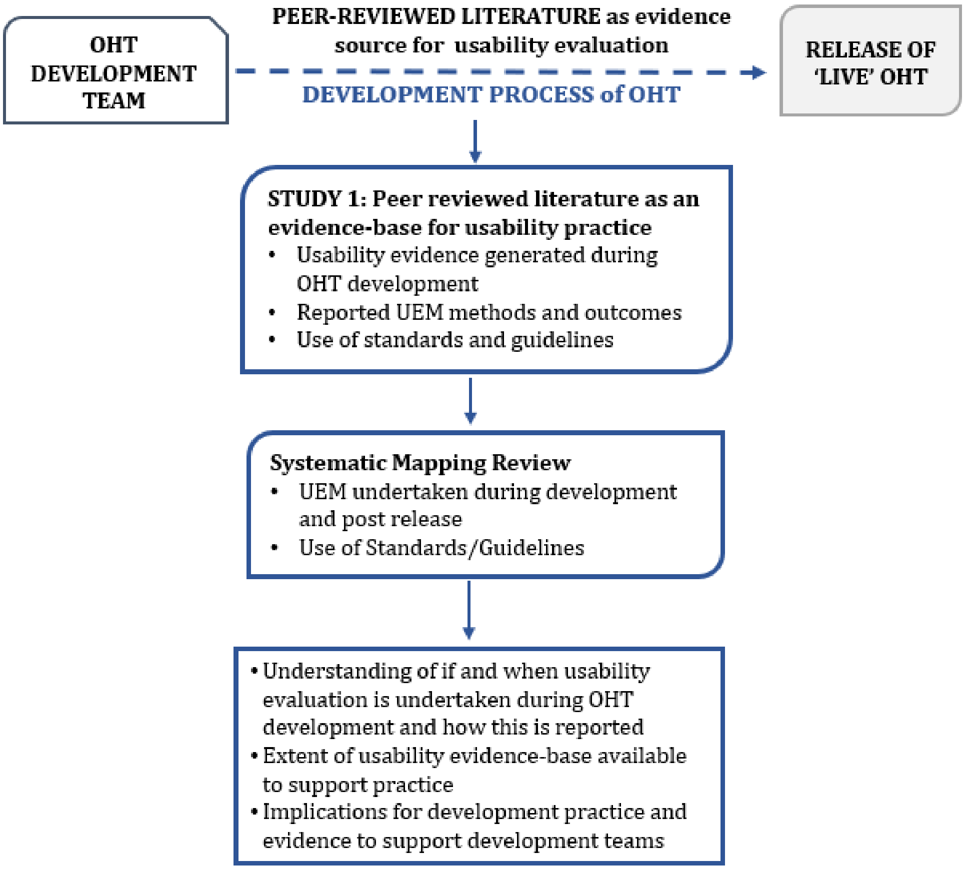


Figure 4.2 Schematic representation of Study 1 within this thesis

4.6.1 MAPPING REVIEW QUESTION

The primary objective of this study was to investigate the current application of usability evaluation methods during OHT development, and subsequently developed the following research question:

"How are evaluation processes applied by developers when developing online health toolkits and are these described comprehensively within peer-reviewed literature to form a reliable evidence base to inform practice."

4.6.2 SEARCH STRATEGY AND STRING DEVELOPMENT

A selection of digital literature databases and libraries was identified as sources of quality literature and a primary source of computer science studies, HCI, psychology, social sciences, health, and medical research. The following library databases were manually searched for conference proceedings and articles that described relevant online health toolkits:

- Electronic Institute of Electrical and Electronics Engineers (IEEE)
- Association for Computer Machinery (ACM)
- Trove
- Google and Google Scholar (applied to the advanced search filter and limited to the first ten pages returned).

An automated search within the metadata of digital databases was undertaken and required developing a search string describing three primary concepts from research question domains (domains of 'evaluation' methods, 'toolkits' as a resource type and within the 'online' environment). The following online databases were included in the automated search:

- Medline (OVID)
- Scopus
- ProQuest
- Web of Science
- PubMed
- CINAHL.

The 'health' domain was limited within each database search interface contiguous to date and language. The search strategy had no limits on retrieval dates; literature was considered from 1946 onwards, acknowledging the limited presence of relevant articles published before 2000. Validation of the initial search string's sensitivity was determined using test-review-modify-retest process, whilst search specificity was determined by the relevance of returned articles to the research question. Once finalised, the strategy syntax was modified for each database. Appendix 4.1 provides a copy of all modified searches. Table 4.1 presents the final Medline/OVID search string.

Table 4.1 Medline/OVID Search terms based on research question concepts (evaluation, online and toolkit)

Number	Searches
1	"Surveys and Questionnaires"/ or evaluation studies/ or interview/
2	(evaluat* or summative or formative or qualitative or focus group* or analytics or quantitative or interview* or survey* or questionnaire* or feedback or usefulness or usage or usability or user testing or accessibility or utility or applicability or medical informatics).tw,kf.
3	qualitative research/ or program evaluation/ or medical informatics/
4	1 or 2 or 3
5	(on line or online or website or internet or web).tw,kf.
6	internet/
7	5 or 6
8	(tool box* or toolbox* or toolkit* or tool kit*).tw,kf.
9	4 and 7 and 8
10	limit 9 to English language

4.6.3 PRIMARY STUDY SELECTION

All retrieved references were imported and managed within the EndNote reference management programme (including removing duplicates, sorting, sharing, and collating primary references). Two reviewers independently screened each retrieved article evaluating the title and abstract. Inter-rater reliability between reviewers was determined using Cohen's Kappa statistic and assumes both reviewers were not randomly selected and accounting for chance agreement. A calculated Cohen's Kappa of 0.82 indicated a high level of agreement between raters.[297,307,308] All publications, articles or conference proceedings were included if studies described an online toolkit guided by the AHRQ[300] definition and supported users within a health domain (including public health, medicine, allied health, including social work, psychology, physiotherapy, and occupational therapy). Studies were excluded if these described hard or paper-based toolkits, reported UEMs of health-related products or systems, highlighted resources hosting a single tool, or were introductory explanations for special issues of books, conferences, or workshops (Appendix 4.2 provides a detailed description of these criteria).

4.6.4 DATA EXTRACTION

Mapping review questions formed the basis of the data extraction criteria within 16 different categories, providing a structured approach to examining the data collated from each publication. As this is a novel mapping review for this type of online resource with limited information available, data harvesting from the included literature was wide-ranging in scope and detail. This approach was utilised to understand various aspects of the current practice environment, and therefore, specific questions were omitted from the discussion within this chapter. Table 4.2 provides mapping review categories, all review questions, and the rationale for including these within the process.

Table 4.2 Mapping review categories, review questions and rationale

Mapping categories	Mapping review question	Rationale
Demographics	DemQ1	Is there a relationship between the country of the primary author's affiliation and the frequency of reporting UEMs in OHT development over time?
OHT Development	DevQ2	How many studies describe how, when or whom the toolkit is targeted towards?
	DevQ3	How many authors describe the underlying knowledge translation approach and objective of the toolkit?
	DevQ4	How many studies describe the evidence base for the OHT development and the types of evidence used to underpin OHT in the literature?
	DevQ5	Of the included studies, how many report OHT effectiveness either as a complete resource or several of its components?
Overall OHT evaluation	EvalQ6	What was the type of evaluation conducted within OHT development?
Usability evaluation of OHT	UEQ7	Do researchers assessing usability in an OHT use a previously validated UEM, or is there a need to modify to create a new, specific version for this use or perhaps are not aware of UEM available?
	UEQ8	How are referencing standards applied in the OHT development process, and are these described or mentioned in the literature?
	UEQ9	Are there stages of the product cycle that predominantly have an increased number of UEMs conducted compared with other phases: Requirements/Research (early pre-design), Design/Development (early prototypes), Implementation (intermediate stage, stable prototype), Post-Implementation (final stage/version before

		release), Mixed or Multiple stage evaluations (iterative or formative evaluations across prototypes or designs) (IEEE[309])?
	UEQ10	What types of UEMs are applied and reported within OHT literature, classified by how each UEM is applied (inquiry, inspection, testing, simulation, analytical modelling) Ivory and Hearst [310]?
	UEQ11	What were the different types of UEMs that developers of OHT utilised, and are there particular methods that have preference over other UEMs?
	UEQ12	How are the UEMs completed during OHT development, are these undertaken using automated software/programs or manually by a human facilitator/moderator/evaluator?
	UEQ13	Were there any 'useful' feedback generated by those informed iterative changes in the design or interface by applying the UEM?
	UEQ14	Are methodological protocols or experimental conditions associated with the UEMs used to evaluate usability reported (i.e., number, archetypes, qualifications or experience levels of users, experts or evaluators involved)?
Evaluation of OHT accessibility	AccQ15	How is accessibility evaluation conducted and reported amongst developers of OHT - including how this is undertaken, when in the cycle. Does the evaluation method provide useful information to make iterative changes to the OHT?
Funding	FunQ16	Does funding source influence the likelihood of developers to undertake and report usability and accessibility evaluations at any stage of product development or release?

Mapping categories were expanded to explore concepts from the research questions creating a set of data variables for each; this was the basis for data collection from literature within the primary cohort included within the review. Appendix 4.3 provides a table of these data variables, including data descriptor extraction variables and their definitions. Data extracted from full-text articles and proceedings were collected and collated using an electronic template to ensure a standardised corpus of information across the complete cohort.

4.6.5 DATA SYNTHESIS

Mixed methods synthesis explored complex relationships between published data and implications for development team evaluation practice by synthesizing both qualitative (summarising the benefits or limitations of the UEMs undertaken in each of the studies) and quantitative data (calculations of variable data frequencies collected within each descriptor) to develop a descriptive narrative (or third synthesis).[311,T]

4.7 RESULTS

4.7.1 SEARCH RETRIEVAL

In total, 2045 publications were retrieved using hand and automated search strategies. After de-duplication across database retrievals was completed, a total of 1259 unique publications were identified. Once screened for relevance, 1,212 publications were excluded, as these articles did not describe OHTs. The remaining 47 publications had full-text versions retrieved for closer examination. On review of the full-text articles, a further 26 publications were excluded from the study. Twenty papers did not describe an OHT, as per AHRQ definition,[300] instead this literature described:

- A collection of individual tools or resources (*n*=3)
- Toolkits disseminated via a website in PDF format (*n*=7)
- OHT were not online (paper-based or hard copy toolkits) (*n*=3)
- Portal/platform or dashboard (*n*=7)

Six publications did meet AHRQ definition criteria but were excluded as the authors described:

- Pre-genesis or secondary OHT (*n*=2)
- Non-health contextualised OHT (*n*=2)
- Health system or service improvement software (*n*=2).

Appendix 4.4 provides the publication list of these 26 full-text articles excluded from the primary cohort for review. After screening, 21 publications were identified for inclusion into the primary cohort for the review. Figure 4.3 provides a flow diagram describing retrievals, inclusion, and exclusion summary of retrieved publications.

[T] Bubble plots were also created to visually represent relationships between sub-research questions and providing an overview of the areas of interest.[59,303,305] As a multi-variate graphing method, bubble plots are X-Y combination scatterplot with a third variable proportional to categorical values.[312] Comparative plots for mapping review questions are presented in Appendix 4.9.

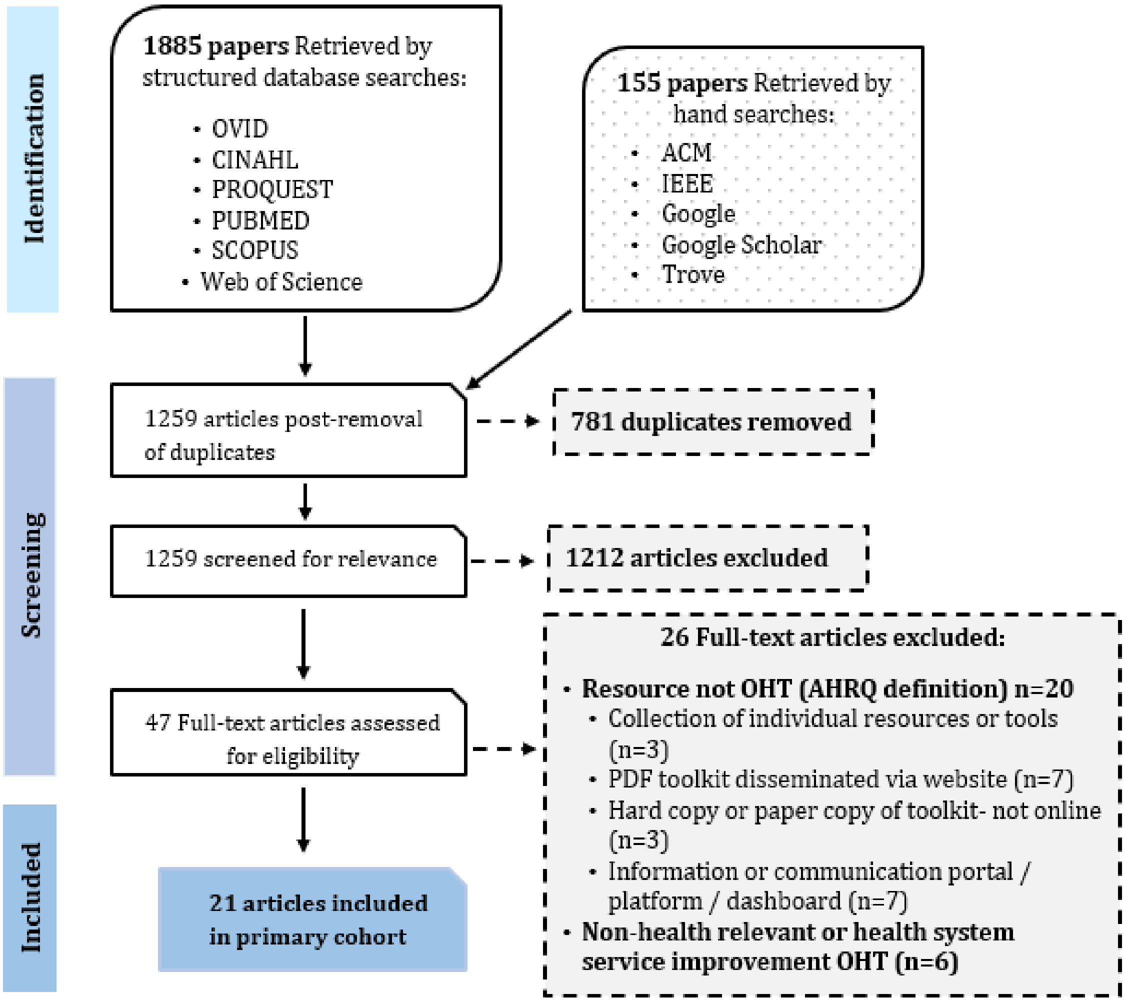


Figure 4.3 Based on the PRISMA flow diagram,[313] systematic identification and selection of articles, conference proceedings and theses for the mapping review

Although not a requirement for reporting publications identified for systematic mapping reviews, this diagram is based on the PRISMA flow diagram[313] (for systematic reviews) outlining the publication screening and selection process. The primary cohort consists of 18 journal articles published in peer-reviewed journals (A), one thesis (T1, Kading[314]) and two conference proceedings (C1[315] and C2[316]). As data was extracted directly from the text available, there were apparent detriments in the number of details available to extract between articles/thesis and conference proceedings. Although OHT relating to conference proceedings were available online, additional searches did not retrieve any related publications which could have been substituted into the review to provide further details regarding OHT development. Appendix 4.5 provides a complete list of included publications. Each publication represents a single OHT except Duggleby et al.[317] and Ploeg et al.,[318] who present sequential articles describing the development and implementation of the My Tools 4 Care toolkit. Two primary authors reported on different OHT, Duggleby [A2[319] and A3[317]] and Gannon [A8[320] and A9[321]].

This comprehensive mapping methodology is presented in four sections below, explicitly relating to questions posed within the mapping categories and how these reported outcomes inform the evidence base for OHT development teams:

1. OHT development team demographics reporting evaluations within the literature, audiences of OHT and funding bodies.
2. Prevalence and quality of usability evaluation reporting within the literature
3. Usability evaluation practice and development processes[U] , including the stage of development and pre- versus post-release evaluations.
4. Correlation between usability evaluation and application of accessibility standards during OHT development.

4.7.2 DEMOGRAPHIC CHARACTERISTICS WITHIN THE LITERATURE OF OHT DEVELOPERS REPORTING EVALUATION PRACTICE

Retrieved literature spanned eight years, published between 2011 and 2018. Journal articles were published between 2011- 2018, two conference proceedings in 2017-2018 and a thesis in 2016. Table 4.3 presents the literature included in this review. This table provides a descriptive summary of the authors, toolkit objectives, settings of use, intended audiences, funding sources, and types of OHT studies reported by development teams. As explained previously, not all data variables extracted from these papers (presented in Appendix 4.3) will be included within this chapter of the thesis due to the comprehensive data mapping extraction of this novel study.

Five different types of OHT studies were reported within the literature. OHT intervention study designs (9/21) presented both pre- and post-release intervention results.

[U] Aspects of data extracted from literature specifically relating to development and overall evaluation of OHT within this mapping review (Development Q3–Q6) will be discussed in thesis main, although the majority sits to the side of the primary exploration of mapping usability and accessibility evaluation in OHT development practice (Appendix 4.8).

Table 4.3 Summary of literature retrieved and included within the systematic mapping review

Ref.	Author, Primary author country affiliation	Toolkit type (Toolkit objective) - Setting of use	Intended users	Study type	Funding source
C1	Babul, S., Pike, I.[315] 2017, Canada	Management (Identifying and management of symptoms of concussion) - Acute clinical, educational and community settings	HCP / HC	OHT Intervention study including outcomes	NFS
A1	Champion, K.E., et al.[322] 2018, Australia	Information (Support for family and caregivers of Methamphetamine users) - Acute clinical, community, primary health, and educational settings	HC	Conceptualisation or development of OHT content	GOV
A2	Duggleby, W., et al.[319] 2017, Canada	Intervention (Support for spouses of women living with breast cancer) - Palliative care and community settings	HC	Feasibility or acceptability of OHT	C/P/NFP
A3	Duggleby, W., et al.[317] 2018, Canada	Intervention (Support for family caregivers of people living with both Dementia and chronic conditions) - Community setting	HC	OHT Intervention study including outcomes	GOV
C2	England, R., Shreeve, P.[316] 2018, UK	Information (Support end-of-life care) - Aged care, community, and palliative care settings	HCP / HC	Outcome measures post-release of OHT use	NFS
A4	Ezzat, A.M., et al.[323] 2017, Canada	Intervention (Support practice of physiotherapists treating Achilles tendinopathy) - Allied health and rehabilitation settings	HCP	Outcome measures post-release of OHT use	NFS
A5	Farndon L., et al.[324] 2016, UK	Intervention (Support consumer podiatry choices) - Allied health setting	HCP / HC	Feasibility or acceptability of OHT	C/P/NFP
A6	Fine, P.G., et al.[325] 2014, US	Management toolkit (Support management of pain of residents) - Aged care setting	HCP	OHT Intervention study including outcomes	C/P/NFP
A7	Gallagher, A., et al.[326] 2017, UK	Management (Support Healthcare Professionals to provide improved dignity of care) - Aged care setting	HCP	Conceptualisation or development of OHT content	C/P/NFP

A8	Gannon, M., et al.[320] 2011, US	Management (Support management of pain symptoms in patients) - Primary care setting	HCP	OHT Intervention study including outcomes	NFS
A9	Gannon, M., et al.[321] 2011, US	Intervention (COPD management of patients) - Primary care setting	HCP	OHT Intervention study including outcomes	NFS
A10	Gulati, A., et al.[327] 2015, UK	Intervention (Identifying skin cancer in patients) - Primary care setting	HCP	OHT Intervention study including outcomes	NFS
A11	Han, C., et al.[328] 2013, South Korea	Information (Support improved management of depression in patients) - Primary care setting	HCP	Outcome measures post-release of OHT use	C/P/NFP
A12	Hitzig, S.L., et al.[329] 2013, Canada	Intervention (Support improved quality of life in people living with a spinal cord injury) - Rehabilitation setting	HCP	Conceptualisation or development of OHT content	GOV
T1	Kading, V.M.[314] 2016, US	Information (Support care provision to patients with perinatal depression) - Acute clinical and primary health setting	HCP	OHT Intervention study including outcomes	GOV
A13	Lobban, F., et al.[330] 2017, UK	Intervention (Support for self-management for relatives of people living with psychosis or bipolar disorder) - Community setting	HC	Protocol for implementation of OHT	GOV
A14	Nicolaidis, C., et al.[331] 2016, US	Information (Support relationships between people living with Autism adults, their primary caregivers and health care professionals) - Primary care setting	HCP / HC	OHT Intervention study including outcomes	GOV
A15	Parker, D.R., et al.[332] 2013, US	Intervention (Improving management of COPD symptoms in patients) - Primary care setting	HCP	Protocol for implementation of OHT	GOV
A16	Ploeg, J., et al.[318] 2018, Canada	Intervention (Support caregivers of older adults living with Dementia and multiple chronic conditions) - Community settings	HC	Outcome measures post-release of OHT use	GOV

A17	Sinclair, L.B., et al.[333] 2015, US	Intervention (Support improvements of clinical access to services for women living with disabilities) **-** Primary care and preventative medicine settings	HCP / HC / OP	Conceptualisation or development of OHT content	C/P/NFP
A18	Starkey, M., et al.[334] 2016, US	Intervention (Support improvements in the care of people living with depression) **-** Acute clinical, and primary care settings	HCP	OHT Intervention study including outcomes	C/P/NFP

Type of literature: **A** = Journal article in a peer-reviewed journal, **C** = Conference Proceeding, **T** = Thesis

Country of primary author affiliation US = United States, UK = United Kingdom

Intended Users: HCP = Healthcare Professionals, HC = Health Consumers, HCP + HC = Both Healthcare Professionals and Health Consumers, OP = Other Professionals

Funding Status: NFS = No Funding Statement provided, GOV = Government funding (Local, State, Provincial, Federal or Commonwealth), C/P/NFP = Corporate, Private, Not-for-Profit Organisations

Those describing conceptualisation or early OHT prototype development and outcome measures at release were equally frequent (4/21 each). There were no observed trends in OHT study type preference across years of publication. OHT study funding status was retrieved from author conflict of interest and acknowledgements descriptions often at the end of the articles. Whilst six authors did not provide a source of funding, Federal or Commonwealth, state or provincial or local levels of government or indirect sources from broker agencies receiving government funding for distribution to development groups funded 38.1% of OHT. Seven (33.3%) development groups were supported by corporate entities, private trusts, charities, or organisations, including internal university or medical centre grants. 50% of United States (US) and Canadian studies (US-A14[331], A15,[332] T1; Canada-A3,[317] A12,[329] A16[318]) were government grant-funded compared with single publications from Australia (A1[322]) and United Kingdom (UK-A13[330]). Corporate, private, or organisational funding supported two UK studies (A5[324], A7[326]), three US (A6[325], A17[333], A18[334]) and one from Canada (A2[319]) and South Korea (A11[328]).

Data extracted from publications also provided opportunities to explore audiences for OHT and if funding arrangements correlated to both settings of use and usability practice was more commonly applied for resources specifically for these end-users. Descriptions of usability evaluations were reported more frequently when OHTs were designed for HCP (52.4%, 11/21) compared with health consumers only (19.0%, 4/21) and 28.6% (6/21) when end-users were generalised (both HCP and consumers).

HCP OHT were more likely to report interventions studies (6/11 publications) with pre- and post-measures to evaluate user satisfaction or gauge the effectiveness of the OHT overall. Alternatively, developers of consumer-targeted OHT reported different types of OHT studies except for OHT conceptualisation. OHTs for both general audiences were representative of all study types except publications describing an implementation protocol. Authors were also more likely to describe OHT for use within primary health or use within a community setting (10 and 8 studies respectively); four publications described OHT for use with acute-care (or hospital setting), and three were specific to use within aged care.

Further analysis demonstrates government funding supported an increased proportion of OHT developed for primary health care setting (5 studies) and the community (4 studies) comparatively than OHT specific for other health care settings and described across all three funding categories (refer to Table 4.3). US government prioritised funding toward OHT for primary health settings (4/6 studies) ahead of community-based OHT. Aged care, palliative care, preventative medicine, and allied health OHTs were supported by funding from corporate, private, or organisational sources rather than government funding. Data suggests US developers having an interest in acute clinical and primary health (describing in publications two or more OHT from multiple funding sources), funders from the UK supported the development of OHT for aged care and community, and Canadian funding sources supported developers of OHT in community and rehabilitation settings (as presented in Table 4.4).

Table 4.4 Intended user groups for the OHT for each publication included in the review

		Reference	Total (%)
Intended Users of Toolkit	Aged Care Nurses (RN, EN)	A6, A7, C2	3 (14.29)
	Clinicians - General	A6, A8, A9, A12, A15, A17, A18, C1, C2, T1	10 (47.62)
	Community Members	A1, A2, A3, A5, A13, A14, A16, A17, C1, C2	10 (47.62)
	Counsellors	A1	1 (4.76)
	Educators - General	A17	1 (4.76)
	General Practitioner / Physicians	A1, A10, A11, A14, A15, A18	9 (42.86)
	Non-Health Professionals	A1, A6, A17, C1	4 (19.05)
	Nurses - Acute (Hospital)	A1, C1, C2	3 (14.29)
	Occupational Therapist	C2	1 (4.76)
	Paramedic	A1	1 (4.76)
	Physiotherapists	A4	1 (4.76)
	Podiatrists	A5	1 (4.76)
	Primary Health Nurses	A1, A11, A14, A15, C1, C2, T1	7 (33.33)
	Psychiatrist	T1	1 (4.76)
	Psychologist - Clinical	A1	1 (4.76)
	Researcher	A12, A17	2 (9.52)
	Social Workers	A1, A17	2 (9.52)

Seventeen different professions/categories as intended users of various OHT were described within the literature. Authors identified three groups of health professionals to be the end-user for OHT, from much of the literature, non-specialist clinicians (10/21), GPs in primary practice (10/21), and nurses in primary care (7/21) were the most common. Occupational therapists (C2[316]), psychologists (A1[322]), physiotherapists (A4[323]), podiatrists (A5[324]), social workers (A1,[322] A17[333]) and counsellors (A1[322]) were all represented with specialised OHTs. Community-based end-users were intended audiences in 9 of 21 publications

Data extraction also highlighted functional OHT components (interactive features, tools, activities, learning tasks, clinical support instruments) specific to each audience type. Evidence or clinical practice guidelines were most common for OHTs developed for HCP and general audiences (present in 7 and 6 OHTs publications, respectively). 6 publications described downloadable information in OHT targeting HCP and consumers, 4 HCP OHT articles and in 3 OHT for health consumers only. Calendars, general resources, links to helpline support, hyperlinks to evidence resources and outbound links to local community groups or organisations were also functional components in OHTs targeting all three user groups. The collation of all OHT functional features extracted from publications is presented in Table 4.5.

4.7.3 PREVALENCE AND QUALITY OF USABILITY EVALUATION REPORTING WITHIN THE LITERATURE

Primary publications were examined for descriptions or processes and generated findings or outcomes from usability evaluation methods during the OHT life cycle. From 21 studies included, 14 reported conducting usability evaluations during either a single or multiple stages of the OHT product lifecycle.

Methods applied in isolation or combination with evaluations undertaken of the OHT as a 'whole' resource utilised outcome or process and outcome approaches. For example, two studies describing the conceptualisation or development of an OHT (A1[322] and A17[333]) did not undertake or report evaluation of effectiveness outcomes of their OHT, although developers did apply and describe outcomes from UEM approaches during development. Sources of funding did not reflect the likelihood of undertaking usability evaluations during OHT development. Half had secured government support, three studies (21.4%) had corporate, private, or organisational funding, and 4 (28.6%) did not report a funding source in the reviewed articles and proceedings. Each of these studies completed an assessment of usability by utilising a pre-existing, non-modified and recognised UEM.

Table 4.5 Functional components (interactive features, tools, activities, learning tasks, clinical support instruments) of OHTs

	Intended Audience			
Components of OHT	**Health Professionals**	**Health consumer**	**Health consumer and Health Professional**	**Total**
Algorithm - assessment or treatment	A4, A6, A18	-	C1	4
Assessment tools	A6, A10, A11, A12, A18, T1	-	A14	7
Blog by experts	A12	-	-	1
Brochures	-	-	A1	1
Calculator	A11	-	-	1
Calendar	A4, A6	A2, A3	A5, C2	6
Case studies	A10	-	-	1
Checklist	A4	-	A14, A17, C1	4
Clinical referral aid	A10	-	A14	2
Communication tool	A12	-	A14	2
Customisable letters	-	-	A14, C1	2
Decision support tools	A9	-	-	1
Description of evidence base	-	A13	-	1
Digital Image library	A10	-	-	1
Downloadable information	A7, A11, A12, T1	A2, A3, A16	A1, A5, A14, A17, C1, C2	13
Education module	A6, A11, A15, A18	A13	-	5
Embedded videos	-	A3, A13, A16	C1	4
Factsheets	-	-	A1	1
Forms	A11	-	C1	2
General resources	A11, A18, T1	A2, A3, A13, A16	A1, A5, A14, C1	11
Guidelines - evidence or clinical practice	A4, A6, A10, A11, A12, A18, T1	A3, A16	A1, A5, A14, A17, C1, C2	15
Helpline: telephone/ electronic support	A12	A13	A17	3
Hyperlinks to evidence sources	A4, A7, A12	A3, A16	A14, A17, C1, C2	9
Instructions for group activities	A7	-	-	1
Interactive forum	A12	A3, A13, A16	-	4
Interactive games	-	-	A1	1
Local community links	T1	A2, A3, A13	A1, A17, C2	7
Personal learning portfolio	-	-	C2	1
Podcast	-	-	-	0
PPT presentation	-	-	A1	1
Quiz	A10	-	-	1
Templates	-	-	A14	1
Webinar	-	-	A1	1

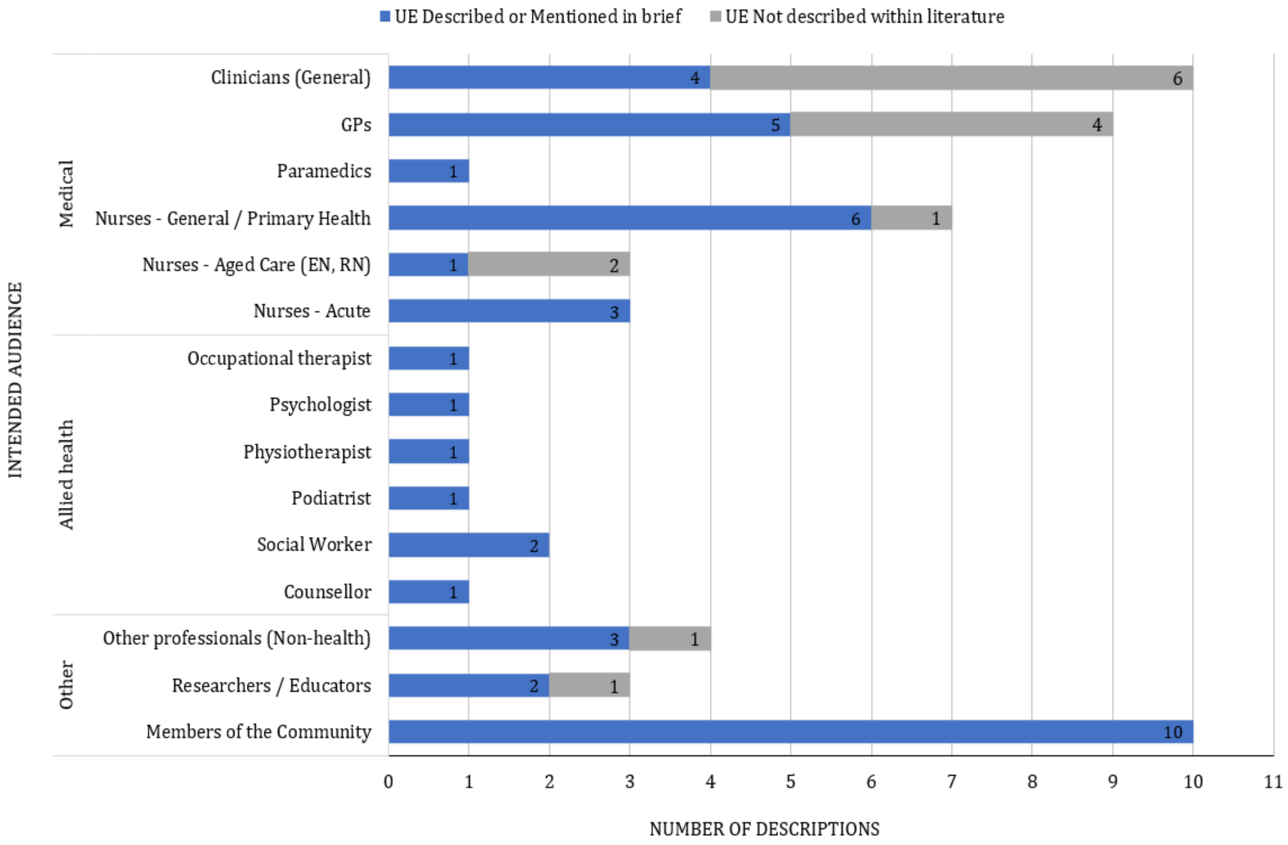
It is timely to note that the absence of descriptions within the literature cannot predicate (with any certainty) that no usability evaluations were completed; instead, no usability evaluation was described within the published study. Evaluations could still have been undertaken during development and contributed to the reiteration of interface design but were not documented. Further analysis found that reporting frequency usability evaluations increased for OHT developed for health consumers, both as a homogenous group and a mixed audience with HCP. All publications described usability evaluation processes, approaches, and outcomes within the related literature OHT designed for use by health professionals only, four studies from eleven (36.3%%) described usability evaluations whilst 63.6% did not provide adequate information on how, when, or why usability was a consideration during the development process. Table 4.6 describes audience type and reporting rates within the literature.

Table 4.6 Usability evaluations reported within review publications and their intended audience

Usability evaluation described within publication	**Intended audience**			**Total (%Total)**
	HC	HCP	HC and HCP	
No – not described within the paper	-	A6, A7, A8, A9, A12, A15, A18	-	7 (33.3)
Yes - described or mentioned in brief	A2, A3, A13, A16	A10, A11, A4, T1	A1, A5, A14, A17, C1, C2	14 (66.6)

HC=Health consumers HCP=Healthcare Professionals

Extracted descriptions of settings of use and usability evaluations indicated 'author intent' to ensure OHT produced was fit-for-purpose for intended end-users. Authors of primary care OHT described usability evaluations in 60% of instances compared to acute clinical care settings, which was 75% of the publications. For those for use within the community (A1,[322] A13,[330] A16,[318] A17,[333] A2,[319] A3,[317] C1,[315] C2[316]), allied health (A4[323], A5[324]), school (A1[322], C1[315]) or palliative care setting (A2[317], C2[323]); *all* developers provided a description of the usability evaluations undertaken. Two of the publications for OHT developed for use within aged care provided no information on usability evaluations conducted (A6[325] and A7[326]), whilst a third provided usability information (C2[316]). Developers were more likely to report undertaking usability evaluation if their OHT targeted nurses (regardless of care setting - primary care (A1,[322] A11,[328] A14[331], C1,[315] C2,[316] T1[314]), aged care (C2[316]) or acute care (A1,[322] C1,[315] C2[316])) and allied health professional (7/8 studies) or were generalised to community members depicting characteristics of UEM undertaken during OHT lifecycle (A1,[322] A2,[319] A3,[317] A5,[324] A13,[330] A14,[331] A16,[318] A17,[333] C1,[315] C2[316]). In OHT for specialised medical professionals consisting of GPs, general clinicians, psychiatrists and paramedics, developers reported details of UEM applied in 46% of publications [(clinicians (A17,[333] C1,[315] C2,[316] T1), GPs (A1,[322] A10,[327] A11,[328] A14,[331] T1[314]), psychiatrists (T1[314]) and paramedics (A1[322])]. Lack of usability evaluations could reflect presumptions by developers of medical specialists' abilities and knowledge of using online health information, where these professionals are assumed to have similar levels of skills and content awareness. Graph 4.1 provides a visual representation of usability evaluation descriptions and the intended users by profession and interest area.



Graph 4.1 OHT intended audience and descriptions of usability evaluations within the literature reviewed

4.7.4 *USABILITY PRACTICE BEING REPORTED WITHIN THE LITERATURE*

Data extracted from the literature provides a comprehensive view of usability evaluation practice undertaken during reported development processes.

The practice described by authors will be explored further by examining the following categories in turn:

1. Development phase where UEM was undertaken
2. Preferences in the class of usability evaluation methods applied
3. Types of methods undertaken within OHT development
4. Evaluators involved in the process
5. Feedback generated from UEM and reiterative changes to the interface.

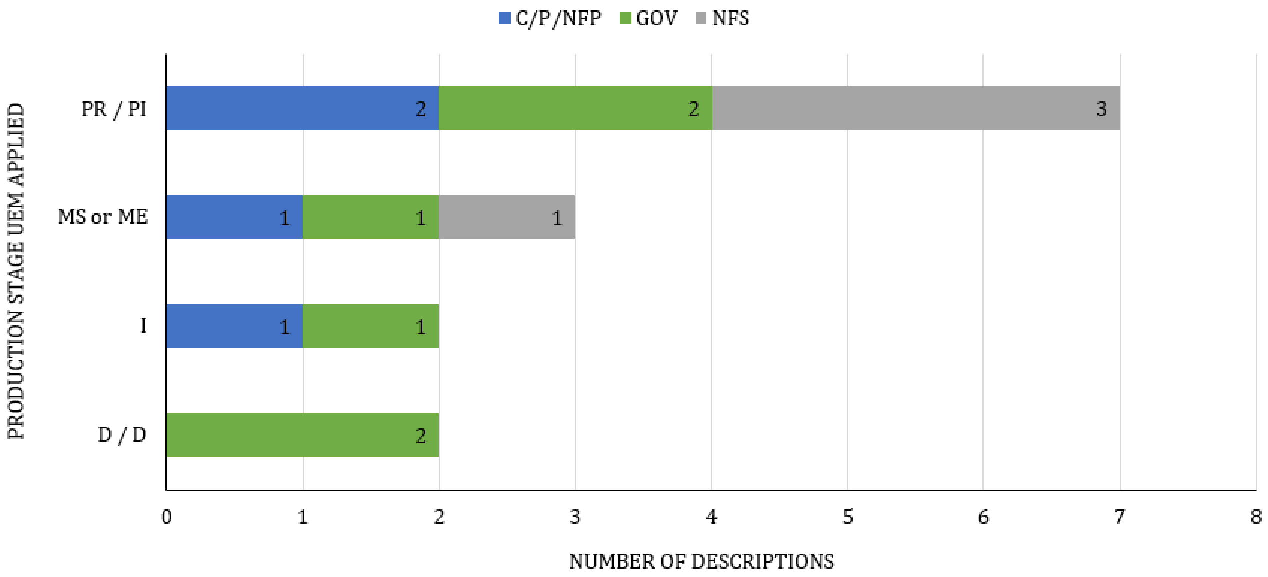
4.7.5 STAGE OF DEVELOPMENT WHERE UEM WAS UNDERTAKEN

Extracted usability evaluation descriptions were categorised into IEEE stages of product development cycle[309]; the analysis determined that 50% of developers completed OHT usability evaluations during the post-implementation/post-release phase. Only two publications (14.3%) reported UEMs during the early prototype design/development phase, and two studies applied UEM on a final prototype version during the implementation phase. Three studies (21.4%) applied UEM across multiple congruent stages or mixed development stages. No studies reported completing the evaluation process during the requirements or research stage of development. Table 4.7 summarises the IEEE stages of product development described within the publications.

Table 4.7 IEEE Stages for publications describing UEM application during OHT development

Production Phase UEM applied	Publications	Total (%Total)
Requirements/Research (pre-development phase)	-	0
Design/Development (early prototype)	A3, A13	2 (14.3)
Implementation (final version prototype)	A2, T1	2 (14.3)
Mixed Stage (MS) or Multiple Evaluation (ME)	A1, A5, A10,	3 (21.4)
Post-release / Post-Implementation	A4, A11, A14, A16, A17, C1, C2	7 (50.0)

Sources of funding did not impact the application of UEM within phases of development. Government funding supported studies that applied UEM across all product development stages (Graph 4.2), 2 in each design or development and post-implementation/post-release stage.



Gov = Government funding, C/P/O = Corporate, private or organisational funding source, NFS = No funding source provided within literature, D/D = Design/Development, I = Implementation, MS or ME = Stage or Multiple Evaluations across stages, PR/PI = Post-Release/Post Implementation

Graph 4.2 Stage of product (OHT) development and funding sources from the reviewed literature

Funding from corporate, private or organisations sponsored studies describing the use of UEM in the implementation (1), across mixed or multiple stages (1) and post-implementation/post-release phase (2). Those studies that did not indicate funding applied UEM during the post-implementation/post-release stage (3 studies) and a single study when UEM was applied across mixed or multiple stages of OHT development.

4.7.5.1 Preferences in the class of usability evaluation methods applied

A review of usability evaluation methods applied to OHT found no requirement for developing new or modifications of existing UEM for specific context or application. Instead, all developers who described undertaking usability evaluations within development lifecycles of their OHT reported applying a previously validated UEM as recognised and employed within the field of usability engineering. Inquiry-based approaches (15, 60.0%) were identified as the most frequently utilised and a reported class of UEM undertaken during online health information toolkit evaluation (focus groups, surveys, questionnaires, clinical vignette, field observations and interviews). Other UEM approaches associated with testing (6, 24.0%) and simulation (4, 16.0%) were also reported. No authors described utilising UEMs classified within both inspection and analytical modelling classes of usability evaluations. Table 4.8 summarises described classes and distributions within the literature. Developers applied a combination of different classes of UEM during development phases; two studies applied three during the development of their OHT (A1[322] and A10[327]), and three development teams completed two different classes of UEM (A11,[328] A17[333] and C2[316]).

Table 4.8 Class of UEM applied by developers for retrieved publications in this review

UEM Class	Publications	Total (%Total)
Testing	A1, A10, A11, A17, C2	5 (23.8)
Inspection	-	0
Inquiry	A1, A2, A3, A4, A5, A10, A11, A13, A14, A16, C1, T1	12 (57.1)
Simulation	A1, A10, A17, C2	4 (19.0)
Analytical modelling	-	0

Three UEM classes were applied across all four stages of development. Testing and simulation UEM classes were applied only during post-implementation/post-release stages or complementing the use of alternative types of UEM when evaluation is undertaken across multiple stages of development. Table 4.9 summarises the evaluation stage of OHT development and class of UEM reported by authors.

Table 4.9 Evaluation stage of OHT development and the class of UEM reported by authors within publications

UEM Class	D/D	I	MS or ME	PR/PI
Testing	-	-	A1, A10	A11, A17, C2
Inquiry	A13	A2, T1	A1, A5, A10	A4, A11, A14, A16, C1
Simulation	-	-	A1, A10	A17, C2

R/R = Requirements/Research, D/D = Design/Development, I = Implementation, MS or ME = Mixed Stage or Multiple Evaluations across stages, PR/PI = Post-Release / Post Implementation

Funding arrangements and frequency of UEM class applied were analysed (Table 4.10), government-funded developers were more likely to apply an inquiry-based class of UEM (6 studies) than UEMs from simulation (1) or test classes (2). A similar pattern was observed for studies funded by corporate, private, or organisational funds (4, 1, 2) and those with no funding description (5, 2, 2 respectively).

Table 4.10 UEM class applied and relative study funding source within OHT retrieved publications

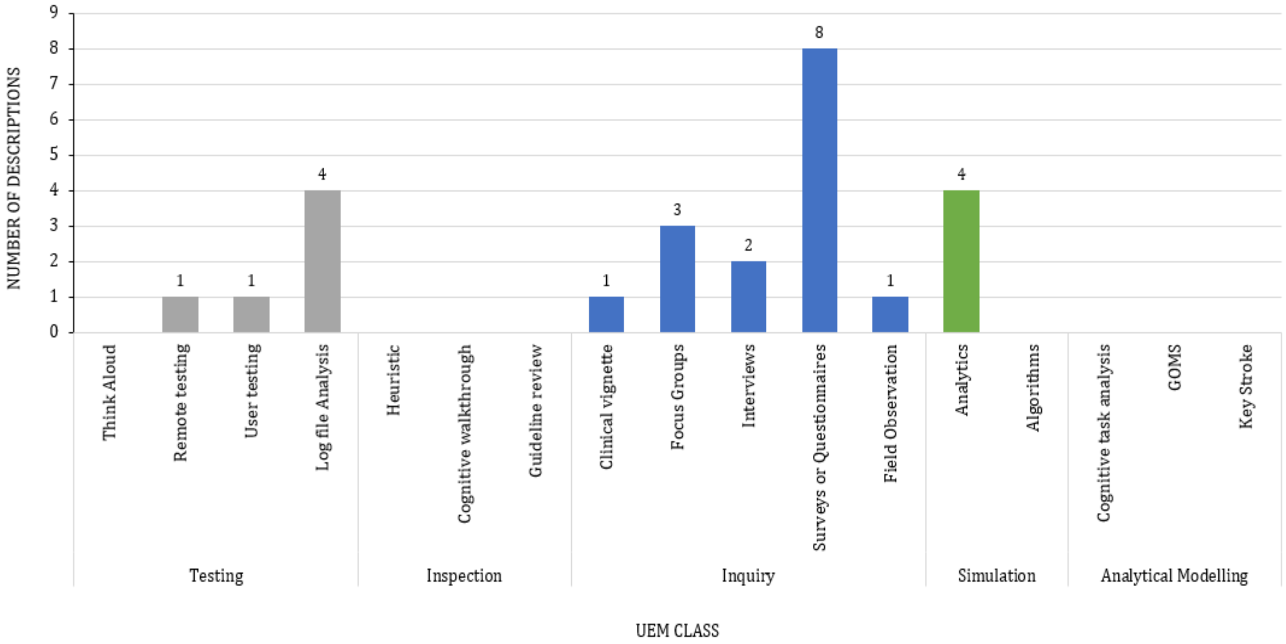
Class	Government	C/P/O	NF	**Total**
Inquiry	A1, A13, A14, A16, T1	A2, A5, A11	A4, A10, C1,	11
Simulation	A1	A17	A10, C2	4
Testing	A1	A11, A17	A10, C2	5
Total (%Total)	7 (35.0)	6 (30.0)	7 (35.0)	

Gov = Government funding, C/P/O = Corporate, private, or organisational funding source, NF = No funding source provided within the literature

4.7.5.2 UEM type undertaken within OHT development processes

Studies reported utilising a relatively narrow scope of UEM approaches that are reportedly available within the usability evaluation field (132 validated UEM across various HCI disciplines where usability is evaluated[310]). This group of developers did not describe traditional usability engineering UEMs (such as think-aloud, cognitive walkthroughs, heuristic evaluations, case studies or personas). However, it is unknown if these could have been employed (but not reported within studies represented within this cohort of literature). OHT developers applied seven different types of UEM from three UEM classes (testing, simulation, and inquiry), which were observed from within the extracted data. OHT developers applied inquiry-based UEM more frequently in 60.0% of publications than other classes of UEM, including surveys and questionnaires (8 [A1,[322] A2,[319] A4,[323] A10,[327] A11,[328] A14,[331] C1,[315] T1[314]]), focus groups (3 [A5,[324] A10,[327] A13[330]]), interviews (2 [A13,[330] A16[318]]), clinical vignette and field observations (1, [A4[323]] and [A5[324]] respectively).

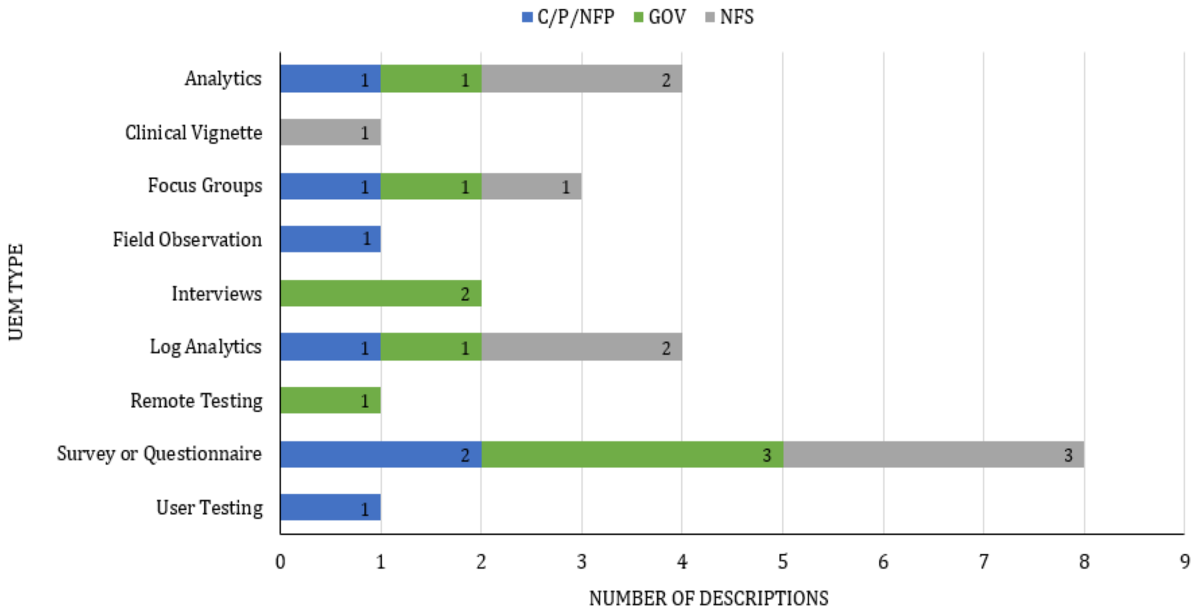
Four studies utilised site-log data analysis and website analytics (A1,[322] A10,[327] A17, C2[316]) and one study tested for usability either remotely or in-person (A1[322] and A11,[328] respectively). Graph 4.3 displays the distribution of UEM types reported class and description frequency within the reviewed literature. Appendix 4.6 presents the frequency of UEM type employed and development stages where the evaluation was conducted (classified into one or more categories; the summation of percentages is, therefore, greater than 100).



Graph 4.3 UEM class and types of UEM described within the retrieved publications

Four studies described using site-log analysis and website analytics in combination applied during MS or ME and PR/PI stages of development ([A1[322], A17[333]] and [A17,[333] C2[316]] respectively). OHT developers (A1[322]) provided the only description of utilising remote user testing across multiple development stages, complimenting the use of log file analysis, website analytics, surveys, and questionnaires.

One study (A13[330]) applied two different types of UEM, interviews and focus groups during the design or development stage only. The implementation stage of OHT development had only two studies employ inquiry-based surveys and questionnaires (A2[319] and T1[314]) to assess usability. Three studies (A1,[322] A5[324] and A17[333]) utilised five different UEMs across multiple stages of development from three classes. UEM from each class indicate the diversity of choice in UEM against funding base; Graph 4.4 illustrates similar utilisation levels between three funding levels. Government-funded studies described six different UEM from a total of nine, which was equal to developers with studies supported by corporate, private, or organisational funding, whilst for studies with no funding description, developers employed five different types of UEM.



Gov = Government funding, C/P/O = Corporate, private, or organisational funding source, NFS = No funding source provided within the literature

Graph 4.4 Type of UEM applied during evaluations of usability and funding source of publications within this review

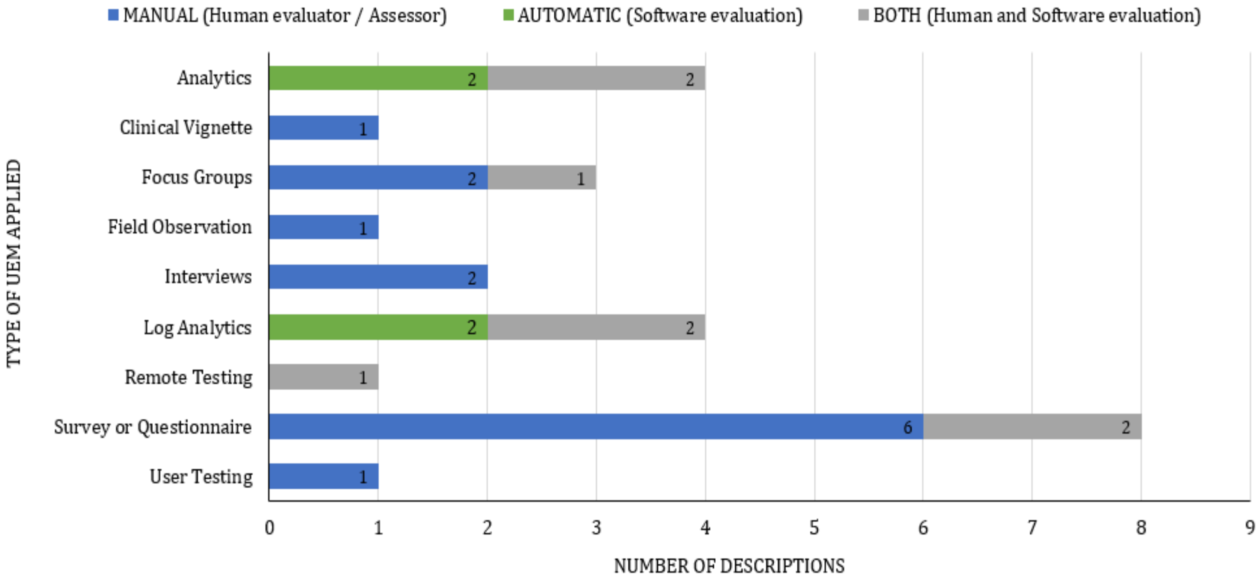
4.7.5.3 Evaluators and others involved in usability evaluation processes

Developers describing their usability evaluation methods were more likely to undertake methods requiring a manual approach involving human-generated data and an evaluator who assesses outcome data (Table 4.11).

Table 4.11 Role of humans in assessing UEM data as described in OHT evaluation publications

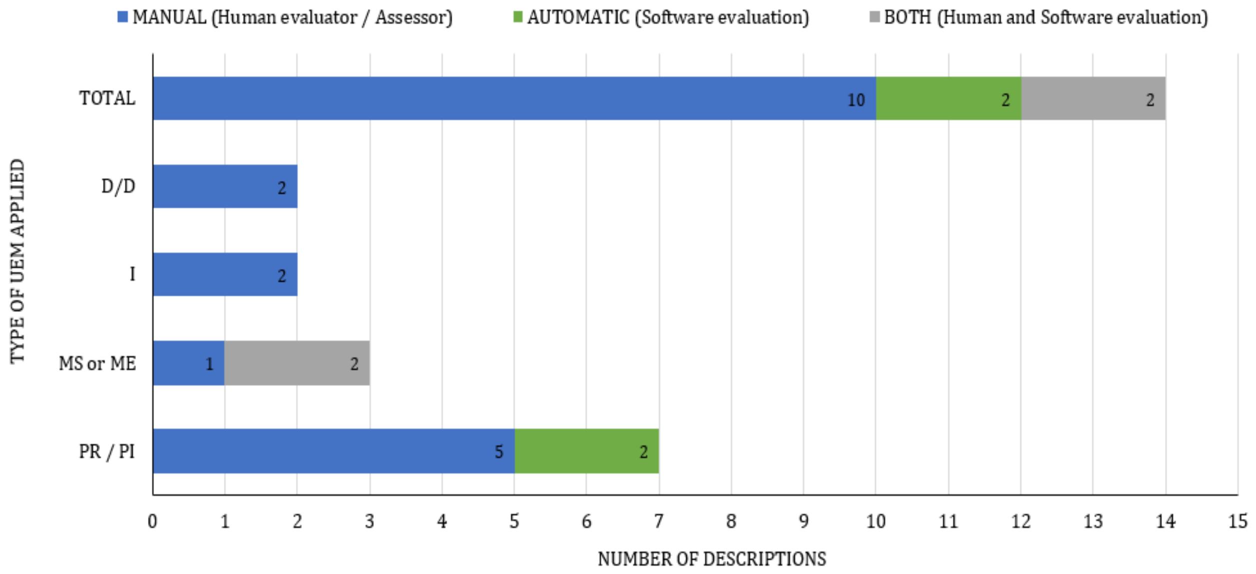
Type of evaluation completed by UEM	Publications	Total (%Total)
Manual - Human-generated data and evaluator	A2, A3, A4, A5, A11, A13, A14, A16, C1, T1	10 (71.4)
Automatic - Software generated data/ human assessor	A17, C2	2 (14.3)
Both manual and automatic processes across more than one class of UEM	A1, A10	2 (14.3)

Within 10 of the 14 (71.4%) studies, developers reportedly completed manual evaluation methods (requiring non-machine generation, reporting and analysis of data) compared to deployment of automatic processes. Mode of evaluation correlates to class/type of UEM undertaken (Graph 4.5) and stage of development where deployed (Graph 4.6), although automatic machine-based evaluations (automatic) were applied during post-release/post-implementation stages (2, 14.29%). These OHT studies are more likely to be government-funded and primarily involve conducting surveys and questionnaires, focus groups, interviews, group discussions, F2F user testing and assessing clinical vignettes.



Graph 4.5 UEM process involving humans as generators and assessors of data and UEM class described in publications

Two studies (A17[333] and C2[335]) described automatic evaluation processes where software generates data requiring human assessors to interpret findings. Studies A17[333] and C2[316] report using simulation (site-log analytics) and testing (web analytics) classes of UEM. Two studies reported a combination of UEM that involved manual and automatic evaluation processes across more than one class. A1[322] and A10[327] developers completed inquiry-based UEM (manual process human-generated data and assessor) and analysed site analytics (test and simulation class UEM) categorised as automatic processes. For many developers, the choice of UEM would be a function of the toolkit itself, with decisions driven by the characteristics and instruments present within the OHT and the type of feedback required for either reiteration or exploration of user behaviours within the interface.



R/R = Requirements / Research, D/D = Design / Development, I = Implementation, MS or ME = Stage or Multiple Evaluations across stages, PR/PI = Post-Release / Post Implementation

Graph 4.6 Stage of usability evaluation conducted and UEM process of assessing outcome data reported within-study publications

Unsurprisingly, UEMs with automatic processes for assessing data, belonging to the simulation and testing class, analysis and interpretation of website analytics completed post-release or post-implementation of OHT providing indications of use and user behaviour.

Assessment involving manual and automatic processes across UEM class related to those usability evaluations conducted during a mixed stage or multiple evaluations across stages. As with all experimental protocols, UEM protocol descriptions should include participants involved within evaluations, including users, evaluators, and experts (in either role). These descriptions were more likely to include information and explanations of participants involved in usability activities, 11 authors provided detailed explanations reporting the number and archetype of users involved (78.6%, A1-A5[317,319,322-324], A10-A11[327,328], A14,[331] A16,[318] C1,[315] T1[314]) as compared with publications (21.4%, A13,[330] A17,[333] C2[316]) who provided limited to no information regarding UEM protocols applied. Descriptions of how individuals were involved within the evaluation methodologies within the extracted data are provided in Table 4.12.

Table 4.12 Participant status within UEM as applied in the stage of development

Participant Type	Stage UEM deployed	Number, archetype of participants involved in UEM	No description of participants
Users	D/D	A3	A13
	I	A2, T1	-
	MS or ME	A1, A5, A10	-
	PR/PI	A4, A11, A14, A16, C1	A17, C2
Experts	D/D	-	A3, A13
	I	-	A2, T1
	MS or ME	A1 (No number), A5	A10
	PR/PI	-	A4, A11, A14, A16, A17, C1, C2
Evaluators	D/D	-	A3, A13
	I	-	A2, T1
	MS or ME	-	A1, A5, A10
	PR/PI	A16	A4, A11, A14, A17, C1, C2

D/D = Design/Development, I = Implementation, MS or ME = Stage or Multiple Evaluations across stages, PR/PI = Post-Release/Post Implementation

Studies described participants as users in the approach across all development stages. The type and number of experts participating in the UEM were expressed in two studies, with both UEM applied across multiple stages or mixed evaluation classes. A16[318] was the only study providing information on how evaluators engaged in the UEM approach during the implementation stage. No pattern was observed between funding source and descriptions provided within the publications of participants involved in the UEM approach as users, experts, or evaluators, especially considering user involvement, archetype and number evaluated.

4.7.5.4 Feedback generated from UEM and reiterative changes to the interface

Data analysis identified six studies (42.9%) where developers stated that usability evaluation data guided further OHT iterations or issues identified offered inferences for design improvement. UEM data descriptions within four of the 14 studies (28.6%) found that developers indicated generation of usability issues by UEM undertaken, although these were not necessarily applied to prototypes as expressed. Four studies gathered feedback or data from their evaluation methods but did not specify whether these were applied to the design in any meaningful way. There was no pattern observed between the source of funding and the descriptions of the application of user feedback to reiterate the UI.

Four further studies (28.6%) did not explain how, or if, usability feedback was utilised to modify prototypes. Table 4.13 presents data on how feedback was applied to improve the OHT interface being produced.

Table 4.13 UEM feedback applied, and stage of the OHT development cycle of usability evaluations described

Useful feedback via UEM	D/D	I	MS or ME	PR/PI
No - Evaluation method generated a list of usability issues (not applied)	-	A2, T1	A10	A16
Not described	-	-	-	A4, A14, A17, C1
Yes - Evaluation method provided guidance or inference for improvements in design based on usability issues identified	A3, A13	-	A5	A11, C2

D/D = Design/Development, I = Implementation, MS or ME = Stage or Multiple Evaluations across stages, PR/PI = Post-Release/Post Implementation

Two studies (A3[317] and A13[330]) applied feedback obtained to the early prototype during the design or development phase. Study A5 inferred changes to their OHT prototype across stages of development whilst developers of studies A11[328] and C2[316] used feedback to guide improvements of OHT during the post-release/post-implementation phase. Developers of OHT in studies A2,[319] T1,[314] A10[327] and A16[318] did not provide adequate information to determine if the feedback shaped the prototype interface. Appendix 4.7 provides a table summary of funding sources and descriptions of participants' roles and feedback generation to shape the interface in publications reviewed.

4.7.6 REFERENCING STANDARDS AND GUIDELINES DURING OHT DEVELOPMENT

All descriptions within the publications were examined for referenced standards or guidelines that could contribute to the development of usable, accessible, and high-quality OHT resources. These reference/standards could include usability.gov or ISO standards for usability, WCAG/WAI/W3C accessibility standards, and content quality/reliability (HONcode). An examination of all 21 studies found no descriptions by authors of consulting or applying recommendations from any of the referenced standards for usability, accessibility, or quality of content within the publications. Further, all 21 developers did not describe or comment on any evaluations, assessments, or modifications of OHTs to consider requirements for accessibility or application of universal design concepts to improve user experience. Hence, there was no relationship between relative funding sources supporting OHT development and a need to describe, report or mention accessibility or requirement to ensure universal access to their resources. Accessibility was not described in any of the 21 studies included in this review.

4.8 DISCUSSION

Systematic mapping of published literature has provided an opportunity to explore two dichotomies of OHT development. Firstly, outcomes from this review offer insight into the current practice of development teams when designing, developing, building, and releasing OHTs. Secondly, analysis of extracted data allows examination of quality and detail of published reporting, which is considered a source of evidence to support new or emerging development teams to undertake usability and accessibility of their OHT resources. Discussion of findings of this mapping review is strictly limited to data identified within the publications, and extrapolation of the intentions and/or processes of authors has been intentionally avoided.

4.8.1 SNAPSHOT OF CURRENT OHT DEVELOPMENT TEAM PRACTICE VIEWED THROUGH THE LENS OF THE PUBLISHED LITERATURE

The geographical locations of reporting development teams were relatively limited; those with increased numbers reflected nationalities endowing organisations to help researchers translate evidence/information into healthcare systems to support patient care provision. Canadian, US and UK-based research groups had the highest representation within publication cohorts, which is associated with these same countries having Government agencies/institutions supporting the integration of research evidence into healthcare systems. Specifically, Canadian Institutes of Health Research (CIHR), US-based Agency for Healthcare Research and Quality (AHRQ), National Research Council[18] and National Institute for Health Care Excellence (NICE) in the United Kingdom - alluding to these authors having increased awareness of the importance of publishing findings as an expected outcome from research activities, and in turn thus providing evidence-based research for the broader research/academic community. Publication frequency and awareness of the need to report outcomes did not translate to improved usability or accessibility processes or descriptions of the development teams' method. Similarly, the source of funding had no direct influence on these factors.

OHT development teams frequently reported needs assessment to ascertain appropriate evidence or resources and review or evaluate designs or prototypes before release as a preparatory activity during OHT development. UCD cycle encourages end-users to be involved in all development stages and evaluation, primarily in a consultative role within the OHT development process. Development teams engaged with user peer-groups and experts (academics, health professionals, staff, or workers within the OHT user setting) early within development cycles. These groups provided input identifying gaps or horizon scanning of problems for users in the real world,[319,322,323] provided feedback for iterative modifications of prototypes or wireframes,[322,324,330,331] and engaging in inquiry-based methodologies that generated evidence to inform OHT content.[317,322,324,331] Team composition and leadership roles within the development process were not defined clearly within the OHT literature. This created difficulty to appreciate the level of experience each team had within their existing structures and how this could have impacted evaluation practice.

In over 90% of papers, the evidence base for OHT content was reported within the literature. Instead of using traditional sources of evidence (such as literature reviews, reports or guidelines), authors preference inquiry-based activities to elicit responses from stakeholders[324,326,330,331] or engagement with their experts to identify suitable resources.[317,323,333] Data suggests that the development process diverges when considering the end-user group or profession and setting of OHT use.

For nurses in various settings (A7,[326] A15[332]), allied health professionals (A4,[323] A5[324]) and consumers (A2,[319] A3,[317] A13,[330] A14[331]), developers employed evidence generated from inquiry-based engagement eliciting robust interactions between academics, end-users, and experts either in a group or individual dialogues. Conversely, for OHT developers for clinicians or GPs, specialists or in acute/primary care settings, evidence for the content of the OHT was derived from high quality, reviewed or published and validated or accredited evidence. These findings were unsurprising, and high-quality evidence is standard for informing clinical practice and is crucial for providing current guidance to medical personnel. For either process, evidence base reinforcing OHT content regardless of the setting of use or intended audience must be sufficient in scope, explicit for OHT objective and proportionate to mitigate potential risk to users.[335] Both approaches equally produce a rich source of informed and relevant information. OHT structure and interface design are vital mechanisms for end-users to interact with OHT content. Usability evaluation and accessibility standards increase user experience opportunities and success levels to promote learning, change behaviours, or foster online social engagements.

4.8.1.1 Reflections of usability practice in 'real OHT development'

Similar discord between reported usability practice between teams developing for HCP end-user groups of medical specialities and those catering for a generic audience (heterogenous users including both nurse and allied health HCP and health consumers) is noted. For these generalised audiences, OHT developers were more likely to report UEM (including approaches, processes, and outcomes in publications). All authors described UEM for OHT designed for community settings or specialist care setting such as allied health, schools or palliative care. They indicate developers are aware of inherent differences of health consumers whilst readily accepting that nursing professionals are a heterogenous end-user group, where members have differential skills, education levels, ages, socioeconomic backgrounds, and technological capabilities. Current practice indicates that developers are aware of these differences where user-groups were nurses across all care settings and allied health professionals, including counsellors, occupational therapists, physiotherapists, podiatrists, and social workers. Therefore, usability evaluation is a practical solution for these development teams to ensure end-users can access and use the intended OHT.

Conversely, OHT development teams appear to treat HCP as a homogenous group and assume equal technological abilities, content knowledge and access to OHT. This presumption could be due to HCP serving in highly specialised employment or settings predicating extensive education and reflecting high digital or technological skill levels. As evidenced by a lack of UEM descriptors within the literature, OHT developers for audiences of medical specialists (such as GPs, psychiatrists and paramedics) reported undertaking UEM only in 45.8% of publications and were less likely if their setting of use was in primary health (60%) or acute clinical (75%). These assumptions allow developers to assert that usability evaluations of interfaces are not required and dismiss the need to report findings under the erroneous principle that professional status indicates equivalence in interacting successfully in the online environment. Nielsen and Loranger[117] define this as a *developer-centred user experience* whereby developers apply their intuition to interface design based on their assumptions of the end-user group abilities. From the findings of this review, this stipulation cannot be similarly applied to the development team's usability practice when intended audiences are nurses or health consumers.

Development teams of health toolkits were most likely to implement inquiry-based UEMs to generate user feedback, a choice reflecting an intrinsic relationship within 'health' as a discipline and a natural extension of human interactions between and within the health system (and all of its components). Inquiry-based UEM is reportedly advantageous to developers, providing user interaction feedback (concurrent response to interaction with the interface) which generates formative usability data and reflective feedback by the user framing their experience through analysis and interaction interface interpretation.[336] Identification and level of barrier obstruction to undertaking usability evaluation was well-defined within the literature. Authors seemed hesitant to employ, or perhaps report, more than one type of UEM across the development cycle, which may be due to several factors directly relating to practice - such as time constraints, lack of usability experience, or uncertainty in balancing data from different UEM classes.

Analysis of data indicates that time may be the crucial factor influencing choice and application of UEM for OHT developers, as indicated by over 50% of studies reporting isolated post-release UEM in-lieu of pre-release usability. Post-implementation UEM conducted in isolation was reported in 57% of studies. Although these methods are valid and still provide usability data, developers face increased expense in rectifying a live resource's issues, both monetary and sacrificing user experience of already engaged users. For some development teams, experience using multiple UEM in sequence or in-combination across development processes was not a factor for poor reporting behaviour. However, it is noted that authors did not deliberate on why or when they evaluated during development. There may be UEM undertaken but not reported within the literature, as developers may not perceive this reporting to be of importance.

Recognised as a process increasing opportunities to improve UX by allowing developers to explore different aspects of the UI[54] such as information architecture, navigation, information flow, visual representations, OHT developers applied simulation and test UEM classes in combination with inquiry-based UEM to identify interface issues. These included pinch or pain points, bounce rates, path analysis or interpretation of user engagement through time on page or heat map exploration. Specifically, analytical or log analysis UEM was most likely undertaken to report traffic trends for funding justification or as an indication of use post-implementation.[322,327] Usability evaluations of mature OHT (artefacts greater than 6-months live) were also not reported by development teams even though there would be an expectation of continuous cycles of evaluations to refine and shape interfaces of existing OHT. They were perhaps reflecting a decline in funding, raising issues around product sustainability due to lack of enthusiasm, unexpected costs, or natural project cessation.[54]

4.8.1.2 Use of guidelines, standards, and reference materials

The use of specialised guidelines or reference standards readily available to all developers did not appear to inform usability practice and consideration of accessibility within these development teams. Accessibility was not mentioned nor described in any of the publications analysed. Outcomes from this study cannot confirm with certainty that all developers were aware of or applied standards or guidelines to evaluations during OHT as these were not reported in the literature. Therefore, it is difficult to draw conclusions on the impact of incomplete and varied usability practices on interface design from the inconsistent or absent descriptions within the literature. An examination of post-release interfaces of the 'live OHT' was warranted to test the proposition that accessibility was undertaken but not described in publications and usability as reported impacted interface design of OHT (undertaken as Study 2 and described in Chapter 5 of this thesis). There was no tangible or real relationship between funding sources, required legal compliance with accessibility within the country of development and reported consideration of accessibility for audiences' inclusivity.

In summary, if taken from descriptions of usability and accessibility evaluations applied by OHT development teams as reported within literature identified within this review, there is strong evidence that online health toolkits are assessed using 'skunkwork' usability.[117] Skunkwork usability practice is driven by limited recognition or ignorance by funding bodies of user experience's importance with no approved budget or defined process to incorporate evaluation into development. Usability research is undertaken ad-hoc and is often guided by advocates within the team who are not experts in the field, making do with what they have available where some evaluation is better than no evaluation at all.[337]

4.8.2 CAN THE LITERATURE SUPPORT THE EVALUATION PRACTICE OF NON-SPECIALISED DEVELOPMENT TEAMS?

The retrieval number of relevant publications indicates a relatively small number of development teams reporting processes and outcomes from both development and evaluations of OHT. Two-thirds of studies explored in this review did report undertaking usability evaluation within the literature. Notably, a third did not describe details of UEM applied. Non-reporting affords novice developers ambiguity over processes undertaken, not described, or not evaluated or not completed at all. Subsequently, non-reporting or non-evaluation contributes little to improve the comprehensiveness or quality of an evidence base supporting best practice for development teams. Lack of guidance could impact how inexperienced, naïve or novice, non-specialised teams develop into the online environment, affecting process, evaluation and ultimately relevance and usefulness of OHT produced. Evident in OHT artefacts that are multifaceted or have complex or diverse audiences include multi-formatted activities or materials, and for whom the targeted users face barriers to access or use of online health resources. Characteristics of intended users directly influence digital skills and technology use or health literacy, including their SDOH. Therefore, it is important to discuss if literature within this review forms a credible and relevant evidence base that development teams could freely access to support their development or evaluation practice - particularly in areas of OHT complexities.

4.8.2.1 Evidence to support early development practice

The primary intent of developers was to report on the development of the OHT. Teams described various approaches when developing their OHT products, offering adequate narratives of possible directions to forge when designing products. Examples include participatory[331] or co-design models,[322] frameworks for knowledge and content creation (knowledge to action[314,329] and action research[326] frameworks), and approaches in generating or identifying high-quality evidence to support content development through inquiry-based activities with stakeholders or working with subject-matter experts. Descriptions, measures, or outcomes within other areas of development were inconsistent. For example, overall OHT effectiveness measures were not started, or if completed, these reports were incomplete[329] or are only described sparsely within the literature. Other elements were absent, such as the inclusion of content reliability, quality, and trustworthiness (HONcode accreditation). Whilst it is plausible to describe descriptions of OHT development as patchy with inconsistencies, it is sufficiently available to provide developers with a starting point, to prompt searches for other sources of information offering greater detail and explanations in how to develop or engage with stakeholders to identify user needs, develop content and formulate early prototypes of interfaces. After all, these processes can be flexible, varied, and individualised to specific OHT content and design factors that can be suitably applied to OHT catering for diverse audiences with barriers to using and accessing online resources. Unfortunately, this is in direct opposition to the rigours and consistency required for usability evaluations to produce meaningful, relevant, and useful information to improve OHT interfaces' inclusivity for all end-users.

4.8.2.2 Usability evaluation within OHT development

The reviewed literature more commonly offered examples of variable usability evaluation practice punctuated by poor reporting and, unlike descriptions of early development processes, do not offer the same level of evidence supporting development teams. Especially those looking to engage with information to guide practice and is crucial for development teams that do not have embedded or access to a usability specialist or interface design experts. Reporting why, how, and when evaluations were undertaken, participants involved, and outcomes or findings offer an invaluable source of evidence to inform others on undertaking rigorous usability. OHT developers were most likely to report moderately detailed usability evaluation protocols and provide an inconsistent explanation of process and outcomes. For example, authors recognised the importance of providing descriptions of end-users involved in each UEM (contextualised to OHT setting, intended audience and roles within activities). This consistency did not carry through to descriptions of experts involved in the process (limited to three studies[318,322,324]). An absence of expert descriptions directly impacts an audience's ability to extrapolate a reliable and repeatable working usability protocol. These protocol gaps become apparent when usability evaluations are considered a 'quasi-experimental' process by experts, development teams, authors and publishers.[338]

There is also a lack of clarity around using UEM to evaluate different types of interactive features that are defining features of OHT compared to uni-dimensional or flat online resources.[300] These features encourage engagement in in-depth complex interactions in which social interaction and building connections between learners are fundamental.[339,340] Activities within publications included interactive forums,[317,318,329,330] webinars,[322] games[322] or embedded videos,[315,317,318] encompassing other Web2.0 features - such as wikis, blogs, videos, podcasts, social networking, interactive user-expert webcasts, forums, and rich site summary (RSS) feeds.

The frequency of interactive features within the interface increases complexity for developers and the user. An increase in complexity impacts functionality consequently adds to the challenge for developers in assessing usability and accessibility. In effect, identifying and directly distinguishing issues affecting 1) end-users and interactive features, or 2) end-users and the native interface. Notably, limited interactivity due to Internet access and download speed should be considered during usability assessment of OHT, particularly for those OHTs where widgets demand high-speed or are large-format requiring large capacity data exchange.

Evidence of practice described within reviewed publications found no referrals to standards, guidelines, or reference resources for usability. However, knowledge of current guidelines and resources available for use by members of the development team would be dependent on an individual's field of expertise. For example, content specialists who work within the digital environment may know HONcode accreditation. Software engineers or developers of systems, platforms or devices should have exposure to IEEE, and ISO standards. Web designers may have experience in evaluating accessibility using the W3C/WCAG guidelines. However, in a real-world setting, this cannot be assumed to be typical everyday practice for any of these professional groups; the application of these standards would be based on awareness and knowledge and previous professional experience. Therefore, a lack of written testimonials may be a true reflection of development team structures rather than a blatant disregard, active circumvention of compliance or illicit adherence to legislation (in the case of accessibility).

4.8.2.3 Recommendations for practice from research findings

Based on current legislative requirements, OHT funded via government support should comply with the minimum accessibility standards defined within the WCAG2.0/W3C guidelines; otherwise, risk a breach of law. Although usability evaluation is not underwritten by law, funding support also impresses requirements on OHT artifacts that are usable, reliable, accessible, trustworthy, and effective for users identified as the intended end-user for these information resources. Perhaps there is a need by funding bodies to recognise relationships and responsibilities that their investments (in money, personnel, and time) carry forward to development teams and OHT artefacts to ensure that intended audiences for which it is designed to serve can provide:

- Information, linkages to communities or social networks
- Means for peer-peer or professional communication
- Sources of personal learning or professional education
- Clinical guidance for practice or service improvement
- Gateways to services or support organisations.

Funders should subsequently expect these artefacts to have undergone evaluation during development to assess end-user needs and use post-release to determine if this was an efficient mode of translation and cost efficiency (or value for money). By applying accessibility and usability guidelines and design principles, development teams foster a foundation for interface design, reflecting the needs of a specific design domain.[341] Adhering to guidelines and principles of evaluation and development to interface designs decreases types and frequency of usability/accessibility errors, decreasing the amount of time, effort and money to undertake the 'test-redesign-test' cycle during evaluations before OHT release.[341,342]

Overall, current literature does not provide adequate descriptions of the process, method, and outcomes of usability (and accessibility) evaluations to function as an evidence base to support development teams in undertaking rigorous assessments of OHTs. Further, the reviewed literature provides evidence at a superficial level of product improvements resulting from deploying UEM within the process. Although these are limited to descriptions of the interface areas improved through feedback generated by qualitative methodologies and reporting of analytical data indicating uptake and use by toolkit visitors. The actual indicators of successful mitigation of usability (or accessibility) errors are more likely to be revealed in artefacts that have been outcome evaluated post-release, longevity as verification of user acceptance and adoption and OHT which have been embedded into systems, sectors or services as a reflection of being an easy to use relevant and accessible resource. Developers did not report these indicators, and perhaps there is a need to develop a reporting standard for evaluation practice. One could be ideally based on the STARE-HI statement[343] however, simplified to a format such as the PRISMA.[313]

Therefore, the relationship between OHT longevity and outcomes of usability evaluations will be explored through post-release analysis of OHT interfaces in the second study of this thesis, reported in Chapter 5. Notably, descriptions within this literature review did not provide clear evocation if the application of UEM within OHT development hindered or added value to the process for development teams. Study 3 (Chapter 6) examines the application of UEM within a real-world OHT development approach to understand if different types of feedback can improve OHT interfaces and if these evaluations add value to the overall process.

The necessity for these evaluations will force a priori agreement between commissioning bodies and development teams to undertake and disseminate OHT development processes. Funders can support teams by establishing subsidies within funding structures and encouraging usability and accessibility evaluation by linking income to reportable milestones within project timelines.

Discrete funding markers could compel developers to undertake and report these processes to funders themselves and within peer-reviewed journals to build an evidence-based usability practice in online health information. Dissemination of usability evaluations via a standardised AIMRaD structure would allow experimental replication and quality and rigour analysis. Further, requiring developers to undertake, report and disseminate usability and accessibility evaluations of their OHT as an obligation tied to funding would not only increase the scope and quality of usability practice within projects but also positively influence levels of engagement with all end-users to assist in making health decisions for themselves and the people they care for.

4.9 STRENGTHS AND LIMITATIONS OF THIS STUDY

A limited number of publications identified in this mapping review presents difficulties in describing definitive practice trends or patterns in developing, evaluating, and reporting online health toolkits. The relatively few publications identified was despite the development and deployment of a comprehensive search strategy within a large number of databases, which can be considered a strength of this study. An essential finding of the mapping review was that only a few publications across multiple disciplines provided any description of OHTs, development, and evaluation - perhaps, reflecting a very small and inhibitive body of evidence to inform the development teams of process and methods. There are also limitations associated with the search strategy's inability to apply databases and hand search methods to identify all available literature in the review. There may also be a presence of bias within the review method relating to publication type where a greater number of papers with positive outcomes are more likely to be published. There were limitations associated with the systematic mapping procedure[59,303] as the objective was to categorise data extracted from the literature, which cannot provide the rigorous, formalised critical analysis and synthesis of empirical data provided by a formal systematic review.

4.10 CHAPTER SUMMARY

This study has explored if peer-reviewed literature could be considered an evidence base supporting usability and accessibility practice during the development of OHT, especially for usability/development naïve or non-specialised OHT development teams. Exploring content derived from descriptions provided difficulties in extrapolating real-world practice; this review methodology produced a fragmented data set that was problematic to explore without formulating assumptions or drawing inference from partial narratives provided within the literature. Whilst descriptions were adequate to inform developers seeking assistance on the development process. Literature could not form a fundamental evidence base to support or guide usability and accessibility evaluation practice in a real-world scenario. Findings suggest that usability and accessibility evaluation is rarely undertaken and reported in full *if* the practice is reflected within the literature reviewed. Development teams are likely to experience difficulties in the development process as inferenced by the high frequency of post-release or post-implementation UEM reported and the relative lack of in-depth user testing methods. Unfortunately, the literature excludes explanations as to why evaluations were not undertaken. Therefore, explanations could include practitioner ignorance or inexperience, flawed methodology or development process inhibiting the application of UEM. The analysis was careful to discuss findings in context with written narratives within each publication and which, due to the small numbers and patchiness of details, it was challenging to draw firm conclusions about the 'current state of play' within the OHT field of development. Could examining online 'live' versions of these OHTs provide further clues to current practice and the value of usability evaluation and accessibility to improve OHT interfaces by development teams?

The following study seeks to explore interfaces of 'live' OHT identified within this chapter's review and analyse features, functions, and interface design to compare published written narrative descriptions and real-life applications of usability and accessibility evaluations.

CHAPTER 5 - EXPLORING ‘LIVE’ OHT INTERFACE DESIGN CHARACTERISTICS AND MEASURES OF ACCESSIBILITY AGAINST EVALUATION DESCRIPTIONS FROM THE MAPPING REVIEW LITERATURE

In this chapter, Study 2 explores the pragmatic development and evaluation practice of OHT developers by analysing the influence of described usability evaluations on the shape of the post-release interface. Research considers the relationship between formative usability evaluation practice, levels of post-release accessibility and design characteristics of the live OHT interfaces identified within the peer-reviewed literature from Study 1.

5 STUDY 2. PRE-RELEASE USABILITY EVALUATIONS AND THEIR INFLUENCE ON POST-RELEASE OHT INTERFACES – A VIEW OF PRAGMATIC DEVELOPMENT PROCESSES

5.1 CHAPTER INTRODUCTION

This study builds on the systematic mapping review undertaken in Chapter 4. It explores 'live OHT' interfaces to determine if development teams considered *accessibility* evaluation a critical facet of interface usability by reviewing compliance in 'real world' artifacts from reported literature. The systematic mapping review explored narratives described within peer-reviewed literature as a proxy to current evaluation practice and observed the suitability of reported usability and accessibility evaluations to support development. Inconsistent reporting of evaluations within the formal literature by non-specialist development teams made this an unreliable source of evidence to assist practice. Accessibility was not described within the literature, and whether this crucial aspect of user experience was a consideration for developers is unknown given the importance of creating inclusive interfaces designed for a diverse audience of health toolkits.

5.2 BACKGROUND AND RATIONALE

Different realities are experienced by teams developing, designing, and evaluating interfaces in commercial versus commissioned health resource development. Organisations have a less complex brief for development: to design an interface purpose-built for a specific, homogenous end-user group accessing ample resources and readily available user representatives to generate feedback. The maturity of development teams affords a relatively timely and uncomplicated development process with an embedded evaluation approach. This multi-specialist or 'ideal' development team[198] has expertise across all facets of development, including usability or UX professionals whose sole purpose is to ensure the resource meets the developer's objectives and interface considers the needs, abilities, and requirements of the end-users. The key for specialist teams is that the end-users are known, their abilities recognised, and the level of engagement or knowledge of the content is not assumed (Figure 5.1).

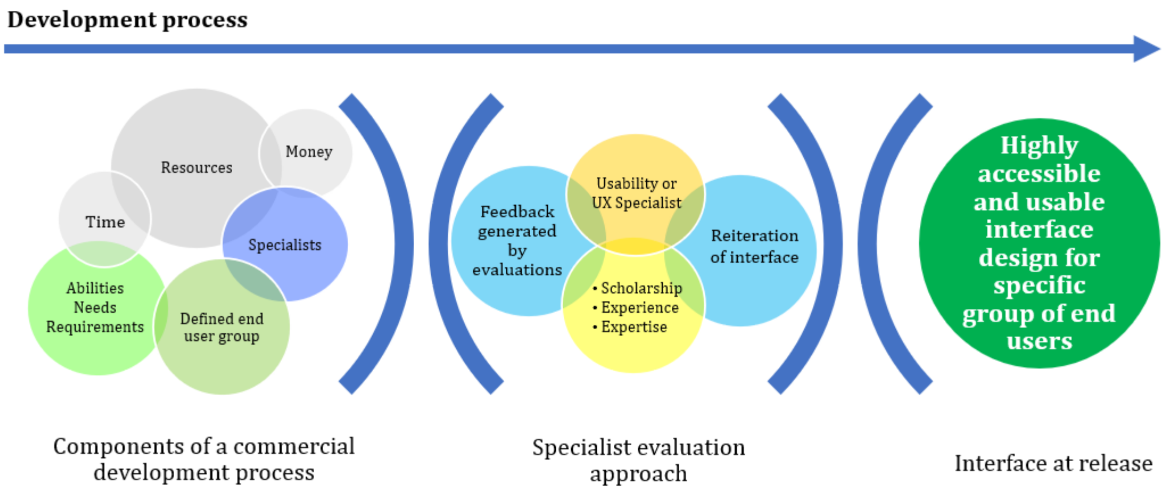


Figure 5.1. Diagrammatic representation of typical development and evaluation process

For developers of health information resources, team composition and resource allocation are unlikely to mirror those creating commercial interfaces.[344] Multidisciplinary project teams are examples of ‘non-specialised’ or ‘non-traditional’ development teams often in academic settings funded to translate research evidence into online websites, toolkits, apps, or devices.[106] Being non-specialised *does not infer* non-expert; instead, expertise is concentrated in areas other than development or evaluation. Project development teams have reduced resources, limited web development, usability, or digital translation experience, and often online development is commonly outsourced to designers and software programmers.[344] Further complicating relationships between resources, team composition and evaluation are abilities to undertake a user-centred approach in development settings attuned to academic processes and research.[106] These factors will be explored further in Chapter 6.

For many health information resources, audiences are generalised, and therefore, subsequent end-users are diverse in background, technical ability, knowledge, and literacy. Relationships and interactions with resources are likely transients for the duration of an illness or condition or, in the case of palliative care, until the person dies, and the resource is no longer required. Diversity of end-user populations requires the application of universal design principles[206] which seek to provide design solutions for a majority of the intended audience without modifications. Universal designs are created to ensure the majority of the audience can use and access information without specialised or adaptative requirements allowing for individual preference.[13,208] Ultimately, developing and designing interfaces for every user is impossible.[345]

Consequently, developers require practical skills and knowledge to weight evaluation feedback to render interface designs accessible and usable for a large proportion of health consumers[V].

Embedded UCD principles and advocates can help operationalise usability evaluation within team and organisation processes[346]; access to usability practitioners or UX specialists who understand usability principles, have experience applying guidelines, knowledge of usability evaluation methodologies, and interpret feedback to shape interfaces.[198] Non-traditional, multidisciplinary teams without evaluation expertise must rely on translating guidelines or standards or understanding outcomes from empirical studies to inform their usability practice to ultimately reiterate health interfaces for a population of end-users, including those whose levels of digital equity and experience place limitations on abilities to use health interfaces (represented in Figure 5.2) successfully.

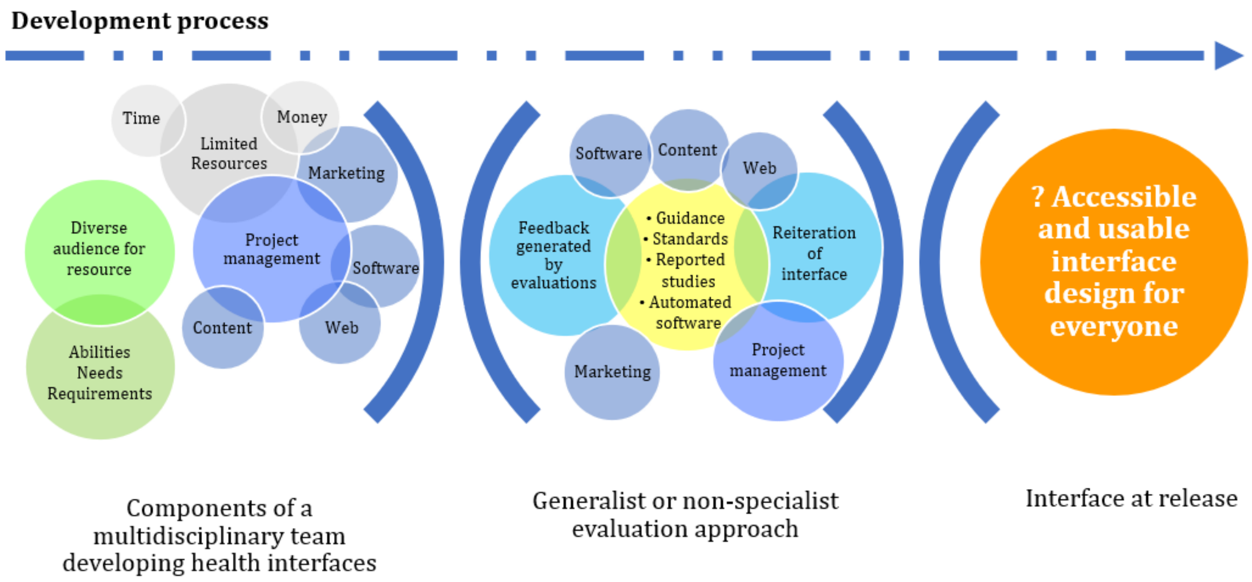


Figure 5.2. Diagrammatic representation of a multidisciplinary team developing health interfaces for a generalist audience

The systematic mapping review (Chapter 4) found that developers of health toolkits are unlikely to report usability evaluations within the peer-reviewed literature, and if included, descriptions are incomplete or fragmented in most cases. Guidance and standards were also absent from the

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[V] Non-specialised development teams could potentially benefit from guidance informing evaluation practice against a universally inclusive design criteria specifically for health interfaces.

literature. It was unclear if automated software was applied to inspect for errors to inform design modifications resolving usability or accessibility interface flaws.

5.2.1 ACCESSIBILITY AND THE WCAG STANDARDS

As established earlier within this thesis (section 2.2), Web Content Accessibility Guidelines[171] (WCAG) are conformance assessed stable technical standards which organisations can measure the extent of legal compliance for resource interfaces. However, implementing WAI/W3C-WCAG guidelines to digital artefacts does not ensure a person living with a disability can fully access websites.[223] Interface designs are assumptive of ability, knowledge, or technology for end-users to customise or augment browser features and are idealistic[24] expectations by developers. WCAG standards rely on a tripartite approach to web development for accessibility.[24] Success relies on:

1. Users being able to operate and set up their equipment
2. Development of content management systems, authoring tools, multimedia, browsers, assistive technologies that produce accessible and usable software/interfaces/technology
3. Design of content for online resources is accessible and is compliant with software/interfaces/technology.[347]

Unlike the complex nature of usability evaluations, assessment of accessibility rarely involves users or identification of issues using models or simulations due to the practical difficulties of hosting disabled users within testing facilities and variation in the assistive technologies used.[348] Conformance testing[26] of accessibility requires automated software tools (online services, applications, plug-ins or extensions for authoring tools or web browsers or command-line tools[33]) or inspections with manual identification of issues by experts against standards.[34] Automated accessibility evaluations have advantages over expert-based methods. These are more affordable and reliable due to the absence of human interpretation of the guidelines or standards against the online resource's performance indicators.[349]

5.2.2 WAVE ANALYSER AS AN EXAMPLE OF AN AUTOMATED ASSESSMENT TOOL

WebAim's Web Accessibility Evaluation Tool[350] (WAVE analyser) is an example of an automated software tool for assessing interface conformance against standards within the WAI/W3C/WCAG 2.0 guidelines and compliance to Section 508 (amended (2015); US Government Rehabilitation Act, 1973). WAVE analyser is freely accessible online and is relatively uncomplicated to use by non-experts who can systematically resolve errors by improving accessibility for individual's using assistive technologies (e.g., screen readers) or interface customisations. Developers can assess the degree to which as many people can use their interfaces by evaluating levels of accessibility.[351] When accessibility is a consideration during development, usability is also *improved* for users with other specific needs that share barriers to access, such as novice and infrequent users, individuals with low literacy levels or people who are culturally diverse in language and older people.[30] Accessibility also can alleviate barriers for individuals experiencing situational limitations[28,352] including those relating to the environment (low bandwidth, inadequate internet coverage or older technology) or device limitations (mobile phones, smartphones, tablets). Pragmatically, inexperience in evaluation practice can lead developers to fail to acknowledge the complex relationship between usability and accessibility, to understand interface designs supporting general usability and those essential for accessibility[353] whilst skilfully avoiding creating new errors in the process.

5.2.3 THE COMPLEX RELATIONSHIP BETWEEN USABILITY AND ACCESSIBILITY

The conceptual and practical relationship between usability and accessibility is complex. ISO and Web Accessibility Initiative (W3C) defines each as a sub-component of the other - where "*accessibility issues are a type of usability problem*,"[348(p398)] and usability issues are described as sub-type of the problem affecting accessibility for users.[348,354] Although the types and implications of issues identified are dependent on end-user capabilities, Petrie and Kheir[348(p398)] suggest there are three overlapping sets of usability and accessibility issues experienced by developers:

1. *"Pure accessibility problems"* (only disabled people)
2. *"Pure usability issues"* (non-disabled users)
3. *"Universal usability problems"* (affect both disabled and non-disabled users).

Therefore, usability and accessibility have a considerable overlap of interface features supporting quality of use,[30,98] specific to user characteristics, objectives, context, or environment of interactions.[52] Conceptually, developers should concomitantly attend to both error sets to improve universal interface designs as not to compound or accentuate errors by the implemented solutions. How non-evaluation expertise of non-traditional, multidisciplinary teams creating health interfaces affects pragmatic solutions to accessibility and usability interfaces is unknown. There is a sense that developers may regard accessibility and usability issues as *two distinct, independent, non-overlapping sets of issues,* being assessed independently, addressing errors with user-based testing or applying WCAG guidelines[348] if at all.

5.2.4 UNDERLYING ASSUMPTIONS OF DEVELOPER BEHAVIOURS SURROUNDING THE LITERATURE

Assessment of usability and accessibility as a compulsory component of development can support diverse audiences in characteristics impacting digital skills and health literacy. This may include people who are likely to be older, live with chronic disease or illness, have English as a second language (ESL) or are culturally diverse. In attempting to understand evaluation approaches and the extent of overlap between usability and accessibility issues[30,98] impacting interface quality for OHT studies identified within the systematic review, there are a series of underlying assumptions of non-traditional teams' practice when designing OHT stemming from descriptions within the literature:

1. Acknowledge the likelihood of a non-linear development process where evaluations may have been undertaken and issues resolved at some point within the process but not reported within the literature.
2. Where usability evaluations are reportedly undertaken, there is an assumption of resolution before the OHT release, even if not explicitly narrated.
3. If usability evaluations were not described within the literature, we could not assume no evaluations were undertaken, and the interface remained unmodified until release.
4. As accessibility was not described nor referred to in any of the studies within the systematic mapping review, one is unable to assume interface accessibility was not attended to before release.

These presumptions of practice inform the potential understandings of the realities of pragmatic evaluation practice in non-traditional teams developing health interfaces. Although peer-reviewed literature can offer a somewhat fragmented snapshot of usability evaluation, how these outcomes inform modifications within the interfaces and the impacts on levels of accessibility are even less clear.

5.2.5 SIGNIFICANCE OF THIS STUDY

Descriptions of usability and accessibility evaluations from Study 1 found reporting of usability evaluations to be scarce within the peer-reviewed literature and would offer little evidentiary support to inexperienced or non-specialised multidisciplinary teams. Whilst lack of reported usability within OHT development cannot be assumed as an indicator of non-practice, the absence of reported accessibility assessment of the interfaces produced is concerning, given the importance of resolving usability and accessibility errors to improving user experience. The complexity of interaction between usability and accessibility can complicate interface designs. Subsequent resolution of both sets of errors can remove barriers to access, use, and increase the inclusiveness of the interface[355] health resources are designed for a general population and will be needed to be used by the whole population with diverse needs and abilities.

An exploratory investigation was undertaken to examine relationships between peer-reviewed descriptions of usability evaluation from the systematic mapping review conducted for Study 1 and assessed levels of accessibility within the corresponding 'live OHT' interfaces using the WAVE automated software platform. This study sought to determine if usability and accessibility evaluations are treated independently by OHT developers and if the subsequent lack of usability is matched by levels of under-reporting of accessibility evaluation within 'live OHT' interfaces. Results from this study can provide additional observations to current evaluation practices by OHT developers and contribute to recommendations to improve quality, usefulness, and access for all audiences.

5.3 RESEARCH QUESTION AND STUDY OBJECTIVES

RSQ2: Are descriptions of OHT development and evaluations reported within peer-reviewed literature a true reflection of real-world practice by development teams as explored by 'live OHT' interface design?

5.3.1 STUDY OBJECTIVE

1. To examine relationships between levels of accessibility within 'live OHT' and corresponding descriptions of usability evaluations undertaken and reported by non-specialised development teams within the peer-reviewed literature.

5.4 STUDY DESIGN

As this study builds on the previous chapter's systematic mapping review findings, artefact OHT from all development processes described within the peer-reviewed mapping review will form the basis for further evaluation practice within these teams. Freely accessible OHT were retrieved online, and their interfaces were analysed for interactive features, then an automated software package was applied to identify accessibility errors. The characteristics of 'live OHT' were compared to usability evaluation variables identified and extracted from corresponding publications as part of a systematic review described in Chapter 4. Study design and relationship to this previous study is presented schematically in Figure 5.3.

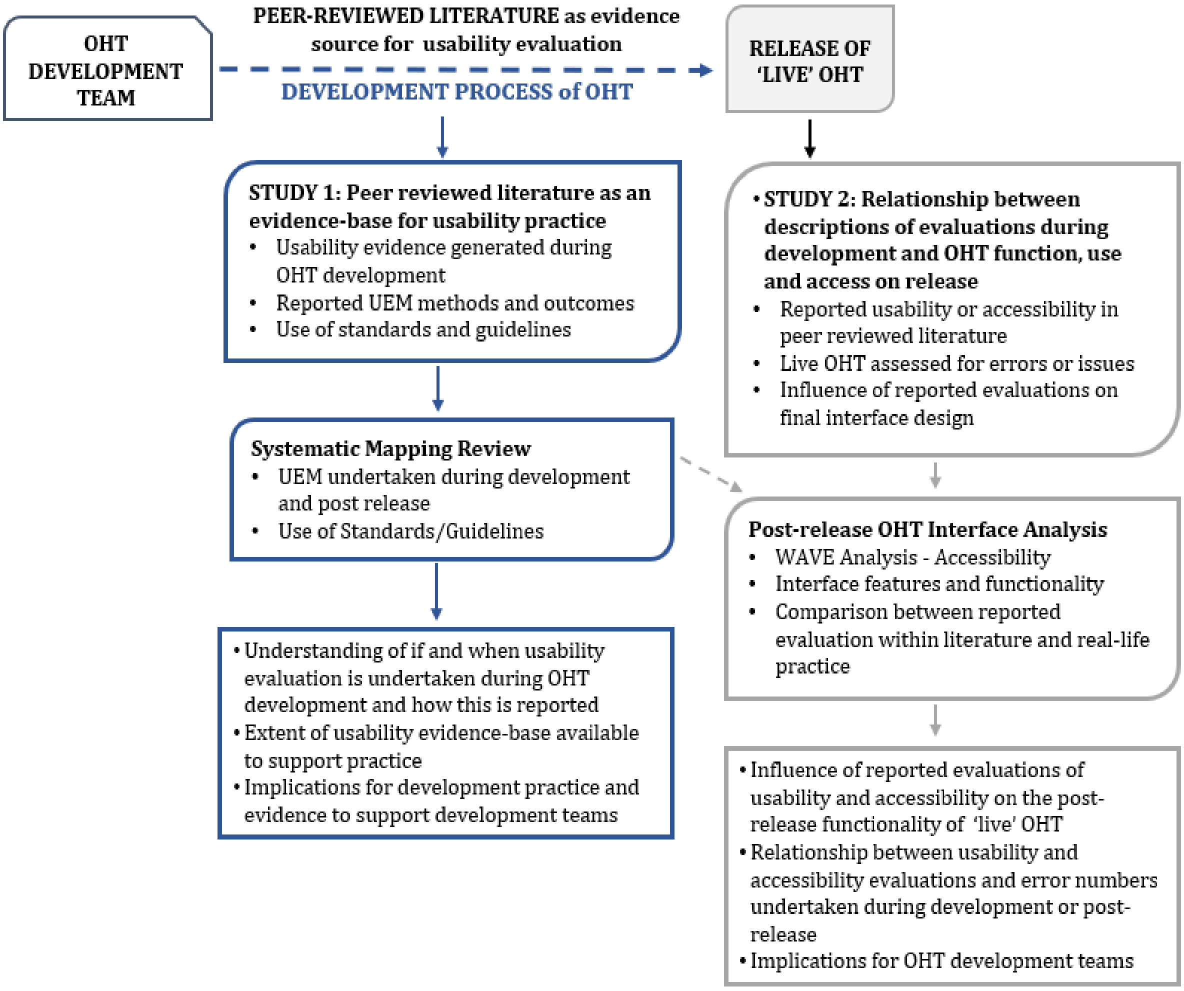

Figure 5.3. Schematic representation of Study 2 (and relationship to Study 1) within this thesis

5.5 METHOD

All OHT identified within the systematic mapping review were collated, and accessible 'live' versions were identified online. For 14 OHT available, content characteristics were mapped against data variables that reflect development and evaluation descriptions presented in peer-reviewed publications examined in the previous study (section 4.7.3). Appendix 4.3 provides data variables and descriptions for each variable identified within OHT interfaces. Further analysis examined features or characteristics reflecting the choice of platforms, software templates, embedded features, and interactivity levels that would influence usability aspects (ease of use, efficiency, and levels of satisfaction). Assessment of accessibility was also undertaken by applying an automated evaluation program, WAVE Analyser, across 'live OHT' interfaces.

5.5.1 MEASURES OF ACCESSIBILITY AND USE OF WAVE ANALYSER

To explore levels of accessibility compliance, WAVE Analyser[350] was applied to each 'live OHT' interface, measuring the number and type of errors relating to both content and structural components. In addition to the evaluation and development assumptions outlined in section 5.2.4, this analysis method assumes the use of an accessible compliant OHT skin with the 'aAA change text size' function as an indicator that accessibility may have been a consideration during development even if not reported within the peer-reviewed literature. WAVE analyser tool was applied to OHT 'Home' or top page, and one randomly-selected lower level or 'inside' page was examined, and frequency and type of accessibility errors were identified. Inside (or lower level) pages were classified as any page below the level of the Home page. One inside page was selected manually at random from each of the toolkits to be analysed. Page selection was independent of amount of content or layout of the interface. The analysis provided two different sets of accessibility errors recorded, general and contrast as described:

1. General accessibility errors (ONLQ16 'Errors') describing non-compliant webpage elements including affecting:
    - Functionality of screen readers (missing alternative text for images [Section 508 (a); WCAG2.0 1.1.1 Non-text Content (Level A)].
    - Absence of document language descriptions in HTML [3.1.1 Language of Page (Level A)].
    - Empty function or descriptors for buttons [WCAG2.0 1.1.1 Non-text Content (Level A) and 2.4.4 Link Purpose (in context) (Level A)].
    - Users directly - such as lack of appropriate or missing hyperlink text [WCAG2.0 2.4.4 Link Purpose (In context) (Level A)].

2. Contrast Errors (CE, ONLQ17) are more likely to impact users with a visual impairment. CE algorithm calculates contrast ratio between text foreground to a background colour with those having elements less than 4.5:1 or for larger text sizes a ratio of 3:1 (larger

than 18pt or 14pt in bold) highlighted as non-compliant errors (as per WCAG2.0 Standard 1.4.3, contrast as minimal Level AA).[350]

5.5.2 DATA VARIABLES AND EXTRACTION

Descriptors and data variables for exploring 'live OHT' interfaces are summarised within Appendix 5.1, including collated data from cross-tabulations between online OHT data variables (ONLQ2-Q8) and variables extracted from respective peer-reviewed publications previously extracted (Appendix 4.3) and presented in the previous chapter (section 4.7.2-5). Data includes descriptions of development and evaluations undertaken throughout development compared to 'live OHT' content and accessibility and contrast errors measured by the WAVE analyser tool.

5.5.2.1 Data variables and statistical analysis

'Live OHT' interface data was extracted, measured, and contrasted against narrative descriptions identified from within peer-reviewed literature using three different comparative strategies:

- Contrasting in-site descriptions of development and evaluation processes of 'live OHT' content and peer-reviewed literature
- Accessibility, contrast errors and features of 'live OHT' interfaces compared with reported narratives of usability evaluations
- Contrasting measures of accessibility and contrast errors against descriptions of usability evaluations reported within the corresponding peer-reviewed publications.

Table 5.1 presents a summary of variables explored and statistical analyses applied to frequency data and measures of accessibility errors.

5.6 RESULTS

Appendix 5.2 summarises the status of OHT availability of the 21 reported studies included within the primary review data set (as identified in Chapter 4). 13 OHTs (57.1%) were freely available on the Internet, with one having been retired (or 'gone dark' on December 31, 2018) during the duration of the study period. OHT A12[329] was still available for analysis via an archived version of the content with limited functionality via The WayBack Machine.[356] Eight remaining OHT (38.1%) were developed or evaluated within a VPN (a virtual private network) located within a protected organisational or clinical practice Intranet. Available OHT (*n*=13) were device-agnostic, with two constructed within non-responsive skins (A6[325] - Web1.0 and

A17[333] - Web2.0). Appendix 5.3 provides images taken from 'Home pages' of freely accessible 'live' OHT analysed.

Table 5.1 Summary of data and statistical analyses applied to data variables describing 'live OHT' interfaces

Objective	Description/Variables	Descriptive statistics
'Live OHT' content describing development and evaluation processes	Content descriptors within 'live OHT': • EB for Toolkit for content development • Content development process • Expert involvement within the process • Evaluation process during development • Publications related to the development • Accessibility Evaluation • HONcode Accreditation	Live OHT descriptors compared with descriptions provided in reciprocal peer-reviewed publications (Chapter 4) Web1.0 and Web2.0 live OHT interfaces: • Binary counts of absence or presence of information found within live OHT with data summarised by percentages of totals
Accessibility errors and features of 'live OHT' interfaces	Characteristics of live OHT interfaces and the number of accessibility errors identified by WAVE tool: • Accessibility errors - Home Page • Contrast errors - Home Page • Accessibility errors - 2nd level page • Contrast errors - 2nd level page • Intended Audience • Web1.0 or Web2.0 • Usability evaluation described in a publication • In-skin ' aAA change text size' Indicator present	Data presented as counts of errors and binary counts of absence or presence of information found within live OHT • Accessibility errors presented as mean errors per publication
Accessibility interface errors and usability evaluations reported within publications	Accessibility interface errors of 'live OHT' compared with descriptions of usability evaluation undertaken within development processes (from peer-reviewed literature): Accessibility and Contrast errors compared with: • *Type UEM [UEQ11]* • *Stage of Development UEM applied [UEQ9]* • *Class of UEM applied [UEQ10]* • *Description of Feedback from UEM [UEQ13]* • *Overall OHT Evaluation Type [EVALQ6]* • *Stage of Development UEM applied [UEQ9]*	Accessibility and contrast errors are presented as counts and mean number of each error type per publication

These variables were extracted from the literature describing evaluation practice from Chapter 4, systematic mapping review (refer to section 4.6.4 for a detailed description).

5.6.1 'LIVE OHT' CONTENT DESCRIPTIONS OF DEVELOPMENT OR EVALUATION PROCESSES

Tables 5.2A and 5.2B summarises the presence or absence of development and evaluation descriptions within OHT content (in-site). It indicates if descriptions of the same processes were provided within the peer-reviewed literature from OHT development as represented by ^ within the results table.

Tables 5.2A and 5.2B. Characteristics of available OHT compared with descriptors of evaluation process presented in published literature^ (*n*=14)

Table 5.2A Web 1.0 OHT interfaces (static information hyperlinks)

Study	Audience	OHT Name	EB for Toolkit [ONLQ2]	Content dev. process [ONLQ3]	Expert involved in process [ONLQ4]	Evaluation process during dev. [ONLQ5]	Publications related to dev. [ONLQ6]	Accessibility evaluation [ONLQ7]	HONcode [ONLQ8]
A4	HCP	ATT	1^	1^	1	1^	0	0	0
A5	HCP / HC	If the Shoe Fits	1^	1^	1^	1^	1	0	0
A6	HCP	ACHLPICME	0^	1	1	0^	1	0	0
A7	HCP	ENACT	1^	1^	1	0	0	0	0
		Total (%Total)	3 (75.0)	4 (100.0)	4 (100.0)	2 (50.0)	2 (50.0)	0	0
		^Total	4 (100.0)	3 (75.0)	1 (25.0)	2 (50.0)	*	0	0

Abbreviated Titles: ATT= Achilles tendinopathy toolkit, ACHLPICME= Academy for Continued Healthcare Learning Performance Improvement Continuing Medical Education toolkit, ENACT= Empowering nurses to provide ethical leadership in care homes toolkit
HCP=Healthcare professionals HC= Health Consumers A=Published article ^Reported within the literature EB=Evidence base dev=development
1= is present within the OHT interface, 0 = Absent from OHT interface

Table 5.2B Web 2.0 OHT interfaces (interactivity and connectivity)

Study	Audience	OHT Name	EB for Toolkit [ONLQ2]	Content dev. process [ONLQ3]	Expert involved in process [ONLQ4]	Evaluation process during dev. [ONLQ5]	Publications related to dev. [ONLQ6]	Accessibility evaluation [ONLQ7]	HONcode [ONLQ8]
A1	HCP / HC	Cracks in the Ice	1	1^	1^	0^	1	0	0
A2	HC	MaTT	0^	0^	0	0^	0	0	0
A3	HC	My Tools 4 Care	0^	0^	0	0^	0	0	0
A16			0^	0	0	0^	0	0	0
A12	HCP	PAR-QoL	1	1^	0^	0	1	0	0
A13	HC	REACT	0^	0^	0	0^	0	0	0
A14	HCP / HC	AASPIRE	1^	1^	0	0^	1	1	0
A17	HCP / HC	AMCHP Disabilities Toolkit	1^	1^	1	0^	1	0	0
C1	HCP / HC	CATT	1^	0	1	0^	1	0	0
C2	HCP / HC	Derbyshire End of Life Care	0^	0	0	0^	0	0	0
		Total (%Total)	5 (50)	4 (40.0)	3 (30.0)	0	5 (50.0)	1 (10.0)	0
		^Total	8 (80.0)	7 (70.0)	2 (20.0)	9 (90.0)	*	0	0
		Overall Total (%Total)	**8 (57.1)**	**8 (57.1)**	**7 (50.0)**	**2 (14.3)**	**7 (50.0)**	**1 (7.1)**	**0**
		Overall ^Total (%^Total)	**12 (85.7)**	**10 (71.4)**	**3 (21.4)**	**11 (78.6)**	*	**0**	**0**

Abbreviated Titles: MaTT = Males Transition Toolkit, PAR-QoL= Participation and Quality of life toolkit, REACT= Relatives Education and Coping Toolkit, AASPIRE= Academic-Autistic Spectrum Partnership in Research and Education toolkit, AMCHP= Association of Maternal & Child Health Programs toolkit, CATT= Concussion Awareness Training Tool HCP=Healthcare Professionals HC= Health Consumers A=Published article C= Conference Proceeding EB=Evidence base dev=development

^Reported within the literature * Number of publications not a characteristic within reviewed literature, observation of OHT only

1= is present within the OHT interface, 0 = Absent from OHT interface Web1.0 = static information hyperlinks

5.6.1.1 Preference by audience and levels of interactivity

Development teams preferred interactive features and content describing development and evaluations depending on the target audience. For OHT designed explicitly for use by health consumers (A2[319] [MaTT]; A13[330] [REACT]; A3,[317] A16[318] [My Tools 4 Care]), no information that could assist users to understand quality processes underlying development and evaluation of the resources were provided (across ONLQ2-8) even though an explanation was provided within respective articles (Appendix 5.4). Health consumer OHT were also more likely to be characterised by multiple interactive features and users' ability to create, edit, and share content within the OHT structure (Web2.0), with A13[330] providing an expert-based interactive forum. OHT were also more likely to display an indicator of accessibility (aAA indicator) within their skin and had described usability evaluation within the corresponding peer-reviewed publication.

Conversely, all OHTs for HCP use included an explanation of the content development process (A4[323] [ATT], A6[325] [ACHLPICME], A7[326] [ENACT] and A12[329] [PAR-QoL]) with 75% including descriptions of evidence bases and explanations of involvement of experts within OHT content. The ATT (A4[323]) developers also provided information regarding the evaluation process undertaken during the product cycle, and OHT A6[325] included a description of development processes within the content. HCP OHT were also more likely to feature Web1.0 functionality, with unidirectional interactivity characterised by static information embedded with hyperlinks to secondary sources; 75% Web1.0 OHT (3/4) displaying these minimal interactive features were targeting HCP (A4,[323] A6,[325] A7[326]). Of the six 'live OHT' targeting both HCP and health consumers, (A5[324] [If the shoe fits], A1[322] [Cracks in the Ice], A14[331] [AASPIRE], A16[318] [AMCHP Disabilities], C1[315] [CATTonline] and C2[316] [Derbyshire End of Life care]), five featured descriptions of the evidence base and related published articles, four described content development processes and expert involvement. 'If the shoe fits' OHT was the only OHT to include information on evaluation processes (variable ONLQ5) undertaken, which reflected the same description within the reviewed journal article. This contrasted with other OHT whose developers reported completing evaluations within peer-reviewed literature but did not include this information in the online versions.

Five of six OHT exhibited to Web2.0 interfaces characterised by multiple interactive features and the ability for users to create, edit and share content within the OHT structure, with two having links to social media platforms (A1[322] and C1[315]). Only the AASPIRE OHT (A14[331]) provided a text-change indicator within the site's skin. 'If the Shoe Fits' OHT (A5[324]) was the only resource to provide a complete description of all development and evaluations available to users within their OHT, although publication descriptions were not definitive of accessibility evaluations and HONcode accreditation.

Overall, 50% (5/10) interactive Web2.0 OHT included both in-site descriptions of evidence base (ONLQ2) and any related project publications (ONLQ6). Four OHT (40%) provided an in-site explanation of content development processes undertaken during development (ONLQ3), and 30% of these studies gave descriptive accounts of experts involved across development. Noticeably, developers of all Web2.0 OHT *did not* provide depictions of evaluation types (UEM or accessibility) undertaken during the product cycle in any OHT surveyed, although usability evaluation protocols and methods were provided by 90% of developers within the respective literature reviewed. Developers of AASPIRE OHT (A14[331]) included an accessibility statement within the online content. However, within the related journal, this was not reciprocated.

5.6.2 ACCESSIBILITY ERRORS AND DESCRIBED USABILITY EVALUATION PRACTICE

'aAA' functional icons, buttons, menus, or text are situated within the skin of websites or OHT and are crucial for users who require text augmentation due to difficulties associated with visual impairments. This review assumes that adding these specific attributes to the skin postulates that accessibility may have been a consideration for development teams during construction or evaluation of featured OHT. As a difference, 'Home page' and a single, randomly-selected internal page was analysed using the WAVE accessibility tool across all fourteen available OHTs. Appendix 5.5 illustrates WAVE error data and a summary of OHT characteristics. MaTT OHT (A2[319]) was not analysed using the WAVE tool as the content was 'protected' behind a password enabled home page. 'My Tools 4 Care' OHT (A3,[317] A16[318]) provided adequate information for the software to generate errors, but a sign-in function protected internal webpages and, therefore, could not be interrogated further.

WAVE software experienced similar issues with two other OHT, an archived version of the 'PAR-QoL' toolkit (A12[329]) which could not be analysed and 'AMCHP' toolkit (A17[333]) opened into 'pop-up' windows within an existing website which produced conflicts with HTML code and JavaScript elements of the webpage and the WAVE tool. One OHT, 'CATTonline' (C1[315]), measured an increased number of errors across 'Home page' (74 errors) compared to 'internal page' (32 errors), and in total errors across all OHT (103 accessibility errors).'Cracks in the Ice'

OHT (A1[322]) followed this trend with more errors identified within ‘Home page’ than internal (28 to 20 respectively) with others having a more even spread between the ratio of home:internal pages (C2[335] – Home page 12:10 internal, A4[323] – Home page 18:17 internal, A5[324] – Home page 6:7 internal) and remaining OHT having a greater frequency of errors identified on the internal page than on the Home page (A13[330] - 6:20 and A14[331] - 7:22 respectively).

5.6.3 USABILITY EVALUATION PRACTICE AND ACCESSIBILITY ERRORS

OHT with an embedded accessibility indicator had an overall lower number of errors identified than ‘live OHT’, who omitted an accessibility indicator in-site (51 errors [M=12.75 errors/publication], contrasting with 293 errors [M=32.56 errors/publication] respectively). Total error counts (both accessibility and contrast) were also found to be less in OHT whose developers both reported (a) usability evaluations and (b) indicated accessibility within the live OHT (51 total errors [M=12.75/publication] to 246 total errors [M=35.14/publication] as presented in Table 5.3.

Table 5.3 Accessibility indicator described usability evaluations within publications and the number of accessibility errors

Accessibility Indicator ‘aAA’ [ONLQ16]	Usability Evaluation (UE)	No. of Publications	**ONLQ16**				Total errors (Mean errors/ publication)
			Errors - Home Page	CE - Home Page	Errors - 2nd level page	CE - 2nd level page	
Present on site	UE - described or mentioned in brief	A2, A3, A14, A16	9	20	16	6	51 (12.75)
	Unknown – UE not described	A12	-	-	-	-	0
Absent on site	UE - described or mentioned in brief	A1, A4, A5, A13, A17, C1, C2	65	75	44	62	246 (35.14)
	Unknown – UE not described	A6, A7	19	18	4	6	47 (23.5)
	Total	14	93	113	64	74	

CE= Contrast errors

Descriptions of the different characteristics of usability evaluations provided by developers within publications included:

a) Type of usability feedback and if this guided development [UEQ13]

b) Evaluation approach completed [QUALQ6]
c) Stage of development that the UEM was employed [UEQ9].

Accessibility errors identified through the WAVE analyser tool application were collated against each usability evaluation characteristic extracted from Study 1 (Table 5.4). Five studies described how usability evaluation feedback enhanced interface design improvements, having 119 errors (*M*=23.8/publication). Four studies did not provide information on how usability feedback shaped OHT during development. In these four studies, the WAVE analyser uncovered a total of 214 accessibility errors (*M*=71.3 errors/publication). Those development teams not reporting an evaluation approach within the literature [EVALQ6] produced interfaces with an average of 20.70 (124 errors in total) accessibility errors per publication. OHT with published process and outcome evaluations (including measures of satisfaction, usefulness or other positive effects) produced a total of 75 accessibility errors (*M*=18.8 errors/publication), compared with non-reported outcome evaluations where 145 errors were identified at an average of 36.3 errors/publication. These developers did not describe how usability feedback was applied to design [UEQ13] within the related articles.

An increasing trend was observed in the frequency of accessibility errors identified within OHT interfaces when examining wherein the phase of development usability evaluation was completed. The frequency of accessibility errors increased when UEM was reportedly applied late in the development process. Early-stage UEM 'live OHT' accessibility errors increased from 36 errors (*M*=18.0 errors/publication) to 200 errors (*M*=33.3 errors/publication) when UEM were applied post-release/post-implementation phase of development. Sixty-one errors (*M*=30.5 errors/publication) were observed in OHT interfaces when UEM were undertaken during mixed stages or multiple UEM evaluations across stages.

Relationships between the UEM development stage of deployment as detailed in reviewed publications, class, and type of UEM applied, and the number of accessibility errors identified within the 'live OHT' were collated (Appendices 5.6-5.7). Inquiry-based UEMs were applied across all four stages of development. Analysis detected an increasing number of accessibility errors identified the further into the product development cycle the UEM was undertaken by developers [design and development stage (1 OHT, total=25 errors, M=25.0 errors/publication), implementation (total=48 errors, *M*=48.0 errors/publication) and post-implementation or post-release (total=213 errors, *M*= 71.0 errors/publication].

Table 5.4 Characteristics of described usability evaluations and accessibility errors identified by WAVE analyser on respective live OHT

	Description within OHT publication	**Number of publications**	**ONLQ16**				**Total errors (Mean ./ publication)**
			Errors - Home page	CE - Home page	Errors - 2nd Level page	CE - 2nd Level page	
Description of feedback from UEM [UEQ13]	UEM provided guidance or inference for improvements in design based on the usability issue identified	A1, A3, A5, A13, C2	15	47	23	34	119 (23.8)
	UEM generated a list of usability issues (not applied to protocol)	A2#, A16	2	9	-	-	11 (11.0)
	Unsure / Not described	A4, A14, A17*, C1	76	57	41	40	214 (71.3)
Overall OHT evaluation type [EVALQ6]	**Outcome evaluation:** Evaluation and assessment of changes influenced by OHT use reported by users	A3, A6, A13, C1	47	46	17	35	145 (36.3)
	Process and outcome evaluation: Usefulness and satisfaction relative to objectives for iterative improvement	A2, A4, A14, A16	22	14	30	9	75 (18.8)
	Unsure / Not described	A1, A5, A7, A12, A17, C2	24	53	17	30	124 (20.7)
Stage of development UEM applied [UEQ9]	Design / Development - early prototype	A3, A13	6	10	10	10	36 (18.0)
	Implementation - final version prototype	A2#	-	-	-	-	-
	Mixed Stage or Multiple Evaluations across stages	A1, A5	7	27	9	18	61 (30.5)
	Post-Release / Post Implementation	A4, A14, A16, A17*, C1, C2	61	58	41	40	200 (33.3)

CE= Contrast errors

*A17 – WAVE Analyser unable to process URL

#A2 - OHT on password-protected secure site - WAVE Analyser unable to process

Total accessibility errors averaged 30 errors/publication for OHT identified as undertaking surveys, questionnaires or focus groups guiding user feedback across multiple evaluations or mixed development stages. During mixed stage or multiple usability method evaluations, website analytics were applied in combination with site log analysis and remote user testing during the development of the ‘Cracks in the Ice’ (A1[322]) resource. Alternatively, developers of the ‘Derbyshire End of Life Care’ OHT (C2[316]) employed web analytics in conjunction with site log analytics during the post-implementation/post-release stage of development. WAVE analyser tool found there was an increased number of total errors identified in the UI of ‘Cracks in the Ice’ OHT (48 errors) deploying three UEM compared with the ‘Derbyshire End of Life Care’ OHT (22 errors) in which developers applied only analytics and site log analysis post-release.

5.7 DISCUSSION

For developers, accessibility, usability guidelines, and design principles provide a fundamental guide to designing interfaces for purpose.[341] Applying guidelines to initial UI designs can decrease users' classes and frequency of usability or accessibility errors before evaluation, decreasing time, effort, and money to undertake the ‘test-redesign-retest’ cycle during development.[341,342] Outcomes provide little clarity around referencing or applying standards or guidelines to support the development of OHT. Perhaps there is little evidence to support the proposition ‘that all developers were aware and utilised the standards and guidelines supporting quality, usability or accessibility for development and online build of their OHT’ - as demonstrated by high frequencies of accessibility errors identified within ‘live OHT’ interfaces investigated in this study. The AASPIRE Toolkit[331] described the evaluation of accessibility within OHT content, perceived as relevant for the resource’s targeted user cohort (people living with autism). Analysis of ‘live OHT’ interfaces demonstrated perhaps equal levels of variability in real-world evaluation processes and those narratives describing evaluation reported within reviewed literature.

5.7.1 EVALUATING ACCESSIBILITY WITHIN OHT DEVELOPMENT

OHT interface design and evaluation methodologies depended on targeted audience types and applied their knowledge of end-users' capabilities, access, and knowledge to design interfaces, mainly where HCP as homogenous groups are concerned. Neglected evaluations or assessments are undertaken later in development phases imparted greater error numbers with the interface than those describing usability evaluations as components of the development process.

Development teams did not indicate the application of accessibility evaluations, and with significant levels of both overall and contrast errors present in most interfaces analysed, these resources are at risk of contravening legislated standards of access.

Extrapolating the average and the total number of errors across the toolkits as a whole, it is conceivable that these resources have higher than average accessibility errors compared to health websites currently live on the Internet (48.5 errors/site[350]). Errors and the degree to which a diverse audience can use OHT could be more severe in resources where feedback was not informing reiterative designs to resolve usability errors. Legal compliance has focused on government policies in countries of authoring papers within this review, with interest in commercial entities facing repercussions for failure to comply with accessibility without equal due diligence to health information resources.

For example, US legislation (Section 508 Amendment to the Rehabilitation Act of 1973 and Section 255) requires US Federal agencies to make their electronic and information technology accessible to people with disabilities and does not require compliance from private/non-government websites. This includes groups receiving federal funds or under contract with federal agencies (United States Access Board, 2017). European Commission has proportionated legislation (EN-301 549 Accessibility requirements for public procurement of ICT products and services in Europe), and Canada has released their federal Accessible Canada Act (July 2019). Australia appears to be lagging other developed countries in a legislative context supporting accessibility compliance of online information. There are no direct legal consequences for non-compliance with W3C/WCAG2.0 standards.[357] This is contrary to the ratification of the United Nations Conventions of the Rights of Persons with Disabilities and commitment to National Disability Strategy 2010-2020[358] as underwritten by the Australian Government Disability Discrimination Act 1992.[359]

Within this review, developer-centred assumptions could reinforce views that accessibility is not of concern for certain end-user groups due to abilities associated with their profession. For example, a working HCP is unlikely to experience disabilities that could affect their interaction with OHT (including sight, psychological, intellectual, motor or physical limitations or those related to age) - therefore, there is no need to assess the interface. There is evidence that these same postulates are in play for developers of OHT designed for health consumers or health consumers and HCP, as supported by the absence of reporting of evaluation of accessibility detected in this study. Unfortunately, compared to HCP, there is an increased prevalence of individuals with specific needs or deficits in abilities in these user groups,[360] which has been disregarded as a critical end-user group for these resources and are likely end-users of the OHTs. Everyone, therefore, would bring their capabilities and experiences (as their baggage[247]) to their interaction with OHT resources. Baggage varies between individuals and be influenced by physical, emotional, cognitive, and sensory abilities that could be permanent or transient[247] but should be considered and evaluated to ensure access for specific and incidental user groups.

There is also evidence of a bias in types of development information included within live OHT. Those designed for an audience of HCP were more likely to include content describing the development process, the evidence base and experts involved in the approach for users to access. In contrast, the review of OHT for a combined health professional and consumer audience found a variation in the detail and comprehensiveness in the information available, including development processes. OHT content included descriptions and links to the evidence base or publications, and interestingly there was only one OHT that included descriptions of evaluations undertaken even though many authors included these narratives in the formal literature.

Findings could reflect a skewed belief by developers that HCP makes judgments on the value, relevance, and quality of OHT by actively reviewing online evidence that supports development processes (hence a desire to include this information within the OHT interface). Health consumers are not afforded the same easily accessible and visible online content to aid in assessing OHT for quality and trustworthiness, which are two aspects of digital health literacy that support their health-related decision-making for themselves or for someone they may be caring. Therefore, developers of OHT for a combined audience may unwittingly provide support to consumers to make these decisions on quality and trust by including the development descriptions within the online content that would be an inclusion to reassure health professionals of the quality processes undertaken to produce this resource.

5.7.2 CONGRUENCE OF ACCESSIBILITY AND USABILITY EVALUATION OUTCOMES

The intricate relationship between interface accessibility and usability has been previously established within this thesis, although the impact of the lack of usability evaluation or poor evaluation practice on interface accessibility has not been explored.

There is an acknowledgement that there may be other landmarks within the skins of OHT, which could indicate accessibility was a consideration for developers. The ‘aAA change text size’ is one of these features assumed to signify developers evaluated accessibility at some stage during the OHT build process. It is also reasonable to presume that for some developers, this may not have been included in their design consciously because many pre-packaged skins have this feature included as a coded function within the ‘standard’ skin of websites. OHT reviewed retrieved only five OHT featuring in-skin ‘aAA’ indicators, all constructed within the latest skin versions that provided Web2.0 characteristics. Data suggest that accessibility may not have been evaluated in this OHT due to overall error frequency numbers. OHT with the ‘aAA’ indicator had fewer errors found by the WAVE analyser tool across both ‘Home page’ and internal page than the nine other OHT without the ‘aAA’ feature. Therefore, the assumption of evaluation accessibility practice within OHT development cannot be corroborated.

Analysis of WAVE Analyser data and usability evaluation descriptions within the literature reviewed recognise complexity in the relationship between usability evaluation practice and efforts to resolve these issues and accessibility errors within the UI.[348] The literature's descriptions of usability evaluation correlate with a higher frequency of accessibility errors identified than lower error counts. This association was identified in interfaces from authors who fail to describe usability evaluation processes during development. Hence, there are contradicting notions of an instinctive proportional relationship between rectifying usability and accessibility evaluation outcomes within the OHT UI – where the resolution of usability issues based on user feedback is assumed to eliminate accessibility errors within the same interface.

Accessibility standards organisations, W3C/WAI[171] and ISO[98] provide intangible and non-concrete definitions of the sub-component association between accessibility and usability.[52] Observations from this study support the pragmatic proposition that although these are conceptually on a continuum,[361] developers consider usability and accessibility two independent, non-intersecting issues. Modifying the UI to accommodate specific end-user accessibility needs compromises the quality of use as measured by interaction relating to context, environment, and user characteristics.[52,98,352] Universal design could offer a solution that considers this heterogeneity of needs within the intended audiences.[206] Findings suggest the frequency of accessibility errors within the OHT interface was influenced by methodologies, processes, and juncture in the development lifecycle when UEM were employed.

5.7.2.1 Described usability evaluation methods and processes

Accessibility error numbers were more frequent where OHT developers described undertaking outcome evaluation (as a measure of OHT effectiveness at implementation or during the post-release period as reported by the end-user) compared to process and outcome evaluation undertaken within or across the pre-release stages. Process evaluation provides feedback assessing end-user satisfaction, levels of usefulness and positive or negative effects relative to objectives. Developers can iteratively improve interfaces over many evaluation-redesign cycles until acceptable levels of user experience (through usability and accessibility) are reached.[52] This resource 'tailoring' to end-user needs leads to improved design acceptability before release compared to OHT ad-hoc post-release evaluation and re-design often completed as a requirement for reporting purposes. This observation is supported by increased frequency of accessibility interface errors when UEM is applied at implementation or within the post-release period compared to OHT interfaces where UEMs are employed at all other development stages (design or development and across multiple stages). Utilising UEM during early phases or across stages of OHT development have a greater impact[362,363] and can increase opportunities to identify usability errors in the interface by design reiteration considering feedback generated from end-users involved in evaluation processes.[362] Early evaluation is beneficial to development by improving usefulness and effectiveness and decreasing risk.[103]

Financially, usability or accessibility issues are often less complicated, less severe, and cheaper to rectify during development than evaluations undertaken post-release.[364] Finally, the type or class of UEM employed during the development of OHT surveyed also influenced the number of accessibility errors identified. Intriguingly of all UEM classes employed by OHT developers, usability evaluated by survey or questionnaire was associated with UIs with the higher number of accessibility errors. This perhaps speaks to ease of distribution and the simplicity for end-users in identifying features that work or do not work from dichotomous survey questions. All OHT had similar audience types - health consumers as either primary audience or in combination with health professionals.

Within usability evaluations, surveys and questionnaires elicit feedback from end-users in either open or closed formats. The sole purpose is to generate feedback on personal experience with their UI, most likely through encouraging rich qualitative narratives via probing using open-ended questions or statements.[54,365] One explanation for the high number of accessibility errors associated with inquiry-based usability evaluation methods could be the over-modification of the interface based on end-user design feedback. This feedback is generated through reflective practice to identify issues or problems with the interface and possible design solutions based on end-users' experiences.[336,366] Although researchers have found that this feedback often compliments interaction data and identifies different usability issues in specialised contextualised settings, where end-users are considered experts.[336,367] There are also adverse effects impacting downstream development processes, compromising UI improvements more specifically for generic online resources as end-users do not know what they need from the interface and are not design experts.[336,368]

As established earlier, this study found limited descriptions of rigorous evaluations undertaken during resource development and evidence of non-descriptions that yielded little value or evidence to inform practitioners on how to repeat development or evaluation processes. These extremes of dissemination were independent of level or source of funding, and there was no suggestion of accessibility evaluation undertaken by any of the published authors investigated for this study. Although usability evaluation is not underwritten by law, funding support impresses the requirement that online artefacts are usable, reliable, accessible, trustworthy, and effective for those users identified as the intended end-user for these information resources. It is unlikely that usability evaluation will be accepted as part of regular development practice if legal compliance does not impress the same development teams to undertake accessibility evaluation. Perhaps compliance should be actively encouraged by tying project funding to evaluation milestones within development requiring both reporting and completion of evaluations to increase usability and accessibility of health information for all end-users.

5.8 STRENGTHS AND LIMITATIONS OF THIS STUDY

Although sample numbers from the mapping review only identified 21 possible OHT, over 60% of these were freely available to analyse interface accessibility and assess usability, presenting an opportunity to explore live functionality and differences in OHT interface design, evaluation, and compliance across a selection from each intended audience (HCP, health consumers and general audiences). An advantage of retrospective exploration of development processes via the published literature and analysing live artefacts affords a greater understanding of processes undertaken to produce these online resources and perhaps insights into issues or problems encountered by teams. This approach's strength allowed for comparisons of general usability practice and measured accessibility errors to extricate complexities between both aspects of quality of use. Deeper understandings of relationships between real-world usability and accessibility practice and levels of experience of the development teams are limited as this was not clearly defined within the OHT literature extracted as part of the mapping review.

Whilst ‘aAA change’ was applied as a point of differentiation between those developers considering accessibility and those who did not, it is acknowledged that this feature's presence or absence did not necessarily correlate with accessibility compliance as demonstrated by a high frequency of accessibility errors. This indicator is often an embedded feature of site skins that are a component of purchased templates available to developers and may not indicate an intention to evaluate accessibility at all. Unfortunately, incomplete descriptions of evaluations within the published literature leave areas of speculation, and this variability does not provide concrete understandings of practice and its inherent interaction with accessibility. It was highlighted by the developers' assumptions around the development/evaluation approach and the method itself, making it very difficult to identify errors that were missed during accessibility evaluations or those that were never attended to in the first place. The WAVE tool also experienced issues with some internal functionalities of selected OHT, reducing the number of pages contributing to analyses.

5.9 CHAPTER SUMMARY

All OHT analysed were found to have high accessibility errors, either relating to overall accessibility or those specific to colour differences between background and foreground text, a crucial indicator for developers attending to colour blindness. Those with a ‘aAA change’ indicator within the toolkit skin demonstrated lower frequencies of accessibility than those without this feature. Arguably whilst this could demonstrate consideration of accessibility by these development teams, there is a likelihood that resolution of usability errors may create or exacerbate interface accessibility errors, especially in those applying inquiry-based UEM or in teams who undertake usability evaluations at later phases of development, including post-release period. Reflecting on an earlier proposition asking if descriptions of OHT development and evaluations reported within the literature are a true reflection of real-world practice, findings from these analyses overall in this study would suggest that it is inconclusive. There is no wholesale measure of usability, and whilst accessibility practice seems unreliable, incomplete, and variable, like reports within published literature, these outcomes demonstrate a delicate balance between usability errors and accessibility compliance. Arguably, attending to one and neglecting the other or not considering either is considered poor evaluation practice and impacts the universality and inclusiveness of the interface.[369] Particularly given forced adoption of digital health technologies facing individuals even if they are unable to, do not want to or are hesitant to do so. Studies 1 and 2 have established deficits in evaluation practice within OHT development through published literature and analysis of OHT interfaces. The factors driving inconsistent, variable or incomplete usability could be internal (within team or process) or due to extenuating elements impacting evaluation within the process of development. These are the components explored in this thesis's subsequent study, which focuses on evaluation practice and development processes within academic settings.

CHAPTER 6 – EXAMINING THE BARRIERS INFLUENCING THE LIKELIHOOD OF USABILITY EVALUATIONS BEING UNDERTAKEN BY MULTIDISCIPLINARY TEAMS WITHIN COMPLEX DEVELOPMENT PROCESSES

The research described in Chapter 6 shifts focus from the evidence to support evaluation practice to the impact of the process on the likelihood of non-specialised development teams undertaking evaluations during health interface development. Study 3 explores applying a structured evaluation approach within the development of a palliative care toolkit interface. The analysis focuses on user-based, expert-based and content-based formative evaluations to examine the barriers to pragmatic evaluations for non-specialised teams.

Peer-reviewed articles produced from this study

1. **Adams A**, Miller-Lewis L, Tieman J. 2021. Usability testing of a palliative care information resource - outcomes from a formative evaluation of The CarerHelp Toolkit. Informatics for Health and Social Care (*under review*).

Author contribution

AA, LML and JT conceived the study. AA designed, recruited and conducted the research, then analysed and reported the findings to the NRG. AA prepared the first draft of the manuscript, JT and LML provided important contributions to re-drafting the final manuscript for publication. All authors read and approved the final manuscript submitted.

2. **Adams A**, Miller-Lewis L, Tieman J. 2021. Learning Designers as expert evaluators in usability evaluations: Understanding their potential contribution to improving online

health information resources. International Journal of Human-Computer Studies (*under review).*

Author contribution

Amanda Adams: Conceptualization, Methodology, Investigation, Validation, Formal Analysis, Resources Data curation, Writing - Original Draft, Writing - Review & Editing, Project management. **Lauren Miller-Lewis:** Conceptualization, Methodology, Writing - Review & Editing, Supervision. **Jennifer Tieman:** Conceptualization, Methodology, Writing - Review & Editing, Supervision

Conference presentation

Adams A. None, one or some - is the usability testing method all we need when developing and evaluating health information interfaces? Presented at the Australian Institute of Digital Health Summit. 25th November 2020, Australia.

6 STUDY 3. BARRIERS TO PRAGMATIC USABILITY EVALUATIONS FOR MULTIDISCIPLINARY TEAMS WITHIN PRAGMATIC DEVELOPMENT PROCESSES

6.1 CHAPTER INTRODUCTION

Previously, studies have sought to understand how development teams undertake and report development processes and undertake usability and accessibility evaluations of the health information resources produced. Findings suggest that usability and accessibility are crucial activities that directly impact interface errors and influence successful use and access to online health information. Descriptions from peer-reviewed literature offer very little guidance or support for development teams, and lack of knowledge or sponsorship could be the origin of poor evaluation practice, but there are likely to be other reasons that impede these activities. It is reasonable to assume that inexperienced development teams may not have conducted usability and accessibility evaluations due to other circumstances unrelated to lack of familiarity with evaluations per se. These factors could be directly related to development processes, team structures or evaluation methodologies that impact these groups' capability to undertake evaluations of online health information resource interfaces, hampering efforts and delaying evaluations until the post-release or post-implementation phase of development. Established previously, late evaluations directly influence the frequency and types of errors that can increase barriers to successfully using these interfaces to inform health decisions. This chapter will explore applying a comprehensive evaluation model to the development process of an OHT to examine components of practice that could obstruct usability and accessibility evaluation practice.

6.2 DISCLOSURE

The researcher's principal supervisor led the website development team at Flinders University, who facilitated access to the CarerHelp prototype and provided opportunities to observe the development process. The researcher was autonomous across all aspects of the study methodology and worked independently from all partner and contracted organisations to the development process. The researcher's principal supervisor was not involved in recruiting study participants or *organising, conducting or analysing feedback generated from the evaluation activities within this study.*

6.3 BACKGROUND AND RATIONALE

The subject domain for the OHT evaluated within this study is palliative care. Therefore, it is essential to understand the caregiver's need for the resource in their role of providing palliative care to their loved ones. This in turn, gives the context to their participation in the evaluation as the primary and intended audience of the CarerHelp resource. Within a complicated development and evaluation process, the palliative care context is an additional complexity requiring consideration.

6.3.1 THE PALLIATIVE CARE CONTEXT

The World Health Organisation (WHO) defines palliative care as "*Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with a life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.*"[370] Palliative care is an approach to support patients, carers and families[210-212] for the duration of their life-limiting illness and bereavement. For people approaching their 'end of life', clinically, if individuals are likely to die in the next 12 months,[371] primary carers provide both emotional and physical support whilst being involved in all aspects of care.[210,W]

For family carers, care given to loved ones is given without obligation nor financial gain. It can conflict with other commitments or responsibilities requiring external support mechanisms (such as recruiting friends or extended family, support from a carer or government organisations), ensuring well-being and independence.[373] Research has shown that the burden

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[W] According to Australian Bureau of Statistics 'Survey of Disability, Ageing and Carers', over 2.65 million Australians were providing informal care and 861,000 are primary carers.[372] Informal primary carers provide unpaid care for people living with a chronic or mental health condition, disability, are frail aged and those individuals who have a terminal illness,[373] who are often family members. Due to societal structure changes, families are geographically spread or fractured, carers of the ill may not hold traditional next of kin relationships who may not be able to or be recognised nor supported by services or organisations due to this relationship.[374] Majority of primary carers aged between 35 and 54 years old, with older individuals more likely to provide care than younger people. Women are also more likely to provide care up to age 65, men over 65 are more likely to be carer providers than women over 65, with 55 being the average age of primary carers in Australia.[372,373]

of caring for individuals with palliative needs impacts all aspects of psychosocial health,[375,376] including experiencing sleep disturbance,[377] depression,[378] stress,[379] anxiety,[380] burnout and fatigue.[381]

6.3.2 PROVIDING PALLIATIVE CARE AT HOME

Within the last year of their lives, individuals living with a life-limiting illness spend most of their time at home being cared for by their loved ones,[382,383] and then for most, the increasing burden of care leads to palliative care provided in specialist settings such as hospice or hospitals or a residential aged care facility. For many, receiving palliative care within the community ensures home as a place of death is a realistic option.[384] However, choice in place of death is often mediated by the level of support provided by palliative care services especially given carers reported feelings of inadequacy.[385] For community groups impacted by existing health and social inequities, such as their socioeconomic status, ethnicity, geographical location, and cultural background,[386] access to services by underserved or vulnerable populations are limited or intermittent depending on resources.[123]

Online palliative care resources can offer an alternative source of reliable information for carers beyond the reach of services or when they are searching for answers during periods of calm or during the night. Demographically, carers are likely to be engaged with the online environment,[372] accessing the Internet to search and retrieve health information, participate in learning activities to gain knowledge or practical skills, and build social support networks via digital media platforms.[139] Diversity in carers' backgrounds, ethnicities, previous experiences, online accessibility, digital skills, and health literacy requires resources with interfaces supporting end-users with wide-ranging literacy levels, knowledge, information needs, and technical abilities. Consequently, development teams are well-placed to acknowledge the need to evaluate usability and accessibility to shape their resources to the intended carer audience.

6.3.3 DEVELOPMENT TEAMS, PROCESSES, AND EVALUATION OF ONLINE HEALTH INFORMATION

Traditional, specialist or 'ideal' web development teams are professionally diverse with expertise spanning both back and front ends of development[387] including technical, evaluation, marketing, and UX.[198] These teams are commonly embedded within commercial organisations or companies or are independent entities externally contracted to build, evaluate or maintain online resources. Conversely, research or academic project teams are funded or produce online resources as artefacts of research undertaken, and these could be websites, toolkits, apps, or devices. The tension and imbalance in attempting to accommodate commercial, pragmatic usability evaluation practice within development processes aligned with academic objectives, outcomes and dissemination is problematic[106] for non-specialised development teams designing user-centred health technologies.

Project teams operate in the nexus between university academia, not for profit organisations and independent research groups. Figure 6.1 illustrates differences in team compositions.

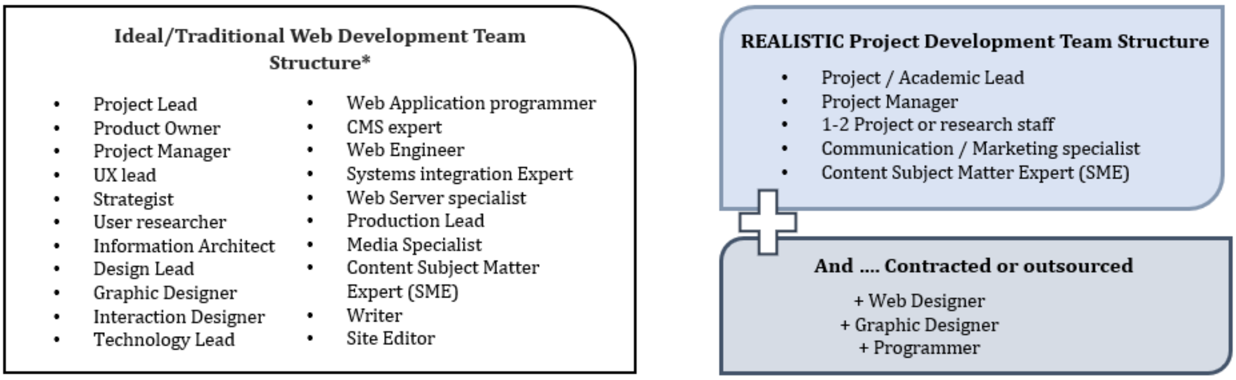


Figure 6.1 Comparison of team composition between traditional and project development groups

[Figure adapted from information within the book chapter. Lynch PJ, Horton S. Web Style Guide: Foundations of User Experience Design. New Haven, US: Yale University Press; 2016. (accessed July 15, 2021). Available from: https://webstyleguide.com/].

This diagram illustrates that project development teams have reduced resources, limited web development experience, digital translation, and often online development outsourced to designers and software programmers. Contractual delegation of activities can impact conceptual and functional interface design due to misunderstandings or miscommunication between groups, negatively influencing overall development and evaluation processes. Project team staff are also likely to be unaware of web development management strategies and the importance of usability in ensuring interfaces can be used successfully by intended users.

Although scarce, there were exemplars of peer-reviewed articles (identified within Chapter 4) that project teams could access online resources to support their development practices. Application of either HHS guidelines or WDMHC framework (described in sections 2.3 and 2.4, respectively) during online health information resources development could provide similar recommendations to design valuable and useable interfaces. However, undertaking protocols and interpreting feedback from appropriate usability evaluation methods may depend on developer experience, team structure, or available resources. WDMHC model has been pragmatically applied across a diverse range of resources and reported to be a valid approach to: i) improving usability and access of health websites for health consumers,[388] ii) informing the development of a social media resource centre for COPD patients,[232] and iii) supporting the design a web-based health information database and call centre.[233] A literature review has found no framework to support the design, development, and evaluation of online health information toolkits.

6.3.4 DEVELOPMENT OF AN ONLINE TOOLKIT FOR CARERS

The Centre for Palliative Care (CPC) in Melbourne, Victoria, was funded by the Australian Government Department of Health (Public Health and Chronic Disease program) to develop a freely accessible, nationally relevant online toolkit to support family caregivers of relatives or friends with advanced disease. For this study's purpose, the characteristics and objectives of OHT are described previously in section 4.2.5. Content development for 'The Australian Carer Toolkit for Advanced Disease' (known here as 'CarerHelp Toolkit' or 'the Toolkit') began in December 2018, with online design and build stages undertaken in July 2019, the final version released in October. Summative evaluations were undertaken in the post-release period from July 2020 onwards. Three organisations were involved in the development cycle of this resource: the CPC developed content and design of the toolkit, CareSearch (Flinders University) was responsible for online build, and the University of Technology Sydney (UTS) completed all overall evaluations and reported all process outcomes. The Toolkit objectives centred on increasing family carers knowledge and their expectations of end-of-life caring through a series of learning modules, access to how-to guides in the form of vignettes, interactive activities, and video clips. Hyperlinks to other relevant, high-quality resources from organisations and government departments to support caregiving at home were embedded within the Toolkit. A participatory model of consultation with stakeholders and guidance synthesised from available quality evidence-based information was the basis for developing the content for the CarerHelp Toolkit.

6.4 REVIEW OF THE LITERATURE

As the systematic mapping review demonstrated (Chapter 4), in the four years previous, there have been many online toolkits developed and released for use by health care consumers and HCP; however, there is limited literature to describe the process and evaluation steps undertaken by resource authors. Study findings (as discussed previously in section 4.8) identified a relatively low number of published papers within peer-reviewed literature that included detailed descriptions of the development and evaluation of OHT (14 of 21 peer-reviewed articles). Some provided an inconclusive record of usability testing conducted with post-release evaluation documented in 57% of these 14 articles. Developers of OHT whose audiences were not medical or medical specialists were more likely to report (and undertake) usability evaluations, including OHT for health consumers, health workers, nurses or allied health practitioners reflecting a diverse range of health areas and disciplines OHT were supporting. Outcomes suggest OHT peer-reviewed literature is inadequate as an evidence base to support practice for inexperienced developers. Developers were unaware of the different types of authorial sources of guidance available to assist with development or evaluations, shown by an absence of descriptions of applying usability or accessibility guidelines to OHT. We could infer from the extracted data that those developers did not fully report UEM, and development teams were unaware of their requirements under the law to ensure that OHT meets minimum standards for accessibility and successful use.

A scoping review of online toolkits undertaken by Barac et al.[250] assessed diversity and comprehension of OHT as a knowledge translation strategy, potentially identifying 83 online toolkits released in eight years. Thirty-one were evaluated for the effectiveness of the knowledge translation as a learning strategy post-release. Further, a systematic review of online toolkits' effectiveness as a strategy for implementing research evidence into clinical care was undertaken by Yamada et al.[252] Outcomes identified a relatively low number of quality toolkits available reporting evaluation outcomes (6 of a potential 39 rated as moderately successful in changing behaviour or affecting clinical care). However, there is limited literature investigating the OHT evaluation process, specifically formative and post-release evaluation activities (as described within section 4.8.2). Researchers acknowledge reports of evidence-based usability evaluations completed within the UCD approach are limited,[244] and of those results published, these are often poorly designed and reported and of low quality.[277,388,389]

6.5 SIGNIFICANCE OF THIS STUDY

Underlying KT processes and the inclusion of self-directed learning activities as a format to encourage change in behaviour or practice has increased the prevalence of online toolkits. For developers of health information resources, OHT provides an opportunity to engage with users from diverse backgrounds and experiences to participate in learning activities to improve knowledge or behaviours amongst specified groups. Usability engineering and health informatics researchers recognise the importance of having readily available, evidence-based guidance on the process involved in producing high-quality, accessible websites (UCD, www.usability.gov and WDMHC) for consumers. Development teams creating OHT could access this guidance, and although evidence and recommendations are specifically for websites, applying this advice increases the opportunity to produce valuable and relevant resources. There are uncertainties regarding the influence evaluation has on the end-'users experience of the interface as findings from the first two studies suggest a) developers are concerned with implementation outcomes rather than formatively evaluating their resources, b) formative evaluations are less of a concern than post-release evaluations and c) developers are inexperienced in attenuating usability errors to improve interfaces.

For non-specialised development teams, the provision of a comprehensive evaluation approach could potentially improve the likelihood of evaluations being undertaken during OHT development processes if structured methodologies are known and available. However, it is not known how development team structure, the process and the quality of evidence generated by usability evaluations in a systematic approach influences acceptance of recommendations to improve the user experience of the interface. This study provided independent insights into the development processes of a non-specialised multidisciplinary team creating a palliative care OHT in the real-world development process. This study also investigated if applying a comprehensive usability evaluation approach within a typical development process was valuable in improving interfaces when designing health interfaces for diverse audiences.

6.6 RESEARCH QUESTION AND STUDY OBJECTIVES

RSQ3: Does a comprehensive, structured evaluation approach, when applied within a real-world development process, increase the likelihood of undertaking usability evaluations, and can a formal approach inform the multidisciplinary team's reiteration of the OHT interface?

6.6.1 STUDY OBJECTIVES

1. Determine if current UCD approaches in identifying issues and problems through comprehensive usability testing validated for website development can be applied equally to OHT resources given their increased interactivity and functionality of the interface design.
2. Observe, measure, and analyse categories of usability issues identified by representatives from users who are informal carers for family or friends with palliative care needs to examine any commonalities or differences in detected problems to ascertain if these are a specific usability issue for this specific group of users (such as levels of understandability, technological impedances, or age-induced detriments to accessibility).
3. Investigate how the application of usability engineering reporting mechanisms influences developer modification choice of usability problems or issues identified from iterative feedback generated through expert and user-based evaluation methodologies.
4. Measure and analyse the CarerHelp Toolkit's post-release UX and determine if iterative pre-release feedback from the WDMHC evaluation process influenced accessibility and improved user satisfaction with the online resource.
5. Describe the developer experience of the evaluation process to determine if this framework provided a valuable 'add-on' to the overall UCD approach considering non-technological (usability) expertise within the development project group.

6.7 STUDY DESIGN

This study encompasses both quantitative and qualitative (or mixed) observational approaches to usability evaluations outlined in the WDMHC[218] (section 2.4, Figure 2.1). An outline of this study's process in context to the development of CarerHelp Toolkit is described in six phases below:

Phase 1

A preliminary interview with the CarerHelp Project Lead was conducted to understand their previous experience and perceptions of usability evaluations within development processes. A series of systematic formative evaluations were then undertaken during the CarerHelp Toolkit development process before OHT release. Consisting of three evaluation stages:

- Expert-based (peer review)
- Content-based (measures of understandability and readability)

- User-based (think-aloud assessment, measures of health literacy and satisfaction)

Phase 2

On completion of formative evaluations, commercially-standard formal written usability report describing types of errors, severity rating of each of the issues, observations, and results from the formal usability testing sessions (including questionnaire data). CPC project team received this report for consideration before the release of the Toolkit[X].

Phase 3

Information within this report complemented data generated from formative user-testing (as part of typical development) led by the Flinders University web development team. The National Reference Group (NRG) independently discussed findings to formalise modifications to the CarerHelp Toolkit interface before release.

Phase 4

Re-iteration of Carer Toolkit prototype interface undertaken with final NRG modifications and released on 16th October 2019. Once publicly available, the UTS evaluation team began a series of outcome evaluations of the Carers Toolkit, which continued to recruit participants remotely and collect data for six months post-release.

Phase 5

Independent of UTS evaluation, this current study attempted to collect post-release evaluation data via remote online surveys from two user groups:

- Group 1 consisted of carers who participated in usability evaluation sessions and received an online survey probing their thoughts on the changes between the two versions of the toolkit, pre- and post-release.
- Group 2 received an online feedback survey and was composed of carers who have pre-registered interest in evaluating the toolkit and was circulated to each group the week after release.

Phase 6

[X] Outcomes from both expert-based and content-based evaluations (as outlined in 6.7.6 and 6.7.7 of this chapter respectively) *did not* contribute to overall feedback provided to project development team at completion of evaluation phase. This ensured independence of the 'pre-build review process' to be undertaken by the CPC team/CareSearch project teams.

Follow-up telephone interviews and discussions with the CPC development and web team members were conducted post-release to gauge the developer's experience and how the usability evaluation results were applied to the Toolkit prototype to improve the resource's user experience.

Importantly, not all phases of the WDMHC are reported within this study. Phases 3 and 4 were outside the scope of this research. Phase 5 surveys were distributed however, no surveys were returned. Phase 6 telephone interview with CPC Project Lead could not be arranged due to time constraints and availability.

Figure 6.2A presents a diagrammatic experimental flow diagram and methodologies for each evaluation process described in detail in the following sections. Figure 6.2B provides the in-parallel WDMHC evaluation approach relative to the development process for this study.

6.8 METHODS

6.8.1 ETHICAL APPROVALS AND PERMISSIONS

Before recruiting carers and experts, an ethics application was submitted to the Flinders University Social and Behavioural Ethics Research Committee (SBREC) for consideration. This study received full approval (Project 8347) (Appendix 6.1) and, as such, complies with the Australian ethical standards and guidelines of the National Statement on Ethical Conduct in Human Research under the National Health and Medical Research Council Act.[390] This approval covers all aspects, including subsequent modifications associated with social media advertising, recruitment and post-release evaluation surveys.

6.8.2 SETTINGS FOR EVALUATION SESSIONS

All usability evaluations were completed within the Rehabilitation and Palliative Care building in the Flinders Medical Centre (FMC) precinct in Adelaide, South Australia. Phase 1 user-based sessions were conducted in a quiet room with two laptops, and a wireless Internet connection allowed the researcher to observe and record participant activity. Peripherals and devices were made available to each participant to customise their online experience (i.e., laptop or tablet, mouse or touchpad and screen augmentation) to reflect typical interaction environments at home. All participants completed an identical set of questionnaires and scenario-based online tasks. Phase 1 expert-based review sessions (with technological and content-specific experts) and phase 6 interviews were undertaken remotely or F2F in a private space within the FMC precinct.

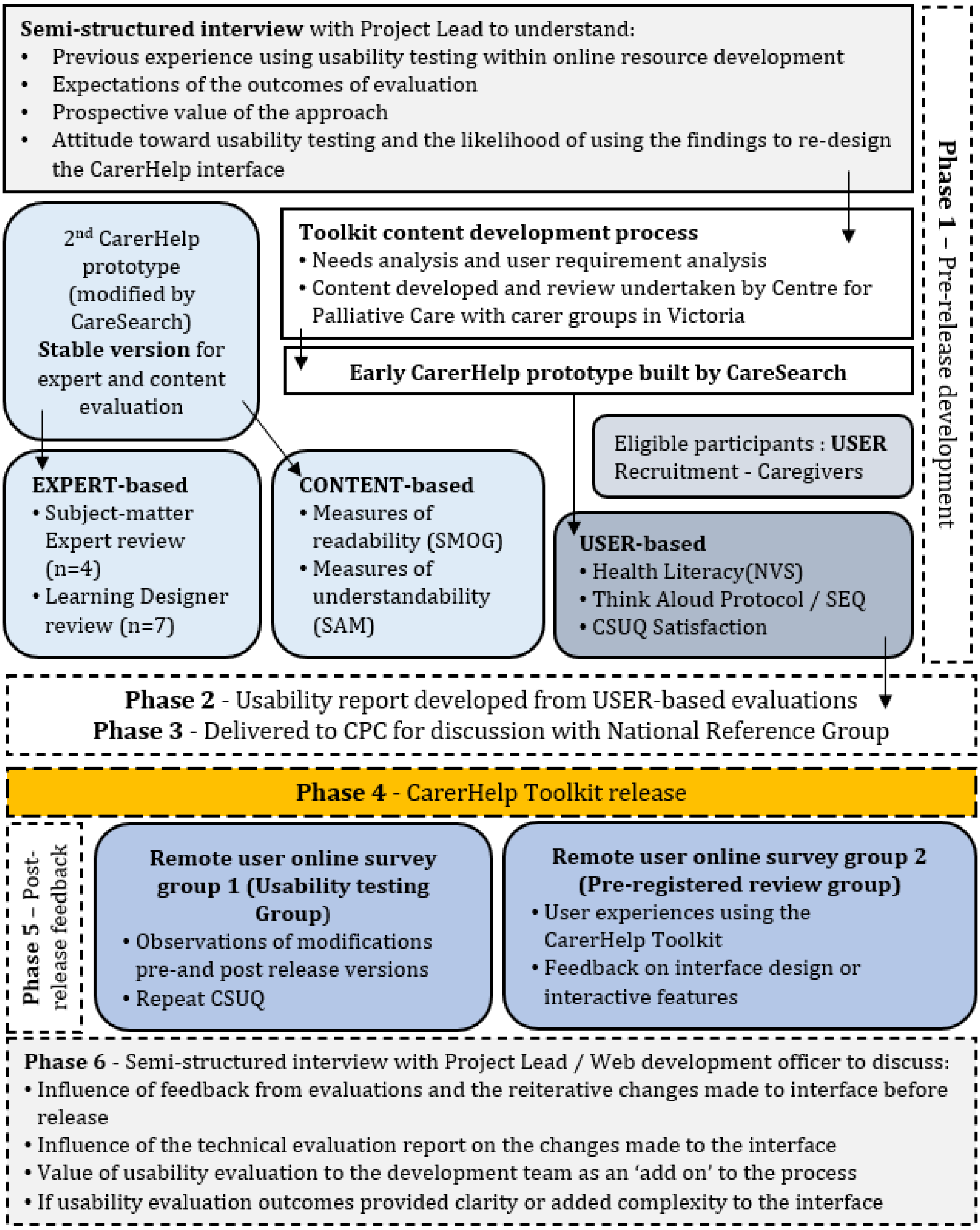
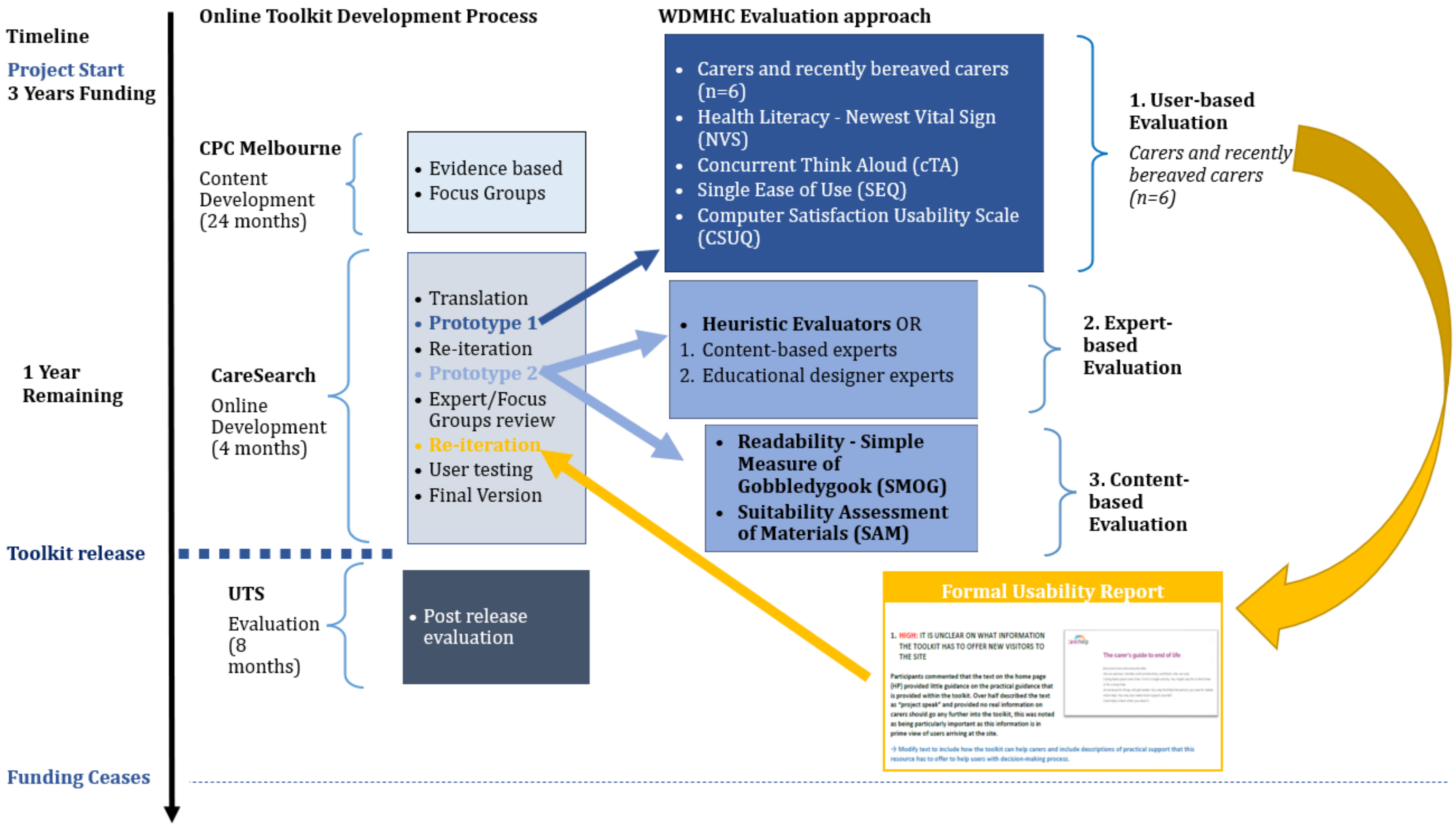


Figure 6.2A Study 3 Experimental flow diagram



1. HIGH: IT IS UNCLEAR ON WHAT INFORMATION THE TOOLKIT HAS TO OFFER NEW VISITORS TO THE SITE

Participants commented that the text on the home page (HP) provided little guidance on the practical guidance that is provided within the toolkit. Over half described the text as "project speak" and provided no real information on carers should go any further into the toolkit, this was noted as being particularly important as this information is in prime view of users arriving at the site.

→ Modify text to include how the toolkit can help carers and include descriptions of practical support that this resource has to offer to help users with decision-making process.

Figure 6.2B In-parallel WDMHC evaluation approach relative to the development process and project timeline for Study 3

6.8.3 DESCRIPTIONS OF PARTICIPANTS IN THIS STUDY

Carers involved in the user-based evaluation process are representatives of the CarerHelp intended audience and therefore are referred to as USER/S. Healthcare Professionals (HCP) involved in the expert-based evaluations are considered subject-matter experts (SME). Learning Designers (LD) encompass professionals[Y] who work within higher education or the private sector to build educational resources for students. EXPERT is combined group data analysed from both SME-HCP and LD groups.

6.8.4 DEVELOPMENT PROCESS AND RE-ITERATIVE PROTOTYPE VERSIONS FOR EVALUATIONS

Due to the overlap in Phase 1 between the 'live' development process and in-parallel independence of this study, user-based evaluations were conducted on the earliest version of the CarerHelp prototype. After which, developers rectified critical interface issues to produce a second early prototype version. This version of the pre-release prototype was duplicated within the server to create a stable copy of the CarerHelp Toolkit for the expert-based review group to evaluate and assess the content. Usability testing sessions were undertaken approximately eight weeks before the OHT release date. Six weeks before the hard release date, a technical usability report was provided to the CPC team (Phase 2), which allowed time for discussion with NRG to model iterative changes and undertake further modification of the Toolkit as required (Phase 3). Post-release online surveys were designed to investigate the final (Phase 5) third version of the toolkit that would remain stable until the development group undertook further re-iterations six months after release.

6.8.5 PHASE 1 USER-BASED EVALUATION: USABILITY TESTING

6.8.5.1 *Usability evaluation sample size*

Objectives of formative evaluation methodologies focus primarily on discovering issues, errors or problems encountered by users during the completion of specified tasks within an online resource.[66] Sample size estimates require using the Probabilistic Model of Problem Discovery manipulating binomial probability formula to determine relationships between the number of

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[Y] Learning designers have three different professional titles: educational designer, learning designers (LD) and instructional designers (ID) depending on geographical location. In Australia, professionals can have one of three titles and undertake the same role within higher education or private sector. Educational or Learning Designers are more commonly recognised within the Australian education sector.

users required to discover an error (Equation 6.1), probability of this error occurring at least once during the test procedure and levels of acceptable error.[66]

Equation 6.1: Probabilistic Model of Problem Discovery calculating the total number of users required to discover usability errors[66]

$$\text{Total number of users (n)} = \frac{ln\ (\ 1 - \mathrm{P}\ (\ x > 1\ )\ )}{ln\ (\ 1 - \mathrm{P}\ )}$$

n = number of users required to discover an error
p = probability of this error occurring at least once during the test procedure
P (x > 1) = level of acceptable error discovery (problem discovery goal)

Previous empirical studies suggest acceptable levels for both probabilities of an event occurring at least once (*p=0.31*) and problem discovery goal to be 85% (0.85) lead to a sample size of 5 users.[391,392,Z] For the rigours of this study, the modified binomial probability formula (Equation 6.1) was used to calculate the number of users required to discover an error (*n*) using the recommended value for *p*=0.5 (likelihood of an error occurring at least once 50% of the time) by Sauro and Lewis,[66] and level of acceptable error discovery P (*x>1*) of 98% (0.98). The calculated number (*n*) of participants for this usability evaluation sample was six members of the intended user audience: palliative care caregivers.

6.8.5.2 Identification of participants

Inclusion criteria for participation within this study required carers who were actively caring for the palliative care needs of a loved one within the community. Carers who were recently bereaved (between 6-12 months post-death) were also eligible to participate in the usability sessions. This study excluded those individuals who did not reside locally and could not participate in F2F moderated sessions. Usability testing also required participants to have an adequate level of English due to the complexities of questionnaires and assessment activities.

[Z] Use of 'Nielsen's rule of 5' is an agreed benchmark within usability sector although other practitioners propose that these values tend underestimate the actual number of users required to find equivalent number of problem (for example, 50 users by Spool and Schroeder[393] or Hwang and Salvendy's 10+2 rule.[394] Nielsen[391] acknowledges that whilst additional users tested may increase the problem discovery goal value (P(x > 1)) from 85% closer to 100% detected, the return on investment (in terms of time and money,[395] does not translate to improved outcomes especially where this formal process is iterative and involves multiple different evaluation methods having a high likelihood of uncovering those missing 15% of problems.

6.8.5.3 Recruitment

Two recruitment strategies were employed to reach potential carers within the community. The study was advertised and promoted using online communication channels of carer organisations supporting carer communities within the southern Adelaide region. Three organisations were approached and initially indicated in- principle support to distribute study information - Carers Australia (SA), Health Consumer Alliance SA and Carer Support SA. Of the three, Carers Australia SA was the only organisation that promoted this study to their audience through social media channels, Carers SA and Young Carers SA Facebook pages. Four posts were placed within both channels two weeks before the scheduled start date for usability testing.

Direct recruitment via Laurel Hospice Southern Adelaide Palliative Services (SAPS) Caregiver Network at the FMC assisted in identifying and inviting palliative carers to participate in the study. The Caregiver Network Facilitator advocated on behalf of the researcher to identify then approach carers who may be interested. Once study requirements were explained and their involvement was agreed upon, their details were forwarded to the researcher. The researcher then contacted and explained the study, confirmed informed consent then arranged a time and date for usability evaluation sessions conducted at the carer's convenience.

6.8.5.4 Usability evaluation methodology

Carers attended the Rehabilitation and Palliative Care building in the FMC precinct on the day and time specified. Participants provided informed consent after being settled into the testing room. The session protocol was explained to each carer, and the following activities were outlined:

1. A brief survey of self-reported levels of online ability and behaviour
2. Measures of health literacy levels (NVS questionnaire)
3. Scenario-based usability session with single ease question (SEQ)
4. Completion of the Computer Satisfaction Usability Questionnaire (CSUQ).

The allocated session time for compulsory components of evaluations was 60 minutes. The overall session protocol is now described, and each activity is explained in turn.

NVS - Measures of User Health Literacy Levels

The Newest Vital Sign (NVS) literacy screening tool was developed for use within primary care as a validated alternative to the time-intensive Test of Functional Health Literacy in Adults

(TOFHLA). Weiss et al.[396] found that the NVS tool was reliable ($\alpha > 0.76$) and successfully correlates to the TOFHLA in sensitivity but not specificity. Participants completed the NVS questionnaire by reading an exemplar nutritional label on an ice cream container and applying this information to answer six scenario-based numeracy and literacy questions. Each question was scored as 1=correct or 0=incorrect. Totals greater or equal to 4 indicates a lower likelihood of having low health literacy; conversely, those with totals equalling three or less will have a higher likelihood of having limited health literacy levels. Appendix 6.2 provides a copy of the NVS screening tool.

Participants were asked to customise laptops and peripherals for familiarity and comfort, ready to begin scenario-based task activities.

Scenario-based usability assessment using cTA

Usability testing, which assesses efficiency, effectiveness, and satisfaction of interface interactions,[289] reflects cognitive processes driving interactive behaviour.[57] Usability testing can yield practical feedback to improve health interfaces[397] as end-users identify usability errors related to an individual user's characteristics, context, and use environment.[57] A crucial element of formative usability testing is understanding these cognitive processes underpinning the interactions between the end-user and the interface[AA]. The concurrent think-aloud approach (cTA) requires participants to verbalise thoughts and feelings. Each task is undertaken within the interface with the resulting narrative around scenario task completion as a rich source of information analysed for errors, issues, and user attitude using the Toolkit.[401] Narratives can describe misconceptions or misunderstandings of content or functionality of the interface and aspects of complex tasks.[400] The traditional cTA approach[398] requires limited moderator-user interaction with only minimal responses provided to participants once the testing is underway to limit the moderator-effect bias (i.e., no probing words except “keep talking;” after 15 seconds of silence). cTA elicits users' behaviours when completing these tasks in a real-world scenario.[271] Moderators (researchers) record narratives and comments as users complete required tasks,

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[AA] Think Aloud approach (TA) is a widely applied research method examining the relationship between cognitive processing and a wide range of activities including chess, reading, and writing.[398,399] TA approach has also been applied to development of online resources as a usability evaluation method for developers[395] to undertake with users to understand both the processes used in working memory[271] and higher-level cognitive processes as users’ complete given tasks.[400]

providing greater procedural feedback as the user's working memory is engaged with actions required to complete scenarios.[400]

Once participants were comfortable, the moderator highlighted the need to continually verbalise thoughts and actions as users moved through the interface reminding participants that there were no incorrect answers and that the task was testing the resource and not the users' skills. All eight tasks asked users to complete an action, such as locating a piece of information, downloading a resource, or finding an answer to a proposed question relating to OHT content.

Each task had a 3-minute time limit. If the item was identified within this time, tasks were considered a success. Tasks were recorded as failures if participants identified the incorrect item, if time had elapsed or if the task was abandoned. After each task, participants completed the Single Ease Question (SEQ), rating their confidence and difficulty finding the information requested on a 7-point Likert scale(Appendix 6.3). Each SEQ question was averaged across all six participants to calculate an overall task average score. These three averages provided a measure of ease of use, satisfaction, and confidence across where higher mean values indicating greater ease in completing the task, experienced high levels of satisfaction and confidence that they found the correct information.

All scenarios and post-test descriptions of users' experiences were audio and video recorded for retrospective analysis; all findings contributed to the usability report.

CSUQ - Assessing interface satisfaction

The 16-items of the CSUQ Version 3[402] (CSUQ-V3) (Appendix 6.4)[BB] questionnaire measure overall satisfaction with the CarerHelp Toolkit, with three subscales assessing interface usefulness (USE=Q1-Q6), information quality (INFOQUAL=Q7–Q12) and interface quality (INTERQUAL=Q13–Q15). All CSUQ questions are on a seven-point Likert scale with the anchor points, at strongly agree to strongly disagree, and was initially designed to be completed remotely.[403,404] Calculation of overall CSUQ and subsequent subscales as an average of the questions contributing to each measure. Overall satisfaction of the CarerHelp Toolkit Scores was calculated from the average scores from all sixteen questions.

[BB] Developed in 1993, Computer System Usability Questionnaire (CSUQ) was designed as a variant of Post-System Satisfaction Usability Questionnaire (PSSUQ[403]) for large scale usability testing of the early IBM systems.[402] Further refinement to CSUQ reduced question number (in relation to current PSSUQ) and syntax simplified to improve efficiency of the questionnaire.

Higher averaged scores indicate a greater level of satisfaction with the end-users interaction with the Toolkit [CC].

6.8.6 PHASE 2 USABILITY EVALUATION REPORT FOR CONSIDERATION BY THE DEVELOPMENT TEAM

Standard commercial practice requires a formal usability report to summarise findings from expert, content, or user-based testing. This document informs development teams of favourable/adverse outcomes from usability testing processes and guides iterative changes to interfaces. The formal commercial report for the Carer Toolkit was based on a template[407] to organise, rank and classify issues or errors[197,408,409] identified within the usability sessions. The template provides a standardised structure to present usability tests outcomes whilst avoiding blaming the participant for the outcomes and presenting findings in a simple, contextualised, and non-technical layout for a non-specialised audience to understand then interpret. This report included an executive summary, a brief and succinct report of findings, including practical recommendations, positive and negative findings, and participant quotes where appropriate.

6.8.6.1 Usability report data variables

Outcome data variables reported within the formal report provided to the development team for consideration:

1. **Participant's demographic data**
    - Self-reported internet behaviour
        - Frequency of Web Usage
        - Internet Use
        - Device Choice
        - Self-Assessment of Technical Ability
    - NVS score indicating health literacy level
2. **Descriptions of scenario-based tasks and targets for each task**

[CC].CSUQ-V3[402,405] was presented to users with modified terminology to reflect the type of resource being assessed. 'System' was replaced with 'online toolkit' to improve clarity and increase participant understanding. These modifications did not affect reliability, sensitivity, or validity of psychometric measurements of CSUQ-V3 questionnaire.[402,406]

3. **Identification of problems and issues within the interface**

   All visual, audio, and written moderator notes were annotated and collated digitally into a running commentary on all issues identified by participants. Analysis of this data was completed by undertaking a qualitative meta-summary of findings within data content, then aggregating errors by applying quantitative logic to each descriptor generated to include interface issues, opportunities or suggestions for change, content or resources missing from the interface and associated pages. Notable quotes from users summarising conceptual ideologies[410] were also highlighted. Qualitative descriptors collated each instance where an issue caused the user frustration or annoyance, disrupted or impeded completion of a task or features of the interface being recognised verbally incorrect, absent or if carers were unable to locate targeted objectives of the task.

4. **Nielsen's Severity Rating for each issue within the interface**

   Once errors had been identified, each issue was reviewed, and severity ratings were applied as per Nielsen's severity scale of usability issues.[411] Each error was assigned a rating depending on the number found, level of frustration caused, difficulty to recover, effects critical area and ease to fix.

   The severity of interface errors is then assessed on three factors[411] influencing usability:

   I. Frequency of the occurrence within the interface
   II. Impact of the error (if it occurs) for users to overcome
   III. The persistence of the error within the interface continuously affects evaluator interactions.

   In considering these factors, each error was assessed and, using Nielsen's Severity Rating scale,[411] received one of the following severity ratings:

   0. I disagree that this is a usability problem at all
   1. Cosmetic problem only: need not be fixed unless extra time is available on the project
   2. Minor usability problem: fixing this should be given low priority
   3. Major usability problem: important to fix, so should be given high priority
   4. Usability catastrophe: imperative to fix this before a product can be released.

In rating interface issues, errors persistently having a significant impact on evaluators received the highest severity rating.

Error Severity Ratings were translated into the following groups for usability report:

- *GOOD* - The design was simple, and users understood it. Keep it.
- *NEGLIGIBLE* - Cosmetic problem only: need not be fixed unless extra time is available on the project.
- *LOW* - Design or feature caused little confusion or frustration; the feature is not in a high priority area.
- *MEDIUM* - Design or feature caused some moderate confusion or difficulty.
- HIGH - Design or feature caused extreme confusion or frustration; the problem greatly impacts task flow.

5. **Metrics of efficiency and effectiveness**
    - % Effectiveness - number of tasks completed successfully to the total number attempted
    - The ratio of completion to failures for each task
6. **Mean SEQ score for each task**
    - How easy was it to complete the task?
    - How confident are you that you completed the activity fully?
    - What was your level of satisfaction after completing this task?
7. **Mean CSUQ score measured across domains of:**
    - System usefulness (USE) (Items 1-6)
    - Information quality (INFOQUAL) (Items 7-12)
    - Interface quality (INTERQUAL) (Items 13-16)
    - Overall satisfaction (OS) (Items 1-16)

The NRG independently reviewed the report, decided which extent of errors to modify independent of the researcher. This prototype was then re-iterated, becoming the final version released on 16th October 2019.

6.8.7 PHASE 1 CONTENT-BASED EVALUATION: CONTENT READABILITY AND SUITABILITY

6.8.7.1 Measures of readability - Simple Measures of Gobbledygook (SMOG)

Readability is defined as *“the ease of comprehension because of the style of writing.”*[412(p203)] This definition considers the user’s need to understand contextualised health information encountered within the interface. Simple Measures of Gobbledygook (SMOG) tool was employed to assess readability levels within the OHT prototype [DD]. All first-level pages of the Toolkit were analysed using SMOG calculation. For webpages whose content was less than 30 sentences on each page, and all text was included in subsequent analyses (Equation 6.2[415]). Variables were hand-counted across all sentences, along with the number of polysyllabic words (> 3 syllables). The subsequent SMOG grade level calculated was equivalent to the number of years of ‘Western’ formal education required to understand a passage.[416]

Equation 6.2: SMOG calculation for webpages containing less than 30 sentences in total[415]

$$\text{Grade Level} = \sqrt{\left(\frac{\text{Total Number of Polysyllabic Words}}{\text{Total Number of Sentences}}\right)\left(\begin{matrix}\text{Number of Sentences}\\ \text{Short of 30}\end{matrix}\right) + \left(\begin{matrix}\text{Total Number of}\\ \text{Polysyllabic Words}\end{matrix}\right)} + 3$$

Due to the text length on the ‘About the Project’ page, the ‘traditional’ SMOG analysis tool was applied. Ten consecutive sentences near the beginning, middle and end of the webpage were manually selected at random, equating to 30 in total, were used within the analysis. The calculation was conducted using an online SMOG tool (http://wordscount.info/wc/jsp/clear/analyze_smog.jsp), 30 randomly selected sentences from the beginning, middle and end of the text were entered into the calculator. SMOG analyser tool applied the following Equation 6.3 to calculate SMOG grade level:

Equation 6.3: Readability grade level of content as calculated by the SMOG formula[414]

$$\text{grade} = 1.0430\sqrt{30 \times \frac{\text{number of polysyllables}}{\text{number of sentences}}} + 3.1291$$

[DD] Readability formulas do not consider factors contributing to comprehension including active reader roles and reading ease.[413] Many OHT features that influence usability are not factored in the resultant score of readability formulas[413] including visibility, legibility, individual differences, and logical determinants.[414]

The resultant readability grade level for toolkit webpages was compared with the recommended benchmark of Grade 8 (the equivalent of a child of 13-16 years with eight years of formal education in Australia) as guided by SA Health[417] and Cheng and Dunn.[416]

6.8.7.2 Measures of understandability - Suitability Assessment of Materials (SAM)

To assess Toolkit resources appropriateness across different mediums, including video, audio, written and online formats,[418] the Suitability assessment of materials (SAM) instrument was applied to selected materials within the Toolkit prototype. SAM provides a comprehensive, structured, and quantitative measure of different informational aspects influencing understandability by intended audiences.[419] All pages and project-generated PDFs embedded within the Toolkit were assessed and scored applying Doak's evaluation criteria [p.49-59, Doak[418]]. Each page/PDF was assessed for 22 factors across six categories: content, literacy demand, graphics, layout and typography, learning stimulation/motivation and cultural appropriateness. Each factor scored as 2 (superior), 1 (adequate) or 0 (not suitable) and for those which are not applicable (N/A), were scored as -2. The total sum of all factors was divided by the highest possible total (maximum 44 or adjusted down appropriately to reflect included criteria total) and multiplied by 100 provided a final score as a percentage. Doak[418] interpreted these total scores as superior (70–100%), adequate (40–69%) and not suitable (0–39%). Appendix 6.5 presents the SAM scoring category and factors.

6.8.8 PHASE 1 EXPERT-BASED EVALUATION: PEER REVIEW

Inspection usability evaluation methodologies are assessments where experts detect usability issues within the interface; examples include heuristic evaluations, cognitive walkthroughs and peer review. Heuristic evaluations require experts to assess the interface's usability against a set of guidelines or principles.[89,91] Cognitive walkthroughs invite experts to undertake activities within the interface, to behave like a user relative to their cognitive model of the resource, informed by objectives or needs and knowledge.[89,420] Expert-based usability inspection methods can offer a high rate of return for a relatively small investment of time and money[270,421] compared to usability testing[57] by outsourcing usability expertise to specialists. Expert peer-review also considers end-users knowledge and awareness of the subject domain and specific content-based errors detected by domain specialists based on the understanding and context of the objective and application of information provided within the resource.[422] All three methodologies require experts to have subject domain knowledge and an awareness of how end-users will behave within the interface. Only heuristic evaluation requires participant evaluators to be double experts who are either experienced or trained by resource developers in assessing the usability and are content specialists.[89,90]

While each methodology has advantages and disadvantages, expert inspectors identify between 30-60% of errors,[423] and on average, 49% of common errors are shared between methodologies. Double experts do not have the abilities to emulate errors associated with critical end-user behaviours,[218] resulting in a high frequency of false positives identified, non-veritable errors for end-users, and missing errors severely impact end-users interactions with the resource.[423,424] For development teams applying expert peer-review, this raises the question of whether HCP with a humanistic perspective to understand patients or carers interactions based on practice experience[218] are adequate to identify a majority of usability problems that impact end-users or if a double expert could improve evaluation outcomes.

6.8.8.1 Composite double experts for usability evaluations

As evaluators, double experts examine interface flaws objectively, comparing content to domain knowledge to judge quality, reliability and accuracy whilst subjectively assessing the interface for technical errors associated with operational or functional aspects that decrease usability and impede end-user interactions. A potentially rich source of technically skilled professionals who could participate in evaluations in conjunction with HCP are individuals having awareness, knowledge, and expertise in usability within the academic environment. Universities engage with learning or educational designer specialists working across interaction, visual and education design to build digital materials for students. Learning Designers (LD, are also known as educational or instructional designers depending on country of employment) work in consultation with academics to guide development, incorporate learning pedagogy, to construct measures or instruments to assess the effectiveness of materials to build learner's knowledge and improve outcomes within a directed-learning scenario delivered in a digital classroom. Alignment between designing educational materials, Toolkit instructional components,[252] and evaluation practice could place LD in an ideal position to develop health information resources in multidisciplinary settings. The ability to understand features that contribute to end-user acceptance and functionality of the interface design enhances the competency to identify issues or errors that contribute to levels of usability. The literature has not previously reported recruitment, participation, and outcomes from usability evaluations of health information resources undertaken by LD during development.

6.8.8.2 Sub-Study design summary

Traditional usability practice requires developers to recruit three to five heuristic double experts[425] having expertise in both domain content knowledge and experience or training in usability.[273] Factors such as identification, access, and availability of suitable experts or representative end-user recruitment influence evaluations' likelihood of integration into typical development processes. The involvement of a small number of HCP who are equally skilled in usability to heuristically evaluate online health and medical interfaces is appealing for developers as it can alleviate the need for end-users[426,427] saving limited resources. Given the scarcity of experts in the health domain with usability expertise, recruiting representatives from both reviewer groups could balance the identification of both content-based and usability errors whilst countering any perceived weaknesses in each group's ability to detect interface issues, especially in scenarios where end-users are deficient in the process. Saroyan[428] found that instructional designers and Subject-Matter-Experts (SME) identified different issues and problems within a written educational text by employing different cognitive methods. LD adopted a generalist view of the text and used a comparative review model compared with SME, whose specialist approach was directed by domain knowledge and utilised a sequential review method.

WDMHC peer review process undertaken within this study further explored differences in usability issues/problems identified by SME (HCP) and LD expert groups in usability evaluation of the CarerHelp Toolkit and was conducted as an adjunct activity. The primary objective of this study was to investigate the feasibility of involving subject-matter experts (HCP) and technical experts (LD) in a modified expert review process to explore their availability for recruitment and the appropriateness of their feedback to reiterate a palliative care resource interface through error identification.

6.8.8.3 SME Recruitment – Palliative care HCP

Potential palliative care HCP were identified from local, state, and national organisations whose members support primary carers in the community who provide palliative care to their loved ones. Representatives from Southern Adelaide Palliative Service, Palliative Care Queensland, and the Australian and New Zealand Society of Palliative Medicine were sought to participate in the peer review. HCP were invited to participate via e-mail. After registration of interest was received, the study and perceived risks were explained to participants, who provided informed consent.

6.8.8.4 LD Recruitment

LD were initially sought from Flinders University Centre for Innovation for Learning and Teaching. As no interest was received from local University staff, the professional organization for online designers (learning, educational and instructional) working within the private and higher education sector, the Australasian Society for Computers in Learning in Tertiary Education (ASCILTE), was approached and assisted by promoting the study to their membership.

6.8.8.5 Expert-based evaluation methodology

The peer-review sessions were undertaken remotely and structured in two parts. Firstly, to review the secure version of the Toolkit prototype, recording their thoughts within a feedback document offering guidance on the sections or features that were 'in scope' of the review process. Secondly, evaluators were required to participate in a debrief session with the researcher. This protocol is now outlined in detail.

Before commencing the review process, participants provided informed consent after explaining the research protocol and perceived risks involved. Each expert was then asked for descriptions of their professional credentials (professional title, professional practice setting and post-qualification years of experience working as either an HCP or as an LD) and to self-rate their level of technical ability using the Internet by responding to the following question: I am

a) An avoider of everything online
b) A novice or learner or beginner
c) Mostly confident - having intermediate skills
d) An expert who is confident in finding and using online information.

Evaluators completed the review process in two stages; the first was a digital document providing a structure and guiding interaction with the prototype. Professionals were asked to comment and record their thoughts on content, navigation, interface features, interactive activities, or widgets, including what they determined necessary for the end-user within a digital document. All reviewers were invited to provide as much or as little feedback as they liked. Reviewers were not limited to the guiding questions or statements within the review document. Although some activities embedded within the Toolkit were out of the scope of the review.

Once the review document was completed and returned to the researcher, participants undertook the second stage of the review process by remotely de-briefing their findings during a 30–45-minute online interview session and providing an opportunity to explain their written feedback. The functionality of the conference software[429] demonstrated visually issues that were critical to function, incorrect or non-sensical in the context of the content, information flow and navigation across and within the Toolkit pages. Session length varied; duration depended on the quality of written feedback descriptions (reducing the need to orate issues) or on an individual's intent to work through each issue and provide alternate solutions that resulted in longer consultations. Each LD received a $25 honorarium for their participation after the evaluation process.

6.8.8.6 Expert-based data variables and statistical analysis

After deidentifying the data collected from both evaluator groups, a qualitative meta-summary of content findings was generated from both the written feedback document and other narratives from the de-brief interviews from both reviewer groups. Quantitative logic was then applied to aggregate error types between participants and provided a process to assess the frequency of error types and identify problems, missing resources or content, and opportunities or suggestions for interface improvements. Error type descriptors included:

- Accessibility
- Information architecture
- Information flow
- Interaction
- Navigation
- Pedagogy
- Recovery
- Site/platform
- Specific content
- Utility
- Visual representation.

Further analysis of content-specific errors written information within the interface required frequency-based analysis of the types of content errors detected by reviewers. A modified coding schema was applied to accommodate the interface's online environment, and technological aspects to error data (Table 6.1) identified adapted from an original schema to review written text.[428]

Table 6.1: Coding groups for analysis of online toolkit content by expert reviewers (modified Sayoran 1992[428]

Proposed coding group	Description
Revision statement	Explicit verbalisation or text statement with the intent to change current to an ideal state
Knowledge statement	Problem with specific content knowledge
Problem identification	Explicit reference to an issue or problems
Evaluation	Positive or negative comments from reviewers, judgements, or preferences
Text knowledge	Comments or statements from reviewers on learnings from the text
Strategies	Explicit reference to underlying strategies or the need to apply strategies to the content
Resources and activities	Explicit reference to embedded resources and learning activities

All error data generated within expert-based evaluations were reported as frequency or percentages for each reviewer group across the interface areas and by type of error detected. The commonalities and differences of errors identified between experts and end-users were analysed using a meta-aggregation approach addressing the type, severity, and exclusivity of errors detected during the evaluation sessions.

Meta-aggregation of usability errors

All types of errors from all three reviewer groups (USER (carers), HCP and LD) were collated in a single list, with meta-aggregation applied to produce classes of usability errors detected within the Toolkit interface across all reviewers. Aggregation provided an opportunity to compare and contrast commonalities or differences in error types identified by evaluator groups, further providing the capacity to highlight interface problems that are discovered exclusively by a single reviewer group or are perceived (shared) across more than one reviewer group.
Classes of usability error included:

- Content-specific
- Design or content construction
- Information flow

- Navigation
- Embedded resource or activity
- Pedagogy or educational strategies
- Minor typographical or grammatical errors
- Major typographical or grammatical issues.

The severity of interface errors was then assessed using Nielsen's Severity Rating as previously described in section 6.8.5.4. These errors are reported as frequencies and percentages for each group of reviewers with pair-wise analysis of means determining levels of significance (95%CI, significant $p<0.05$) using Independent t-tests[276] and Welch-Satterthwaite method to adjust for violation of equal variances assumption within the data[430] using SPSS software.[431] These outcomes are reported as *t(df)=t-statistic, p=significance*.

6.8.9 PHASES 5 AND 6 POST-RELEASE USABILITY EVALUATION

6.8.9.1 Remote user evaluation of post-release CarerHelp Toolkit

Two different carer user groups were surveyed to ascertain satisfaction levels (or dissatisfaction) and generate feedback on the post-release version of the CarerHelp Toolkit.

Phase 5 User Group 1 – Carers from user-based evaluations

All six carers who participated in the usability session self-nominated to be involved in the post-release review (Group 1); each received an e-mail at one-week post-release with an invitation to participate and a hyperlink to an online survey (Appendix 6.6). The survey asked a series of questions probing carers thoughts on toolkit interface changes in the period since interacting with the early prototype. This information could determine if these users could detect modifications relating to critical errors identified within usability testing. Modifications to the dynamic versus stable version of the prototype in the period between the post-formative evaluation period and release will be identified by analysing prototype images and extensive descriptions of errors from evaluators. This survey also included a CSUQ-V3 questionnaire assessing UI satisfaction and would repeat the same questionnaire completed during moderated usability sessions. Feedback was collected via Qualtrics platform,[432] and carers were asked to provide their feedback within three weeks of receiving the invitation e-mail.

6.8.9.1.1 Phase 5 User Group 2 – Interested audience of the toolkit

A second online survey was circulated to individuals who had voluntarily signed up to review the Toolkit via the Carer Toolkit 'splash page' during the development period. This survey was also constructed in Qualtrics,[432] asking reviewers to provide written feedback on aspects of the Toolkit, including navigation, structure, information flow, content and their thoughts on the relevance or usability of the toolkit interface (Appendix 6.7). The survey was circulated via registered e-mail addresses to eleven respondents. Reviewers received their invitation and online survey link in the same post-release week as Group 1 and were requested to complete their feedback survey within three weeks of receiving the initial e-mail.

6.8.9.2 Phase 6 Post-release interviews with project team members

Project Lead

An invitation to participate in a follow-up interview was provided to CPC Project Lead (PL) during the post-release period to discuss the following aspects of user-based evaluation and development processes specifically:

1. Did outcomes from the technical report of usability testing influence modifications of the OHT interface?
2. Was there perceived value for developers to undertake evaluations?
3. Were issues identified within the usability report helpful to resolve problems, or did this report generate more confusion or increased number or complexity within the interface?
4. Did the technical report provide support to aid decision-making or discussions with external stakeholders?

This interview was to be undertaken within three months post-release period.

Web development officer

An informal interview was undertaken with CareSearch's web development officer (WDO) to explore the influence and downstream work generated by usability evaluations of the Carers Toolkit. The primary role of the WDO within the project was to construct and modify online versions of the toolkit during the development phase of the Toolkit project. This interview was completed two weeks post-release in a quiet room within the FMC building, and after providing informed consent, the WDO was asked to reflect on development processes and identify problems or issues that he considered to impinge or impede their workflow. The usability report had not been available previously and viewed with interest which provided context to some of the modifications requested. Awareness of usability and accessibility was discussed, along with thoughts on optimising evaluations within a streamlined process formulated with the researcher. Interview data were annotated and recorded for retrospective analysis if required.

6.9 RESULTS

6.9.1 PHASE 1 USER-BASED EVALUATION

6.9.1.1 Project team experience and perceptions of usability evaluation

Three independent project groups collaborated to design, build, and evaluate Carers Toolkit resources. Each is described as a diverse group of professionals with experience in health (palliative care), academia, project management, expertise in web development and capabilities in promoting or communicating products into intended consumer or HCP markets. The PL (and their CPC team) were responsible for project management and toolkit content development, discussed their previous experiences in developing online health resources and awareness of usability evaluation via telephone before the study's commencement. The PL had previously contributed to global palliative care resources acting as a subject expert and content manager, supporting the development of the conceptual design of an online resource for carers overseas. There were synergies between described development processes previously experienced and those undertaken to develop Carers Toolkit content, including participatory methodologies through focus groups or meetings with carer representative groups. PL recognised early that the CPC Project group lacked capabilities to build the resource online and evaluate outcomes. Collaborative agreements with partners with these skills were established, and NRG oversaw all partner organisations and advised on product and project development. PL acknowledged that whilst there was limited exposure to usability evaluation within the CPC team, there would be an effort to endorse any modifications suggested by the evaluation as there is a recognition of the value assessing usability can deliver for the resource, including a reduction in risk and improvement in the overall quality of the product.

6.9.1.2 Usability testing of CarerHelp Toolkit prototype

CareSearch’s web development team provided access to a functional early prototype version consisting of ‘Home Page’ and eight first-level pages allowing users to interact with Web 1.0 styled information and an opportunity to view videos/learning modules. This ‘early’ version was considered a working prototype. Known issues with design, layout and content were present within the interface. These were not modified pre-evaluation as there was an imperative to let the carer representatives identify these issues and, if possible, explore their thoughts and suggestions for improvements to the aspects of the interface.

6.9.1.3 Recruitment and characteristics of carers for user-based usability evaluation

Due to sensitivity of content and context of use, difficulties were experienced identifying carers to participate in usability testing sessions. Three carer organisations failed to communicate further with the researcher after in-principle support was given. Carers Australia (SA) helped distribute study information through two social media platforms, but this engagement activity yielded no response from the community. Active palliative care carers and recently bereaved primary carers were identified within the Laurel Hospice Caregiver Network (SAPS). The Caregiver Network Coordinator assisted in recruitment by identifying and approaching carers who may potentially be interested in helping with evaluations.

Active carers were reluctant to participate; individuals reported being time-poor, too busy, or the timing was not ideal with their current caregiving trajectory. Bereaved carers were also difficult to recruit; their declination or hesitancy was due to apprehension of what reviewing the Toolkit may evoke for them. Carers reported not being emotionally ready and that it may be too soon after the death to provide objective opinions.

6.9.1.4 Characteristics carers in usability testing sample

The duration of the usability sessions was, on average, 75 minutes. It varied depending on the lengths of discussions with carers who valued the opportunity to divulge their personal caring experiences and, importantly, how these related to the Toolkit context of use. Six carers were recruited into the usability session, two were actively caring for the palliative care needs of their spouse living at home, and the remaining four were recently bereaved (6-8 months post-death). All carers were female and aged between 36-74 years (M=62.7 years, SD=13.5) who were frequently engaged online using various devices, although with varying levels of self-assessed technical ability across the sample (one expert, four of intermediate abilities and one online avoider). On average, the carer group were likely to have relatively high levels of health literacy (NVS score: M=5.83, SD=0.41) and overall reported moderate levels of satisfaction after interacting with the CarerHelp Toolkit prototype to complete eight scenario-based tasks as assessed by the CSUQ-V3 [M_{OS}=3.95 (SD=1.16), M_{INFOQUAL}=3.99 (SD=0.78), and $M_{\text{INTERQUAL}}$=3.75

(*SD* 1.62)]. Appendix 6.8 (section 4.2.2) summarises carer demographics, self-reported descriptions of Internet use, NVS scores and CSUQ-V3 measures.

6.9.1.5 Analysis of usability testing error data post-session

User SEQ ratings of usability measures, reporting task completion as a ratio of success: failure achieving a goal or task objective reflecting difficulties in navigation structures, menu, and information architecture on the ability of users to complete tasks was analysed post-session (summarised in Appendix 6.8, Section 4.2.3 and 4.2.4).

Findings from task 7 produced contradictory observations and measures from within the carer group. Target information item was not identified within any of the trials. However, they generated relatively high measures of confidence and satisfaction completing the task within participants as assessed by SEQ. Conversely, task success and corresponding SEQ measures of Task 2 and 8 indicated that participants found these the easiest to complete within the interface. Performance measures indicate Task 6 provided the greatest difficultly (success rate=33%, M_{SEQEase} =3.0), and participants were not confident or satisfied in locating 'Things to discuss with your Healthcare team' PDF during Task 3.

Post-session analysis of notes and recordings identified specific errors and issues within the prototype interface relating to content, navigation, information flow and page architecture. After aggregation and collation of errors from across all sessions, severity ratings were calculated for each error to identify specific issues that cause the greatest difficulty and inconvenience for carers when completing the tasks within the interface. Table 6.2 summarises relationships between carer age, self-reported technical ability and types of errors, severity ratings, and interface areas where these were detected.

The two eldest carers (aged 70-80 years) detected an increased number of errors (21 errors, *M*=10.5) and identified a higher number of errors rated as medium severity than other carer groups. Errors detected by older participants were more likely to be related to problems navigating within the prototype when compared to frequency and type of errors identified by the younger carer (*n*=1, 30-40 years, 14 errors). Carers aged 60-70 years detected a higher proportion of content specific errors than other aged groups. Carers with intermediate technical skills identified a higher proportion of navigation and specific content errors within the interface (61.1% total, *M*=8.25).

Table 6.2. Aggregated interface errors identified in usability evaluation by carers (participants)

		Age group (years)			Self-Reported Technological Ability			
		30-40	60-70	70-80	Expert - confident	Intermediate - mostly confident	Online avoider	
		n=1	*n*=3	*n*=2	*n*=1	*n*=4	*n*=1	**Total**
Total errors identified (%Total)		14 (25.93)	19 (35.19)	21 (38.89)	14 (25.93)	33 (61.11)	7 (12.96)	54
Mean errors / user		14	6.33	10.50	14	8.25	7	**Total (%Total)**
Type of error	Accessibility	0	2	0	0	0	2	2 (3.70)
	Information flow	4	2	3	4	4	1	9 (16.67)
	Navigation	2	4	10	2	12	2	16 (29.63)
	Site / Platform	1	3	2	1	5	0	6 (11.11)
	Specific content	7	8	6	7	12	2	21 (38.89)
Nielsen's Severity Rating	High (1)	5	5	5	5	6	4	15 (27.78)
	High - Medium (1-2)	1	1	0	1	1	0	2 (3.70)
	Medium (2)	3	3	7	3	7	3	13 (24.07)
	Medium-Low (2-3)	0	0	0	0	0	0	0
	Low (3)	5	10	9	5	19	0	24 (44.44)
Area of toolkit	Site	0	2	2	0	4	0	4 (7.41)
	Home page	2	2	4	2	5	1	8 (14.81)
	Carer Pathway	2	0	0	2	0	0	2 (3.70)
	Being a Carer	1	0	3	1	3	0	4 (7.41)
	Being an EoL Carer	0	1	1	0	2	0	2 (3.70)
	Being Prepared	0	3	0	0	2	1	3 (5.56)
	Caring for the Dying	2	1	1	2	1	1	4 (7.41)
	After Caring	0	4	3	0	7	0	7 (12.96)
	Carer Library	6	6	7	6	9	4	19 (35.19)
	Terms and Conditions	1	0	0	1	0	0	1 (1.85)

S-R TA=Self-Assessment of Technical Ability: a) Avoider of everything online – you would prefer to find a 'real' person to help, b) Novice or Learner or Beginner, c) Having Intermediate skills for those who are most confident, d) Expert who is confident in finding and using online information

Self-reported level of technical ability did not affect detection of highly severe errors (ranging 4-6 across groups), although ‘mostly confident’ carers were more likely to identify low severity errors (19 errors) compared to experts and online avoiders (5 and 0 errors respectively).

6.9.1.6 Qualitative narratives from the CTA approach

Through carer CTA narratives, usability testing also uncovered contradictory feedback on the language and tone of the content presented within the interface; opinions varied between the usability testing cohort and external user group engaged with content development. Often polarising, perspectives were fervent and passionate, focusing on the fundamentals of what it means to be a carer for someone who was going to die. Opposing views were expressed between the use of terminologies such as ‘death’ and ‘dying’, the inclusion of confrontational information about what to expect as a carer experiencing the dying process, and controversial content (for example, relating to the management of medication and syringe drivers) and balancing divisive emotional tones (such as motherhood statements) and use of impersonal language, for example:

> *“I think being a carer is more emotional than this … the hard bit about caring is that you have already started to lose your relationship with your loved one; if you are a carer, that relationship starts to change. When you are being a carer and not a wife, daughter, or whatever, I think this [pointing to text] really highlights this. Caring is a personal journey that is already eroding a relationship ... not breakdown, but the dynamics change, and that is part of looking after someone that is dying. And to have things like that makes even more depersonalising experience.”*
>
> *(Carer, aged 63 years)*

For the development team, usability testing did not provide a definitive solution to assist in balancing the tone, sharpening the message within the interface to improve usability for carers who are time-poor, emotional, tired and under pressure:

> *“Because when you are stressed out and caring for someone, and you are doing all that, the last thing you want to do is to sit here and click, click, click”.*
>
> *(Carer, aged 36 years)*

6.9.1.7 Phase 2 Usability evaluation report

All user-generated data was analysed and developed into a usability report. Components included those described previously in section 6.8.6.1. Appendix 6.8 provides a complete version of the formal usability report.

Influence of usability report on Carer's Toolkit final version

After receiving a usability report, the CPC team deliberated with the team at Flinders University and on a single occasion with the NRG. These sessions considered all feedback generated from the standard practice of user-testing and information provided within the usability report to formalise and reach consensus on reiterations of the prototype interface. Findings from user testing and usability testing failed to be influential in solving the contentious issues around designing for different audiences due to the opposing views from carer representatives involved in the content development phase, which included alternative perceptions of the interface by other carers regarding acceptability and tone of language used.

Heuristic analysis of the interface (Pre- versus post-release version)

Analysis of the post-release interface found that of the 19 usability issues detailed within the usability report, 14 (73.68% of total errors) were fully resolved, and 1 (5.26%) remained within the post-release interface. Although out-of-scope, information about complex illnesses was not considered technically resolved as the content remained absent from the interface post-release from an end-user perspective. Four (21.04%) errors were slightly modified or semi-resolved within the interface, errors describing page layout, language revision (balancing user expectations whilst maintaining an authoritative voice), and the other horizontal menu was still evident but revised. Reiteration of the Toolkit interface resolved all usability errors relating to critical operating and functional interactions (such as the menu, accessibility, and navigation) rated by carers as having high, high-medium, or medium levels of severity. Errors associated with information flow or architecture, specific content and language were semi-resolved. These issues were more likely to be both a source of negotiation between experts within the development team and tension for carers with a legitimate right to be heard. Reiterative changes reflected a form of compromise or optimisation rather than offering a full resolution of all issues within the interface. Appendix 6.9 presents areas and resolution of interface errors modified between the pre- and post-release versions of the toolkit.

6.9.2 PHASE 1 CONTENT-BASED EVALUATION OF THE CARERHELP TOOLKIT PROTOTYPE

The Toolkit prototype content was assessed for readability and understandability levels by applying the Simple Measure of Gobbledygook (SMOG) and Suitability Assessment of Materials (SAM). Readability of all content pages included in SMOG analysis except 'About the Project'/'National Reference Group' page due to an extensive list of names only; no other content was present. Appendix 6.10 summarises calculated SMOG scores for each Toolkit page. 'About the Project' page had the SMOG score calculated using the online calculator as the number of sentences>30 within the content module (34 in total) whilst SMOG readability scores for remaining pages were calculated manually (as sentence number<30). Overall Toolkit pages averaged 8.27 sentences/page (range 3-19, median=7.0), containing on average 6.73 polysyllabic words (range 1-20, median=4.0) and produced an overall readability score SMOG=5.08 (range 2.83-8.27, median=4.73).

Pages with the highest graded score were 'About the Project' at 8.27 and 'Being an EoL Carer' at 7.62. Overall, calculated grade levels for the Carers Toolkit content prototype were pitched at a suitable level for audiences with a reading level equivalent to high school Grade 8 level to read and comprehend, with a notable absence of medical jargon and confusing terminology extensively long complicated text. This user-friendly content is likely to reflect users' online reading behaviour (usually scanning and reading only 28% of words on a page[433] and information structure within online toolkits with intentions of providing direct, concise, and non-loquacious information.

The Toolkit prototype's PDF documents and pages were assessed for relevance, readability, and understandability using the SAM measurement tool (Appendix 6.11). All prototype pages examined provided no summary or review statement at text body conclusion. One page had a modelling behaviour activity ('Carer Voice'), whilst four content pages had interactive materials integrated within the layout (modules, interactive forms and tools). All pages exhibited acceptable content and appropriate images or examples that accurately reflect the intended audiences' culture, context, and environment. 'Carer Library' did not have an image or example as this page was considered a repository of resources, and an image may not be required or is absent due to the amount of content on the page. Pages assessed identified areas that could be improved, content and literacy demand (M=1.70, SD=0.6) whilst other assessment variables were highly acceptable such as layout/typography, learning simulation, graphics and cultural appropriateness averaging $M_{\text{SAMLayout/Typography}}$=1.86 ($SD$=0.5), $M_{\text{SAMLearningSimulation}}$=1.92 ($SD$=0.3),

$M_{\text{SAMGraphics}}$=1.93 (*SD*=0.4) and $M_{\text{SAMCulturalAppropriateness}}$=2.0 (*SD*=0) respectively. SAM protocol was applied to project generated PDFs; all documents lacked advanced organisers and online interactive components [EE]. Two PDFs displayed tables ('Checklist for Moving Forward' and 'Medication Template', respectively). These PDF documents also scored poorly in providing a summary or review statement after content block (*M*=0.65, *SD*=0.9) and reading grade measured by Flesch-Kincaid (*M*=1.35, *SD*=0.8). Appendix 6.12 provide SAM data collated from PDF analysed within the Toolkit.

6.9.3 PHASE 1 EXPERT-BASED EVALUATION OF CARERHELP TOOLKIT PROTOTYPE

During Toolkit interface re-iteration, experts in content and learning design were recruited to undertake an expert review of a slightly modified version of the prototype that was the basis for user-based evaluation assessed earlier in the study. Evaluators provided their written feedback in an interactive document for the researcher to analyse. All reviewers were then invited to de-brief with an informal discussion over conference software, in person or over the phone. This de-brief session combined a semi-structured interview and an open discussion allowing experts to clarify their documented responses and discuss the informational needs of carers and the roles of online health resources in providing information.

6.9.3.1 Demographics of expert reviewers

The demographics of participants within each of the expert review groups are presented in Table 6.3.

HCP

Four palliative care HCP were recruited for the study. Two were from Palliative Care Queensland, and one from both the Australian and New Zealand Society of Palliative Medicine and Southern Adelaide Palliative care Service. HCPs had a minimum of seven years specializing in palliative care (range 7-20 years, median=12 years). Three of the four rated themselves as having expert technical skills, with the remaining self-rated as being of intermediate level.

LD

Seven LDs were recruited in total, and all were members of the ASCILTE organization. All participants were employed within the University sector and held positions in institutions

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[EE] Documents were acknowledged as being draft versions. SAM assessment scores would have expected to increase if analysis was undertaken on final versions of PDFs. One could speculate if this content was uploaded as is, either unchecked or unmodified by inexperienced development teams, would fail both SMOG and SAM analysis, but also be assessed harshly by users as being too hard to read, too long and overly complex to understand.

within five different states of Australia. All LDs were self-assessed as experts in using technology whose combined experience spanned 24 years post-qualification (range 3-27 years, median 12 years). Two participants were managing academic units; although they had extensive experience as educational technologists, the other five LDs actively practised the design of educational materials.

Table 6.3. Demographics and characteristics of expert-based evaluation groups [Healthcare Professionals and Learning Designers]

Review group	Expert reviewer	Professional position held	Practice setting	Years' experience	S-R TA^
Group 1 **Healthcare Professionals (HCP)**	ERPC1	Nurse Practitioner	CC	10	Expert
	ERPC2	Nurse / Director of Service	A-CC	14	Expert
	ERPC3	General Practitioner / Director of Service	A-CC	20	Intermediate
	ERPC4	Social Worker	A-CC	7	Expert
Group 2 **Learning Designers (LD)***	ERLD1	Learning Designer	HE	27	Expert
	ERLD2	Educational Designer	HE	15	Expert
	ERLD3	Educational Technologist	HE	12	Expert
	ERLD4	Educational Technologist	HE	20	Expert
	ERLD5	Educational Designer	HE	3	Expert
	ERLD6	Learning Designer	HE	5	Expert
	ERLD7	Educational Designer	HE	12	Expert

HE=Higher education CC = Community care A-CC = Acute and community care
***Learning Designers:** Professionals in the design and implementation of online educational materials employed higher education sector. Other standard equivalent professional titles include Instructional Designer or Educational Designer with Educational Technologist working between educational/learning design tasks and deployment within technological systems or platforms.
^**S-R TA=Self-Assessment of Technical Ability:** a) Avoider of everything online – you would prefer to find a 'real' person to help, b) Novice or Learner or Beginner, c) Having Intermediate skills for those who are most confident, d) Expert who is confident in finding and using online information

6.9.3.2 *Prototype interface errors*

The analysis identified two sets of errors identified within the interface by experts and end-users. Typical interface errors were problems detected by evaluators contributing directly to the usability of the prototype. Content-specific errors identified by experts were also extracted, including exploring the types of feedback provided during the review process. These are now presented in turn.

6.9.3.3 Errors detected by experts

LD found 202 (72.40% of total) errors, with each designer detecting *M*=28.26 errors, compared with HCP, who identified 77 (27.60%) errors at an average of 19.25 errors/ reviewer. For HCP, years of experience did not reflect an increase in the number of errors detected. An inverse trend was observed where newer HCPs, on average, were more adept at identifying higher frequencies of interface errors ($M_{\text{HCP6-10 years}}$ = 22 errors, 57.1% total: $M_{\text{HCP 11-15 years}}$ =1 error, 22.1%: $M_{\text{HCP 16-20 years}}$ =16 errors, 20.8%) suggesting the presence of age-related increase level of tech-savviness in less experienced HCP.

Those HCP who had been practising palliative care between 6-10 years identified the highest number of errors with a medium-low severity compared with other cohorts. 79.2% of interface errors were detected by HCP who are *self-rated experts with technology* compared to intermediate skilled HCP reviewers (20.8% total). For LDs, years of experience designing online positively influenced the frequency of error detection. Although LDs with greater than 16 years' experience identified an equivalent number of errors as those with less experience (104 errors, 51.49% versus 98 errors, 48.51%), LDs with increased practical experience on average detected 52 errors compared with M=19.6 errors for LD with less than 16 years designing experience. For LDs, years of experience designing online positively influenced the frequency of error detection.

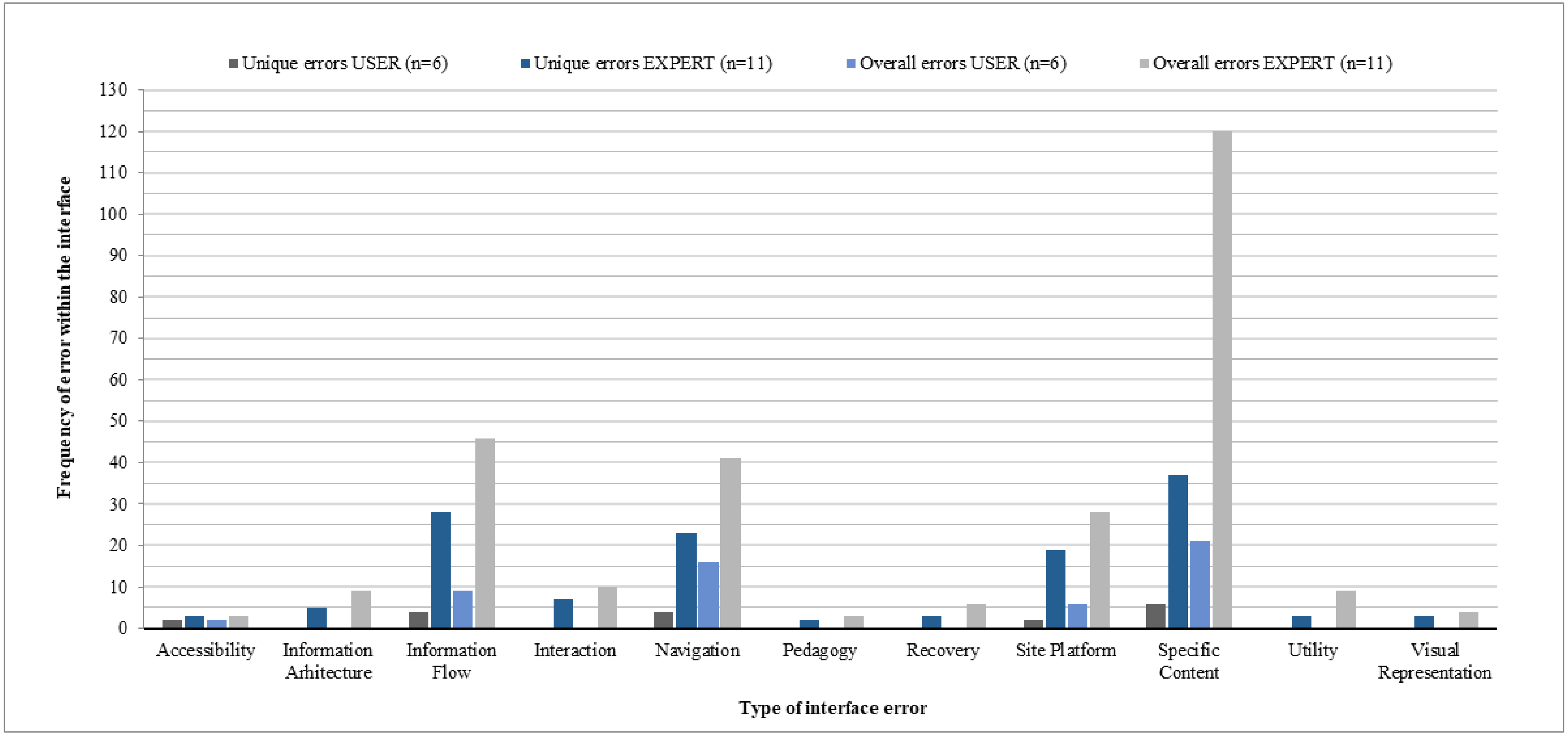
Although LDs with greater than 16 years' experience identified an equivalent number of errors as those with less experience (104 errors, 51.49% versus 98 errors, 48.51%), LDs with increased practical experience on average detected 52 errors compared with M=19.6 errors for LD with less than 16 years designing experience. LDs also identified a higher frequency of errors rated highly severe than errors found by HCP, with 71.4% of the most severe errors detected by LD with between 11-20 years' experience. Errors with the highest frequency were proportional to LD and HCP reviewer groups when calculated as a percentage of total errors identified. Specific content errors constituted over 50% of total errors detected by HCP and 38.1% for LD. The frequency of navigation issues was comparable between 14-15% of total errors per group, and LD identified a higher proportion of errors impacting information flow (18.3% total errors) than the HCP reviewer group (11.7% total errors). Appendix 6.13 summarises these results.

6.9.4 INTERFACE ERROR DETECTION BETWEEN EXPERT REVIEWERS AND USERS

Similarities and differences in the error type and frequency of detection by reviewer groups involved within the Toolkit usability evaluation approach was explored by meta-aggregation of HCP, LD, and USERS data to characterize error occurrences within the interface. Errors were categorized by reviewer, by type, level of exclusivity or inclusivity and if the errors were unique or co-existing across reviewer group. Unique errors are discernible occurrences identified by single or multiple reviewers when aggregated, decreasing total interface error counts compared to the overall error number. Seventeen reviewers identified a total of 333 errors that did not occur exclusively for any single reviewer group, and these were co-existing within the interface and identified by all three reviewer cohorts. Further analysis found 167 unique errors occurring once within the interface (Graph 6.1 and data presented in Appendix 6.14).

The HCP reviewer group identified similar frequencies of co-existing and uniquely occurring errors (23.12% and 25.15%, respectively), whilst the USER group detected 25.15% of unique errors, although only 16.22% of the overall errors within the interface. LDs identified an increased number of unique and co-existing errors within the interface (104, 34.7% and 202, 60.66% respectively) compared to the other reviewer groups and detected higher frequency on average per reviewer in both inclusive (M_{LD}=28.86:M_{HCPs}=19.25:M_{USERS}=9.0 errors) and uniquely occurring issues (M_{LD}=15.29:M_{HCP}=10.0:$\mathrm{M}_{\mathrm{USER}}$=3.0 errors).

Differences in the rate of error identification between the USER and expert reviewers widened when combing error counts into a single EXPERT cohort (HCP+LD). The EXPERT group attributed 279 errors (83.78% of the total) and 133 uniquely occurring errors (88.10% total) at an average of 12.09 errors per expert. Exclusive and mutually inclusive errors were identified across and between reviewer groups (Appendix 6.15), the total overall error count remained constant (N=333). Further data consolidation into combinations of reviewer groups where each error instance is assigned a single (mutually exclusive) identifying group decreased the overall unique error count from N=167 to N=143.



Graph 6.1 Interface errors identified by reviewer group (unique interface errors *N*=167, overall interface errors *N*=333)

Similarly, the analysis found that LD identified over 50% of the total unique errors compared with HCP (16.08%) and 5.59% for the USER review group. Consequently, review groups in combination with LD were more likely to identify an increased proportion of unique errors when compared to other HCP or USER group combinations (Figures 6.5 and 6.6).

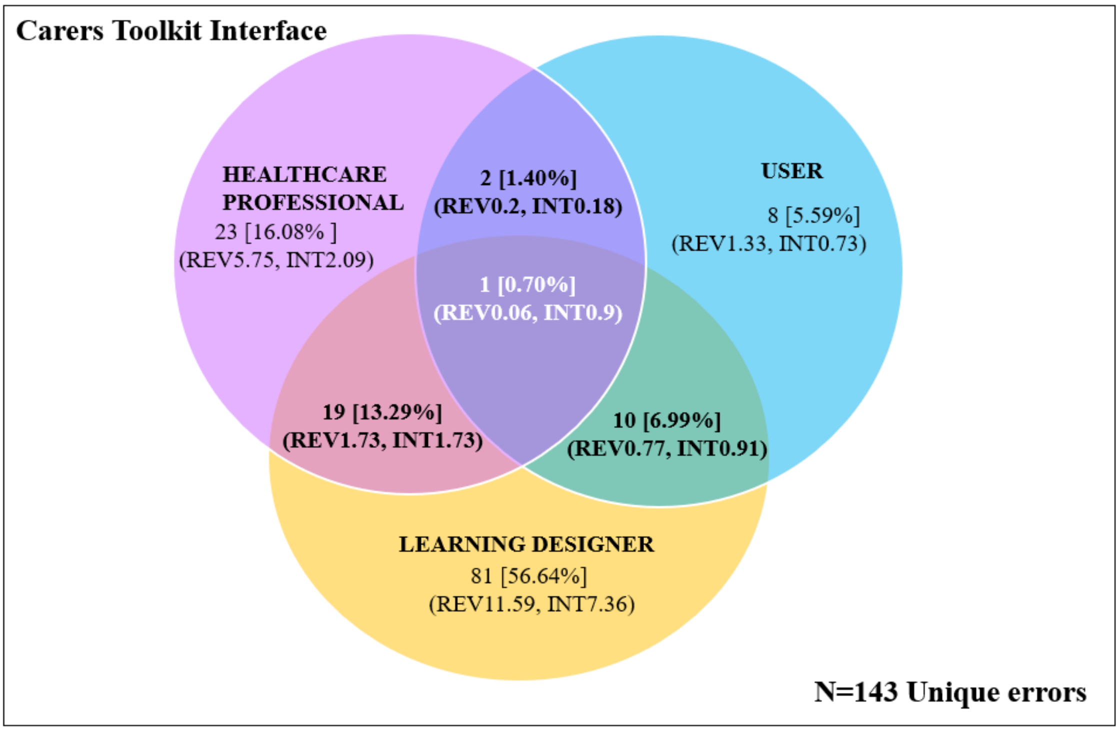
This pattern is analogous to counts of overall co-existing errors. LD was also more likely to identify errors or issues with site or platform performance and accessibility for end-users. Five distinct accessibility issues were detected by only LD reviewers and the LD+USER group.

Accessibility errors were most likely identified due to carers difficulties interacting with functional aspects of the interface due to age-related physical (or cognitive) decline and levels of technical abilities in older participants. LD have previous professional knowledge and practice designing with awareness to consider accessibility due to student diversity.

Differences in error detection rates between groups were analysed using independent t-tests[FF] and significance was indicated when $p<0.05$ at 95% confidence level. LD identified on average, a significantly greater number of overall errors within the interface than all other reviewer groups except the HCP+LD review group: HCP [*t(11.361)=-2.460, p=.031*], USER [*t(10.521)=2.983, p=.031*], HCP+USER [*t(13.25)=2.545, p=.024*], LD+USER *[t(20)=2.144, p=.044*] and HCP+LD+USER [*t(20)=2.747, p=.012*]. LD identified a significantly greater number of unique errors within the interface than other reviewer groups except the HCP+LD+USER group: HCP [*t(12.043)=-2.204 p=.048*], USER [*t(10.707)=2.864, p=.016*], HCP+LD [*t(11.402)=2.392, p=.035*], HCP+USER [*t(10.555)=2.573, p=.027*] and LD+USER [*t(10.662)=2.788, p=.018*]. Significant differences were also observed between the average number of overall errors detected by the HCP reviewer group compared to HCP+USER [*t(10.55)=2.573, p=.027*] and HCP+LD+USER groups [*t(10.309)=2.712, p=.021*].

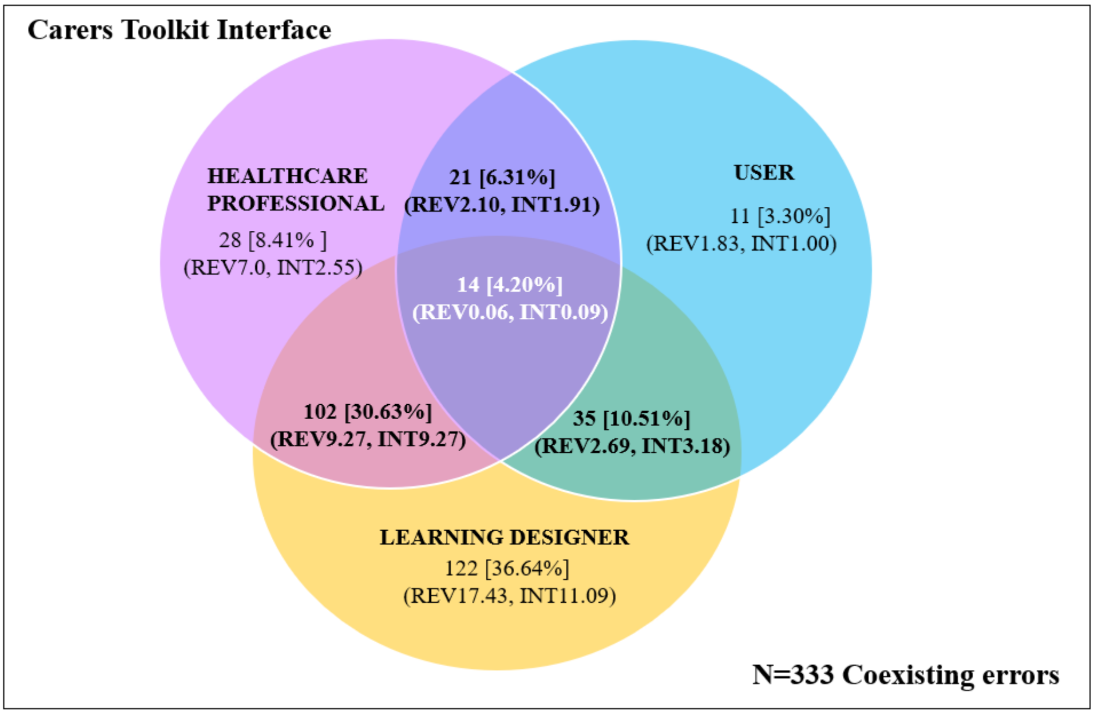
There was only a single error type that all three reviewer groups identified. An error relating to grammatical or spelling errors specific to content within the pages or activities appeared in fourteen instances across the interface and was mutually inclusive to all reviewers participating within the evaluation process.

[FF] Homogeneity of variance as assessed by Levene's Test for Equality of Variances and where failed, t-test for equality of means was conducted using Welch-Satterthwaite method.



Descriptors: Number of unique Errors [%Total] (REV = mean unique errors identified per reviewer, INT = mean unique errors identified by reviewer group across the interface)

Figure 6.5 Unique exclusive and mutually exclusive interface errors identified by reviewer groups

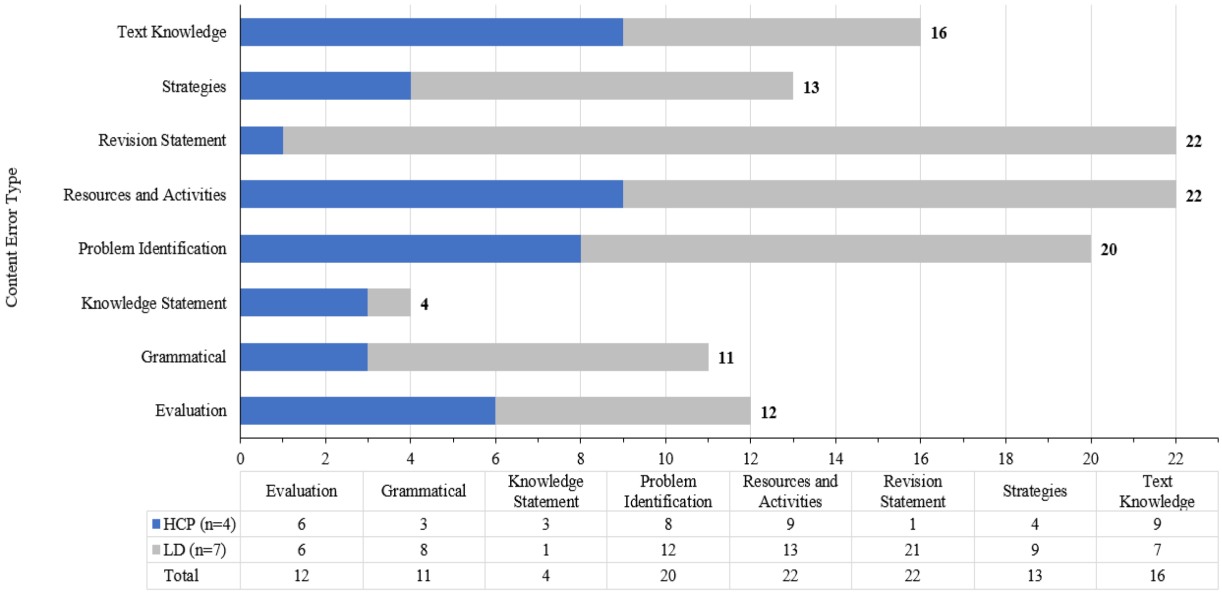


Descriptors: Number of overall errors [%Total] (REV = mean errors identified per reviewer, INT = mean errors identified by reviewer group across the interface

Figure 6.6 Coexisting errors identified within the CarerHelp Toolkit interface

6.9.4.1 Types of feedback generated when identifying content-specific errors

Across the eleven experts, 120 content-specific errors were identified and categorized into eight types of errors (Graph 6.2, data presented in Appendix 6.16).



	Evaluation	Grammatical	Knowledge Statement	Problem Identification	Resources and Activities	Revision Statement	Strategies	Text Knowledge
■ HCP (n=4)	6	3	3	8	9	1	4	9
■ LD (n=7)	6	8	1	12	13	21	9	7
Total	12	11	4	20	22	22	13	16

Graph 6.2 Specific content errors identified by expert reviewer groups

Whilst LDs detected a greater frequency of overall content errors than HCPs (77 errors, 64.2% versus 43 errors, 35.8% respectively), average errors per reviewer were similar across groups (M_{LD} =11.0, *SD*=5.9 versus M_{HCP}=10.8, *SD*=3.1). Types of content errors with the greatest frequency detected within the interface by experts were related to specific errors within resources (18.3%), for example

> *"Need to make sure that this toolkit provides information for carers on how to improve and sustain person's quality of life when at home"*
>
> [HCP reviewer],

descriptions of errors requiring rephrasing with examples of revisions statements (18.3%) such as

> *"Caring for someone who is dying is the end of a journey of caring ... – could be something like: 'Caring for someone dying also means that your role of carer will come to an end after the person has died. These resources help you to be prepared for dealing with the end of*

life care"
[LD Reviewer],

and explicit reference to problems within the interface (16.4%), including

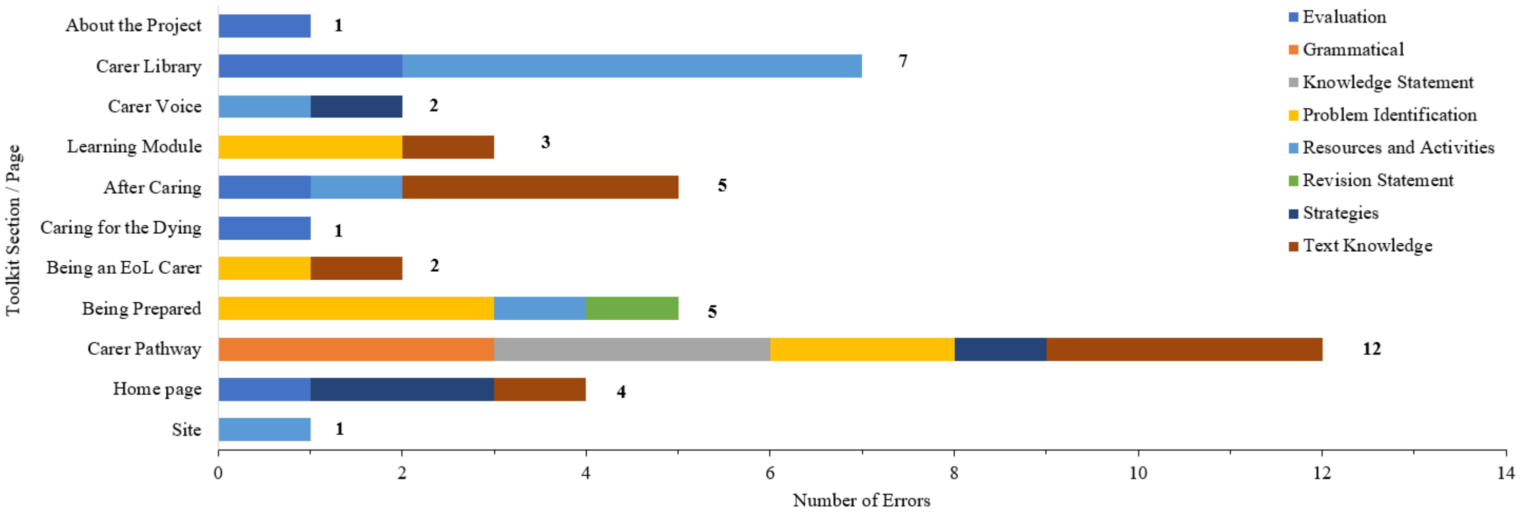
"I think language is okay, but there are just too many words",
[HCP Reviewer]

or

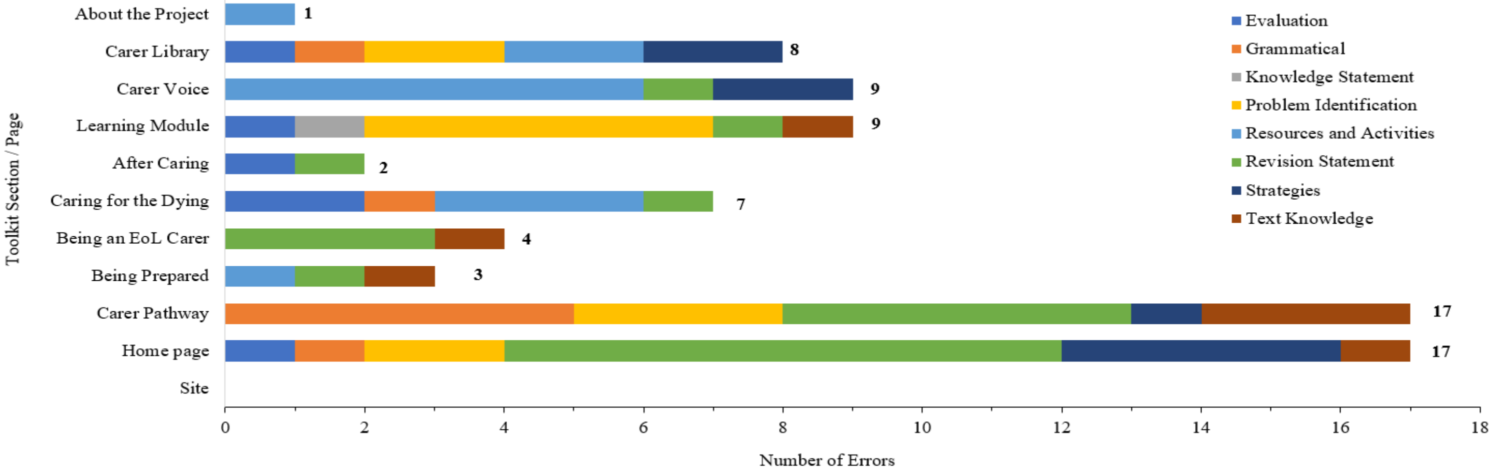
"...appropriate to also insert a link here to take the users back to the first page, rather than telling them to go to and use the menu (where is that?) to get back to the main page."
[LD Reviewer]

HCP and LD detected equivalent numbers of error descriptions with a provision of evaluations statements and assertions on the learnings from the text. LD identified a greater frequency of errors describing grammatical or spelling errors (3 HCP:8 LD), were more likely to provide suggestions on applying strategies to content (4 HCP:9 LD) and were more forthcoming with the provision of alternate text through revision statements compared with HCP (1 HCP:21 LD). HCP identified specific issues or errors within the written content of the Toolkit webpages and were skilled at detecting content mistakes in-text to provide feedback based on statements of their knowledge of palliative care.

There were areas of the interface that accumulated a higher number of errors than other prototype sections. The 'Carer Pathway' page generated the greatest frequency of detected errors (12 HCP and 17 LD) - the grammar used, specific reference to issues, suggestions of strategies applied to the text and comments regarding errors based on text meanings was contentious between the two expert review groups. HCP identified additional errors relating to knowledge statements which contrasted to revised text offerings by LD. 'Carer Library' was another highlighted by both expert groups having an increased number of content errors within the container modules. HCP identified seven errors concerning evaluation and resources/activities whilst LDs detected five different content error types. However, there was overlap, including suggestions of content or text strategies and knowledge statements. Unsurprisingly, the HCP group were more likely to identify specific content issues. Graph 6.3 and Graph 6.4 graphically represent these relationships.



Graph 6.3 Content errors identified in the interface by HCP/toolkit section page



Graph 6.4 Content errors identified in the interface by LD /toolkit section page

6.9.5 RELATIONSHIP BETWEEN USABILITY ERRORS AND EVALUATION MEASURE OF CONTENT

Across the Carer Toolkit prototype pages, trends between interface error numbers and independently assessed SAM and SMOG scores were observed when categorised by the evaluator. Low SAM score on 'Home Page', 'Carer Pathway' and 'Carer Voice' content pages had an increased number of interface errors identified by LD. There was a positive trend between the SMOG score and the frequency of errors detected by LD on the 'Being an EoL Carer' content page. 'About the Project' content webpage was the only page that exhibited a high SMOG grade (above Grade 8), a low SAM score (80%) and a relatively low number of interface errors discovered by LD and HCP. Appendix 6.17 presents graphically associations between SAM, SMOG and types of interface errors identified within the interface.

6.10 DISCUSSION

This study provided the opportunity to undertake a structured and comprehensive evaluation approach to a resource prototype for the CarerHelp Toolkit in parallel to the real-world development process undertaken by the Project team. The objective was to explore the barriers and identify complexities influencing the likelihood of including usability as part of the typical development practice. The findings from the application of three different UEMs suggest that factors are influencing the barriers to usability practice in a multidisciplinary setting. Complications in setting, process, professional experience in development and evaluation were identified as considerations, and pragmatic aspects of the methodologies themselves, such as access to participants and experts, were critical influencers in the potential adoption of evaluation into typical practices.

6.10.1 OBSERVATIONS OF THE CARERHELP TOOLKIT DEVELOPMENT PROCESS

There was an acknowledgment of the advantages for the CPC team to collaborate with an experienced team at Flinders University who could rapidly build, evaluate, and reiterate the interface for the CarerHelp Toolkit, given the tight development schedule. The first 18 months of the project were assigned to identifying user needs and gaps within the carer information available using a participatory method to content development. The remaining 18 months were inclusive of resource development and evaluation in the post-release period. Delays in content production were experienced by the CareSearch team within the first two months of online build, pressurising downstream activities and subsequently pushing back the release date. Late content delivery is the primary cause of web development project delays[434-436] affecting commercial and non-commercial products. Content delays in the CarerHelp development process impacted the ability to incorporate prototype evaluations into earlier stages of the development, as recommended by the UCD approach. Assessment of the interface was seen as the 'final step' before release. The inexperience of Project Managers in developing into the online environment was evident; subsequent delays 'snowballed', creating a pressurised development process at risk of losing essential activities due to time and budget constraints. Underestimation of the time to write, review and translate content for online resources further delayed subsequent steps required to make pages release-ready, including adding links, references, images and interactives, completing search engine optimisation of text and construction of metadata. Inexperience in development and evaluation leads to project delays due to time lag and project creep, impacting deadlines and payment for production when tied to milestone delivery. Commercial developers contractually ensure full payment is received and account for delays due to client non-responsiveness[436] before release or incorporating clauses to release the site without content to push clients to meet deadlines. This is an important aspect of the contractual agreement as the content developers are typically the product owner and therefore control component delivery. For commercial and non-specialised teams, rushed, late, or pressurised development processes decrease the opportunity for timely usability and accessibility evaluations. Realistically, within pressurised timelines and processes, what can small, non-specialised teams, do in terms of usability evaluations and meeting their obligations to commissioning funders?

A revised framework exploring this question is proposed and described in section 6.11.1 of this chapter.

6.10.2 PROCESS LINEARISATION BY PROJECT MANAGEMENT

An independent examination of the development process for the CarerHelp Toolkit suggested approaches to project management, and the influence of the grant funding arrangements created a linearisation of the development process. Indications from independent observations of the process suggest that waterfall management strategies were the driving approach applied to Toolkit development. This approach offers a step-wise sequential uni-directional approach[437] more suited to health research requiring rigid oversight[102] and rigorous reporting,[104] and not reiterative or user-centred approaches.[438] Due to a lack of flexibility, this style of management contributed to development lag, delays and linearised what should have been a non-linear, iterative and dynamic process.[439]

A retrospective examination of the time for each phase of the project by applying the waterfall approach to the process suggests Toolkit delivery is at risk from very early on in the process before commencement of the online build. Based on a three-year grant, each project stage was similar to the requirement for waterfall management[438]: ~18 months identifying requirements [waterfall 30-40% time]; ~9 months on design and building [30-40% time] and ~9 months remaining time invested on testing the final design and evaluating post-release [20-40% time]. Inability to factor time into stages of development and the step-wise strategy compromised forward movement of the build, creating lag[437] and pushback onto other stages requiring reconsideration of internal deadlines to deliver on time; likely short-cutting processes[440] or skipping steps altogether[117]; to come in on time and budget.

Findings indicate that traditional research project management and inexperience in web development could influence linearisation of processes, limiting the ability for teams to undertake evaluations and reiterative cycles of evaluation to ultimately improve UIs (diagrammatically presented in Figures 6.3A and 6.3B).

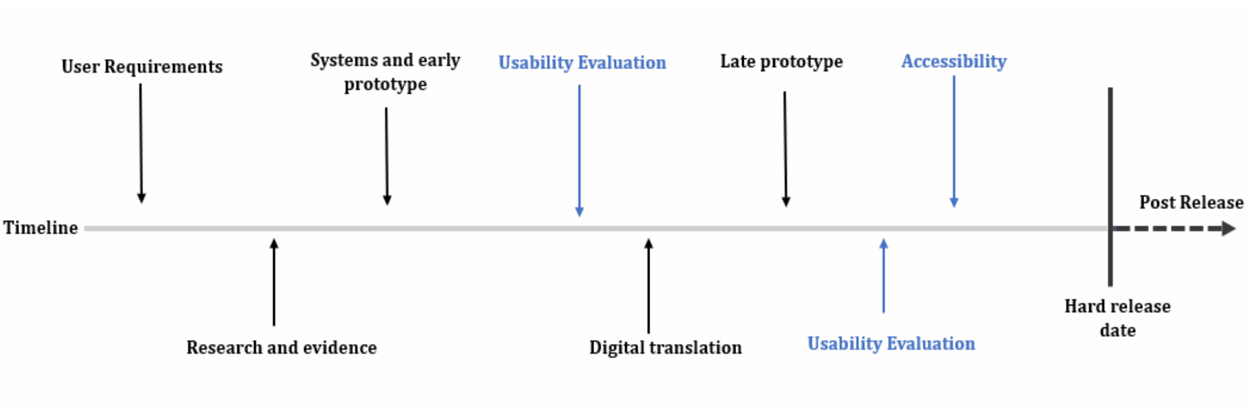


Figure 6.3A Linearisation of the development process by non-specialised project management

Process linearisation is enabled by contextual factors limiting the teams' ability to undertake comprehensive development or evaluation processes. Some are attributed to individuals' skills or experience, and others are directly related to resources allocated to undertake the process.

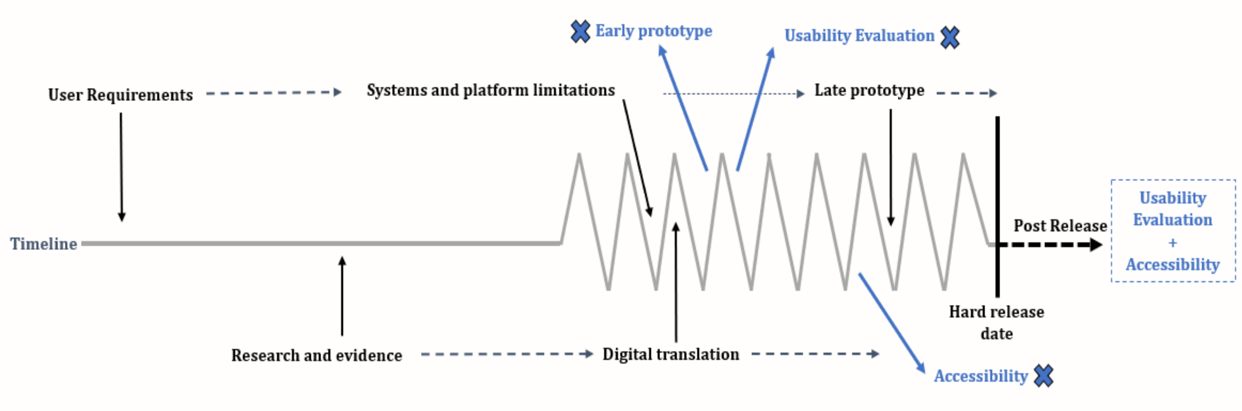


Figure 6.3B Project slippage, overlap and evaluation as jettison components due to linear project management

Skills and experience working across technologies and digital landscapes provide managers or leads with an understanding of technical professionals' terminology and vernacular, ability to translate knowledge into an online medium, awareness of the importance of usability/ accessibility evaluation, and the skills to mediate and manage unreasonable expectations from partner organisations. There is arguably a need to deploy agile (and hybrid) management strategies as these offer optimal evaluation conditions as these are flexible, rapid and consider UCD iterative processes[104] prioritising efficiency, speed within a user-centred approach to development.[106]

Exacerbated costs for inexperienced or multidisciplinary teams to work with information technology partners is underestimated by commissioning funders, and this is not just limited to the build itself. IT partners incur a cost for all modifications, and given the exponential increase for significant re-designs, there are budgetary limitations on the extent to which these partners can participate in development processes.[440] Consequently, this could influence how outcomes from formative evaluations are rationalised if high costs are involved in the re-design. Lack of appropriate funding[216,441] combined with traditional management practices can place health resources interfaces at risk of not being evaluated for usability or accessibility. Due to their impacts on pressurising development process, outcomes from the previous two studies suggest there are implications for end-user if evaluations are left until the post-release period, with developers creating overly complex interfaces within increasing accessibility and usability errors. Poor usability evaluation practice places interfaces equally at risk,[117] so an evidence base to support practice becomes increasingly important to support rigorous methodologies and interpret outcomes into meaningful improvements. Subsequently, multidisciplinary and inexperienced developers of health resources are in a quandary, questioning how inexperienced staff applies and interprets standards, guidelines, or peer-reviewed evidence to evaluation practice in pressurised, under-resourced, and time-poor processes.

6.10.3 INFLUENCE OF USABILITY EVALUATION REPORT ON INTERFACE REITERATION

Production of the usability report is the juncture where this study actively contributed to the CarerHelp Toolkit development. This report described the usability testing approach, documented findings as evidentiary data to inform the NRG of potential interface improvements. Post-release heuristic analysis of the interface indicated that the formal usability report provided sufficient evidence and authority to the NRG to resolve all usability errors identified within formative evaluations. As reported within the document, usability evaluation highlighted critical errors relating to the feasibility and acceptability of resource design to the intended audience, navigation issues and problems with site information flow. Descriptive commentary included in the report also provided insight into the interface areas that were difficult to understand or required further improvements.

Based on heuristic post-release analysis of the Toolkit, there was the potency of the report to encourage interface modifications; the report did not reassure the development team that all usability errors were identified in this single round of evaluations, or that solutions did not create further increasingly problematic, contradictory errors or increased complexity of the interface for users. Although, the contribution of other UEMs undertaken external to this study cannot be underestimated as contributing to the resolution of the errors in the prototype interface.

Arguably, additional evaluation cycles or summative evaluations may resolve the remaining interface issues *if* development teams have the time, resources, and energy to undertake further evaluation activities - discussions of anticipatory assumptions influencing this practice when applying the WDMHC evaluation approach follow later in this chapter. Overall, the usability report was a valuable document to focus the attention of project management on the evidentiary data generated from the intended audience of the resource.

Outcomes from the evaluation approach found on balance; (a) caregivers were always correct in the types of errors identified within the CarerHelp interface, and (b) caregivers could not identify *all of the errors* as suggested by the comparative findings from error analysis across evaluators.

The development team encountered difficulties balancing opposing views from representative carer user groups, between carer representatives working with CPC to develop content whilst offering opinions on the interface as a user-testing group, and understandings from carers involved in usability testing. Sentiments were polarising, fervent, and passionately centred on the fundamentals of being a carer for someone who will die. Each narrative demanded a resolution within the interface. Examples included the use of terminologies such as 'death' and 'dying', divisive conveyance of messages using soft tone and emotional language, confrontational information, or descriptions about experiencing death as a primary or family carer, and controversial carer information (i.e., management of medication and syringe drivers). Ideally, these questions and subsequent disagreements raised during formative evaluations should have been resolved during the needs analysis phase of development. It was perhaps indicating that often, there is not one single or perfect solution acknowledging all perspectives and are accounted for during development. As demonstrated in the CarerHelp OHT evaluation approach, it is impossible to counter the diversity of all contradictory viewpoints from caregivers within the reiteration of the interface.

Balancing the appearance of *doing something* within the interface with pragmatically *doing nothing* with unsolicited demands from external organisations and stakeholders were also a challenge for the development team. This strategy was employed not to offend, discourage or impede these relationships seen as mutually beneficial for the resource moving forward. However, tending to some feedback from a political stanchion and ignoring or dismissing others created risks of alienation of the project team from the community the Toolkit was designed to support. The dismissal also denies the realities of caring, and the lived experiences of the other carers involved in the content development external to this study. End-users tested the feasibility and accepted the interface design during usability testing, dampening some of the disquiet; findings from expert-based evaluations could have further supported and reassured external groups of the quality and relevance of the information provided to support carers needs. The importance of amplifying the end-user voice through usability evaluations through the lens of the WDMHC evaluation approach is discussed in greater detail later in this chapter.

6.10.4 ADDITIONAL BENEFITS OF A COMPLEX EVALUATION APPROACH

Johnson and Turley[218] consider usability essential to test design acceptability and interpret procedural information to identify interface functionality issues. Observations indicate additional benefits to undertake usability evaluations for multidisciplinary development teams besides those solely relating to isolating interface issues within prototypes.

6.10.4.1 Combatting pre-existing expectations and conceptual designs

The findings of the usability evaluations from the WDMHC approach had inherent power to dispel predestined perceptions or idealistic designs that may arrive with individuals responsible for driving development or design in a preconceived direction. Pre-conceived as a reference-based learning resource by the principal investigator, the web development team proposed re-conceptualisation and modification of interface content to be more relevant and useful to end-users. Perhaps highlighting negotiation as a critical skill required to circumnavigate project teams and development to operationalise evaluation. The final interface design was supported by an end-user exploration of the interface during usability testing. Although not fully endorsed by the carers group involved in the content development, evaluations provided substantiated evidence to produce a very different resource than was initially conceived by the CPC team.

6.10.4.2 Attending to errors within the interface

Errors associated with specific content, information flow and navigation were found to be shared between evaluator groups. There were also differences in the types of errors identified by experts and not end-users, including accessibility, information architecture, utility and site or platform issues. In attempting to attenuate errors impacting the end-user experience of the interface, expert feedback offers an opportunity to consider this information by placing equal weight on all feedback across groups, effectively treating their feedback as a different group of end-users. Applying Nielsen's severity rating[411] provided clarity to the participants' voices by objectively analysing the frequency, area of the interface, and extent of the barriers created for each end-user. It is important to note that attenuation of functional errors within the interface was easier to resolve across evaluators, as these were not contested in meaning or impact. Evaluations also leveraged discourse between management and stakeholders, which commonly stall due to disagreements or lack of understanding of the purpose of the design.

6.10.5 STRATEGIC USABILITY EVALUATION IN DEVELOPMENT PROCESSES

Undertaking strategic usability evaluation requires planning by development teams, creating difficulties for multidisciplinary developer teams to schedule UEM, especially if the development process is inefficient or unstable. Decisions surround formative or summative UEM type and if evaluation is continuous across stages or undertaken at a single point during development. Unfortunately for inexperienced, multidisciplinary non-specialist teams applying the UCD or WDMHC, findings from this study suggest evaluations with multiple rounds and use of different formative UEM places developers at risk of being overwhelmed with too much information.

One-off evaluations of usability and accessibility are appropriate for stable interfaces with limited interactivity, information or evidence which does not lose currency or have strictly homogenous audiences. Given these stipulations, it could be argued that one-off evaluations are not appropriate to the development in the majority of online health information resources; however, as observed in this current study and from Study 1, this appears to be typical practice for non-specialised or multidisciplinary developers. So, is this a situation of 'is something better than nothing when evaluating health resources? Moreover, if so, can these replace usability testing in a pressurised development process?

6.10.5.1 Formative evaluation methods

Given the small samples involved in formative usability assessments, the tools and scales used in this study were found adequate and valuable to identify errors within the interface. Errors and issues identified within the interface were highly likely to represent the wider caregiver population, as the evaluation approach applied five formative UEMs across the development period. Methods included qualitative and quantitative approaches triangulating errors to inform reiterations, assessing key factors contributing to usability and accounted for diversity in caregivers' backgrounds, life experience, health literacy and technical abilities. The decision to deploy user testing as a formative UEM undertaken before release to gain general acceptance and usability data by CareSearch was driven by two factors, the ease and cost-effectiveness of the method. Conceptually and practically, these methods are very different. User testing assesses the end-users' needs *for* the Toolkit providing road map validation of design and content,[442] and as established earlier, usability testing considers interactions in context to a user's environment, context, and objectives of use.[443] The web development team acknowledged the inequivalence of these methods. The distribution of an online survey to request feedback generated formative feedback informing re-iteration and is unlikely to identify all of the errors found during moderated usability testing.[444] However, this UEM was still likely to identify cursory errors or issues external stakeholders view as significant could be addressed before release and therefore considered a valid UEM in this context.

If not a surrogate or an equal for usability testing within a structured development process, again, there is a question of *is their value in undertaking some evaluation compared to not evaluating at all, particularly for teams with limited budgets, time, and expertise?*

To ignore evaluation altogether places the resource in danger of designer-centred user experience[117] whereby developers impose and apply their intuition to interface design based on their assumptions or knowledge of intended users. No evaluation in some cases is better than poorly conducted, ad hoc “skunkwork” usability[117] or “half-assed” assessments[445] and for multidisciplinary project teams with limited resources and experience, discount that usability methods could offer a solution. These approaches yield up to half of the same usability errors identified in moderated usability evaluations.[202,444] Unfortunately, scheduled discount usability methods rely on a stable development process and availability of evaluators with usability evaluation experience, neither of which are readily available to non-specialised development teams.

6.10.5.2 Summative evaluation methods

Commonly undertaken post-release, summative evaluations generate implementation or outcome data at a one-time point. As observed in this current study and reflected in the data extracted from reporting of other development teams practice described in Chapter 4, developers tend to prefer online surveys over other types of UEM. Reasons are similar to their use within the pre-release stages. They are inexpensive to build, circulate and analyse, easily customised to specific resource type and content, surveys distributed widely to reach a diverse and sizeable potential sample of intended populations. The choice between single and continuous evaluations post-release are reasoned given the disproportionate amount of time, money and resources invested during development compared to the commitment to maintain and continually evaluate the resource post-release.

Post-release evaluation is costly,[69] and outcomes are reported to funders to justify project continuation into the future[275] rather than continually assessing interfaces to ensure the intended audience's needs. Inquiry-based UEM provides in-depth feedback contextualised with users experience of the interface compared with simple questions within a survey. UEM such as interviews, focus groups, journey mapping, or usability testing is not viable due to practical limitations, including time and costs. Cynically, inquiry-based UEM could force developers to reconsider aspects of their information and interface design with an obligation to re-iterate and modify to cycle into further rounds of formative assessment. Re-design or site update would be warranted depending on the duration of exposure, the advancement of skins or interface features and assessment of feedback generated from end-users (such as applying severity ratings to errors identified within the interface). There could be a reasonable assumption that some developers may not want to ask for feedback in this circumstance as they fear the implications and amount of work that would ensue.[446]

6.10.5.3 Post-release evaluations and the need for funding support

Funders also impose no reporting requirements to undertake time-intensive, expensive, complex evaluations post-release. Observations of the current CarerHelp Toolkit development process and parallel analysis of evaluations demonstrate an argument for funding extensions over and beyond the three-year funding round. Benefits for direct end-user engagement with the health interface during the post-release period can validate interface design and features. Summative methods can form the basis for benchmarking improvements[65,447] as continuous formative evaluations are undertaken to assess the function, relevance, quality and usefulness of the information within the interface over time. These usability indicators can inform and enable continuous improvements to the UX of the content and the interface.

Given the current funding, the post-release budget is divided between promotional and engagement activities, with the resource having six months of liveability. Resources will often live on in a digital environment unmaintained and 'go dark' once monetary support for website hosting is exhausted.[344] Defined as the 'sunset period', developers initiate a plan to provide sustainability for the resource post-funding. Extending online health information resource support an additional 1 to 2 years would allow for valuable inquiry-based UEM to be applied to interfaces, generating data to inform improvements over time. Increasing funding and project duration would also provide an increased opportunity to embed the resource within the community and health sector, subsequently increasing familiarity and engagement of users who are more likely to be involved in further re-iteration of design to improve interaction.

An additional advantage to commissioning funders is increasing the period of sustainability and eventual sunsetting, potentially reducing duplication of resources[448] due to closing the cyclical gap between sunset of one product and the refunding of the same resource. Long-term budgetary savings are possible due to the costs of redeveloping recently abandoned resources and consumer preventionist behaviours driven by exposure to high quality, up to date, usable health information resources.

6.10.6 FUNDAMENTAL ASSUMPTIONS OF THE WDMHC EVALUATION APPROACH

A series of assumptions were either implied or silently accompanied the success of each phase of the cycle in *this* process, which are easily persuaded by situational or circumstantial factors that could influence difficulties that can be detrimental to the completion of evaluation before the release of the online resource. The model assumes that identification, access and cooperation between users and suitable experts are implied without providing a warning of inevitable delays in development caused by ethical requirements, lack of expertise or enthusiasm to be involved or limitations in identifying possible participants (due to geographical isolation or controversial and sensitive content).

6.10.6.1 Recruitment of ready and willing participants

For the evaluation phase of the WDMHC to be a success, it was assumed that developers had ready access to groups of individuals who were willing, able, and available to be involved in the different evaluation activities. There were inherent difficulties in identifying and recruiting specific users to participate in usability testing for online health resources than inviting participants to evaluate generalised or commercial resources. For information resources serving complex health-subject domains with complicating factors, including multidisciplinary team interventions,[449] patients with multimorbidity or areas of care that are sensitive,[450] recruitment becomes increasingly exigent. Accessing palliative care patients receiving palliative care or their carers to be involved in usability evaluations was challenging due to three factors influencing recruitment of potential volunteers from 1) within the community,[451] specialist palliative care services or from acute care settings,[452] 2) the gatekeeping protecting participation due to their perceived 'vulnerability' by HCP,[453-455] and 3) availability to be involved due to time constraints,[456] or caring commitments.[451]

The key to successfully recruiting palliative care caregivers in this study was not through social media or digital communications with carer organisations, rather through an advocate from the Laurel Hospice Carer Giver Network who has an established professional relationship with this carer group. However, this may not be as straightforward for other development groups and speak to the value of the project professional relationships. Derived rapport with gatekeeping advocates[457,458] are founded on established trusted relationships, and there is no guarantee of assistance from gatekeepers,[459,460] or that their patients, carers or members are keen, able or available to participate. This barrier can immediately increase pressure on the evaluation and downstream development approach. There are also dangers relying on a single cohort of preselected end-users formed to closely work in focus groups in a national project like the CarerHelp project. Participant feedback is vulnerable to sponsorship or membership bias[93] reflecting the relational beliefs of associated organisations or biases due to social desirability or acquiescence to agree with others in the focus groups.[461] As issues other than functional interface errors were identified across different caregiver groups in this study, to support a diverse audience requires involvement from more than one end-user group whose constituents are recruited randomly from the representative population to reduce potential bias.

6.10.6.2 Surrogate end-users when ideal participants are scarce

Lack of access to active carers did not prevent or impede usability testing of the CarerHelp Toolkit. Evaluations involved surrogate participants, those individuals who share characteristics with the intended audience but may not ever use the resource[462] was a plausible option. Surrogates in this study were bereaved carers who are ideally placed to not only identify errors or issues within interfaces of carer-specific products but also recognise information that would benefit others based on their perceived successes or failures due to lack of knowledge, practical skills or support, healthcare professional interventions or system failures. Bereaved carers were quick to recognise their ability to assist active carers by informing Toolkit content because

> *"you do not know what you don't know."*
> [Carer feedback provided during usability testing]

Bereaved carers shared the knowledge domain whilst observed to mirror similar interactive behaviours within the interface as active carers, identifying errors and offering a different, rather retrospective view of caring for someone dying. Surrogates brought their caring experience, good and bad, powered by hindsight, and linked their real-life palliative care journey with information found within the Toolkit. Surrogate involvement in usability evaluations has limitations, including stereotyping, bias, and pragmatic differences between user-surrogates,[463] which can influence the interpretation of feedback. However, the imperative for developers to engage with end-users during the development of health resources should override the perceived risk. User-surrogates could provide valuable feedback in-lieu of end-user representatives[462,464] who belong to socially or digitally excluded groups, those who are hard-to-reach or belong to vulnerable populations.

Established personal relationships in the context of this study were not imperative to recruit palliative care experts to participate in the expert-based evaluation of the WDMHC approach. However, it is acknowledged that the PhD researcher's relationship with the Institution, CareSearch and CarerHelp may have facilitated this process. Instead, an awareness of the intrinsic value of the CarerHelp Toolkit to palliative care carers resource was crucial to foster engagement and ensure involvement in the evaluation process. Palliative care HCPs offered to participate in the formal review process on the proviso sessions were relatively brief, could be successfully slotted into professionals' schedules, and could be undertaken remotely. Regardless of speciality, HCP were constrained by time. However, they were still enthusiastic about being involved as the Toolkit had perceived benefits for patients and their carers.

6.10.7 DIFFICULTIES OF WDMHC EVALUATION APPROACH DEPLOYMENT WITHIN COMPLEX DEVELOPMENT PROCESSES

The WDMHC is an example of an intensive development model requiring personnel, time, and resources to undertake. Applying the evaluation phase to the CarerHelp Toolkit highlighted the pragmatic barriers development teams face when evaluating usability using user, expert and content-based assessments.

In isolation, the evaluation approach by Johnson and Turley[218] would require a lead-in time, estimated at 8-12 weeks in real-time equivalent to allocated project time. There is limited flexibility in the process if issues or problems compromise progress, delivery, recruitment, funding, or time. As observed in pragmatic development by multidisciplinary teams, content delivery, complications or disagreements in software or platform capabilities, ability to recruit for evaluations, contradictory feedback, and discord in agreements on interface modifications between team members or organisations are all issues potentially impacting project deliverables.

6.10.7.1 Outsourcing usability evaluations

There are options for multidisciplinary teams to outsource this process to external organisations or collaborate with partners to undertake usability evaluations. Not knowing or understanding the requirements, structure and function of the intended at the outset of the project would make it extremely difficult for Project Leads to conceptualise and describe to external contractors. This translation could further increase costs, given the risk of delays in development. Commissioning funders are unlikely to fund usability evaluations, given that the current commercial costs are between $USD 10-25,000.[465] Speculatively, it would be difficult to envisage research funding bodies supplementing already tight budgets to account for additional costs for outsourcing usability evaluations to external experts. Outcomes from this study suggest that without additional funds, the status quo would remain, and non-specialist development teams, under time and budgetary pressures, will continue to undertake evaluations as discretionary activities.

6.10.7.2 Non-specialists, multidisciplinary teams, and usability evaluations

Applying this model in the real world highlights the difficulties in building a project team with expertise in development, evaluation, and technology integration required when "*the structured and iterative nature of human-centred design can often present a challenge when design teams are faced with the necessary, rapid, product development life cycles.*"[101(p1)]

Arguably, there would be few academics, research staff or project managers who would have previous experience across all aspects of online resource construction: from conception, content research and development, the conceptualisation of resource design and translation of content to online mode, evaluation of the design and reiteration of the interface, promotion and communication of the product to audiences and post-release evaluation to determine outcomes. These skills can only be attained through previous experience at all levels, supporting an understanding of the process or requirements, and speaking to managing expectations of what can be built in specific online environments in projects constrained by time and money. Successful application of the WDHMC evaluation approach assumes established clear and coherent expectations across the development team, organisations, and personnel. There is little room in the tightly scheduled activities for positing politically or internal disharmony creating internal timeline delays due to team inexperience, unrealistic or unbalanced workloads between partners.

In this study, observations of the mechanics of interactions between partner teams suggest expectations were not fully mapped before the commencement of the build, being more complex than initially anticipated. However, it is acknowledged that mapping a concept to create an end-product with inadequate levels of understandings in direction, shape, content and visual appearance is complex and time consuming within a sizeable collaborative partnership.

Apparent difficulties between the inexperienced and experienced in online development were evident, especially in naivety to the intricacies, nuances, and time requirements. Responsibility for project delivery lies in partner co-dependence, shared between all groups aware of their roles within the development and the importance of delivering each component to progress the project. When the antithesis is in play, development becomes increasingly complicated over time. For multidisciplinary teams who are not experienced in online development or evaluations, there is a high probability of unawareness of downstream implications of mismanagement, double-handling, or continuous interjecting in independent processes that have the potential to blow out costs and impinge on tight deadlines.

Recruiting project staff with appropriate skills is essential for all technological-based projects, but projects become imperative for these health-related resources due to the complexity of content, audience diversity, and resource usability. This expertise is also not limited to project staff extending to those responsible for translating the resource's conceptual design into an online entity that reflects the relationship between content and audience and enhances opportunities for interactions.

Commonly, multidisciplinary teams will collaborate with technical professionals (software programmers, information architects or front-end developers) and web designers through a contractual arrangement to fill their need for technical expertise. Resistance and friction from and between software programmers and web designers to make any changes to the interface can be due to:

1. The incongruity between experts' assumptions of how users will experience the interface and tangible feedback from users.
2. Suggested modifications to the interface challenge their authority, beliefs, and professional expertise, whereby all others (including members of the project teams and reviewers – users or experts) are not specialists in the design. Therefore, recommendations are to be minimised or dismissed with no room for compromise.
3. Designers with UX experience acknowledge the need for usability evaluations during development, and technical professionals are often unwilling to accommodate usability evaluations within formative development due to feedback in reiterations as it is considered a distraction to delivering the product.[466]

4. Technical experts typically apply a traditional one-size-fits-all approach producing interface designs that are not optimal for health resources with minimal participation from the intended audience.[467,468]

Health information interface designs are informed by the end-users needs, the context of the use[469] and software capability or platforms. Programmers and designers translation of issues or solutions in descriptions or explanations of interface design or functionality is further complicated by their unique lexicon. Arguably, neither technical group has the expertise or inclination to undertake usability evaluation of resources during development. The lack of usability expertise leaves non-specialised teams with limited options to undertake evaluations that are not costly, such as undertaking the approach and activities themselves or budgeting for expensive usability consultants to fill the void.

Considering scenarios where usability evaluation is not undertaken, is undertaken poorly, or completed in late stages of development (including post-release); modifications could likely be wide-ranging, complicated with the possibility of re-designed health resources incurring exponential increases in IT costs to resolve issues, especially if negotiated on a per-hourly basis.

6.10.8 WDHMC EVALUATION APPROACH AND IDENTIFICATION OF USABILITY ERRORS

The involvement of experts was a requirement in the WDHMC evaluation approach applied to the CarerHelp Toolkit prototype, being subject-matter or content experts (palliative care HCP) to participate in a peer-review methodology. The approach to expert-based evaluation in this model has effectively excluded professionals who have experience in usability and accessibility and muted identification of these types of errors within the interface. Arguably, excluding or not involving these double-experts renders this model askew to knowledge experts and at risk of being less usable. Peute et al.[231] proposed a revised, concise version of this model to include heuristic experts only, at SME reviewers expense, and producing a highly relevant and usable health resource. In this current study, there was an opportunity to explore the potential value to multidisciplinary teams in having access to ‘composite’ heuristic experts to improve designs for diverse audiences by exploring OHT interfaces. Inviting LD to be involved in evaluations provided a unique opportunity to compare and contrast types, frequency and severity of errors identified between evaluator groups. Although not discussed in detail, this sub-study investigated the development and implementation of an alternate, hybrid UEM for evaluating health information resources in an academic setting. A combination of the peer-review and cognitive walkthrough methods envisaged both LD and HCP evaluating interfaces from alternate perspectives, as experts in subject domain or technology, to produce a viable UEM when participants for health or medical resources are scarce.

6.10.8.1 Types of interface errors identified by reviewer groups (users, HCP and LD)

Meta-aggregation and applying quantitative logic to the analysis highlighted the presence of interface errors that were shared or discrete to reviewer groups (HCP, LD and USERS (carers)). Experts (LD and HCP) were equally skilled at identifying high-frequency content errors, and LDs were more sensitive to errors affecting the UX of the information. LD errors were more likely associated with information flow between and within pages, navigation devices or scripted hyperlink text, and interactions between the site and the end-user. HCP identified common technical errors, perhaps reflecting issues that they, as typical users, had previously experienced during their interactions with online technologies. As experts, HCP and LD identified examples of all categorised error types. As a reflection of their usability knowledge and professional practice, LD detected four discrete error types that can improve interactions for users who face barriers to use or access to health information, including visual representations, utility, error recovery, and accessibility.

As a single reviewer group, LD demonstrated the ability to detect errors at a greater frequency than HCP and carers whilst, on average, having improved efficiency to identify errors per evaluator. Rates of error identification across the interface of the CarerHelp prototype indicated that LD detects similar quotients of errors as heuristic double-expert evaluators.[470] In some cases, this was in higher percentages.[297,427,471] For HCP, this pattern was not observed, identifying a relatively low rate of errors[297] across the interface compared to double heuristic experts, however when combined as an 'expert' group with LD, this group identified over 80% of all errors within the prototype when rates were compared to carers. This is a pattern observed in health,[421,472] non-health focussed interfaces,[90,473] and other research studies.[474]

Outcomes from data analysis suggest LD and USERS are more likely to identify similar errors, having identified a higher number of shared error types than the frequency of shared errors within the HCP and USER group. This finding indicates the commonality between LD and USERS in how to interface information is perceived, understood, or comprehended within the context of being a non-specialist in the palliative care domain. It is essential to acknowledge that USERS identified similar confirmatory error types as expert reviewers, although lower in frequency.

6.10.8.2 Veritable errors and contradictions between evaluators

Unlike confirmatory errors or errors detected similarly by more than one reviewer group, error contradiction between groups recognises the presence of an error whilst the other does not perceive the same. For developers, error 'false alarms'[423,475] are generated by *equally* weighting the opinions of one group against the other. These are pragmatically 'true' interface errors. Veritable errors are identified by experts in either content or technology or by the critical eye of an intended user in this study (albeit to the view of both researchers and usability engineers, end-users cannot be believed as experts in content design.[336] Experts are not usability specialists nor designers of interfaces. Whether identified errors are from an expert's technical point of view or based on rules of interactions,[422] evaluators are *individuals* with personal lived experiences that shape their view of the Toolkit interface - including someone who has cared for a loved one who is dying or can articulate empathy for someone or has had a personal connection to someone they know to be a caregiver in the future. For HCP, professional practice adds another perspective. Although these are pragmatically 'true' interface errors for every reviewer, the complexity for developers lies in deciding which are more important or have the greatest impact on the user's experience of interfaces. If expert and user error data are equivalent, how do developers reconcile these 'true' errors to fix or ignore within interfaces?

6.10.8.3 The advantages of a hierarchy of errors

Applying severity and interpretation of deidentified error data across the reviewer group provided a measure of impact and impedance to UX within the CarerHelp Toolkit interface. Error-values are subjectively calculated on frequency, level of critical impact and resources required to rectify effectively producing a 'hierarchy of errors'.

Severity ratings removed bias associated with the evaluator type and the number involved within the evaluation process. However, even usability specialists cannot agree on a criterion of the types of usability errors having the greatest impact on the usability of interfaces and therefore list the errors developers need to attend to urgently.[476] For non-specialist teams, this is likely to add to the confusion and increase the risk of increasing interface errors for end-users. Outcomes from this study highlight the importance of a mixed-method approach to triangulate critical, functional, and content-based errors across methods and between evaluator groups. Severity ratings are assessed objectively to create a hierarchical list of errors to be systematically resolved; errors are verifiable across evaluators and UEM. From these observations, the 'loudest voice' should always belong to the users. Involvement of LD in usability evaluations of health resources to compliment HCP could provide the 'casting vote' in cases where there are contrary interface issues. Indications from the results of this study support the involvement of LD in usability evaluations of health resources, not as a replacement for HCP, instead of serving as supplementary to processes providing a knowledgeable source of error identification to act as the referee to cast the deciding vote in cases where there are contrary interface issues. However, developers need to acknowledge that users are not experts in design, content, accessibility or usability, and equal consideration should be granted to expert voices, whether they are HCP or proficient in technology or online design.

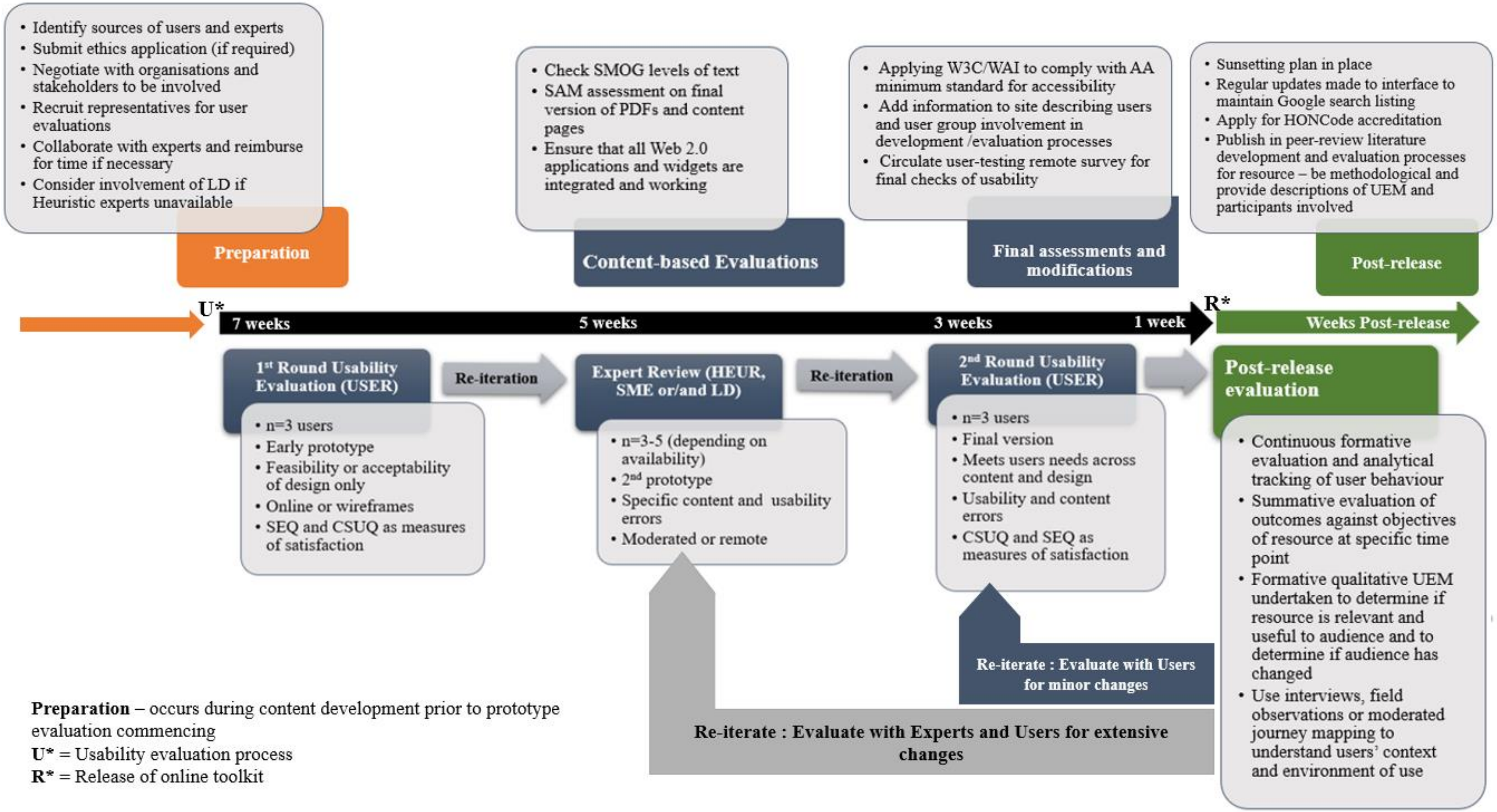
6.11 IMPLICATIONS FOR REAL-WORLD DEVELOPMENT PROCESSES

Observing a real-world development process through the lens of usability evaluation practice has provided valuable insight into the complexities surrounding the development environment. Internal organisational and operational difficulties and external mitigating factors impact the abilities of these teams to integrate usability evaluations into typical practice supporting the release of high quality, relevant and usable health resources. Therefore, outcomes from this study can also influence change and encourage discussions to improve the development and evaluation process for online health information resources, primarily as the health sector directs health consumers to engage digitally with their health.

6.11.1 THE REVISED EVALUATION PROCESS FOR ONLINE TOOLKITS

A revised evaluation process for online toolkits (and potentially health websites) is proposed; this process simplifies practice for development teams by recommending a step-wise flow of activities undertaken to begin once a stable prototype has been produced. For this example, a non-specialised team has created a stable prototype of an OHT seven weeks before release.

A flow diagram of this revised approach is presented in Figure 6.4. It includes all three aspects of triangulation of identifying usability errors (user-, expert- and content-based evaluation) whilst considering critical factors identified within this current study to be considered and planned for *in advance,* reducing opportunities to short-cut activities due to time and budgetary constraints.



Preparation – occurs during content development prior to prototype evaluation commencing
U* = Usability evaluation process
R* = Release of online toolkit

Figure 6.4 Evaluation process and timelines for the development of online health toolkits based on observations and outcomes from this study

- Agreement reached between project group members to undertake a series of usability evaluations during the development and post-release period. Partial funding is provided to the project team once evaluations tied to milestones within the development process have been undertaken and reported in full to the funder. Contractual financial penalties for non-fulfilment of milestones are an option, although they would be difficult to enforce at a development team level, given that these groups are non-commercial entities. An unlikely alternative is to shift accountability for evaluations to institutions of the project collaborators. These organisations would be liable for financial penalties if evaluation milestones are not completed or reported adequately.
- Anticipatory preparations of ethics, identifying reviewers and planning sustainability and sunsetting route are examples of these factors to be considered before undertaking evaluation cycles. Ethical approval will be required for recruitment and development within research, healthcare or service setting, or if findings are to be disseminated within the public domain or if the participants' audio, video or personal details are shared between partner organisations. Ethical approval would not be required (although consent would still be required) if recruiting from the general population and findings were to remain in-house as part of standard business practice.
- Two rounds of user-based evaluation recommended in-lieu of a single method specified in the WDMHC, one round of usability evaluation undertaken on the early prototype defining feasibility/acceptability of design or concept (at seven weeks).
- After expert/content review, the second at three weeks before release confirms the final version's textualized content, information flow, accessibility, and usability.

This revised framework also proposes that post-release evaluations should include summative assessments of outcomes or process/outcomes.

- Contextual and environmental information on how users engage with the resource are generated from round(s) of formative evaluations assessing continual use, relevance, and acceptance of the resource to the intended audience involving in-depth collaborations between users and developers.
- Analysis of this essential feedback ensures the resource is servicing users’ needs, gauging if the audience has changed or if the resource is used for other purposes and providing empirical evidence to commission funding bodies to sustain funding to support longevity.

Although external to project deliverables, publication of development and evaluation processes in the peer-reviewed literature is also a critical aspect of the post-release activity. Reporting could increase the depth and scope of evidence-based practice to guide development teams to produce quality resources for health consumers.

6.11.2 RECOMMENDATIONS FOR OPERATIONAL ENTITIES INVOLVED IN TOOLKIT DEVELOPMENT/EVALUATION

Observations and assessment of usability evaluations from this study have led to a series of practice recommendations being critically important in assisting project teams and, particularly project leads or managers, having limited experience developing and evaluating health resources online. Study implications have been transposed into recommendations enmeshed across operational levels that influence evaluation processes and are specific to each functional entity and appended to this thesis as:

1. Commissioning funders such as government, organisations, or private contributors (Appendix 6.18)
2. Project leads/Managers (Appendix 6.19)
3. Web development teams (Appendix 6.20).

6.12 STRENGTHS AND LIMITATIONS OF THIS STUDY

The strength of this study lies in the ability to observe in real-time a development process undertaken by a multidisciplinary team whilst applying a structured and comprehensive evaluation approach to the same prototype in parallel. This strategy provided an opportunity to understand and investigate the pragmatic aspects of development that could reduce the likelihood for usability evaluations to form a part of typical practice. By remaining independent of the process, resultant observations and recommendations on improvements to evaluation processes during development are purported without bias. Criticism cannot be mistaken for judgment on individuals or teams involved, challenged by circumstances beyond their control influencing outcomes.

Limitations were evident during different stages of the study. The misalignment of usability evaluations hampered the ability to access a stable version of the prototype with the stage of development in a real-world development process. As a result, two slightly different versions of the prototype were assessed between the carers (user-based) and experts (expert-based) evaluations. Whilst this difference in interface design likely influenced error detection between groups, modifications between the first and second versions of the early prototype addressed critical errors. Expert reviewers would likely have identified these errors in the first instance, and developers chose to resolve them as these impacted their interactions with the interface. As reviewers tend to get 'hung up' on apparent problems, these errors can interfere with their ability to see past them to other more important issues within the online prototype.

Another limitation was using a single moderator and facilitator to elicit and analyse the feedback generated during user-based evaluations. Usability practice recommends deploying multiple facilitators to examine the data and collate findings from the sessions, although this was not possible for this study. These limitations were countered by recording sessions to ensure data was not missed, and analysis was undertaken on de-identified data to limit bias as much as possible.

The involvement of surrogate users in-lieu of 'real' users in these sessions was not considered a weakness of this study. Defined by caring status, four of six users were surrogates, recently bereaved instead of acting as an active carer when undertaking usability. As discussed previously, whilst bereaved carers were not technically representative of the intended audience, surrogate feedback data reflects active carer user experiences, and surrogate users are accommodated in typical usability practice. Another potential limitation was the level of experience held by the development team. CareSearch has at least ten years of experience developing health information resources, including websites, platforms, and apps. The team was very well led and understood requirements, deliverables, project milestones, and what needed to be completed to reach the hard release deadline. The involvement of a less experienced web development team may have also produced findings that would have highlighted additional areas of development that are crucial for incorporating usability into the process. Arguably, an increased range of complications, shortcomings and management issues may have been uncovered if all partners were relatively inexperienced in both development and evaluations.

6.13 CHAPTER SUMMARY

This study has highlighted the difficulties, complexities, and barriers to usability evaluations for multidisciplinary teams within a typical development of the CarerHelp Toolkit. The application of the evaluation phase of the WDMHC process was undertaken in parallel on early prototypes of the Toolkit, carried out in real-time, in parallel with the build of the Toolkit. Usability testing was essential for shaping the Toolkit interface, with carers being indispensable to providing rich narratives and performance data contributing to a formal reporting of the outcomes to the NRG. Whilst the formal report was an effective method to present evidentiary findings from the testing, the process highlighted the difficulties in securing participants from vulnerable populations. Difficulties were encountered in recruiting experts for expert-based evaluations, like palliative care patient populations. Experts were time-poor, and securing participants created unanticipated delays even with a vested interest in the resource. Expert-based evaluations provided an opportunity to investigate a hybrid method of evaluations, a combination of cognitive walkthrough and peer review with LDs and HCP.

Outcomes suggest that for health resources developed within academic settings, LDs can complement HCP to evaluate the interface as a technical expert forming a composite heuristic expert who could pragmatically assess the interface if carers were not available or not accessible. This series of evaluation activities were created and then added to the compendium of problems or issues impacting development and usability practice. It is important to note that many of these observed problems are inherent to the development team structure, their experience and ability to apply an appropriate management approach to development. These deficiencies are intrinsic to multidisciplinary teams who may be specialists in content, evidence or research but are inexperienced in development and usability evaluations. The key to ‘normalising’ evaluations into typical practice is to ensure stability within the development process. The first two studies identified the need for developers to access guidance to inform usability practice; this current study highlights the existing barriers for developers even when a structured usability evaluation approach guides practice. Barriers identified speak directly to the process, team structure, expertise, experience, and access to participants in usability evaluations to assist in shaping interfaces for a diverse audience.

Subsequent research within this thesis now focuses on end-users; to explore how developers can identify, engage, and involve individuals with diverse characteristics in usability evaluations. Study 4 examines recruitment strategies to engage with end-users from hard-to-reach community groups who face barriers to accessing and using online information. Strategies will include assessing characteristics influencing digital readiness, including socio-cultural demographics, health literacy, digital health literacy and Internet behaviours.

CHAPTER 7 - END-USERS FACING DIGITAL EXCLUSION AND BARRIERS TO USE – REACH, ENGAGEMENT AND PARTICIPATION IN USABILITY EVALUATIONS

Chapter 7 presents the research undertaken in the fourth study of this PhD. Study 4 and Study 5 (described in Chapter 8) concentrate on the third factor influencing the evaluation practice by non-specialised teams - participation by end-users. In recognising the importance of diversifying evaluation samples to shape universal health interfaces, this study explores strategies to recruit participants who can offer crucial feedback on interface designs but who are typically excluded due to digital or social exclusion. This research investigates recruitment strategies development teams could employ to engage hard-to-reach groups within the community. Analysis of socio-demographic and online behaviours explore the end-user characteristics that make these individuals essential participants in usability evaluations of universal health interfaces.

7 STUDY 4. END-USERS FACING DIGITAL EXCLUSION AND BARRIERS TO USE – REACH, ENGAGEMENT AND PARTICIPATION IN USABILITY EVALUATIONS

7.1 CHAPTER INTRODUCTION

Earlier chapters have looked at the impact of evidence for practice and the influence of usability processes. For developers, successful usability practice requires investment and support from commissioning funders whilst practically, support comes in the form of evidence, knowledge and experience, ready access to evaluators and strategies to manage complex projects across teams or between professions. Chapters 7 and 8 explore the impact of end-user identification and involvement, particularly concerning the needs and characteristics of different users and their inclusion in usability testing. In these two chapters, Study 4 and Study 5 explore the difficulties facing development teams when and if diversity becomes a driving factor in shaping interfaces for generalist audiences. This thesis chapter explores strategies to engage and recruit end-users living within the community who are inadvertently excluded[247] from evaluation samples due to their socio-cultural demographics and lived experiences.

7.2 BACKGROUND AND RATIONALE

Within an evolving health environment, there is an acknowledgement that consumer access to health information has shifted with a greater reliance on digital resources to support all aspects of consumer information needs,[477] self-care capabilities,[111-113] and to participate in managing their health across online systems or services.[123] As discussed in the introductory chapters, forced adoption and increased dependence on websites, apps, platforms, mobile or in-home devices can increase the divide between those who can use and those who cannot successfully use health interfaces to support their healthcare needs.[178] The COVID-19 pandemic has highlighted pre-existing flaws and gaps in universal access and assumptions of use, especially in communicating crucial health messaging to vulnerable and isolated populations within communities.[478] Reliance on digital health information and electronic messaging to reach and engage individuals is counterintuitive in groups with:

- A mistrust of the Internet,[96]

- Who are intermittent users or avoiders of technology,[479]
- Whose preference is for printed information or verbal interactions over online communication, or
- Where there are issues with interactions[480] determined by socio-cultural background and levels of digital readiness,[96] or competency.[141]

When funders, developers and usability practitioners assume access to health interfaces equals successful use,[481] interface design and content errors are more likely to arise. Unintentional exclusion could lead to missed opportunities to create resources that can meet the needs of the most at risk in the community. To negate this, health interface developers can apply inclusive and universal principles to the interface design. This is likely to promote interface design solutions[13] that increase the access and use of health information by those who regularly experience barriers to being online.[13,247] There is a growing interest in the role of universal and inclusive principles in online health development. Beyond the implications for interfaces design development teams will need to consider how planning for usability evaluation can address the need for an inclusive and diverse intended end-user audience.[208,247,482]

Recruitment strategies need to avoid inadvertent bias[247] arising from recruiting only digitally engaged convenience samples, which are likely to overlook errors or design barriers to information use that generalist audiences may encounter within the interface.[93-95] Ideally, usability evaluation samples should realistically reflect the end-user community, to include representations from culturally diverse communities, older people,[176,201] low socioeconomic groups,[483] people with low English proficiency,[173,174] geographically isolated residents,[136] and migrant or refugees populations.[175] Due to the interactive challenges and barriers experienced, participants will likely identify errors offering feedback to improve digital health interfaces for everyone, patients, caregivers and consumers.

7.2.1 DIFFICULTIES FOR DEVELOPERS OF HEALTH INFORMATION RESOURCES

Previous chapters have established that development teams are likely to face budget and time constraints within pressurised development processes. Compounding these complications is the differences between audiences for commercial products and health resources. Unlike defined commercial audiences of an online product,[484] health interfaces are generalist and relevant to a broad range of heterogenous end-users[485,486] living within the community. Ambiguous archetypal or typical end-users of generalized health resources can be challenging to identify due to their casual and transient relationship to the health content domain. Complicating practice further is the ability to decide who should be involved. How can developers decide which types of end-users are represented within evaluation samples, given that small groups (i.e., usability testing sample *n*=6) are typically required during formative stages of development? There is understandable uncertainty around which user characteristics, background, and capabilities are preferred to generate and maximize feedback to inform interfaces reiterations that benefit all end-users.

7.2.2 RECRUITMENT FOR USABILITY SAMPLES -WHO IS IN AND WHO IS OUT?

Individuals who are most likely to 'volunteer' for recruitment within usability evaluations are typically technically-savvy.[93-95] Commonly having previous online experiences alleviating potential apprehension, fear or mistrust of technology; and have sufficient literacy to understand the context, language, and content resource associated with experimental protocols.[93,97] Inadvertent[247] or unintentional exclusion of individuals by developers from evaluation practice arguably produces a false representation or skewed sample of the intended audience. This practice results in evaluations failing to identify problems or issues that segments of the public will encounter as barriers to finding, accessing, and understanding online health information. The divide between those who can or cannot regularly access the Internet or use technology further complicates evaluation practice. There is a need to encourage and support intermittent Internet users or avoiders of technology to be involved in the development process. Feedback provided by these individuals assists in the identification of errors and reduce design barriers to shape interfaces[13,247] for an audience with diverse needs or requirements.

7.2.3 END-USER CHARACTERISTICS LIMITING ONLINE INTERACTIONS

Digital inclusion follows economic and social contours,[10] and factors influencing regular online engagement for two and a half million Australians[10,108] are varied. Community groups face differential levels of digital exclusion (Table 7.1). Some individuals have a multiplicity of factors impacting online engagement with health information, almost a *perfect storm* of intersecting factors negatively influencing affordability of broadband, access to technology, health literacy, attitudes and acceptance of digital devices and digital skills affecting digital competency.

Table 7.1. Groups within the Australian community recognised as experiencing levels of digital exclusion

Low-income households (income below $35,000 per year)[129]
Individuals without fixed broadband access (mobile phone-only users)[10]
Individuals aged over 65[135]
Individuals who did not complete secondary school education[10]
Indigenous populations[10]
Ethnically or culturally linguistically diverse backgrounds[10]
Geographically isolated, rural, or remote populations[10,129,136]

Each factor is affected by an individual's baggage,[247] a combination of unique characteristics influencing an individual's acceptance and adoption of technology, their operational and functional capabilities using a device or working across platforms or programs, and performance within an interface to successfully achieve their intended goal for the online visit (Figure 1.3). Hesitancy or aversion to being online makes the involvement of these individuals an essential part of effectively evaluating interfaces for their suitability for diverse populations. Consequently, for developers, these same characteristics are likely to influence abilities to identify and connect with these individuals or groups within the community.

7.2.4 WHAT MAKES THE DIGITALLY EXCLUDED POPULATION HARD-TO-REACH?

Development teams in a commercial environment rely on word of mouth, snowball recruitment to identify and invite individuals.[487] Teams also utilise usability panels comprised of pre-registered individuals who are readily available, interested, and not necessarily tightly bound to any specific resource or product being developed.[95,488,489] For multidisciplinary teams designing generalist health interfaces, identifying and accessing a suitable cohort is difficult (as was observed in Study 3) and time-consuming. Practically, the reliance on fast and efficient digital communication strategies (electronic communications or social media) to reach target audiences could be advantageous when resources are limited. Exclusively employing this strategy would inadvertently exclude individuals who are averse or experience difficulties with technology, dislike the Internet or social media, or cannot afford to access the online environment. Engaging with these hard-to-reach individuals and groups within the community may require alternate strategies. Palliative care caregivers are an example of a vulnerable population, and perhaps like hard-to-reach populations, a F2F approach using derived rapport employed within Study 3 may prove more successful than relying on digital communication only. However, requiring developers to recruit for diversity within these small, hard-to-reach groups of health or medical cohorts could be nearly impossible. Further, the question of whether diversity within usability evaluation samples for health or medical resources targeting the general population is realistically achievable for multidisciplinary teams is unexplored.

7.2.5 DIGITAL EXCLUSION AND SOCIAL DETERMINANTS OF HEALTH

As preluded in the introductory chapters (section 1.63 and 1.7.2), the characteristics influencing digital equity and access, digital competency, acceptance, or avoidance of technology are the same as those impacting health literacy and digital exclusion. Importantly, having low health literacy levels does not imply digital exclusion; instead, it recognises the mutual impacts of shared characteristics across both outcomes. Characteristics responsible for successful interactions within the online environment are similarly effective in driving the determinants in outcomes of health, health-related attitudes, beliefs, knowledge, and behaviours[164] regularly targeted by self-care, health promotion and disease prevention digital health interventions. The compounding effects of overlapping SDOH decreases health literacy, influencing the ability to assess health information for trustworthiness, increasing the risk of exposure to inaccurate or online falsehoods.[112,161,168,177]

Health literacy (HL) and digital health literacy (DHL) share core aspects of general literacy,[490-492] and both are complicated by skill elements required for 1) comprehension and application of health information to decision-making processes,[490,492] and 2) abilities to problem-solve through the application of the information in electronic form. DHL requires three further literacies: computer, media, and information.[492,493] Challenges are apparent for developers designing health information within the digital medium. Complex site structures compromise digital translation with complicated navigation flow, adding requisite literacy demands[492,494] and cognitive workload for users[492] when using the interface. Significantly, "*digital health literacy is a predictor of critical internet use,*"[495(p8),161] and are characteristically impacted by "*super social determinants of health.*"[178(p1)] Using differing measures of DHL, researchers have found associations between DHL and SDOH including levels of education,[123,177,496-498] age,[177,496,498,499] disease condition,[177] income,[499] frequency of Internet use,[177,499] self-reported health status,[496,499] and use of information.[496]

Specific community groups facing barriers to DHL are also vulnerable to being digitally excluded and having lower health and general literacy levels. These individuals characteristically belong to lower socioeconomic groups,[177,490] have low educational attainment, are older[490,497,500] and are from CALD groups.[490,501]

Unlike some longitudinally stable characteristics, health literacy and DHL can increase or decrease over time with changing skills, improved abilities, age, attitudes toward knowledge currency, and affordability of technology. Community-based health literacy programs can support individuals to improve health literacy in a cultural and social context.[502] Building community capacity[503] can address community and organisational aspects of digital and health literacy. Examples include local governments, primary health networks and local health district initiatives[503] to recognise literacy and digital skill-building benefits for specific community segments. As part of health literate organisations, local government public libraries promote access to healthcare by providing health information and linkages to services[504] and improving digital skills.[505] For digitally excluded populations that tend to be culturally or ethnically diverse, living within low socioeconomic areas or whose residents are older than 65 years, local council libraries offer F2F programs to improve numeracy and literacy skills, levels of health[158,506-509] and digital health literacies.[510] In-person training is the preferred mode of learning for older people,[511] programs also increase confidence and online privacy skills.[512]

7.2.6 MEASURING HEALTH LITERACY

The Internet and adoption of technology have seen the electronic health literacy scale (eHEALS) developed from traditional measures of health literacy including the Test of Functional Health Literacy in Adults and The Newest Vital Sign.[513] The eHEALS is now the most frequently applied measure of self-reported health literacy.[514,515] Based on Norman and Skinner's Lily model of eHealth literacy,[493] the electronic health literacy scale (eHEALS) distinguishes between six types of literacy skills:

1. Scientific
2. Traditional
3. Media

4. Computer
5. Health
6. Information literacy.

There are suggestions that applying eHEALS in the current online environment compromises validity[99] - especially with the emergence of social media, online forums, and telehealth interactions to engage with both healthcare providers and health consumers.[155] This 'new' social norm has encouraged the development of new instruments considering interactions between consumers, online information, and interactional literacy,[155] dynamic interactions including social networking, message creation and privacy.[516]

7.2.7 ASSESSING DIGITAL HEALTH LITERACY

Digital Health Literacy Instrument (*DHLI*) reflects a contemporary measure of health literacy that considers innovative skills required to interact, engage, and contribute to Web2.0 applications, including online peer-peer communication (forums, blogs, social media), peer-service interaction (portals and eHR) and mobile eHealth applications.[152,517] This scale is considered a novel measure of digital health and the digital skills required for users in the current online health environment.[518] A total *DHLI* score indicates an overall level of DHL.[516] Conceptually, the 21-item *DHLI* questionnaire is derived from research examining competencies required to access online health information (Web 1.0) within a cohort of rheumatological patients.[517] van der Vaart et al.[517] identified six independent competencies which were further developed into six sub-scales[516]:

1. Operational skills to use the computer and Internet browser
2. Navigation skills to navigate and orientate on the web
3. Information searching skills, to use correct search strategies
4. Evaluating the reliability of online information
5. Determining the relevance of online information
6. Adding self-generated content to web-based apps.

There is limited research measuring DHL within populations and specific investigations in the applicability of this instrument among groups at risk for low DHL. As the *DHLI* is relatively new, this offers an exciting opportunity to apply this measure of DHL in community groups who are likely to experience low levels of DHL, including individuals from multicultural backgrounds, have low socio-demographic status, are older, are digitally or socially excluded and have low educational attainment.

7.2.8 SIGNIFICANCE OF THIS STUDY

Adopting usability and accessibility evaluations into typical development processes places additional pressure on non-specialised multidisciplinary teams. Complications observed within Study 3 included unstable development processes, inexperience, and access to patients, carers, or consumers to participate in activities. Further complicating the development environment is a requirement to design interfaces for diverse audiences, a feat acknowledged as impossible[13] even for established and experienced web designers, usability practitioners, and interaction experts.[519] An inclusive approach requires evaluations with individuals who experience the greatest difficulties using interfaces. These are 'edge users' who have difficulties accessing or using interfaces,[31] and by resolving their issues, we can improve the UX for everyone.[520] Applying this approach within typical development environments is undoubtedly desirable and can be achieved when the process is managed, resources are adequate, and expertise is plentiful. However, multidisciplinary teams can find recruitment for usability difficult, particularly when needing health consumers who may be time-poor, hard-to-reach or vulnerable. Managing the need to identify and source usability participants from diverse backgrounds and with variable health literacy and digital capabilities can complicate recruitment.

Further, what strategies are required to recruit individuals who are likely to be disengaged from the online environment, intermittent Internet users, or challenged by poor digital skills, and are representatives from these groups even interested in participating in usability evaluations? [GG] The literature has focussed on recruitment strategies to ethically engage with hard-to-reach or vulnerable groups for social research purposes. There is limited information on the strategies to engage with digitally excluded or technically disengaged populations for participation in evaluations. The primary objective of this study is to explore a strategy to engage with hard-to-reach individuals within the community. Distributing surveys using two modalities, digital and F2F, to potentially digitally excluded individuals within the Australian community provided an

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[GG] For health or medical resources with defined audiences, diversity, and the need to engage with representatives from this audience still remains. Identifying and recruiting interest participants who face barriers to access and use of health information within these cohorts is further complicated by access to patient or caregiver populations and their vulnerability or exclusion status.

opportunity to examine socio-cultural and demographic characteristics, Internet behaviours, and their association to health literacy levels in respondents.

7.3 RESEARCH QUESTIONS AND STUDY OBJECTIVES

RQ4: Which survey modality, paper-based or digital (online), as an engagement approach provides access to digitally excluded or technically disengaged individuals living within the community to participate in usability evaluations of health interface?

RQ5: What are the associations between respondents' mode of survey return and their socio-cultural demographics, online behaviours, and levels of health literacy?

7.3.1 STUDY OBJECTIVES

1. Explore modalities of engagement to identify, engage and recruit survey respondents from digitally excluded or technically disadvantaged individuals within the Australian community.
2. Examine relationships between survey response preference and participants' socio-cultural demographics, online behaviours, and levels of health literacy.
3. Examine the associations between respondents' preferences for a survey response, their levels of DHL, electronic HL and user characteristics.

7.4 STUDY DESIGN

This study was conducted in two stages. Stage 1 was descriptive, undertaken using a multimodal survey sampling cohort from the general Australian population and described within this chapter. A sub-sample from this study were recruited to participate in the second stage to form two stratified cohorts delineated by measures of DHL levels to undertake a series of UEM, and this study is described in detail in the subsequent chapter. Survey respondents for the current study were self-selecting samples and were recruited from various sources, including groups currently involved in community social or educational programs at local sites around Adelaide, South Australia. As a probability sample is beyond the scope of this study, a convenience sample was sufficient, particularly in this exploratory study. Individuals used paper or online versions of the same survey and completed general demographic questions, electronic and DHL measures, and computer anxiety levels. Figure 7.1 presents a diagrammatic representation of study design and flow for Stage 1 (Study 4, Chapter 7) and Stage 2 (Study 5, Chapter 8). This chapter describes the Stage 1 procedure, results, and outcomes from the survey exclusively.

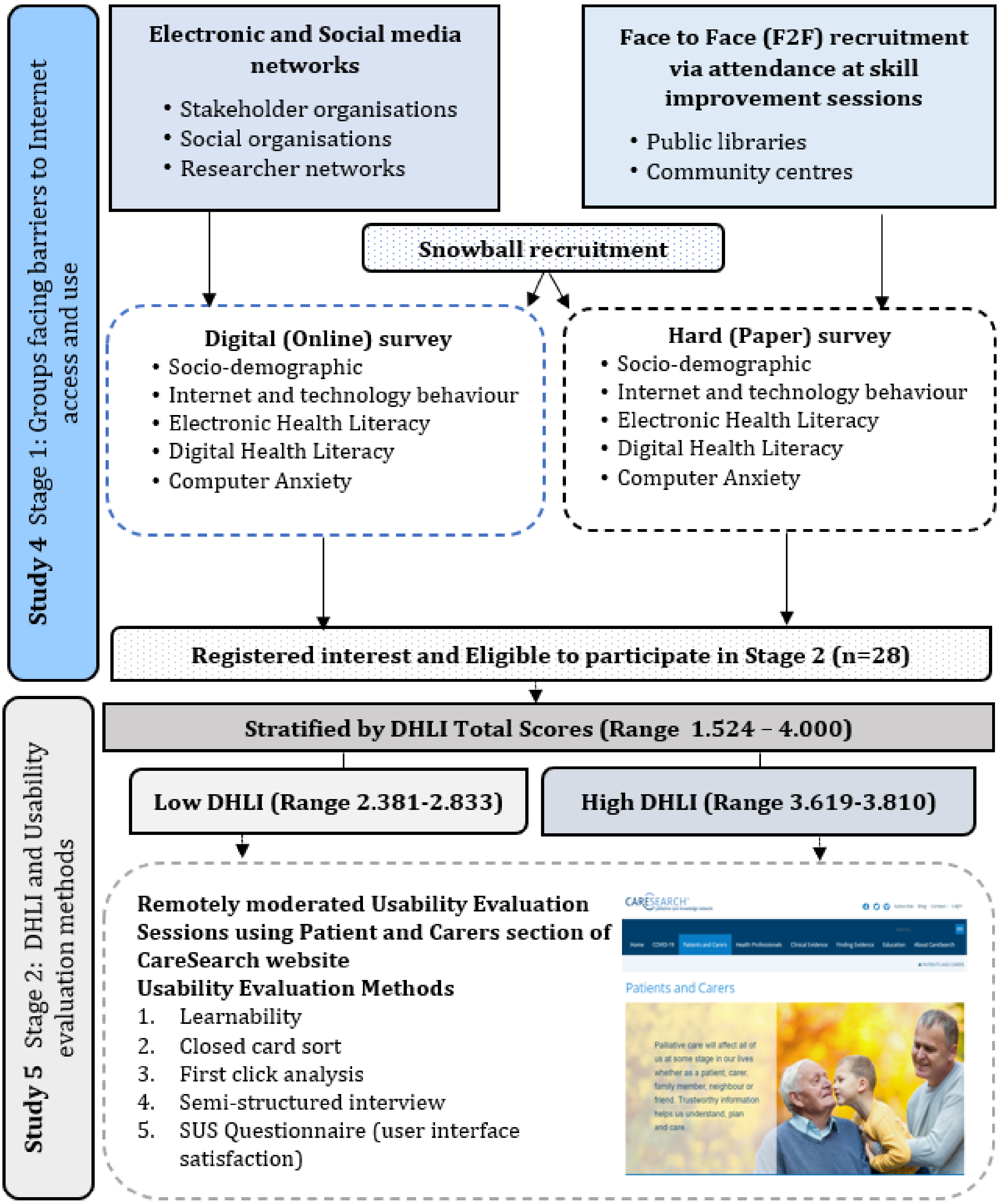


Figure 7.1 Study 4 and Study 5 procedural flow diagram

7.5 METHOD

7.5.1 ETHICAL APPROVALS AND PERMISSIONS

This study (and subsequent Chapter 8 research) received ethical approval from Flinders University Social and Behavioural Research Ethics Committee (Project 8627) (Appendix 7.1) and, as such, complies with the Australian ethical standards and guidelines of the National Statement on Ethical Conduct in Human Research following National Health and Medical Research Council Act.[390] Permission was sought to use the Digital Health Literacy Instrument (*DHLI*) from scale developers. Professor Constance Drossaert, and on behalf of co-developer Dr Rosalie van der Vaart, provided approval for unrestricted use of this tool within this study (Appendix 7.2 provides a copy of this permission).

7.5.2 SETTING

This research was conducted across two mediums: paper (hard copy) surveys and as a digital online version, hosted on the Qualtrics Survey platform.[432] The surveys included the opportunity for respondents to participate in a remote, online card sorting activity with a content focus on palliative care. Surveys were open for anonymous data collection for six weeks between 31st July to 11th September 2020. Paper surveys were distributed in person to patrons of local South Australian Government libraries attending different educational, social sessions held within community centres or on library premises. F2F distributions were undertaken during the six-week survey data collection period and were sporadically attended by patrons due to COVID-19 restrictions. The first session was on 31st July 2020, and the final session was on 7th September 2020. No follow-ups to collect missing data were required due to the anonymous nature of the study.

7.5.3 PARTICIPANTS

Study participants were recruited from the broader Australian community, reflecting the generalised audience readily interacting with health information resources. All respondents were 18 years or older and understood English, given the requirement to follow instructions within the survey platform. Inferred consent was granted by respondents reading the study information, the survey instructions, and then beginning the survey. Direct rapport was established with advocacy, educators or stakeholder organisations representing or supporting individuals who would typically face barriers to online engagement. Study information was distributed via digital communication channels, including social media networks, e-messaging, e-newsletters and blogs to access the online survey directly. These channels were chosen to potentially increase the reach and uptake within hard-to-reach population groups.[521-524] Facebook and social media are effective means to recruit for online health and medical surveys[522] due to low costs and rapid distribution.[525] Snowball recruitment occurred using respondents personal networks via social media and personal communication with participants interested in inviting family or friends. F2F distribution of hard copy surveys occurred through attending skill-building sessions at community public libraries.

7.5.3.1 Power calculation for survey sample size

A priori power analysis was conducted using G*Power3.1.9.2[526] to test the difference between two independent group means using a two-tailed test, an intermediate effect size (Cohen's d= .50), and an alpha of 0.05. Results indicate that a total sample of 128 participants with two equal-sized groups of *n*=64 was required to achieve a power of 0.80.

7.5.4 DATA SECURITY AND PROTECTING PRIVACY PROCEDURE

Qualtrics Survey software[432] was utilised to construct and manage the online questionnaire. Participants completed the card sorting activity within the Optimal Sort platform.[527] Both platforms offered exclusive access to generated data via secure password protection. All data were extracted from the survey platform on survey closure, and data was managed within Excel.[528] Data from questionnaires, demographic survey responses and card sorting activity were stored electronically within a password-protected University server accessed only by researchers. All data were de-identified before analysis, ensuring participant confidentiality and privacy.

7.5.5 RECRUITMENT

Using indirect (non-targeted) and direct recruitment strategies increased opportunities to reach individuals with varying demographic characteristics, including age, education level, socio-economic backgrounds, ethnicities, geographical location, and gender. There was a genuine effort to include those population cohorts who may have limited experience with technology or limited digital skills. Organisations who aid these groups within the community were sought to participate in survey distribution; by encouraging in-person (F2F) delivery of paper surveys and online recruitment utilising corporate social media or online communication networks. Local Government council libraries and community centres throughout the Adelaide metropolitan area were included within the recruitment strategy. An indication of a successful recruitment strategy would be reflected in a diverse representation of respondents within the survey return cohort, with varying characteristics across sociodemographic, Internet use and online behaviour.

7.5.5.1 Direct recruitment approach – F2F recruitment

Five Adelaide councils were initially approached seeking support to distribute paper copy surveys to library patrons attending various technology or digital skills facilitated education sessions within community programs. In principle, support was welcomed from four councils, Port Adelaide and Enfield, Marion City Council, Charles Sturt Council and Onkaparinga Council. COVID-19 restrictions limited access to public libraries during the study period, with councils employing varying levels of isolation, social distancing and hygiene policies that directly impacted the ability to facilitate technological or digital skill sessions. Two local metropolitan councils in Adelaide continued to offer modified sessions across this period. Port Adelaide Enfield and Charles Sturt Councils assisted in providing access to patrons attending sessions in self-contained locations across council areas. Library advocates facilitated these sessions with a personal and professional interest in improving digital skills and literacy within their local populations. Participating councils had relatively high numbers of older Australians, newly arrived migrants, and communities of CALD groups living within their boundaries. Library advocates with a personal and professional interest in improving digital skills and literacy within local populations assisted by arranging for researcher attendance at specific sessions. Surveys were distributed across eight sessions at four locations in two council areas between 31st July and 7th September 2020.

Patrons had an option of either:

1. Hard copy survey pack, consisting of:
    - Letter of Introduction (from Supervisor)
    - Information sheet (including information on inferred consent)
    - Instructions to complete surveys (either paper or online - URL link and instructions on how to enter this on a device)
    - Participant information sheet (for both Stage 1 and 2)
    - Paper survey with a reply-paid envelope or an
2. An online pack containing:
    - Letter of introduction (from Supervisor)

- Instruction guide explaining access to the online survey and required URL.

Online packs were offered in response to participants requests to take home a copy of the survey URL, only indicating a preference for online completion. Both paper and online packs were available to patrons' post-session after verbal introduction and explanation provided by the researcher. Table 7.2 summarises session types and includes the number of packs distributed.

Table 7.2. Number of survey packs distributed at F2F education sessions

		Number of survey packs	
Organisation	**Session**	**Paper (hard) copy**	**Online URL 'packs'**
Charles Sturt libraries	NBN Community Workshop	0	1
	Excel Workshop	0	2
	Be Connected digital skills (x2 sessions)	9	1
Port Adelaide Enfield Council libraries	Digital Springboard	1	7
	Book Club	3	5
	English Conversation (Beginners)	5	2
	English Conversation (Conversational)	3	0

7.5.5.2 Direct recruitment approach – Online distribution of study information

Stakeholder organisations or advocacy groups were approached to utilise social media and communication networks to amplify both reach and engagement to a diverse range of community members, all having sociodemographic characteristics recognised as influencing online interactions with health information (as outlined in Table 7.3). A total of 45 different organisations were approached to distribute study information (with a link to the online survey) through their official communication networks. The ethics committee's messages and images pre-approved were provided for use within social media platforms (Facebook, Twitter, Instagram) or other forms of electronic communication, including e-newsletters and blog posts. Messaging and images with ethical pre-approval were provided to those who indicated a willingness to assist. Recruitment via social media commenced on August 1st and concluded with a last online post on August 24th.

Table 7.3. Targeted recruitment for individuals facing barriers to access and use of health information

	Digital skills	Language (English proficiency)	Literacy	Age	SES	Disability	Context to resource
Metropolitan and regional libraries	✓	✓	✓	✓	✓		
Inclusivity	✓			✓	✓	✓	
Multicultural and CALD	✓	✓	✓	✓	✓		
Non-government organisations, including formal social clubs	✓		✓	✓			
Technology support groups for older Australians	✓			✓	✓		
Researchers with interest in disability and inclusion	✓					✓	
Palliative care and carer specific	✓	✓	✓	✓	✓		✓
Disease-specific (conditions influencing access and use of technology)	✓		✓	✓	✓	✓	✓

✓ - indicates individual characteristics contributing to difficulties engaging with online health information within groups targeted for recruitment

Sixteen organisations did not respond to requests and five organisations did not correspond after providing initial in-principle support. Six organisations were unable to distribute study information (including survey link) as formatting or language was not accessible to their audiences, or not suitable medium for distribution given they were stakeholder organisations (Appendix 7.3). Fifteen organisations distributed study information via social media. Flinders University College of Nursing and Health Sciences placed an approved Facebook advertisement within their corporate page, running a two-week campaign from 1st August to 14th August 2020. This advertisement specifically targeted those users who may regularly face barriers to using or accessing technology. Table 7.4 summarises organisations that assisted with the distribution of study information. Appendix 7.4 provides examples of posted social media messaging by organisations.

Table 7.4. Organisations who distributed study information and survey link via social media and communication networks

Organisation	Distribution communication channel
Alexandrina Council library	e-Newsletter
CareSearch	CareSearch Blog and Twitter
Catalyst Foundation	Facebook / Twitter / e-newsletter
Centre for Inclusive Design	Facebook / Twitter / Instagram / Web
Flinders University College of Nursing and Health Sciences	Paid Facebook Ad
Flinders University participant recruitment page	Webpage
Libraries SA	Libraries SA Facebook Tech Savvy Seniors Group Facebook
MND Australia	Facebook / Twitter / e-newsletter
Mount Gambier public library	Facebook
Palliative Care Australia	e-Newsletter
Port Adelaide Enfield Council libraries	Facebook / Twitter / e-newsletter
Port Lincoln public library	Facebook
Researcher - Inclusion and Disability (NSW)	Personal Network
Researcher - Inclusion and Disability (SA)	Personal Network
Welcoming Australia	Facebook

7.5.6 DEVELOPMENT OF DEMOGRAPHIC SURVEY AND QUESTIONNAIRES

Hard and online versions of the survey consisted of the following sections:

1. A total of 21 questions focused on aspects of socio-cultural demographics, online behaviours, and Internet use.
   Questions were adapted from sociodemographic categories within the Digital Inclusion Index[529] and Index of Relative Socio-economic Advantage and Disadvantage (IRSAD).[530]
2. electronic Health Literacy Scale (eHEALS)[493]
3. Digital Health Literacy Instrument (*DHLI*)[516]
4. Short Computer Anxiety Scale (SCAS)[531]
5. Registering interest for Stage 2
6. Registering for the draw for the gift card lottery

The online survey included all the information provided within the hard copy provided to patrons (except information on how to complete and return the survey via post). Hard copy surveys were identical to online versions, with the same questions, order, and structure. A copy of the online survey is included in Appendix 7.5.

7.5.6.1 Sociodemographic characteristics

This survey section explored participant characteristics by utilising short open text, numbered and multiple-choice questions across General (G) and Internet (I) domains. Table 7.5 summarises the demographic questions asked in section A of the survey; branching is evident in questions GQ7, IQ10, IQ13 and IQ14 and indicated as [B] in the table below.

Table 7.5. Questionnaire variables and demographic characteristics prompt for both online and paper surveys

General (G) demographics	Question structure	Descriptor
GQ1. Postcode	Open text	Number
GQ2. Gender	Multiple choice	a) Male b) Female c) Other d) I prefer not to say
GQ3. Age	Open text	Number
GQ4. Aboriginal or Torres Strait Islander status	Multiple choice	a) Aboriginal b) Torres Strait Islander c) Both Aboriginal and Torres Strait Islander d) Neither
GQ5. Language at home	Multiple choice	a) English b) Language if other than English c) Other (Open text)
GQ6. Highest level of education completed	Multiple choice	a) Tertiary degree or Diploma b) Secondary School (Year 12 or equivalent) c) Did not complete high school
GQ7. Current employment status	Multiple choice	a) Full time or part-time employment b) Seeking employment c) Not employed or seeking a job [B7A]
GQ7A. If not employed or seeking a job	Multiple choice	a) Student b) Retired / Semi-retired (volunteer) c) Home duties (caring for children) d) Carer for someone ill, frail or living with a disability
GQ8. Commonwealth assistance status	Multiple choice	a) Centrelink Disability Support Pension (DSP) b) Disability Pension (VDP) from Veterans' Affairs c) Neither
GQ9. Household Income ($year approximate)	Multiple choice	a) Under $35,000 b) 35,000 to $59,999 c) $60,000 to 99,999

		d) $100,000 to $149,000 e) $150,000 or more f) Prefer not to say
Internet (I) behaviour		
I10. Internet use in the last six months	Multiple choice	a) Yes b) No, but I have used the Internet before [B10A] c) Do not use myself; I ask someone else to do it for me [B10A] d) Never used Internet [B10A]
IQ10A. Reason for not using or stopped using the Internet	Multiple choice (More than one)	a) Found it not helpful b) I do not need to Internet c) No longer have a computer at home or unable to access computer d) I no longer can afford Internet at home or on my phone e) Unable to use a computer due to a health condition f) Other, explain
IQ11. How often would you use the Internet	Multiple choice	a) Least once a day b) Once every few days c) Once a week d) Not very often – maybe once a month e) Only when the need arises
IQ12. Most common location to access the Internet	Multiple choice	a) Work – computer or mobile b) Home – computer c) Home – mobile d) Friends or relative house – computer e) Public – computer f) Public – mobile g) Other, explain
IQ13. How often need help with online tasks	Multiple choice	a) Yes, all of the time [B13A] b) Sometimes, depending on the specific task [B13A] c) No, I can usually complete these by myself
IQ13A. If help is needed, who do you ask	Multiple choice	a) Partner or spouse b) Son or daughter c) Sibling (sister or brother) d) Neighbour or family friend e) Friend or acquaintance outside of the family f) A professional relating to the activity or task (such as a health professional, customer service officer, bank officer or librarian) g) Other, specify
IQ14. The physical or functional condition that makes Internet access or device use difficult	Multiple choice	a) Yes [BQ14A] b) No
IQ14A. Conditions that make your online experience most difficult	Multiple choice	a) Sitting for long periods b) Eyes that tire easily c) Unsteady hands or fingers that have pain d) Lack of concentration e) Absence of or pain in the limbs f) Other, specify

IQ15. Use additional devices, technology or features that assist in use or access	Multiple choice	a) Assistive or adaptive technology b) Change information display using monitor or screen functions c) I don't but would like to learn to d) No need for modifications
IQ16. "I find it difficult to know whether the health information I find online is trustworthy."	Multiple choice on ordinal scale Strongly agree - Strongly disagree	1. Strongly disagree 2. Disagree 3. Neither disagree nor agree 4. Agree 5. Strongly agree
IQ17. "I am confident at using computers, smartphones, tablets or other devices to access the Internet"	Multiple choice on ordinal scale Extremely confident – Avoiding computers	1. Extremely confident (expert) 2. Somewhat confident (usually do what I need to) 3. Only a little confident (most things but need regular help) 4. Not at all confident (always help required instead someone else does task) 5. Avoid using computers (dislike technology and/or the Internet)

7.5.6.2 Electronic health literacy scale (eHEALS)

Respondents completed a self-reported appraisal of perceived finding, evaluating, and applying electronic health information skills using online health information. Each of the 8-items was scored on a 5-point Likert scale (i.e., Q1 'I know ***what*** health resources are available on the Internet, 1=Strongly disagree, 5=Strongly agree). Total eHEALS scores were calculated by adding all equally weighted question scores; total scores range between 8 and 40. Higher scores are indicative of higher levels of eHealth literacy.[493,532] Two supplementary questions ask about levels of usefulness and importance of the Internet to inform health decisions. Although these do not contribute to overall scores, they are reliable predictors of electronic health literacy levels (Cronbach's α=.88 with factor loadings ranging from .60 to .84).[493,513,515] Both questions are measured on 5-point Likert scales. Suppl.Q1 asks '*How **useful** do you feel the Internet is in helping you in making decisions about your health*' (1= Not useful at all, 5= Very useful) and Suppl.Q2 asks '*How **important** is it for you to be able to access health resources on the Internet?*' (1= Not important at all, 5= Very important). Research indicates eHEALS is a valid scale and can be applied across nationalities[177,533] and demographic groups such as age,[232,497,506,508,534] English and non-English speaking populations,[535-537] ethnicity,[514,538] socioeconomic[497,538] and levels of illness.[514,515,539,540] Appendix 7.6 presents scale variables for the eHEALS questionnaire.

7.5.6.3 Digital Health Literacy Instrument (DHLI)

Respondents completed 21 questions within the DHLI questionnaire. Q1-18 measured perceived difficulty completing tasks or difficulties experienced during online interactions across all subscales. Q19-21 was related to using social media as a peer-peer communication platform representing the '*Protecting and respecting privacy while using the Internet*' subscales. These three questions were completed by respondents who regularly social media. The total *DHLI* was calculated as an average across all 21 questions. Respondents who were not social media users had their total *DHLI* calculated from the scores averaged across Q1-Q18. Each subscale has 3-items contributing to their average scores, and all questions are assessed on a 4-point Likert Scale. For subscales 1, 3-6; anchors ranged from 4=Very easy, 3=Rather easy, 2=Rather difficult and 1=Very difficult (i.e., *How easy, or difficult is it for you to:* Use the keyboard of a computer (e.g., to type words)? 4=Very easy, 3=Rather easy, 2=Rather difficult, and 1=Very difficult). For the remaining subscales 2 and 7, the anchors were 4=Never, 3=Sometimes, 2=Often and 1=Mostly. van der Vaart and Drossaert[516] reported the DHLI scale as both valid and reliable (Cronbach α=.87), with a moderately high correlation with standard or functional measures of health literacy [eHEALS and NVS], whilst measuring differential DHL skills. Only the '*Privacy*' subscale (Cronbach α=0.57) was shown not to be reliable. Appendix 7.7 presents the DHLI, including subscales and descriptors.

7.5.6.4 A Short Computer Anxiety Scale

Lester, Yang and James[527] developed the Short Computer Anxiety Scale (SCAS) in response to the need for a concise tool to measure computer anxiety in studies. The SCAS has 6-items, two questions measuring comfort (or ease) subscale, and the remaining 4-items measure inadequacy of use. Questions use a 6-point Likert Scale; for items measuring inadequacy (questions 2-5), anchors range from 1 to 6 (i.e., *The harder I work at learning computers, the more confused I ge*t; 1=Strongly disagree, 2=Disagree, 3=Somewhat disagree, 4=Somewhat agree, 5= Agree and 6=Strongly agree). For items describing ease, the scale is reversed with anchors at 1=Strongly agree to 6=Strongly disagree. The SCAS was both reliable and a valid measure of computer anxiety (Cronbach α=.78) and is significantly correlated to the Bear, Richards, and Lancaster's Bath County Computer Attitude Scale.[541] The total SCAS for individuals is the sum of all six question values with total scores ranging between 6-36. A higher score reflects a higher level of computer anxiety. Appendix 7.8 presents the complete SCAS questionnaire and data descriptors.

7.5.6.5 Survey questionnaire data variables and statistical analysis

Table 7.6 summarises survey data variables and statistical analyses applied to survey descriptors of sociodemographic characteristics, Internet behaviours and questionnaires (eHEALS, *DHLI* and SCAS) as described previously.

Table 7.6. Summary of variables and statistical analyses applied to survey data

Description/Variables	Statistical analysis
GQ1. Postcode	• SEIFA[542] to extract IRSAD percentiles and reported as quintiles.
Survey nominal categorical, interval* or ordinal data: GQ2. Gender GQ4. Aboriginal or Torres Strait Islander status GQ5. Language spoken at home GQ6. Highest level of education completed^ GQ7. Current employment status GQ7A. If not employed or seeking a job GQ8. Commonwealth assistance status GQ9. Household Income^ ($year approximate) I10. Internet in the last six months IQ10A. Reason for not using or stopped using the Internet IQ11. How often would you use the Internet? IQ12. The most common location to access the Internet IQ13. How often need help with online tasks IQ13A. If help is needed, who do you ask IQ14. A physical or functional condition that makes Internet access or device use difficult IQ14A. Condition do you experience that makes the experience most difficult IQ15. Use additional devices. Technology or features that assist in use or access IQ16. "I find it difficult to know whether the health information I find online is trustworthy." IQ17. Confident at using computers, smartphones, tablets, or other devices to access the Internet	• Reported as frequencies and percentages (%) of totals. • For nominal data: Two-tailed Pearson's chi-squared analysis using Phi and Cramer's V nominal association (for 2x2 cross tabs) *p*<0.05 (95%CI). • For ordinal data: Two-tailed nonparametric analysis using Mann-Whitney U test comparing either ranked means or medians depending on distribution similarity. Asymptotic significance is determined when *p*<0.05.
Survey continuous data and questionnaire outcomes: • GQ3. Age • IRSAD percentile • IRSAD quintile range • eHEALS total score • *DHLI* total score • *DHLI* subscales • SCAS total score	• Reported as means (*M*), standard deviation (*SD*), minimum-maximum score, median score. • *T*-test for Independent means employed, and Levene's Test for Equality of Variances was applied to determine equality of sample variance (Welch-Satterthwaite method) to determine the level of significance (*p*<0.05, 95% CI).
Relationships between user characteristics (sociodemographic, technological experience and behaviour) and DHL levels • Paper survey group (*n*=12) • Online survey group (*n*=81) • Overall survey response group (*n*=93)	• Hierarchical multiple regression[543] undertaken to determine characteristics that predict *DHLI* levels for two cohorts with larger sample numbers: - Online survey group (*n*=81) - Overall survey response group (*n*=93) • Bivariate analysis was employed to explore characteristics and DHLI in the paper survey group

	due to the small respondent number. Significance was determined when $p<0.05$, 95% CI.

*Effect sizes [544] (Cohens d and r^2) are reported for all inferential statistics reported within this study

The eHEALS and SCAS individual scores are calculated as an overall total, whereas *DHLI* has subscales and an overall total assessing an individual's overall DHL levels. Each survey variable was extracted as a single data point for each of the respondents. As survey questions were based on categorised data assessing ADII,[10] an Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD) value was extracted from the Socio-Economic Indexes for Areas.[542] Respondent's postcode was matched for IRSAD percentile and transformed into quintiles, providing an indicative value of relative geographical, socioeconomic status. The higher the IRSAD percentile represents regions that experience the greatest level of advantage.

All statistical analyses were conducted using SPSS software.[431] For continuous questionnaire data (including demographic data, eHEALS, SCAS *DHLI* total scores and *DHLI* subscales), group means (*M*) and standard deviation (*SD*) were calculated. The between-group analysis subjected means to a two-tailed independent *T*-test.[66] Levene's Test for Equality of Variances determined equality of sample variance for each pair, and the Welch-Satterthwaite method was employed to determine the level of statistical significance between groups 95% confidence interval (*95%CI*) with significance when $p<0.05$. Descriptive statistics also were applied to interval and categorical nominal questionnaire data (including questions probing single construct), expressed as a frequency and percentage for each question. Two-tailed Pearson's chi-squared analysis using Phi and Cramer's V nominal association was then employed to determine statistical significance when $p<0.05$; however, when cross-tabulation produced >20% cells with an expected count less than 5, the two-tailed Fisher's Exact test was then applied for outcomes with 2x2 analyses. Effect sizes[544] were calculated for all inferential statistics reported within this study.

Nonparametric statistics were applied to compare differences between two independent groups with ordinal dependent variables without normal distribution.[430] Normality was established using Shapiro-Wilk significance, and group data were visualised using histograms and box plots to examine distribution patterns. Two-tailed Mann Whitney *U* test compared either ranked means or medians (depending on the similarity of distribution patterns) between groups with significance indicated at $p<0.05$.[543] Hierarchical multiple regression (H-MR)[543] was used to identify predictors of digital health literacy from sociodemographic and descriptors of technological skill or digital confidence or experience within the data collected within both overall (*n*=93) and online survey cohorts (*n*=82). Models predicting dependant DHLI total scores from the independent characteristics were calculated using the 'Enter method' within SPSS.[431] Sociodemographic characteristics were added to the regression model in the first step, and Internet behaviour and technical ability descriptors were added in the second. Collinearity diagnostics were performed on all factors to ensure variance inflation factors and tolerances did not indicate multicollinearity between variables within the regression model.[543] This method was repeated for survey cohorts: overall survey respondent group (online and paper survey participant) and online survey respondent group. Due to the hard copy survey of this cohort's small sample numbers, bivariate Pearson correlations were employed to explore relationships between variables collected. Pearson's correlation (*r*) effect[544] and significance were calculated for each pair of variables ($p<0.05$, *95% CI*).

7.6 RESULTS

7.6.1 ONLINE SURVEY

Over the six-week data collection period, 161 people were active within the survey platform, and the survey generated 52 survey impressions in which only the letter of introduction was read before leaving the survey platform. *N*=109 respondents began the survey after providing informed consent, and the survey had *n*=101 completions at a completion rate of 92.66%. There were eight incomplete surveys: three had only the consent completed, two had consent and Q1 (postcode) completed, and three were completed as blank click-throughs. Personal content authentication relating to the distribution of surveys by organisations was the most likely source. As this survey was anonymous and no identifying information was collected, engagement levels with specific channels as sources of successful recruitment were speculative (distribution summarised in Table 7.4).

Flinders University College of Nursing and Health Sciences corporate Facebook account placed a paid Facebook ad creating 125,106 impressions and 488 interest clicks. The ad targeted groups within the Facebook community who may have difficulty engaging with online health information resulting in the majority of interest from 55 years and older demographic skewed more toward women (63%) than men (36%). Personal requests for study information, online survey links and copies of paper surveys were invited, copies of surveys and information provided to interested advocates. There was no use of personal social media networks to distribute surveys by the researcher to avoid coercion, and the researcher received no negative messages or emails regarding survey content.

7.6.2 HARD (PAPER) SURVEYS

During the six-week data collection period, 35 paper survey packs were distributed, eleven were returned (overall return rate 31.43%). Eight were posted returns (return rate 72.73%) from F2F interactions with patrons at community sessions, and three returned by hand from advocates who had asked friends or families to complete surveys (return rate 27.27%). Advocates preselected these potential respondents as they experienced difficulties with technology or rarely used the Internet. One respondent completed a paper survey and then went on to complete a card sorting activity online. Data from this individual was hand-entered into the Qualtrics survey platform[432] then subsequently extracted as a 'complete' dataset with other online survey responses. Figure 7.2 summarises the number of participants involved in the survey and online card sort activity within this study.

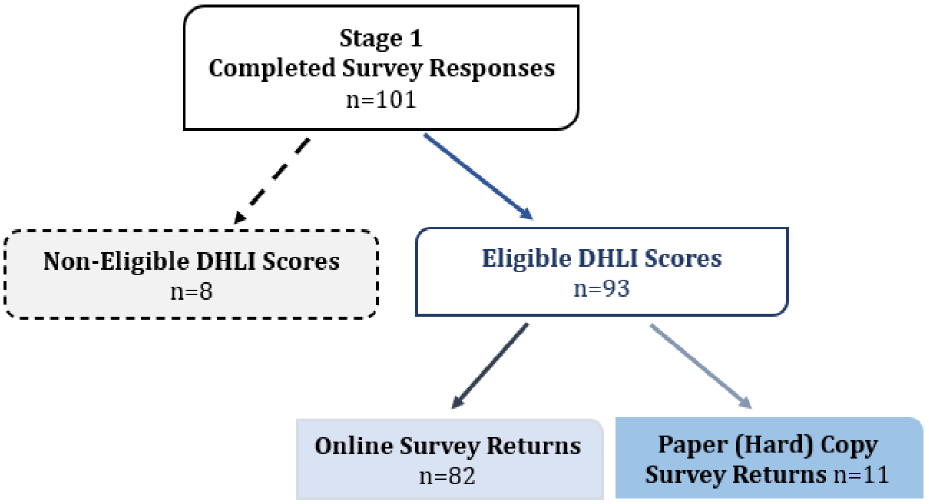


Figure 7.2 Number of participants completing each phase of recruitment, data collection and analysis groups for each stage of this study

7.6.2.1 Relationship between eHEALS, DHLI and SCAS questionnaire data

Before further analysis of participant survey data, data collected from the eHEALS, SCAS and DHLI questionnaires were analysed to explore the range and skew from the respondents sampled.

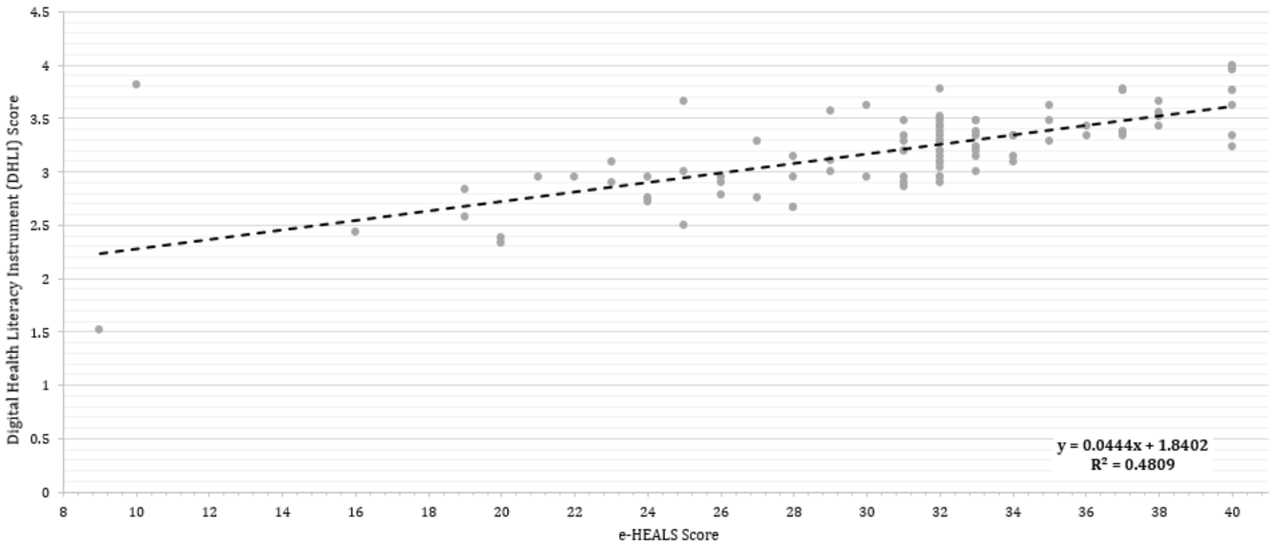
eHEALS mean score (*M*)=30.83, *SD*=6.29 had a slightly skewed distribution (-1.046) and kurtosis=1.666. No respondents scored the floor value of 8, although *n*=8 (8.6% of total) did achieve the ceiling score of 40. SCAS questionnaire data was also normally distributed within this group, M_{SCAS}=17.667, *SD*=2.83, with negligible skew=0.418 and kurtosis=-0.334. No floor or ceiling effects were observed within the survey population (6 or 36 respectively).

DHLI frequency data for DHLI total scores and sub-scales displayed a slightly skewed distribution (-0.826) across respondents with kurtosis=2.349. $M_{DHLI\,\mathrm{total}}$=3.208, *SD*=0.40 with no floor effects however *n*=1 scored the ceiling value=4.000. Ceiling effects were also observed across all *DHLI* sub-scales: 1-*Operational Skills* (*n*=58, 62.4% total), 2-*Information searching* (*n*=6, 6.5%), 3-*Evaluating reliability* (*n*=10, 10.8%), 4-*Determining relevance* (*n*=8, 8.6%), 5-*Navigation skills* (*n*=14, 15.1%), 6-*Adding content* (*n*=29, 31.2%) and 7-*Protecting privacy* (*n*=21, 22.6%). Scores from both eHEALS and DHLI questionnaires indicated a survey population who were highly technologically skilled and digitally literate and did not experience high levels of anxiety or concern when using technology or interacting with the online environment (demonstrated by relatively low mean SCAS scores).

Frequency graphs and distribution descriptors are presented in Appendix 7.9.

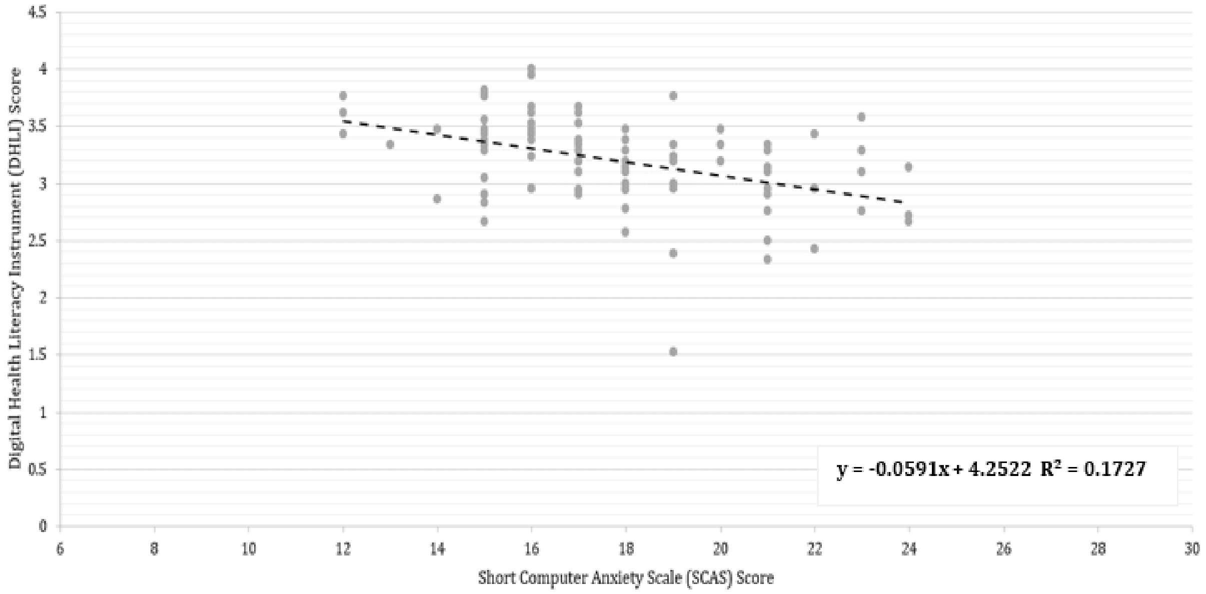
7.6.2.2 Correlation between DHLI and e-HEALS Score

Linear relationships (direction and strength) between questionnaire data were explored using a 2-tailed Pearson correlation using data collected from the survey population. eHEALS and *DHLI* total scores (Graph 7.1) were found to have a significantly positive linear relationship (*r=0.693, p<.001*; *large effect size*.[544]



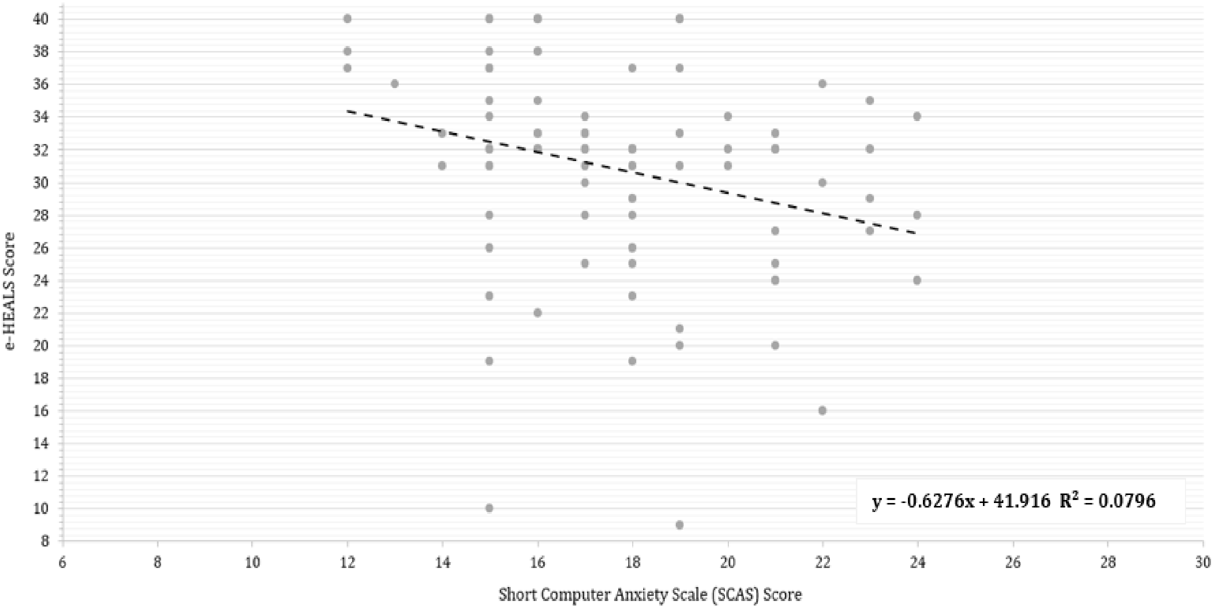
Graph 7.1 Relationship between DHLI total scores and SCAS questionnaire scores

Appendix 7.10 presents a graphical representation of the relationship between eHEALS and all *DHLI* subscales, and each subscale was strongly positively correlated to eHEALS questionnaire data. A similar analysis was applied to *DHLI* total scores and SCAS (Graph 7.2). Pearson's correlation found a significant negative linear relationship between mean SCAS and *DHLI* scores (*r=-0.416, p<.001*; *intermediate effect size*[544]).



Graph 7.2 Relationship between DHLI total scores and SCAS questionnaire score

The final correlation was between eHEALS and SCAS scores (presented in Graph 7.3). Pearson's correlation found a significant negative linear relationship between eHEALS and SCAS scores (*r=-0.282, p=.006*; *small effect size* [544]).



Graph 7.3 Relationship between eHEALS and SCAS questionnaire scores

7.6.3 CHARACTERISTICS OF ALL SURVEY RESPONDENTS (N=101)

Participant characteristics were initially categorised into two respondent groups, first including all respondents (*n*=101), and secondly including participants with valid total *DHLI* scores (completed Q1-Q18 in *DHLI* questionnaire) who returned their surveys either online (*n*=82) or on paper (*n*=11). Tables 7.7A-C present the demographics for the survey group of respondents. Overall, *n*=73 respondents were female (72.28%) and *n*=28 male (27.72%), having a mean age of 54.41 years (*SD*=17.63, range 18-91 years and median=57 years), most of whom converse in English at home (*n*=96, 95.05%). A total of 57% of respondents were employed in full or part-time work; of those not seeking employment, most were retired (84.62%) or students (7.69%). Participants were highly educated, achieving tertiary qualifications (*n*=83, 82.18%), *n*=11 (10.89%) attaining secondary school completion certificates, and *n*=7 (6.93%) not completing high school.

Table 7.7A Demographics of complete survey *n*=101 and online *DHLI* cohort (*n*=82) versus paper (*n*=11) survey return

	All respondents	**Eligible *DHLI***		***p* value**
	n=101	Online (*n*=82)	Paper based survey (*n*=11)	Online c.f. Paper survey
Age (yr) Mean± *SD* [Min-Max, Median]	54.73±17.63 [18-81, 57]	52.70±16.93 [19-91, 54.50]	66.09±16.9 [27-85, 67.50]	*.015* ^{I}
Gender (%Total)				.456 ^{C}
Male	28 (27.72)	19 (23.17)	4 (36.36)	
Female	73 (72.28)	63 (76.83)	7 (63.64)	
IRSAD percentile Mean ± *SD* [Min-Max, Median]	58.41±28.22 [2-99, 59]	59.67±28.25 [2-98, 60]	47.0±29.78 [6-93, 50]	.168 ^{I}
IRSAD quintile (%Total)				.131 ^{M}
Q1 (1-20)	15 (14.85)	12 (14.63)	3 (27.27)	
Q2 (21-40)	11 (10.89)	9 (10.98)	0	
Q3 (41-60)	21 (20.79)	15 (18.29)	5 (45.45)	
Q4 (61-80)	30 (29.70)	24 (29.27)	2 (18.18)	
Q5 (81-100)	24 (23.76)	22 (26.83)	1 (9.09)	
Language (%Total)				.401 ^{C}
English at home	96 (95.05)	79 (96.34)	10 (90.91)	
English as second language	5 (4.95)	3 (3.66)	1 (9.09)	
Employment status (%Total)				*.027* ^{M}
Employed Full / part time	57 (57.0)	52 (64.20)	3 (27.27)	
Seeking employment	4 (4.0)	2 (2.47)	1 (9.09)	
Not seeking employment	39 (39.0)	27 (33.33)	7 (63.64)	
If not employed or seeking employment (%Total)				
Student	3 (7.69)	2 (7.41)	0	
Retired/Semi-Retired	33 (84.62)	22 (81.48)	7 (100.0)	
Home duties	0	0	0	
Carer	2 (5.13)	2 (7.41)	0	
Other	1 (2.56)	1 (3.70)	0	

Education level (%Total)				*<0.001*[M]
Tertiary	83 (82.18)	72 (87.80)	5 (45.45)	
Secondary	11 (10.89)	7 (8.54)	3 (27.27)	
Did not complete secondary	7 (6.93)	3 (3.66)	3 (27.27)	
Commonwealth support status (%Total)				.318 [C]
Centrelink Disability Support	3 (2.97)	2 (2.44)	1 (9.09)	
Disability Pension	0	0	0	
Neither	98 (97.03)	80 (97.56)	10 (90.91)	
Income $ household/year (%Total)				*<0.001*[M]
<$35,000	18 (17.82)	12 (14.63)	5 (45.45)	
$36,000-$59,000	23 (22.77)	16 (19.51)	5 (45.45)	
$60,000-$99,000	27 (26.73)	25 (30.49)	1 (9.09)	
$100,000-$149,000	12 (11.88)	12 (14.63)	0	
>$150,000	15 (14.85)	14 (17.07)	0	
I prefer not to say	6 (5.94)	3 (3.66)	0	

[I]=Two-tailed Independent T-test using Levene's test for equality of variance to compare means where statistical significance is determined when *p*<0.05.

[C]=2x2 Crosstabs using two-tailed Pearson's Chi-squared analysis using Phi and Cramer's V nominal association, for those producing > 20% of cells with an expected count of less than 5, results from the two-tailed Fisher's Exact Test [a] are reported, statistical significance is determined where *p*<0.05.

[M]=Two-tailed nonparametric analysis using Mann-Whitney U test for ordinal variables comparing either ranked means or medians depending on distribution similarity. Asymptotic significance is determined when *p*<0.05.

** = Group mean DHLI scores were not calculated for this group due to incomplete questionnaire data provided by *n*=8 participants

Table 7.7B Online behaviours of complete survey *n*=101 and online *DHLI* cohort (*n*=82) versus paper (*n*=11) survey return

	All respondents	**Eligible *DHLI***		***p* value**
	n=101	Online (*n*=82)	Paper based survey (*n*=11)	Online c.f. Paper survey
Have used the Internet in last 6 months (Yes) (%Total)	101 (100)	82 (100)	11 (100)	
Frequency of Internet use in the last 6 months (%Total)				*<0.001*[M]
Once a day	93 (92.08)	79 (96.34)	7 (63.64)	
Few days	7 (6.93)	2 (2.44)	4 (36.36)	
Once a week	0	0	0	
Once a month	0	0	0	
As the need arises	1 (0.99)	1 (1.22)	0	
Help with online tasks (%Total)				*.005* [M]
Help all the time	0	0	0	
Sometimes depending on the task	24 (23.76)	16 (19.51)	6 (60.0)	
No help is required	75 (74.26)	66 (80.49)	4 (40.0)	
If help is required, who do you ask (%Total)				
Partner	3 (12.50)	1 (6.25)	1 (16.67)	
Son / daughter	3 (12.50)	1 (6.25)	2 (33.33)	
Sibling	1 (4.17)	1 (6.25)	0	
Neighbour or friend	2 (8.33)	1 (6.25)	0	
Friend/acquaintance outside the family	6 (25.0)	3 (18.75)	3 (50.0)	
Specific professional	6 (25.0)	6 (37.50)	0	
Other	3 (12.50)	3 (18.75)	0	
If other, then who helps (%Total)	IT / Service provider, Online friends			
Live with a condition impacts technology and Internet use (%Total)				1.000 [C]

Yes	3 (3.03)	3 (3.66)	0	
No	96 (96.97)	79 (93.34)	10 (100.0)	
What is the condition (%Total)				
Sitting long periods	0	0	0	
Eyes that tire easily	0	0	0	
Pain or unsteadiness in hands	0	0	0	
Concentration	0	0	0	
Pain or absence of limbs	1 (33.33)	1 (33.33)	0	
Other	2 (67.67)	2 (66.67)	0	
If other	(PTSD, BPD), Vision impaired (blind)			
Use of devices, technology or features to help with access or usability of information (%Total)				.479 ^{M}
Adaptive or assistive technology	1 (1.0)	1 (1.22)	0	
Change information on the screen	17 (17.0)	16 (19.51)	1 (9.09)	
I do not but would like to	7 (7.0)	5 (6.10)	1 (9.09)	
I do not need to	75 (75.0)	60 (73.17)	9 (81.82)	
"I find it difficult to know whether the health information I find online is trustworthy." (%Total)				*.003* ^{M}
Strongly disagree	17 (17.0)	16 (19.51)	0	
Disagree	30 (30.0)	27 (32.93)	2 (18.18)	
Neither disagree nor agree	23 (23.0)	20 (24.39)	1 (9.09)	
Agree	27 (27.0)	17 (20.73)	7 (63.64)	
Strongly agree	3 (3.0)	2 (2.44)	1 (9.09)	
Level of confidence using technology to access the Internet (%Total)				*.004* ^{M}
Extremely confident	28 (28.0)	24 (29.27)	0	
Somewhat confident	65 (65.0)	55 (67.07)	8 (72.73)	
Only a little confident	6 (6.0)	2 (2.44)	3 (27.27)	
Not at all confident	1 (1.0)	1 (1.22)	0	

Avoid technology-Internet	0	0	0	

[I]=Two-tailed Independent T-test using Levene's test for equality of variance to compare means where statistical significance is determined when *p*<0.05.
[C]=2x2 Crosstabs using two-tailed Pearson's Chi-squared analysis using Phi and Cramer's V nominal association, for those producing > 20% of cells with an expected count of less than 5, results from the two-tailed Fisher's Exact Test [a] are reported, statistical significance is determined where *p*<0.05.
[M]=Two-tailed nonparametric analysis using Mann-Whitney U test for ordinal variables comparing either ranked means or medians depending on distribution similarity. Asymptotic significance is determined when *p*<0.05.
** = Group mean DHLI scores were not calculated for this group due to incomplete questionnaire data provided by *n*=8 participants

Table 7.7C Health literacy and computer anxiety and of complete survey *n*=101 and online *DHLI* cohort (*n*=82) versus paper (*n*=11) survey return

	All respondents	**Eligible *DHLI***		***p* value**
	n=101	Online (*n*=82)	Paper based survey (*n*=11)	Online c.f. Paper survey
e-HEALS Score Mean ± *SD* [Min-Max, Median]	30.38±6.54 [9-40, 24.5]	31.58±5.92 [10-40, 25]	25.09±6.30 [9-31, 20]	*.001* [I]
e-Heals SQ1. How useful do you feel the Internet is in helping you in making decisions about your health? (%Total)				*<0.001*[M]
Not useful at all	6 (6.06)	3 (3.66)	2 (18.18)	
Not useful	5 (5.05)	2 (2.44)	2 (18.18)	
Unsure if it useful	22 (22.22)	16 (19.51)	5 (45.45)	
Useful	53 (53.54)	48 (58.54)	2 (18.18)	
Very useful	13 (13.13)	13 (15.85)	0	
e-HEALS SQ2. How important is it for you to be able to access health resources on the Internet? (%Total)				*<0.001*[M]
Not at all important	5 (5.05)	1 (1.22)	3 (27.27)	
Not important	14 (14.14)	5 (6.10)	6 (54.55)	
Unsure if important	10 (10.10)	10 (12.20)	0	
Important	43 (43.43)	39 (47.56)	2 (18.18)	
Very Important	27 (27.27)	27 (32.93)	0	
SCAS Mean ± *SD* [Min-Max, Median]	17.67±2.81 [12-24, 17]	17.50±2.70 [12-24,18]	18.91±3.56 [15-24,19]	.122 [I]
***DHLI* total score Mean ± *SD* [Min-Max, Median]**	**	3.277±0.35 [2.333-4.0, 3.167]	2.693±0.44 [1.524-3.333, 2.429]	*.000* [I]

DHLI Operational skills Mean ± *SD* [Subscale 1a, 1b, 1c]	3.736±0.434	3.303±0.795	.105[I]
DHLI Information searching Mean ± *SD* [Subscale 2a, 2b, 2c]	3.004±0.515	2.454±0.582	*.001*[I]
DHLI Evaluating reliability Mean ± *SD* [Subscale 2d, 2e, 2f]	3.033±0.645	2.333±0.683	*.001*[I]
DHLI Determining relevance Mean ± *SD* [Subscale 2g, 2h, 2i]	3.004±0.573	2.485±0.621	*.006*[I]
DHLI Navigation skills Mean ± *SD* [Subscale 3a, 3b, 3c]	3.300±0.469	2.455±0.637	*.000*[I]
DHLI Adding content Mean ± *SD* [Subscale 4a, 4b, 4c]	3.293±0.610	2.970±0.809	.116[I]
DHLI Protecting privacy Mean ± *SD* [Subscale 5a, 5b, 5c]	3.580±0.384	2.833±0.587	*.000*[I]

[I]=Two-tailed Independent t-Test using Levene's test for equality of variance to compare means where statistical significance is determined when $p<0.05$.
[C]=2x2 Crosstabs using two-tailed Pearson's Chi-squared analysis using Phi and Cramer's V nominal association, for those producing > 20% of cells with an expected count of less than 5, results from the two-tailed Fisher's Exact Test [a] are reported, statistical significance is determined where $p<0.05$.
[M]=Two-tailed nonparametric analysis using Mann-Whitney U test for ordinal variables comparing either ranked means or medians depending on distribution similarity. Asymptotic significance is determined when p<0.05.
** = Group mean DHLI scores were not calculated for this group due to incomplete questionnaire data provided by *n*=8 participants

Respondents' yearly household income was wide-ranging and represented all IRSAD advantage/disadvantage levels within the survey results. Overall, 49.5% of respondents' household income was between $36,000-$99,000, and 74.25% of this population were in the Q3-Q5 quintiles (41-100) for relative levels of residential advantage/disadvantage representing moderate to high levels of advantage. Three respondents (2.97% of the total) indicated receiving a Commonwealth Disability support package and lived with the condition that impacted the use of technological devices (pain in or absence of limbs, vision impairment or mental health issues). All respondents were frequent Internet users, with *n*=100 respondents (99%) using the Internet more frequently than once every few days. Survey participants are more likely to be self-sufficient at completing online tasks (although *n*=24 (23.76%) indicated requiring some level of assistance from family and friends) and being either '*somewhat confident* or *extremely confident'* when self-rating their use of technology to access the Internet (92.08%). Views of usefulness and importance the Internet plays in making decisions about health ('*Usefu*l-*Very useful*' (*n*=66, 65.34%) and 'Important to '*Very important*' (*n*=70, 69.31%) respectively) reflected an overall positive attitude to using technology. Respondents had eHEALS scores ranging between floor value (9) and the ceiling value 40 (*M*=30.83, *SD*=6.30) and SCAS ranging from 12-26 (*M*=17.67, *SD*=2.81).

A greater frequency of surveys was received from Charles Sturt public libraries (*n*=16) than from libraries within the Port Adelaide Enfield (PAE) council areas (*n*=3) across both modes of survey completion. Respondents from Charles Sturt were on average older (*M*=62 years, *SD*=21.93, range 18 - 85 years and Median age =71.50 years) than Port Adelaide Enfield patrons (*M*=48 years, *SD*=20.52, range 27-68 years and median age = 49 years) experiencing lower levels of electronic ($M_{CharlesSturt}$*=26.20, SD=7.78* versus M_{PAE}*=35.33, SD=4.51*)and digital health literacy levels ($M_{CharlesSturt}$*=2.968, SD=.606* versus M_{PAE}*=3.286, SD=3.333, p=.408;* d_{Cohens}*=0.257 small -effect size*[544]).

7.6.4 ONLINE (N=82) VERSUS PAPER SURVEY (N=11) RETURN COHORTS WITH ELIGIBLE DHLI SCORES (N=93)

Of the 101 respondents who completed the survey, eight participants did not provide completed

DHLI questionnaires to produce an eligible *DHLI* score.[HH] These respondents' data were excluded from further analysis, resulting in data for *n*=93 respondents having an eligible *DHLI* total score (*n*=93). This data was analysed, and comparisons were drawn between respondents who completed their surveys online (*n*=82) or on paper (*n*=11). Participants completing the survey on paper, aged between 27 and 85 years, were, on average, significantly older compared to the online survey group [M_{Paper}=66.09 years, *SD*=16.9 vs M_{Online}=52.70 years, *SD*=19.93, *t(91)=-2.473, p=.015;* d_{Cohens} *=0.005, of no effect*[544]].

Significant differences in levels of household income were observed in all respondents who completed paper surveys reported incomes less than $99,000 compared with *n*=53 (64.63%) of online survey respondents [*U*(N_{Online}=82, N_{Paper}=11)*=170.50, z=-3.415, p<.001;* d_{Cohens}*=1.339 large effect size*[544]]. A greater proportion of paper survey respondents used the Internet less often than online survey group [*U*(N_{Online}=82, N_{Paper}=11)*=305.50, z=-3.786, p<.001;* d_{Cohens}= 1.335 *large effect size* [544]] and were significantly more likely to require assistance to complete online tasks [*U*(N_{Online} =82, N_{Paper} =11)*=244, z=2.818, p=.005;* d_{Cohens}=1.339 *large effect size*[544]]. There were no significant differences between groups in the uptake of assistive technology or adaptive behaviour to improve interaction with onscreen information or living with the condition that would affect this access. A majority (*n*=8, 76.67%) of the paper survey group either '*Agreed*' or '*Strongly agreed*' that they found it difficult to gauge the trustworthiness of online health information compared with 36.58% of online survey respondents [*U*(N_{Online}=82, N_{Paper} =11)*=208.50, z=-2.982, p=.003;* d_{Cohens}=1.339 *large effect size*[544]]. Online survey respondents were also more likely to self-rate their confidence using technology as being '*extremely or somewhat confident*' (96.34%) compared with 72.73% of paper survey group participants [*U*(N_{Online}=82, N_{Paper} =11)*=250.0, z=-2.917, p=.004;* d_{Cohens}*=1.339 large effect size*[544]]. Analysis of both supplementary questions from the eHEALS survey also suggest online survey respondents were more likely to consider the Internet to be '*important-very important*' (80.49%) [*U*(N_{Online}=82, N_{Paper}=11)*=166.0, z=-3.721, p<.001;* d_{Cohens}*=1.339 large effect size*[544]] and '*useful-very useful*'

[HH] Appendix 7.11 provides socio-demographic characteristics of *n*=8 respondents who did not provide a valid DHLI questionnaire score. Characteristics of this group were not dissimilar to respondents who completed the DHLI questionnaire in full, average eHEALS was lower [M_{NoDHLI}=23.5, SD=7.12 (range 12-32, median=22) vs M_{DHLI} =30.83, SD=6.29 (9-40, 32)] and on average SCAS scores were similar [M_{NoDHLI}=17.75, SD=2.75 (15-21, 17.5) vs M_{DHLI} =17.67, SD=2.83 (12-24, 17)].

(74.69%) [*U(N_{Online}=82, N_{Paper}=11)=93.50, z=-4.516, p<.001; d_{Cohens}=1.339 large effect size*[544]] in assisting with health decision-making compared to paper survey respondents.

Participants in the online survey group were found to have a significantly higher eHEALS score compared to paper return group [M_{Online}=31.58, *SD*=5.92, range 10-40 (ceiling value) vs M_{Paper}= 25.09, *SD*=6.30, range 9-31, *t(91)=3.400, p=.001; d_{Cohens}=1.339 large effect size*[544]]. The online respondent group also had significantly higher *DHLI* total score [M_{Online}=3.277, *SD*=0.350, range 2.333-4.0 (ceiling value) vs M_{Paper}=2.693, *SD*=0.44, range 1.524-3.333, *t*(91)=5.087, *p=.000; d_{Cohens}=1.339 large effect size*[544]]. All *DHLI* mean sub-scores were also statistically significantly different between these groups (Table 7.7C) except for 1-*Operational skills* and 6-*Adding content*. Paper and online survey respondents had a similar level of technological anxiety as measured by the SCAS instrument (no statistically significant differences were found).

7.6.5 PREDICTORS OF THE RELATIONSHIP BETWEEN USER CHARACTERISTICS AND DHLI LEVELS IN SURVEY POPULATIONS

Relationships between users' characteristics and measured DHL levels were explored by conducting correlations and multiple regression analysis for three survey cohorts: paper, online and overall survey groups[II]. Due to the small sample size, H-MR was not applied to user characteristic variables within the paper survey cohort (*n*=11), given that such an analysis would violate data assumptions. Instead, bivariate Pearson correlations were undertaken on this sub-sample dataset. Table 7.8 presents the resultant correlation between participants' characteristics and total DHLI score reporting Pearson's *r* and *p* values (significance *p*<.05, *95% CI*). Two characteristics were identified as having significant linear relationships with mean DHLI total scores within this paper-based cohort: 1) levels of self-rated confidence using technology (*r=-.619, p=.042*), and 2) eHEALS score (*r=0.853, p=.001*) to DHLI score, both demonstrating large effects.[544] All remaining relationships between variables describing user characteristics were not significantly correlated to mean DHLI scores.

Hierarchical multiple regression (H-MR) was used to identify predictors[543] of digital health literacy from socio-demographic and descriptors of technological skill or digital confidence or

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[II] Not all socio-demographic and questions relating to Internet behaviour were included in these analyses as many variables did not have any responses recorded. Other descriptive survey variables collected were not suitable for inclusion in the regression model (such as *'Use of devices'*) and were removed from the analysis experience within the data collected within both overall (*n*=93) and online survey cohorts (*n*=82).

Table 7.8. Bivariate analysis using Pearson's Coefficient correlation between selected user characteristics and DHLI score in the paper survey response group (*n*=11)

Characteristic	Pearson Coefficient *r*	*p* value
Gender	-.173	.612
Age (years)	-.265	.430
Highest Level of education	.471	.144
Current employment status	.176	.606
Recipient of Commonwealth support	.145	.671
Income ($ per household/year)	.078	.819
IRSAD percentile	-.203	.550
Help with online tasks	-.301	.399
Difficulty assessing the trustworthiness of online health information	-.104	.761
Level of confidence using technology	*-.619**	*.042*
eHEALS score	*.853***	*.001*
eHEALS S1. Internet useful for health decisions	.490	.126
eHEALS S2. Important to access health resources online	.408	.213
SCAS score	-.264	.432

df=9 * significance p<0.05 (CI 95%) ** significance *p*<0.01 (CI 95%)

Models of predicting scores on the dependant variable DHLI total scores from independent characteristics were calculated using the 'Enter method' within SPSS.[431] Socio-demographic characteristics were added to the regression model in the first step, and Internet behaviour and technical ability descriptors were added in the second.

Collinearity diagnostics were performed on all factors to decrease the risk of multicollinearity between independent variables within the regression model.[543(p164)] eHEALS, and *DHLI* subscales were removed from both H-MR analyses due to singularity with *DHLI* total scores. Further analysis suggested the presence of multicollinearity between '*eHEALS Supplementary Q1* and *Q2*' and '*Recipient of Commonwealth support*' and '*Living with a condition'* as indicated by high levels of correlations, condition indexes<30 and two or more variance proportions over 0.5. As variance inflation factors (*VIF*) and tolerance values[JJ] were also indicative of the presences of collinearity,[543] as a precaution '*eHEALS Supplementary Q2*', '*Recipient of Commonwealth support*' and '*Living with a condition'* were removed from the H-MR analyses. '*eHEALS Supplementary Q1*' remained as a factor within the regression model

Table 7.9 presents the resultant H-MR analysis for the overall survey cohort (*n*=93), standardised coefficients (β) are reported for both socio-demographic factors (Model 1) and socio-demographic and technology ability/Internet behaviour (Model 2), applying total *DHLI* score as the dependant variable. Regression indicates a collective significant effect on DHLI scores within both models: Model 1 $R^2 = .177$ *p=0.02, F(7, 83)=2.555, 95% CI [2.162, 4.175] (small effect*[544]*)* and Model *2* $R^2 = .528$ *p<0.01, F(11, 79)=8.032, 95% CI [2.172, 4.142] (large effect*[544]*)*. Standardised coefficients (β) were calculated for individual predictors assessing each independent variable's strength and effect on *DHLI* score (between -1 and 1). Income was the solitary significant predictor of *DHLI* score within Model 1 considering only socio-demographic variables (*β =.332, t(2.84) p=.006, 95% CI [0.03, .141]*). On addition of use of technology/Internet variables to Model 1, income remained a significant predictor *(β =.192, t(21.992) p=.05, 95% CI [0.00, .096])* in addition to self-rated level of difficulty assessing trustworthiness of online health information (*β =-.322, t(-3.531) p=.001, 95% CI [-.157, -.044])* and level of usefulness of the Internet for assisting in health decisions *(β =.269, t(2.966) p=.004, 95% CI [.034, .173])* as significant predictors of DHLI Score in all individuals completing the survey.

Table 7.10 presents resultant H-MR analysis of predictors of DHLI total score from data collected from online survey cohort (*n*=82). Repeating the previous regression procedure, two models were entered, Model 1 socio-demographic factors only and Model 2 socio-demographic and technological ability/Internet behaviour. Model 2 was found to have collective significance *R^2=.479 p<0.01, F(11, 69)=5.775, 95% CI [1.984, 4.100] (large effect*[544]*),* and socio-demographic variables alone(Model 1) did not produce an overall significant regression model predicting total DHLI score (*R^2=.089, p=.421, small effect*[544]) in this survey cohort.

[JJ] Ranges in variance inflation factors (*VIF*) and tolerance values for variables: '*eHEALS Supplementary Q2*' ' and '*Recipient of Commonwealth support*' and '*Living with a condition* ' [*n*=93, VIF_{MIN}=1.12 (tolerance 0.893) – VIF_{MAX}=1.800 (tolerance=0.556)] and [*n*=82 , VIF_{MIN}=1.069 (tolerance 0.936) – VIF_{MAX}=3.011 (tolerance=0.332)]

Table 7.9. Hierarchical multiple regression analysis of predictors of Digital Health Literacy Instrument total scores (DHLI) for overall survey cohort (*n*=93) [KK] - Standardised *B* reported

Predictor variable	Regression Model 1	Regression Model 2
Gender *(1=Male; 2=Female)*	.032	.007
Age (years)	-.186	-.060
Highest level education attained *(1=Tertiary; 2=Secondary; 3=DNF secondary)*	.110	.004
Current employment status *(1=Full-Part Job; 2=Seeking Job; 3=Not Employed-job seeking)*	-.108	-.100
Live with a condition *(1 = Yes, I do live with a condition making it hard for me to use technology or the Internet, 2 = No, I do not have a condition)*	-.044	-.043
Income ($ per household/year) *(1=<$35,000; .. 5>$150,000)*	*.332**	*.192**
IRSAD percentile *(0=low advantage; ...; 100= high advantage)*	.033	-.033
Requires help with technology *(1=Help all the time; 2=Sometimes depending on the task; 3=Complete by oneself)*		.159
Difficulty assessing the trustworthiness of online health information *(1=Strongly disagree; ...; 5=Strongly agree)*		*-.322***
Confidence using technology or Internet [*1=Extremely confident (expert); 2= Somewhat confident; 3=Only a little confident; 4=Not at all confident; 5=Avoid using computers*]		-.182
eHEALS S1. How useful do you feel the Internet is in helping you in making decisions about your health? *(1=Not useful at all; .. ; 5=Very useful)*		*.269***
R^2	*.177**	*.528***
$\triangle R^2$	.177	.351
$\triangle F$	*14.672**	*14.66***

H-RM1: $R^2 = .177$ *p=0.02, F*(7, 83)=2.555, 95% CI [2.162, 4.175], Intercept = 3.169
H-RM2: $R^2 = .528$ *p<0.01, F*(11, 79)=8.032, 95% CI [2.172, 4.142], Intercept = 3.157
**p*<0.05 ; ***p*<0.01, △=*Change*

[KK] eHEALS was not analysed as dependant variable (DV) within this thesis, and although highly correlated to DHLI score was not the focus of this research study. Further analysis will be completed as a post-doctoral extension analysing eHEALS using H-MR as a comparison to findings observed with DHLI score within this survey population.

Table 7.10. Hierarchical multiple regression analysis of predictors of Digital Health Literacy Instrument total scores (DHLI) in the online survey cohort (*n*=82) [LL] - Standardised *B* reported

Predictor variable	Regression Model 1	Regression Model 2
Gender *(1=Male; 2=Female)*	-.014	-.016
Age (years)	-.175	-.084
Highest level education attained *(1=Tertiary; 2=Secondary; 3=DNF secondary)*	.014	-.029
Current employment status *(1=Full-Part Job; 2=Seeking Job; 3=Not employed-job seeking)*	-.084	-.064
Live with a condition *(1=Yes, I do live with a condition making it hard for me to use technology or the Internet, 2= No, I do not have a condition)*	-.013	-.046
Income ($ per household/year) *(1=<$35,000; .. 5>$150,000)*	.242	.144
IRSAD percentile *(0=low advantage; ...; 100= high advantage)*	-.012	-.068
Requires help with technology *(1=Help all the time; 2=Sometimes depending on the task; 3=Complete by oneself)*		*.242**
Difficulty assessing the trustworthiness of online health information *(1=Strongly disagree; ...; 5=Strongly agree)*		*-.329***
Confidence using technology or Internet [*1=Extremely confident (expert); 2= Somewhat confident; 3=Only a little confident; 4=Not at all confident; 5=Avoid using computers]*		-.119
eHEALS S1. How useful do you feel the Internet is in helping you in making decisions about your health? *(1=Not useful at all; ..; 5=Very useful)*		*.259**
R^2	.089	*.479***
$\triangle R^2$	.089	.390
$\triangle F$	1.025	*12.917***

H-RM1: R^2 = .089*,* *F*(7, 73)=1.025, 95% CI [2.328, 4.466], Intercept = 3.397
H-RM2: R^2 = *.479 p<0.01,* *F*(11, 69)=5.775, 95% CI [1.984, 4.100], Intercept = 3.042
**p*<0.05 ; ***p*<0.01; △*=Change*

[LL] eHEALS was not analysed as dependant variable (DV) within this thesis, and although highly correlated to DHLI score was not the focus of this research study. Further analysis will be completed as a post-doctoral extension analysing eHEALS using H-MR as a comparison to findings observed with DHLI score within this survey population.

No individual socio-demographic factors were found to be a significant predictor of total *DHLI* score within Model 1. Adding variables describing technological ability and Internet behaviour, '*Assistance required to complete online tasks*' (*β =.242, t(2.346) p=.022, 95% CI [.031, .382]*), '*Difficulty assessing trustworthiness of online health information*' (*β =-.329, t(-3.330) p=.001, 95% CI [-.158, -.040]*) and '*Level of usefulness of the Internet assisting in health decisions*' (*β =.259, t(2.566) p=.012, 95% CI [.022, .176]*) became significant predictors of total *DHLI* score in online survey responders. $\triangle R^2$ measures between Model 1-2 (full sample) and Model 1-2 (online-only sample) indicate that technological ability and Internet behaviour significantly predict total *DHLI* score beyond the socio-demographic variables alone within both survey cohorts. Technology ability and Internet behaviour accounted for an additional 35.1% and 39.0% variance in *DHLI* scores in each model series [full sample $\triangle R^2$ =.351 vs online-only $\triangle R^2$ =.390].

7.7 DISCUSSION

This study's premise was to explore diversifying participant characteristics from a generalised population and meter the level of engagement and capability for those who experience difficulties using or accessing online health information successfully. The discussion will focus on the responses to the survey, including difficulties and barriers to inviting those who are not regularly involved in usability evaluations, diversity in qualities of survey respondents, and probe survey completion modes illuminating specific participant characteristics that developers should target to reduce bias and increase diversity within representative samples.

7.7.1 THE RELATIVE SUCCESS OF RECRUITMENT STRATEGIES

Different strategies are potentially required to reach and identify participants for usability evaluations who are likely to face barriers to use and access health information. Findings suggest strategies require the use of both personal social networks and established organisational communication networks. Whilst snowball recruitment encourages an initial sample to recruit additional participants from their social networks to participate,[457] this strategy can result in self-selection bias within the sample[545] and perhaps limits distribution into digitally excluded or hard-to-reach populations within the community.

The second strategy trialled was accessing community-based populations through organisations, stakeholders, and advocacy groups depending on newly established or pre-existing relationships with gatekeepers.[457,458] Inviting stakeholders, advocacy and social organisations to promote and distribute study information via social media and electronic communication required a 'hard sell' of the study credentials to nominal 'gatekeepers' who often are not necessarily responsible for promotion or marketing decisions but often are relied on to triage to others within the organisation. Gatekeeping sampling is difficult as gaining support or building trust with gatekeepers is challenging over short periods as there is no guarantee of willingness to assist even with perceived benefits.[459,460]

Support to distribute study information was at risk when gatekeepers did not comprehend the study's premise, importance, or significance to the audience they serve. An observation evident in responses received from advocacy groups indicating relative apathy toward the importance of digital health literacy levels within their populations or expressed an appreciation for significance but thought it was not something they, as an organisation, should or could be involved in. Therefore, success depends on an established professional affiliation or awareness of programs to validate credentials but can limit access to social media or digital communication networks due to protective gatekeepers,[457] particularly in hard-to-reach or vulnerable populations.[458] This strategy was more challenging than networking with local councils, identifying and liaising with staff advocates to organise F2F sessions with library patrons. Findings from the survey suggest recruitment from the first two strategies were unsuccessful in identifying or recruiting individuals who would regularly face barriers using or accessing health information, those with low HL and digital readiness levels.

A derived rapport in combination with time-space sampling and open sampling frames[457,546] was undertaken as an alternative approach to recruit individuals who are digitally excluded or are hard-to-reach from within public libraries. By working with health literacy or technology liaisons (as 'advocates or gatekeepers') within specific local government council libraries, opportunities arose to reach individuals and make in-person approaches - these were targeted populations attending libraries to seek assistance or participating in educational sessions to build confidence and aptitudes using the Internet to increase technical or literacy skills. The role of advocates or engaged gatekeepers was crucial in gaining access to hard-to-reach communities, especially those specific need groups detached from digital mainstream communication networks, including individuals with limited access to the Internet and technology.

As highlighted earlier in the chapter, COVID-19 substantially reduced the local council areas and session numbers available for the F2F distribution of the paper survey. The closures potentially impacted levels of confidence, safety and reduced access to the Internet and arguably widened the digital divide.[511] Offers of assistance from library staff and digital literacy program coordinators were not limited to initial requests for permission to attend sessions. Offers of assistance from library staff and digital literacy program coordinators were not limited to initial requests for permission to attend sessions. Assistance was extended to personally-identifying and distributing to older patrons they knew were suitable for the study. These were regular patrons who visited to get assistance with their online social or financial interactions. These interfaces were commonly for Government platforms or portals whose functionality is based on 'developers assumptions' of end-user capabilities. Approaches by staff were crucial to engage with patrons to distribute the survey, particularly to those who have limited access to social media channels; commonly older patrons, people living with chronic illness, newly arrived migrants, refugee populations with ESL and individuals with limited digital competency or confidence using the Internet.

For some people living with a disability, innovative strategies created out of necessity allow full participation in life experiences, and assuming all individuals are unable to participate online is actively denying the opportunity to choose to participate. There was a disparate level of support from stakeholders and advocacy organisations to distribute the surveys electronically. Accessibility was an acknowledged concern, and whilst every attempt was to design a fully accessible survey, autocratic gatekeepers were found to hamper attempts to engage by excluding their entire audiences based on a single inaccessible question within a matrix design. There was also variability in the support provided by ESL organisations and advocacy groups, whilst some were generally empathetic and were appreciative of being included within the study, they acknowledged that only small numbers (if any) respondents would participate, given they have newly arrived migrants or refugees with limited English. However, they appreciated the importance of offering inclusion, as some may accept help from family members, and others would see an opportunity to practice newly acquired English skills. Other organisations declined support as the survey was not available in multilingual versions.

In-person interactions with small beginners and informal English language sessions uncovered a genuine interest, resulting in a low survey return rate. Observations of session learners and discussions with tutors suggest difficulties with content-level prohibitive involvement, including volume, readability and comprehension of consent and participant information sheets. Documents are written to meet ethical approval with critical information explained in detail, creating verbose prose, often hiding implicit messages and is a challenging issue for individuals who regularly use online translators to convert English into their native language and back again. Perhaps an alternative approach to increasing research involvement by multicultural or linguistically diverse groups is to use study information sheets with over-simplified descriptions of involvement and provide only the basics required to elicit informed consent. More complex background and rationale documentation for studies could be provided, explained or translated post-consent to simplify the process for both the participant and researcher.

7.7.2 RESPONSES TO SURVEYS – MODALITY OF RETURN

Overall, the reach of the distribution approach was unknown, based on the reported return completion rate for online surveys of 18%,[547,548] the number of online survey responses met expectations given a relatively short period of recruitment. F2F distribution yielded a small number of paper returns, but as many respondents asked for both paper and online survey links, it became difficult to ascertain the success of an in-person strategy. However, given the complexity, the length of the survey, completion rates could be considered high across online and paper respondent samples. Consequently, significant differences were observed and measured in individuals' characteristics of those completing surveys online versus returning by paper.

Due to the small sample size, it was not possible to describe with any certainty the differences in both the factors and the level of interaction influencing DHL between survey modality groups. Results from H-MR $\triangle R^2$ suggested differences were apparent when paper survey return data was removed from the overall study cohort. Future studies should focus on engaging and recruiting individuals who return surveys on paper. These individuals could provide further understandings of what factors drive DHL in digitally excluded populations. Greater sample size could also highlight statistically significant differences in user characteristics between paper and online survey groups. The current study identified statistically different characteristics between survey groups; however, it is unlikely that differences across all survey questions and questionnaires were detected due to the low respondent number in paper survey sample (n=11).

The analysed data found survey respondents overwhelmingly highly educated and experienced moderate levels of advantage based on income and geographical location. Being mature (aged mid-'50s) or having physical or psychological impairments did not limit their online behaviours; individuals did not live without Internet access or absence of devices. Instead, they reported high levels of self-assessed confidence in their technological abilities and cognitive awareness to find, comprehend and evaluate online health information for trustworthiness. Respondents' health literacy levels (eHEALS) were found to be moderately high and of similar levels previously assessed in an Australian sample.[148] However, the survey respondent group was homogenous in many ways (i.e., gender). It was limited in the targeted representatives from culturally and linguistically diverse communities, living with a disability (visual impairment), and technological avoiders (i.e., limited operational/functional ability using devices or the Internet or are averse to being online). The online survey population reflected a competent, confident sample of individuals who are aware of health information, have the skills to find this information and have the ability to evaluate this information to make decisions about their health.[549]

7.7.3 DIGITALLY EXCLUDED AND HARD-TO-REACH COMMUNITIES

The analysis did identify individuals who regularly face barriers to using health interfaces amongst the paper survey return cohort. Characteristics of the paper survey cohort were similar to US cohorts[507] of late adopters of technology. A combination of age, being increasingly active online, and increased assistance required when interacting suggests that paper respondents are late technological adopters[513] rather than avoiders. Paper respondents were significantly older, retired and had lower educational attainment whilst receiving lower yearly household income on average. Issues and problems encountered with devices or interfaces that required assistance from family or friends were compounded by low self-confidence in using technology and the Internet. Perceptions of technical adversity or disengagement to the online environment are contradicted in the survey group as individuals' frequency of use and level of exposure to interfaces were similar to those returning online surveys.

Paper survey respondents report difficulties in determining the trustworthiness of health information, conceding the Internet as not useful or unnecessary to accessing this information to assist in making health decisions.[514] Combined with low measures of eHEALS and low DHL (where digital skills are a subset), it suggests paper respondents experience increased digital exclusion and face barriers to using the Internet and may hesitate or refuse to interact online due to lack of confidence, anxiety, or fear. For example, if given a choice between paper and online surveys, paper surveys reduced anxiety levels of accessing the Internet and the anticipated technical issues using interfaces and devices, instead offering a stress-free, rapid, and reliable method to submit their responses.

Further analysis of DHLI and its sub-scores suggested that older people over 65 years who are increasingly active online and new to technology,[96] lack the functional aptitudes contributing to 'Internet skills'[550,551] being a product of the frequency of Internet use and confidence to search for information online.[497,532] On average, five of six core digital health literacy sub-scales were significantly lower for paper returners than those completing online surveys. '*Being online'*, using computers or devices to interact with health information requires a minimum level of digital competency[141] relating to the practical knowledge, exposure or experience across a variety and confidence in using different types of digital interfaces and programmes.[552]

Level of confidence was a significant predictor of DHL in this survey group, speaking directly to late adopters of technology abilities to "*search, select, appraise, and apply online health information*,"[516(p2)] levels of comfort, familiarity and judgement of credibility and, crucially, positively increasing operational and navigational skills in the process are fostered as online experience increases. James et al.[553] suggest that users who frequently search for online health information predict a positive relationship to eHEALS scores[177,512,540] as a product of the increasing frequency of Internet use, confidence to search for information online[112,532] and improvement of functional Internet skills.[152,550] DHL levels for these individuals could be considered transient; building literacy, experience, confidence, and digital aptitudes could reflect probable increases in DHL, and this may not be the case for individuals whose characteristics remain fixed over time. Systematic mechanisms limiting access to the Internet or technology, identified as levels of government support, education, and employment in this study; and use of interfaces due to age-related functional decline (including physical, intellectual, and functional physiognomies[247]) impacts abilities to improve DHL levels. It is untenable to predict DHL levels in specific groups or individuals as there are many characteristics, some measurable and some are life experiential, impacting abilities and motivations to interact successfully online. Perhaps this substantiates the proposition that assumptions of user characteristics' can curtail evaluation outcomes if participant selection is centred on obvious demographics that do not differentiate between digital skills and health literacy levels.

7.7.4 USING CHARACTERISTICS TO PREDICT DHL LEVELS

Individualistic patterns were not consistent nor discernible between cohorts from a purely subjective analysis of survey results due to the complex and intersectional relationship between characteristics. Some factors are measurable, and others are life experiential, impacting the abilities and motivations to interact successfully online. The comparison of R^2 and $\triangle R^2$ as outcomes from multiple regression analysis between overall and online survey cohorts reflects similar observed patterns after respondents returned paper surveys were removed from the dataset. Consequently, income was no longer a significant predictor of *DHLI* score within primary models once the paper return group were removed from the dataset. Interestingly, no other variable surveyed related to socioeconomic status presented as a significant predictor of DHL (education, employment status, or IRSAD).

Age held a weak association to digital health literacy across all three survey cohorts. Findings are supported by research undertaken by van der Vaart and Drossaert[516] when assessing an online cognitive behavioural tool's usability. The authors determined that *DHLI* was not correlated to age or education, although age was associated with decreasing task completion and increasing the number of issues encountered within the interface during usability.

Compared to paper survey respondents, demographic data for online survey respondents found online survey responders were more likely to have higher educational attainment, are more likely to be currently employed, and are less reliant on Commonwealth support and live within less disadvantaged areas. Although these were non-significant predictors of DHL, income is the foremost marker of high socioeconomic status resulting from these other fundamental factors contributing to economic success. Consequently, socio-demographic factors influence DHL indirectly, and resultant interactions on DHL are not as clear cut within this cohort as previously observed within paper survey data. Analyses still demonstrate characteristics related to digital skills and capabilities within the online environment are still strong predictors of DHL in online respondents (contributing ~35% variance in addition to socio-demographic characteristics), and costs of broadband or affording devices (‘getting on and staying online’) may also be a concern for these individuals. Confidence and experience using technology are not factors in predicting DHL for online survey respondents, suggesting higher digital competency levels in these end-users.

Online responders have a significant predictive relationship between *DHLI* score and a) ease of completing online tasks autonomously, b) self-rated ability to assess the trustworthiness of online health information, and c) usefulness of the Internet to help make health decisions. Each of these predictors is related to specific capabilities that are elements of DHL. Completing online tasks without assistance requires digital skills, functional understandings of the Internet and confidence borne of previous online experience and device use. Assessing the trustworthiness of health information relies on literacy skills, general and health, reading, comprehending, and understanding the meaning of information held within health resources. Assessing the trustworthiness of health information relies on general and health literacy skills – the ability to read, comprehend and understand the meaning of health information within the interface. Having these skills increases the likelihood that individuals can assess information for relevance, accuracy and reliability whilst recognising markers of trustworthiness (quality and resource authority). Using the Internet as a tool to search and assimilate knowledge to support health decisions requires acceptance of the web as a knowledge base, and for some, this means adopting technology over fear or ambivalence to engage with the online environment. These predictors are skills and abilities considered crucial to DHL over and above baseline digital competencies, even in groups considered 'tech-savvy'.

7.8 STRENGTHS AND LIMITATIONS OF THIS STUDY

Levels of community engagement were both a strength and limitation of this study. Community members and organisations were enthusiastic about being involved in this study. Participation was despite the difficulties with the content domain and decreased access to potential participants due to COVID-19; responses were collected from both online and paper surveys. Analysis of survey data suggests social media and electronic communication networks were not successful in reaching digitally or socially excluded community groups. F2F engagement was self-limiting. There were difficulties visiting all of the possible venues and events identified by council staff due to the time and resource restraints of being a student-led study. The numbers of patrons at educational sessions were variable across recruitment periods, and there was no guarantee of returns on receipt of surveys when handed out in person.

Even with these difficulties and limitations of recruitment, engagement with the community in F2F sessions resulted in paper returns; however, as discussed previously, in very small numbers compared to online survey returns. Given the diverse range of advocates and community organisations who supported recruitment strategies, these numbers were lower than anticipated. The overall sample was skewed towards online survey returns ($N_{online}=82$ vs $N_{paper}=11$), which placed limitations on the ability to identify differences between groups with statistical certainty. Many of the descriptive statistics indicated differences between groups, although not statistically significant. Due to the small sample size, only differences with large effects would be found; subtle differences between groups are likely to be missed. As discussed in section 7.7.2, small numbers of paper survey respondents impacted the ability to compare models of predictors of DHL between survey groups.

It is important to recognise that thesis research is exploratory, and the ability to detect and engage individuals who are hard to reach as a reflection of possible improvements to usability evaluation practice is a proof-of-concept study. Findings suggest that there is evidence to suggest differences in the factors driving DHL in socially or digitally excluded communities compared to those who are comfortable online and technically skilled. The inherent limitations in study recruitment are analogous to the circumstances and possible barriers for non-specialised teams to engage with this cohort for involvement in evaluation. As such, future studies should attempt to recruit adequately to power analysis of the characteristics that influence DHL in hard-to-reach groups, which could mean spending an increased number of researchers, time and money to extend the scope of recruitment areas. Other explorations should examine differences between the geographic and cultural drivers of DHL in metropolitan, regional, rural and remote communities

7.9 CHAPTER SUMMARY

This study highlights practical difficulties development teams would encounter in attempting to engage with individuals who face barriers to digital engagement or only venture online when necessary. These individuals are difficult to reach, and even though stakeholders or social groups are online, there are no guarantees that involved parties will accept or embrace invitations. There is a requirement that practitioners engage with stakeholder organisations and their patrons or consumers to reach those who find technology challenging. It is only at the level of paper versus digital (the Internet) modalities that significant differences are observed. A biased sample was inadvertently created, skewed by confident, tech-savvy Internet regulars who are comfortable online, are confident in being involved in research and have the digital skills to complete surveys. Besides the modality of survey return, DHL was also identified as a potential stratifying measure that could aid diversity in evaluations. As a validated measure, the Digital Health Literacy Instrument demonstrated power in determining explicit factors influencing digital interactions and engagement with online health information. Sub-scales identified characteristics of online behaviours influenced by demographic or socio-cultural elements within groups that are individually indistinguishable. Thus, it may be that neglecting health literacy during development can intensify digital marginalisation[554] and contribute to poorer health outcomes in these already disadvantaged populations.[555-560] Modality of survey return is problematic for development teams trying to adopt an inclusive or universal approach to design, to engage with hard-to-reach populations will impact unstable or pressurised development processes. The final study will explore if stratification by DHL impacts performance and online behavioural outcomes from varying UEM methods, perhaps offering an alternative approach to recruiting to diversify feedback to inform health interface designs.

CHAPTER 8 – THE INTERRELATIONSHIP BETWEEN DIGITAL HEALTH LITERACY, USER CHARACTERISTICS AND OUTCOMES FROM USABILITY EVALUATION METHODS

In this chapter, findings from the final research study of this PhD look to extend findings from Study 4 and explore how end-user characteristics influence feedback generated during evaluation activities. Study 5 investigates an approach to diversify feedback within representative samples evaluating health interfaces. Digital health literacy as a stratification mechanism is examined within a typical usability sample, with research assessing differences in performance and interactive behaviours in participants with high and low levels of digital health literacy.

Peer-reviewed articles produced from this study

Adams A, Miller-Lewis L, Tieman J. 2021. The role of digital health literacy in enabling diversified usability evaluation feedback to improve health interface use: a remotely moderated multi-method study. BMJ Open (*under review*).

Author contribution

AA, LML and JT conceptualized both the research and methodology. AA completed the study investigation, including ethics, recruitment, moderations, data collection and analysis. AA also led the writing of the manuscript. JT and LML reviewed the results and helped to revise then approve the manuscript submitted for publication. JT and LML also provided supervision for AA, a PhD candidate to which this research contributes.

8 STUDY 5. THE INFLUENCE OF USER CHARACTERISTICS AND DIGITAL HEALTH LITERACY LEVEL ON PARTICIPANT FEEDBACK GENERATED FROM USABILITY EVALUATIONS

8.1 CHAPTER INTRODUCTION

Stage 1 of this study, as described in Chapter 7, explored strategies to reach, identify and recruit prospective participants from digitally excluded and hard-to-reach groups from within the community to undertake two usability evaluation methodologies, a survey and open card sorting activity. This first stage focused on communication strategies and mode of engagement through online or paper-based survey return, influenced by participant's characteristics. The analysis explored commonalities and differences in participants' socio-demographic, online behaviour and levels of digital health literacy. Outcomes from the survey highlight the potential application of the DHLI tool to identify differences in digital capability and health literacy which are not evident from a rudimentary assessment of an individual's socio-cultural or demographic characteristics. Application of the DHLI tool as a strategy to stratify participants for usability evaluations was investigated in Stage 2 of this study. Eligible participants from Stage 1 were allocated into two groups, as assessed by their *DHLI* total scores, to form low and high *DHLI* groups. *DHLI* differentiation allows exploration of interactive behaviours and performance outcomes in different evaluation methods between groups with varying DHL.

8.2 BACKGROUND AND RATIONALE

As established early in this thesis, levels of digital inequity increase where an individual's socio-cultural factors, environment, and literacies (computer, media, information,[516] digital,[561] general[510] and health[521]) intersect – the abilities to interact online and to engage in health management,[162] maintain health status and service access[165,166] are impacted. This is reinforced by funders and developers' assumptions of tech-equity of access and use of digital technologies and health interfaces across the population.[562] To negate interface use assumptions, health interface developers can apply inclusive and universal principles to interface designs, increasing the success of end-users who face barriers to use and access information.[13,247] Universal and inclusive design principles move beyond accessibility[13,563] to encourage developers to empathise with end-users,[563,564] and design for maximum participation[208,247,482] by considering the diverse attributes of individuals[247,482] within the general population.

However, even when universal design principles are applied to the development of health resources, there is still a need to identify and recruit diverse users to be involved in usability evaluations to 'test' functionality and acceptability of the design.[482]

8.2.1 INHERENT DIFFICULTIES FOR DEVELOPERS

For developers involved in small organisations, research or project groups constrained by time and budget, recruiting representative users for usability testing is often limited. Strategies commonly rely on snowball recruitment methods directed through specific individuals' networks, recruiting patients attending medical facilities or those receiving online communications or promotional materials through word of mouth or digital messaging via medical or health organisations information channels. These are similar strategies explored within Stage 1 of this study. Advantages of the convenience sampling strategy are related to audience specificity concerning disease state, health profession, or setting around care provision.[522] Larger companies or organisations utilise recruitment agencies with large databases of individuals[92] or panels willing to evaluate online information resources where users are pre-selected based loosely on the intended user group's known archetype. Ideally, usability evaluation practice should attempt to avoid "*inadvertent exclusion*"[247(p21)] of individuals who are true representatives of the intended audience, including digitally or socially excluded and hard-to-reach communities[MM]. Pragmatic development and evaluations of nomothetic interfaces typically see the recruitment of digitally engaged convenience samples,[565] who are characteristically similar to the developers themselves[566] – for example, sharing socio-cultural background or having similar levels of technical ability or experience.[92] This ingrained bias in selection will likely result in more technologically competent participants and will exclude participants with a dislike, disinterest or limited ability concerning the use of the internet and technology devices. Developers are effectively trading off the ease of recruitment with a likelihood of overlooking errors or design barriers to interface use that a diverse, generalist audience may encounter within the interface.[93-95]

[MM] Representations should include individuals from culturally diverse communities, older people,[176,201] low socioeconomic groups,[483] people with low English proficiency,[173] geographically isolated residents[136] and migrant or refugees populations.[175]

8.2.2 USING DIGITAL HEALTH LITERACY TO DISCRIMINATE REPRESENTATIVES

Health UIs are commonly generalist interfaces relevant to a broad range of end-users living within the community. Given that formative usability testing is undertaken with small numbers of participants, development teams need to consciously consider what user characteristics, background and capabilities are needed to generate feedback that will most effectively contribute to interface outcomes that benefit all users. As discussed in the previous chapter, DHL is not only influenced by characteristics of SDOH (such as socioeconomic status, age,[490,497,500] English language proficiency,[490] and literacy levels[161,168,177]); but is additionally shaped by levels of digital inclusiveness and digital competency[178] impacting an individual's health outcomes.[164] DHL considers the relationship between interface information, interactional literacy[516] and an individual's "*baggage*."[247(p36)] A unique and complex combination of fluid physiological, psychological, and socio-cultural factors that are changeable due to environment and time[247] influence the capabilities for successful online interactions. The Digital Health Literacy Instrument (*DHLI*)[516] (explained in section 7.5.6.3) measures competencies across health literacy[99] and skills required for computer, media and information[492,516] literacies. Developed in response to a rapidly changing digital environment and associated online behaviours by users, DHLI is considered a contemporary measure compared to the eHEALS questionnaire[166,516] commonly applied to measure electronic health literacy in individuals. DHLI in Study 4 was shown to be a valuable measure of the characteristics influencing critical Internet use levels[161,495] and gave indications of observed differences in interface behaviours and performance within a technically savvy group. Given the difficulties in *DHLI* in Study 4 was shown to be a valuable measure of the characteristics predicting critical Internet use levels.[161,495] However, further investigations are required to identify differences in performance and interactive behaviours across DHL levels as assessed by *DHLI*.

8.2.3 SIGNIFICANCE OF THIS STUDY

Usability evaluation is acknowledged as being central to the user-centred design approach,[426] and outcomes from previous studies within this thesis have highlighted the presence of inherent difficulties developing health interfaces within complex online environments across disciplines, within collaborative teams and involving participants within health systems or services, patient populations and digitally excluded or hard-to-reach cohorts living in the community. Approaches to increase ease, adoption and establish evaluations within typical development for non-specialised or non-traditional teams are also limited.

There has been significant work investigating content and design factors of interface influencing health literacy across varying types of health interfaces.[567-571] However, these same factors influence DHL and their impacts on usability assessment are less understood. Current research focuses on interfaces of medical devices,[572] integrated in-home monitors,[573] interactive personal health tracking gadgets[574] or mobile applications.[426,552] van der Vaart et al.[495] explored DHL and usability within an Internet-based cognitive therapy interface,[495] observing no correlation between *DHLI* and age or education level. However, a positive relationship was indicated with task completion but not with the number of errors identified. Li and Luximon[552] investigated older adults interface preferences by usability testing content or menu-oriented navigation design patterns using mobile devices and applications. While participants in this study successfully interacted with content-oriented menu patterns, there was no assessment of technological ability, previous experience, literacy, or health literacy levels within this study cohort. Chaniaud et al.[572] examined the roles of technophilia, age, education, and health literacy had on satisfaction, efficiency, and effectiveness in a sample (aged 20-64) when using an in-home medical device. Education was the only factor correlated with usability components; health literacy positively correlated with effectiveness. Similar research is scarce exploring online health information websites and toolkits. The outcomes from this study will provide the first data on how DHL impacts both the overall usability and suitability of participants to specific evaluation methods.

The final study within this thesis examines an approach that, in theory, could increase the acuity of usability feedback by identifying specific archetypes for evaluations of generalist health interfaces whilst easing the recruitment burden on over-committed, under-resourced development teams. The approach was to stratify participants at the level of the characteristics influencing critical Internet use by applying the DHLI to assess digital health literacy. Findings could potentially change how developers recruit for evaluations within the process of health interface development, enhancing the value of usability feedback by optimising the diversification of usability participants.

8.3 RESEARCH QUESTION AND STUDY OBJECTIVES

RQ6: How do digital health literacy levels influence usability evaluations' outcomes and the implications for interface design when designing for everyone?

8.3.1 STUDY OBJECTIVES

1. Determine if levels of digital health literacy and underlying characteristics influence performance and behavioural outcomes of five different usability evaluation methods.
2. Explore complexities of usability evaluation feedback generated by participants with either high or low *DHLI* scores to determine the suitability of methods.

8.4 STUDY DESIGN

Study 5 was conducted as a 5 x 2 group design involving non-probability sampling from the participant group from Study 4 (Stage 1). A stratified purposive sampling approach was applied to a group of self-nominating respondents who indicated an interest in participating and provided a valid Digital Health Literacy Instrument (DHLI)[516] score from the survey. Two homogenous groups with similar DHL levels were created at the two extremes of the *DHLI* score distribution (described in 8.5.4.1), an approach that increased the probability of measuring significant differences between groups by decreasing within-group variability.[151] Participants in both high *DHLI* (H-*DHLI*) and low *DHLI* (L-*DHLI*) groups participated in a single evaluation session to generate usability evaluation feedback data from five different UEMs, which were chosen to explore different aspects of interactions with the interface. Descriptions of usability sessions and UEM activities are now provided in section 8.5.5. All evaluation methods were considered independent trials. Data from observed behaviours and performance outcomes were analysed within and between *DHLI* groups.

8.5 METHODS

8.5.1 ETHICAL APPROVAL AND CONSENT

Stage 2 research has previously been approved under the previously submitted application to Flinders University Social and Behavioural Research Ethics Committee and is pursuant to consent, standards and permissions as outlined in section 7.5.1 (Project number 8627, Appendix 40). Confirmation of involvement and informed consent were obtained after participants had received copies of study information sheets. Participants provided verbal and written informed consent before commencing evaluation sessions. Consent was audio-recorded and retained as per ethical requirements stipulated by the Act. Participants received a $25 honorarium after the session in appreciation of their time.

8.5.2 SETTING

Usability sessions were conducted remotely[429] with participants using their preferred device (desktop, laptop or tablet) and location (with stable Internet connection). All sessions were recorded for analysis via Zoom interface, with video recording centred on voice and screen view. Participants were provided with a session running sheet and instructions on accessing the different platforms being used for activities. This instructional PDF included activity or task descriptions and the URL links to each activity where participants accessed Qualtrics Survey software,[432] Optimal Chalkmark and Optimal Sort platforms[527] and CareSearch website[NN] within their Internet browser.

No moderation or instructions were required for technically-adept participants, and the researcher facilitated between activities to ensure that each component of the activities was completed. For participants in the low *DHLI* group who chose to use their iPad tablets, sessions were fully moderated. Facilitation included a practical demonstration of basic operations and navigation between programs. Two participants had no previous experience using conference software and were required to download an app before the session commenced.

All six usability sessions followed a strict protocol ensuring each participant completed activities in the same order and had similar exposure to the website. Participants evaluated a section of the CareSearch website focussing on palliative care information for patients, caregivers, and families. Session duration was one hour and conducted between 25th September and 4th October 2020 at a time convenient to participants.

8.5.3 PARTICIPANTS

Participants were from a sub-sample of Stage 1 survey respondents. Study participants needed to reside in Australia, to be over 18 years with English sufficient to provide informed consent and follow instructions. Stage 1 respondents were required to register and provide contact details if interested in participating; this also entailed consenting to having their survey data de-identified to calculate DHL scores and contact eligible survey respondents. Completed within the Stage 1 survey, Figure 7.1 diagrammatically represents the procedural flow of the studies (section 7.4).

[NN] CareSearch website Patient and Carers website section URL:
https://www.caresearch.com.au/caresearch/tabid/64/Default.aspx

8.5.4 RECRUITMENT

Respondents who registered their interest in usability sessions were eligible to participate if an eligible *DHLI* total score was calculated from the survey data (as described in section 7.5.5.3). From n=93 survey respondents with total *DHLI* scores, n=28 registered interest in participating in usability sessions. Six participants were required from the 28 individuals registered for this study, reflecting a typical sample size for a formative usability testing protocol.

8.5.4.1 Stratifying usability groups by participant level of DHL

Digital health literacy levels within the registered sample ranged from 1.524 to 3.952, M_{DHLI}=3.118 (*SD*=0.527), and there was an absence of either floor or ceiling scores within the eligible participant cohort. A participant with *DHLI*=1.524 did not have access to a tablet or desktop/laptop configuration and, therefore, could not participate further. Participants were ranked from highest to lowest *DHLI* total score. Offers of involvement were directed to those at the furthest points of the *DHLI* distribution first, and if no response was received to an initial message or reminder or participant declined, the next lowest or highest-scoring participant were invited. This process continued until all six available slots were filled. From ten invitations distributed, two participants declined, two did not respond to requests, and six consented to produce two cohorts, low and high *DHLI* groups n=3 participants in each.

8.5.5 USABILITY SESSIONS

Each participant undertook five usability evaluation activities during the session. Included methods were chosen to explore different interface aspects and to generate quantitative and qualitative feedback. Activities completed by participants in the one-hour sessions were:

1. Site learnability
2. Closed card sorting
3. First-click analysis
4. Semi-structured interview
5. System Usability Scale (SUS) questionnaire.

Activity descriptions, in-site menu or content targets and UEM order were identical across all six sessions to maintain consistency between participants. Table 8.1 provides an outline of activities and the software or platforms used during the sessions. Upon completing each evaluation activity or task, participants indicated the level of ease and confidence using a Single Ease

Question (SEQ). SEQs were completed online using either Qualtrics[432] or Optimal Workshop platform,[527] depending on the platform host. 7-item Likert Scale SEQ was presented with anchors *1=Very difficult* to *7=Very easy* (for 'Ease of completion') and *1=Not confident* to *7 = Very confident* (for the 'Level of confidence'), both SEQ are presented in Appendix 6.3. Closed card sort and first-click analysis (activities 2 and 3 respectively) were conducted within the Optimal Workshop platform.[527]

8.5.6 DATA SECURITY AND PROTECTING PRIVACY

All data collection programs offered password protection for study data, and on completion of usability sessions, all extracted data was managed within Excel.[528] All stored online data and videos are held within a password-protected drive on the Flinders University server. All data was held in a de-identified format to ensure participant confidentiality and privacy.

8.5.7 USABILITY EVALUATION METHODS

8.5.7.1 Evaluation method 1. Site learnability

The ease with which users can learn an online system, software or website as being two dimensional, considered both a measure of task completion by a novice or first-time user[54] and as a sub-component of usability as a concept, a longitudinal process over time.[575,576] The learnability of this website section was examined using a scenario-based task that required users to move through several levels of the Patients and Carers section to locate a specific resource or finite piece of information. Participants attempted this same task three times, alternating between other activities within the one-hour session.

Table 8.1 Activity schedule and platforms/software used during the usability sessions

Zoom function and screen video capture, technology troubleshoot and workarounds						
Session start						
Introductions / Consent / Questions						
3 minutes website section familiarisation						
Evaluation type		**UEM**	**Specifications**	**Data capture**	**Data management**	**Data analysis***
1	**Task**	Learnability	Website# scenario-based task (Trial 1)	• Zoom[429]	• Excel[528]	• Excel[528]
2	**Activity**	Closed Card Sort (10 mins max.)	30 card sort activity [+ SEQ]	• Optimal Sort platform[527]	• Optimal Sort platform[527] • SPSS[431]	• Optimal Sort platform [527] • SynCaps software [577] • Excel[528]
3	**Task**	Learnability	Repeat website# scenario-based task (Trial 2)	• Chalkmark, Optimal Sort platform[527]	• Excel[528]	
4	**Discovery**	First-click analysis	Three scenario-based tasks [+SEQ]	• Qualtrics software[432]	• Excel[528]	
5	**Narrative**	Semi-structured interview (10 mins max)	Personal experience of interface# design features, content preference, hedonistic characteristics [+ SEQ]	• Zoom[429]		
6	**Task**	Learnability	Repeat website scenario-based task (Trial 3) [+ SEQ]	CareSearch website SEQ - Qualtrics[432]		
7	**Questionnaire**	System Usability Scale (SUS) questionnaire	Interface# satisfaction and usability questionnaire [+ SEQ]	Qualtrics[432]		
Session End						

*Statistical Analysis - SPSS[431]
CareSearch website Patient and Carers website section URL: https://www.caresearch.com.au/caresearch/tabid/64/Default.aspx

Data measurement

Participants began reading aloud a written scenario description (provided below) before opening the website section's top header page and searching.

> '*Find some information that will help to ask important questions of palliative care and other health professionals who provide care for patients*'

Success was indicated if the target item was located within the three-minute time limit. Participants were 'correct' if 'target' located within the website at either:

1. *Ask Questions* section of the 'Communicating with Health Professionals' webpage [Patients and carers>Living with illness>Why is communication important?>Communicating with health professionals]
2. Any of the *Questions to ask your doctor or health professionals* in the 'Palliative Care Booklet for Patients, Carers, and Families' (PDF) are available from either [Patients and carers>A Palliative Care Booklet for Patients Carers and Families] or lower on the section header page [Patients and carers]

Task failures included if the target was not identified within the time limit, if participants aborted the task before completion, or refused to begin the task altogether. Performance was measured as a timed task, started at 'first-click' and was completed when the target item was confirmed. Each trial was considered a single data point repeated three times over the session (three data points per participant, nine data points per *DHLI* group). Other behaviours recorded included observations of pathways, verbalisations including comments or frustrations.

The analysis examined two task performance measurements

a. First-use task completion time.
b. Repeated-use task completion time as measured over three tests.

Low first-use task performance time indicated a website with relatively high ease of use and learnability, and improvements in task performance indicate a learnable system.[575] After trial 3, participants provided feedback on how easy or difficult they thought the activity was complete (Ease of completion SEQ, Appendix 6.3).

Data variables and statistical analysis

Timed measures and task completion were observed and recorded for the three trials undertaken during the usability session's alternate stages. Table 8.2 presents descriptions of learnability data variables and subsequent statistical analysis.

Table 8.2 Summary of learnability data variables and statistical analyses

Objective/Measure	**Description/Variables**	**Statistical analysis***
Task performance measures ease of learning the website and learnability over time due to the system's usability.	Time to complete task-based, multi-level, complex, action-based scenario measured during: a) First-use b) Repeated three times across the Stage 2 testing period Performance indicators: • Time	Mean performance indicators calculated for each *DHLI* group Significance between group means using two-tailed, Independent *T*-tests[276] using Levene's Test for Equality of Variances adjusting for unequal variances using the Welch-Satterthwaite method (95%CI, significance *p*<.05) Differences between the mean time of completion calculated repeated measures one-way ANOVA[578]; significance measured between trials for each *DHLI* group: T1 vs T2, T2 vs T3 and T1 vs T3 (95%CI, significance *p*<.05)
	Ease of completion SEQ: Likert Scale (7-item) 1 = *Overall, very difficult to complete* 7=*Overall, very easy to complete*.	
	Target identification: • Success/Failure	% Successful completion. The mean rate of success examined using between-group analysis, (*N-1*) Chi^2 test applied to determine differences (confidence intervals 95%, where significance *p*<.05)

*Effect sizes [544] (Cohens d and η^2) are reported for all inferential statistics reported within this study

8.5.7.2 Evaluation method 2. Closed card sort (CCS)

Card sorting UEM generates an insightful understanding of the relationship between concepts (cards) and categories within which participants[579] choose to group them.[197,580] Open and closed card sorting (CCS) activities inform developers of the information architecture (IA) of resources. As a Research Assistant with CareSearch, the researcher had an opportunity to undertake an open card sorting activity external to the research undertaken within this PhD thesis. This activity involved *n*=48 survey respondents from Study 4 who, in addition to their surveys, participated in a voluntary remote, unmoderated open card sort UEM. The objective of this research was to explore if individual characteristics influenced concept sorting behaviours within the palliative care content domain. The research was a test of the method, matching anonymous questionnaire data to the corresponding card sorting data to compare and contrast the different sorting patterns. Dendrograms and similarity matrices were examined at the level of DHL, socio-demographic descriptors, Internet behaviour and digital skills using Hierarchical Cluster Analysis (HCA). Though this data is not included within this thesis (it will be produced as a white paper post-examination and was subsequently applied to design the Dying2Learn section of the new CareSearch portal), it is important to understand how the parameters and outcomes of the open card sort informed the subsequent CCS in this study. A brief description of the open card sort activity, outcomes and implications for developers are provided before moving into the methods for the CCS for Study 5.

Summary of the method, data collection and analysis

Concepts for the open sort were reverse-engineered from content within the Patients and Carers section of the CareSearch website, stripped from content, similar concepts between pages were de-duplicated, then removed from the sample. A total of 111 concepts were retrieved from 65 second-level web pages. Synonyms and non-parallel exposition structures were employed to reduce keyword matching bias in groupings by respondents.[279] A total of 50 cards (including three auxiliary concept cards: '*voluntary assisted dying*', '*terminal care*', and '*end of life care')* were randomly selected from the total to represent all eight sections of the website proportionally. **The remaining 64 concepts were possible inclusions for the closed card sort activity described in this chapter.**

Participants were asked to group cards into categories, then provide a label for each group of cards. On completion of data collection, sort data was standardised to remove duplication by language, syntax, context or intent of category names and merged with other similar groups as analysis required uniquely occurring categories. Data was then extracted and visualised using Optimal Sort software,[527] analysis of clusters and group membership required SPSS,[431] and SynCaps software.[577] Frequency of card placement and HCA[581-583] was applied to create dendrograms and similarity matrices. Relationships between concept groupings and respondent characteristics were analysed from three different perspectives arising from the exploration of the sort data.

1. An overall cohort (producing three clustered groups
2. Similarity of sorting patterns (two clustered groups by similarity), and
3. DHL level (identifying two clustered groups with low and high *DHLI* scores).

Summary and implications of the findings

Card sorting as a UEM carries a high cognitive load with an intrinsic element relating to the task itself and an extrinsic load due to the representational complexity of the information within the interface.[584] Combining these elements, in effect, accumulating the risk of abandonment or frustration, especially in older participants where: *difficult task + complex information read and comprehend + unfamiliar interface + low digital skill.* This finding has implications for individuals involved in usability evaluations who have characteristics influencing low levels of DHL. In considering levels of DHL, analysis of the dendrograms comparing relatively high and low *DHLI* found health literacy as the key contributor to the differences in sorting behaviours rather than levels of digital competency.

The ability to understand or comprehend semantic or pragmatic phrases created difficulties for individuals with low DHL. This finding potentially identifies another complexity when evaluating hard-to-reach groups, including CALD (ESL), low literacy or educational attainment. Understanding language and an individual's physiology, culture, and environment are intrinsically linked; it is an "*idea that culture, through language, affects the way we think, especially perhaps our classification of the experienced world*."[585(p2)] Therefore, it would be reasonable to assume that language's social determinants affect the interpretation of concept descriptors and the formulation of categories applied to relational arrangements of cards, phrasing describing concepts and interpretation on the context of the meaning, to form conceptual relationships.

Findings from this open card-sort research indicate a potential difference in interaction behaviour between individuals with low and high DHL measures influencing relative success when finding and understanding health information online. The extent and complexity of how intersecting characteristics influence DHL and performance online are yet to be understood. By including a closed card sort in Study 5, outcomes could provide further opportunities to explore how the characteristics are influencing DHL to impact interactive behaviours, specifically in formative UEM. CCS removes the difficulty of creating and self-attuiting category names; providing categories could alleviate some of the difficulties for hard-to-reach participants. However, CCS is more closely related to real-world information search on the Internet, which could intensify barriers to using health interfaces.

Card concepts for the CCS

As described previously in the open card sort methodology, cards were systematically randomised from the Patient and Carer website section (a section sitemap is provided in Appendix 8.1). From the initial 111 concepts, 64 concept cards were possible inclusions. CCS required a total of 30 concepts, and as with the open sort, included auxiliary concepts (if these were deemed to be of importance to audiences and do not appear within the current section). A total of 25 cards were randomly assigned into the closed card sort from 64 available; these were *not* the same concepts presented in the open sort except for:

1. ‘*Access to palliative care services*’ - was included in both sorts due to its significance
2. ‘*Voluntary assisted dying (VAD)*’
3. ‘*Voluntary euthanasia*’ - could be construed as being conceptually different from VAD
4. ‘*When does end of life care begin*’
5. ‘*Explanation of what palliative care is*’ - was added due to misconstrued descriptions often circulating within the public domain.[586,587]

Six cards were directly associated with content from a webpage and related to menu items ‘*Specific Groups*’, ‘*Online Information*’ and ‘*At the End*’, all other concepts associated with second-level pages organised within a secondary menu. Sorting outcomes could provide insight into differences or similarities by each *DHLI* group rather than being tied to a menu category, hence providing a non-discriminant sort. Card numbers from each sub-section of the website section were representatively proportional to total concepts stripped from each. Table 8.3 illustrates the final list of concepts (cards) uploaded to the Optimal Sort platform.[527]

Participants placed cards into ‘baskets’ pre-labelled with category names provided in the website section's primary menu structure; this discriminant method investigated differences between the developer and end-user cognitive informational relationship models. Categories mirrored seven menu items: For Patients, For Carers, For Families, At the End, Specific Groups, Finding Services, and Online Information. The menu item Bereavement, Grief and Loss excluded from the sort as this category would not have uncovered any unexpected sorting behaviours. This was replaced with an ‘Unsure’ basket, which could be used if participants felt the card did not belong in the seven allotted categories. Importantly an explanation was subsequently sought from participants as to why these cards were placed in this category. On completion, participants explained what they found most challenging about completing the sort (as adapted from Sherwin[579]) and asked to complete Ease of completion SEQ (Appendix 6.3).

Table 8.3 Cards (concepts) identified from the 'Patients and Carers' section for CCS activity

Concept / Card number	Menu header descriptor	Concept (card) descriptor
1	How to Care	Impact of looking after someone
2	How to Care	Difficulties of being a carer
3	How to Care	Accepting help when offered
4	Practical Caring Resources	Different types of medicines
5	Practical Caring Resources	Supporting carers to care
6	Practical Caring Resources	How do you say goodbye to someone who is dying
7	Living with Illness	Prognosis and quality of life
8	Living with Illness	Emotional roller coaster for carers
9	Living with Illness	Importance of finding the right person to talk to
10	Living with Illness	Expected costs of care
11	Living with Illness	Dealing with Government departments
12	Living with Illness	Wills, advance care planning and advance directives
13	Living with Illness	Managing symptoms
14	Living with Illness	Communication and being honest and open
15	Specific Groups	Importance of families and community groups*
16	Specific Groups	Understanding the language of palliative care*
17	Bereavement, Grief and Loss	Recognising grief and sadness
18	Bereavement, Grief and Loss	Supporting children during grief
19	Using Online Information	Importance of research and evidence*
20	Using Online Information	Find good sources of information*
21	At the End	Things to think about dying at home*
22	At the End	What happens after death*
23	About Palliative Care	Accessing services
24	About Palliative Care	Organising and keeping track of care
25	About Palliative Care	Ways of finding information about services
26	**Other**	When does end of life care begin
27	**Other**	Voluntary assisted dying (VAD)
28	**Other**	Voluntary euthanasia
29	**Other**	Explanation of what palliative care is
30	**Other**	Navigating the health system

*These cards were taken from web pages with direct association to the 'menu' buttons found on the section header page

CCS examined how each participant utilised website category/menu structures to categorise content and the embodied concepts.[579] Participants completed this activity using Optimal Sort software[527] accessed via URL included within instructional PDF. In-site instructions guided participants, and although moderated, support facilitation was not required.

Data measurement

On completing all sessions, card sort data exported from Optimal Sort platform[527] included datasets in raw and standardised formats and similarity matrix results (.csv files). Data were analysed using platforms and programs outlined in Table 8.1. As CCS provides no opportunity to discover categories (contrary to open sorts), given these are provided to participants and based on menu headings, there are no sub-categories and cards (concepts) are allocated to a single category (or basket).

Extracted sorting data was visualised using Optimal Sort software,[527] managed in Excel,[528] then analysed using SPSS,[431] and SynCaps software.[577] Exploration of relationships between cards (concepts) required two different measures:

a) Hierarchical Cluster Analysis (HCA) is an individual-directed, bottom-up analysis method using systematic agglomerative clustering of content items based on the number of times each 'card' appeared in each category[581-583]; and as paired with another across all participants. The frequency of card placement in each category were collated and applying two visual methods displayed the strength of relationships between cards. These were:
    i. Similarity or proximity matrix to measure how similar two cards were sorted together
    ii. Dendrogram or tree plot illustrating the strength of relationships between cards graphically. These are inversely related to the distance of branches between similarly grouped content items (shorter distance implies increased strength).[272,581,583]

b) Frequency of card placement into created categories by participants using a standardised sorting matrix providing a visual representation of the number of times each card was placed in each of the menu categories within the sort.

Extracted participant performance data included time for task and post-activity Ease of completion SEQ.

Data variables and statistical analysis

Table 8.4 summarises data variables and statistical analysis, and Table 8.1 outlines software and platforms utilised to explore this data further.

Table 8.4 Summary of CCS data variables and statistical analyses

Objective/Measure	Description/Variables	Statistical analysis
1. Examine assumptions and relationships between end-users and developers conceptual map of how palliative care concepts are mapped within the website. 2. Exploring similarities and differences in card sorting patterns at both an individual and *DHLI* group level.	Developer versus end-user sorting of concepts (cards) into categories reflecting menu headings of the website • Sort agreement between developer and end-user (*n*= 6 cards) • Sort agreement between *DHLI* groups for second-level concepts	Frequency of card placement compared with the 'current' structure of the Patients and Families section of the CareSearch website. The level of agreement (%) is calculated between *DHLI* groups, and the number 'correct' in each section reflects the website section.
	Frequency of cards in menu-based categories • Frequency matrix (Low versus High *DHLI*)	Counts of cards placed within each category reflecting website menu headings were extracted from the Optimal Sort platform and reconstructed into a frequency table presented as the percentage of participants in the agreement.
	Strength of relationship between paired 'cards.' • Dendrograms and similarity matrices (Low versus High *DHLI*)	• Hierarchical Cluster Analysis (HCA) method using agglomerative clustering to generate both similarity matrix and relational distance data for a visual illustration of these relationships between cards.[272,583] • Correlation between proximity matrices to determine the similarity using Mantel Test[588](Pearson's Correlation *p*<.05, 95% CI. r describing strength and direction of relationship between matrices).
	Performance indicators: • Time to completion (secs)	Mean performance indicators calculated for each *DHLI* group Significance between group means using two-tailed, Independent *T*-tests[276] using Levene's Test for Equality of Variances adjusting for unequal variances using the Welch-Satterthwaite method (95%CI, significance *p*<.05).
	Ease of completion SEQ: Likert Scale (7-item) 1 = *Overall, very difficult to complete* 7=*Overall, very easy to complete*.	

*Effect sizes [544] (*Cohens d and* r^2) are reported for all inferential statistics reported within this study

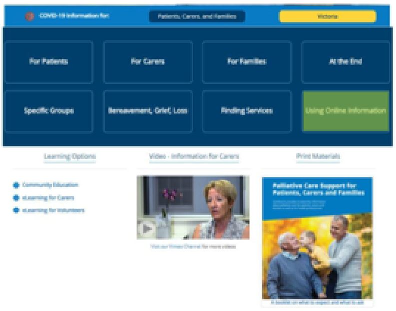
8.5.7.3 Evaluation method 3. First-click analysis

Navigating and locating intended information within a resource is paramount for users and is motivated to invest both time and energy in this process. To investigate website section navigation, menu and category structure, participants completed a first-click evaluation examining how users' interpretation of a scenario-based task influenced their choice in menu labels as an indication of the search path. Research indicates the significance of direct, intuitive navigation and menus structures on task completion. Research suggests that successful completion of a task occurred 87% when the first-click direction was correct. This then decreased to 46% when the participants indicated incorrect first-click direction.[589] Participants completed the first-click activity within Chalkmark software[527] and each task was presented as an image of the menu and embedded hyperlinked options on the header page on the website section. This section header webpage was considered the primary landing page, and therefore, provided a representation of a 'real world' starting point for visitors to navigate into the Patient, Carers and Families section of the website.

Three palliative care scenario-based tasks were developed with a personal narrative and a call to action. Each scenario's Flesch-Kincaid readability scores were assessed using an automated software plug-in (https://www.webfx.com/tools/read-able/check.php) reported with participant performance outcomes in Table 8.13. Figure 8.1 presents scenarios, task descriptors, and correct images for each task (highlighted in green) as uploaded to the platform. Scenarios were presented sequentially; participants read the scenario description first and then pressed the 'Start Task' button before selecting the image's area. On completing each of the three tasks, individuals completed the Ease of completion and Level of confidence SEQ (Appendix 6.3).

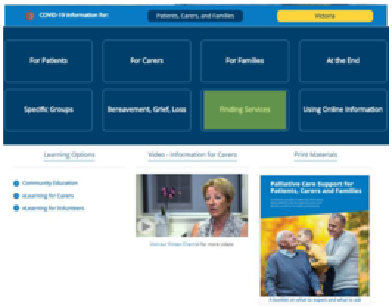
Data measurement

Optimal Workshop's Chalkmark software[527] recorded task completion data, including completion time, path success or failure, and scores from Ease and Confidence SEQ. Table 8.1 summarises all software and platform employed to analyse all data once trials were completed.



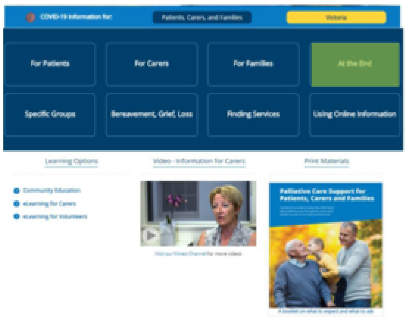
Task 1. You visited a close relative at home who is currently receiving palliative care for an illness that cannot be cured. In your conversation, your relative told you that they were thinking of starting a new treatment that they found online that is reported to help and even cure their condition. You are worried that they have been tricked into finding and believing false or misleading health information.

Find some information that you could show them that will help to give some clues to work out what is a safe, high-quality source of information on the Internet



Task 2. You live in a medium-sized country town a good 4-5 hours from the nearest capital city. Your next-door neighbour lives alone and has asked you to look after their garden as he has been told that things are not going very well with his health. He will need to go to the city to see a specialist. As he does not drive, you are worried about the uncomfortably long bus trip that he would have to take.

You would like to suggest some alternatives and find information about helping them organise transport to the city for his treatment.



Task 3. A close friend has been told that there is no further treatment available for their illness and that it is time to prepare for what lays ahead. You have had a chance to talk about what they would like and their wishes. Your friend has said they would like to die at home, but you are unsure if this is a reality as you are worried about their partner.

Find some information that may help your friend and their family to decide if dying at home is a practical or realistic option for their situation.

Figure 8.1 First-click analysis scenario descriptions and correct areas within the menu

Data variables and statistics

In addition to raw time and success or failures measures, a series of calculated variables from these activity data include descriptions of task performances both within individuals and between *DHLI* groups. Table 8.5 summarises these variables and subsequent statistical analysis.

Table 8.5 Summary of first-click data variables and statistical analyses

Objective	Description/Variables	Statistical analysis
Efficiency and effectiveness of the navigation, menu and category structure and relationship to visual features of the website section	Performance indicators: • Time • Efficiency	Mean performance indicators were calculated for each *DHLI* group. Significance between group means using two-tailed, Independent *T*-tests[276] using Levene's Test for Equality of Variances adjusting for unequal variances using the Welch-Satterthwaite method (95%CI, significance *p*<0.05).
	Ease of completion SEQ: Likert Scale (7-item) 1 = *Overall, very difficult to complete* 7=*Overall, very easy to complete*	
	Success/Failure	The mean rate of success was examined using between-group analysis, (*N*-1) Chi^2 test was used to determine differences (confidence intervals 95%, where significance *p*<0.05).

*Effect sizes [544] (Cohens d and η^2) are reported for all inferential statistics reported within this study

Each participant had four performance variables calculated for each scenario:

1. Time taken to complete each task (secs)
2. Success or failure (success =1, failure=0)
3. Task completion across three scenarios (%)
4. Time-based efficiency (Equation 6.4)- successfully achieved tasks per second.

Equation 6.4: Time-based efficiency calculation[590]

$$Time\ Based\ Efficiency = \frac{\sum_{j=1}^{R}\sum_{i=1}^{N}\frac{n_{ij}}{t_{ij}}}{NR}$$

N = The total number of tasks (goals)
R = The number of users
n_i = The result of task i by user j; if the user successfully completes the task, then
N_i = 1, if not, then N_{ij} = 0
t_{ij} = The time spent by user j to complete task i. If the task is not successfully completed, then time is measured till the moment the user quits the task

8.5.7.4 Evaluation method 4. Semi-structured interview of UX

The semi-structured interview method provided flexibility in collecting self-reported data that encouraged open and explorative narratives[591,592] from users on their Internet behaviours and online experience.

Participants provided narratives on three aspects:

1. Feedback on the structure and function of the' Patients and Carers' section
2. Description of their interactive behaviour with online information resources, including their device choice
3. Preferences for viewing, accessing, and reading online information.

Participants were encouraged to provide positive and negative feedback on interface design and information architecture, navigation and information flow, attitudes (including personal opinions and sentiments) toward content and comments on visual or imagery representations. Each participant received the same series of questions regardless of the assigned group to ensure consistency across interviews.[75,410] Discussions were limited to no more than 10 minutes in duration.

Data measurement and variables

Participants' general narratives and observations were concurrently noted and extracted from a retrospective analysis of the recorded usability sessions.[429] Following descriptions were collated and summarised[410] of:

1. Commonalities and differences of problems and issues encountered when completing the activities
2. Suggestions for website section improvement
3. Content or resources that may be missing from the interface
4. How participants use their devices as part of their everyday interactions with the Internet.

Table 8.6 provides a summary of the variables that were collected and analysed for the semi-structured interviews.

Table 8.6 Data variables collected during semi-structured interviews

Purpose	Description/Variables	Analysis
General narratives and feedback from participants	Patients and carers section of the CareSearch website	Comments or feedback on: • Interface design • Information architecture • Navigation and information flow • Attitudes (personal opinions and sentiments) toward content, and • Visual or imagery representations
	Personal preference for information online	Interact features and medium for consumption: • PDF, videos, pictures / images • Podcasts • Downloads vs screen • Printing
	Preference of technological device	Purpose choice and motivation to learn new skills • Tablet vs phone vs desktop vs laptop • Boundaries and points of frustration

8.5.7.5 Evaluation Method 5. System Usability Scale (SUS) Questionnaire

Participants completed the System Usability Scale (SUS) questionnaire to measure their perceived website usability satisfaction. Although developed in 1986 by Brooke,[593] for now, primitive systems analysis, the SUS questionnaire has been validated[594] and more recently found to assess both perceptions of learnability (2-items) and usability (8-items) in agnostic systems and devices.[245,595,00] Participants were asked to complete an online version of the SUS questionnaire within Qualtrics.[432] On completion, participants completed the Single Ease of Completion SEQ (Appendix 6.3).

<u>Data measurement</u>

Ten SUS questions are measured on a 5-item Likert scale (anchors 1=*Strongly disagree* to 5=*Strongly agree*) and were developed as odd and even schema. Questions were posted positively (e.g., Q1. *I think I would like to use this palliative care website*) and negatively (e.g., Q8. *I found the palliative care website very awkward to use*) to avoid response and acquiescence biases.[597] Each question's score contributes to the final score, ranging from 0 to 4. Positively

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[00] Sauro and Lewis[66] found that SUS questionnaire to be reliable (α=0.93),[402] valid and sensitive to multiple independent variables regardless of setting of use. Majority of developers prefer SUS due its relatively short and simple format,[403] and this questionnaire has been shown to provide confident measures of usability in relatively small sample groups.(where n = 8-12 users).[280] Terminology was modified to reflect the type of resource being accessed, 'system' was replaced with 'palliative care website' to improve clarity and provide context for participants. These changes do not affect reliability, sensitivity, or validity of psychometric measurements of the questionnaire.[402,594,596]

worded even questions were 'normalised' by subtracting 1; conversely, odd-numbered questions totals were calculated by subtracting five from the final score. These adjustments occurred before the final calculation of the SUS total. Summing all ten 'adjusted' scores, the totals were multiplied by 2.5 to calculate a final SUS score out of 100.

Data variables and statistical analysis

Appendix 8.2 presents the question descriptors, scale, scale descriptors and question anchors for the SUS questionnaire. For each participant, SUS questionnaire totals were adjusted and calculated out of a possible 100, with average SUS scores calculated for each *DHLI* participant group.

Table 8.7 presents the data collected and subsequent statistical analysis from this evaluation method. Table 8.1 describes the software and platforms utilised for this analysis.

Table 8.7 Summary of SUS Questionnaire data variables and statistical analyses

Purpose	**Description/Variables**	**Statistical analysis**
Measures of users' perceptions of the learnability (2 items) and usability (8-items) of the website section	Likert Scale (1-5) with summed total normalised. Final SUS score calculated out of a possible 100.	Mean SUS scores were calculated for *DHLI* groups. Significance between group means using two-tailed, Independent T-tests[276] using Levene's Test for Equality of Variances adjusting for unequal variances using Welch-Satterthwaite method (95%CI, significant if *p*<.05).
	Ease of completion SEQ: Likert Scale (7-item) 1 = *Overall, very difficult to complete* 7=*Overall, very easy to complete*.	

*Effect sizes [544] (*Cohens d*) are reported for all inferential statistics reported within this activity

8.6 RESULTS

Mean *DHLI* scores were found to be statistically significantly different between low and high groups [$M_{L\text{-}DHLIGroup}=2.659$, *SD=0.243* versus $M_{H\text{-}DHLIGroup}=3.730$, *SD=0.099 t(4)=-7.066, p=.002;* d_{Cohens} *=0.002 negligible effect*[544]]. Median *DHLI* scores were 1.0 DHLI unit different between groups [$\text{Median}_{L\text{-}DHLI\text{Group}}=2.762$, range 2.381-2.833 and $\text{Median}_{H\text{-}DHLI\text{Group}}= 3.762$, range 3.619-3.810].

Inferential statistical analysis found all seven *DHLI* sub-scales significantly different between groups, except for sub-scale '2-*Information searching*' (*p*=.070; d_{Cohens} *=0.057 negligible effect*[544]) and sub-scale '6-*Adding content*' (p=.078; d_{Cohens} *=0.064 negligible effect*[544]). Appendix 8.3A-C summarises the six participants characteristics collated from survey responses. Demographically, no significant statistical difference was identified between *DHLI* participant groups, as these were similar in age, level of socioeconomic advantage, employment status, household income, and educational attainment. L-*DHLI* group differed from the H-*DHLI* group in female representation and language spoken at home (English). Relative descriptors of Internet behaviour were also similar: frequency of use, amount of help required to complete online tasks, augmentation of on-screen information, and confidence levels technology use and experiencing an increased level of anxiety when using computers/devices. L-*DHLI* group expressed significantly lower self-assessed ability to identify levels of trustworthiness of online information [$U(N_{L\text{-}DHLI}\text{Group}=3,\ N_{H\text{-}DHLI}\text{Group}=3)=.000$, z=2.121, *p=.034;* d_{Cohens} *=0.028 negligible effect*[544]) and levels of the usefulness of the Internet to inform health decisions as assessed by eHEALS questionnaire - Supplementary Question 1 [$U(N_{L\text{-}DHLIGroup}=3,\ N_{H\text{-}DHLIGroup}=3)=.000$, *z=2.121, p=.034,* d_{Cohens} *=0.028 negligible effect*[544]]. L-*DHLI* members also preferred tablets (iPad) compared to a desktop/laptop configuration favoured by participants in the H-*DHLI* group. The analysis also found that the mean number of categories created within the open card sort (Stage 1, section 7.6.6) was statistically significantly higher in H-*DHLI* participants [7 categories compared to 2.50; *t(2)=-9.000, p=.012,* d_{Cohens} *=0.01 negligible effect*[544]]. User characteristics contextualised the 'why and how' strategies employed by participants to complete activities and explained the observed behaviours during usability evaluation sessions.

8.6.1 EVALUATION METHOD 1. SITE LEARNABILITY

Finding the same target information, timed data, success/failure rates, and ease of activity completion SEQ were collected for each participant across three trials. Two participants in the L-*DHLI* group and one in the H-*DHLI* group chose not to complete one of the three trials due to frustration and tiredness. Target information could be found in two different website areas, embedded within a PDF and web page. Participants were not aware of the specific target locations before task commencement. Participants in the L-*DHLI* group located target information within PDF compared to H-*DHLI* participants who identified target information on the webpage. Due to small group numbers and incomplete trials producing missing data points, it was challenging to determine definite trends within and across datasets, especially for L-*DHLI* group measures. Table 8.8 summarises activity trial data.

Table 8.8 Timed and observational data collected from repeated learnability activity for high and low *DHLI* groups

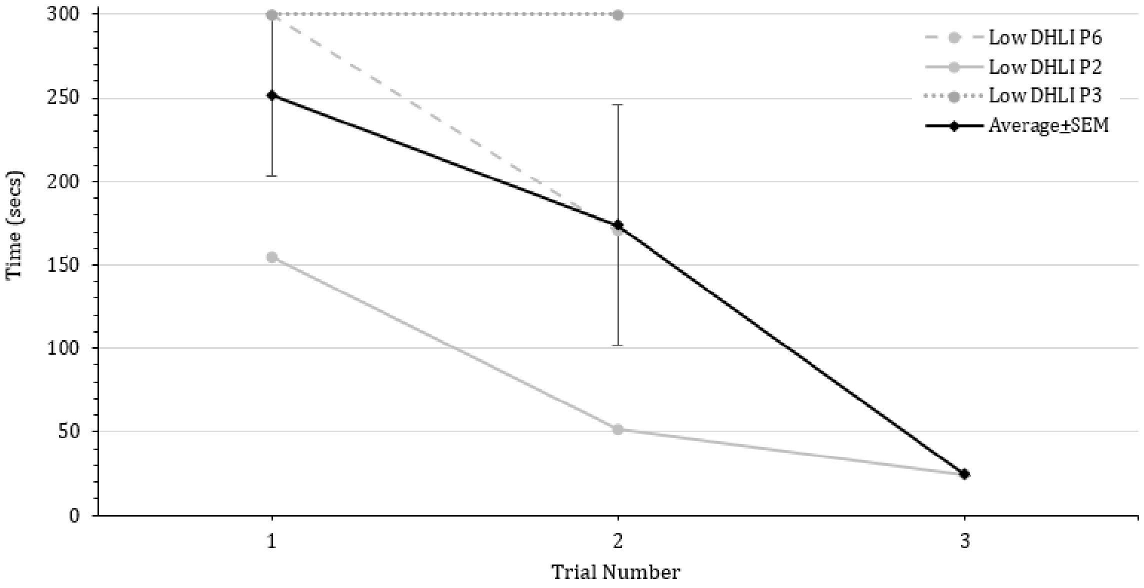
Overall Activity Group Performance	**Low *DHLI***	**High *DHLI***	***p*-Value (d_{Cohens} effect size)**
Mean *DHLI* Score (Mean±*SD*)	2.524±0.208	3.730±0.099	*.001 (d=.001, small)*
Mean SEQ Ease of Completion (Mean±*SD*)	3.33±2.21	5.00±2.65	.526 *(d=.429, intermediate)*
Max average time difference between trials (Mean±*SD*)	87.0±75.35	97.0±47.51	.860 (*d=.702, large*)

		Trial 1 (T1)		**Trial 2 (T2)**		**Trial 3 (T3)**	
***DHLI* group**	**Participant**	**Time (secs)**	**Completion failure/success**	**Time (secs)**	**Completion failure/success**	**Time (secs)**	**Completion failure/success**
Low	2	155	1	52	1	24	1
	3	300	0	300	0	n/a	0*
	6	300	0	170	1	n/a	0*
Mean±*SD*		251.67±83.72		174±124.05		24.0±0.0	
Success:Failure (%Success)			1:2 (33.32)		2:1 (66.67)		1:2* (100.0)
High	1	55	1	15	1	9	1
	4	140	1	136	1	35	1
	5	300	0	n/a	0*	160	1
Mean±*SD*		165.0±124.40		75.50±85.56		68.0±80.73	
Success:Failure (%Success)			2:1 (66.67)		2:1* (100.0)		3:0 (100.0)

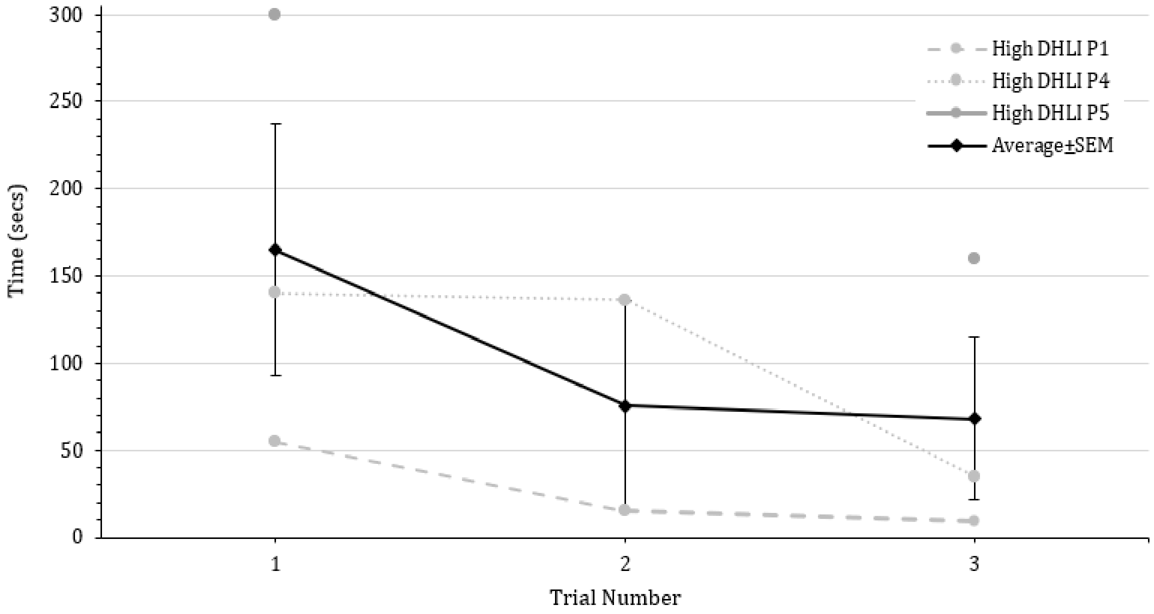
Successful target location = 1 and failure = 0. Participants not wanting to repeat individual trials were recorded as a 'failure' and did not contribute to the analysis (represented by 0*).
Differences in timed performance between *DHLI* groups were examined using one-way repeated measures ANOVAs. The analysis found no significant differences within and between groups for timed completions.
No significant differences were identified between successful completion rates between L-*DHLI* and H-*DHLI* (T1: p=1.00, T2=1.00, T3 *p=0.40*).

For H-*DHLI* participants, time to completion also decreased across trials [M_{Trial1}=165.0 seconds, *SD*=124.4 vs M_{Trial3}=68.0 seconds, *SD*=80.73], although time to complete was not significantly different between first and last trials (*p*=.321, $d_{\mathit{Cohe}\text{ns}}$ *=0.262 small effect* [544]). These participants also had increased success at completing trials (where repetition improved across trial numbers); participants in the L-*DHLI* group were more likely to fail or incomplete trials during the first and last runs of the activity. Notably, there was a measured reduction on average in the time taken finding target for those with L-*DHLI* between T1 - (251.67 seconds, *SD*=83.72) and T2 (174.0 seconds, *SD=124.05*).

Refusals to undertake a third trial impacted the ability to define the rate of improvement for this group. Subsequent trial times can only speculate as to a similar decline rate as observed in H-*DHLI* group trials. Timed differences between group mean for low and high *DHLI* group data were found not to be statistically different when examined using repeated measures one-way ANOVAs. Timed trial data is presented for the L-*DHLI* group in Graph 8.1 and H-*DHLI* group in Graph 8.2.



Graph 8.1 Timed learnability tasks for low *DHLI* group



Graph 8.2 Timed learnability tasks for high *DHLI* group

After each trial, participants self-reported ease of completion for this activity. Table 8.9 summarises this data, including an individual's *DHLI* score, the total number of successes, failures or did-not-attempt across all trials. High SEQ correlated strongly with the ability to complete the trial and self-rated ease of completion.

Table 8.9 Trial success-failure rates and reported ease of completion SEQ for learnability activity

			Total trials in session			
	Participant	***DHLI* score**	**Success**	**Failure**	**Did not attempt**	**Ease of completion SEQ**
L-*DHLI*	2	2.4285	3	0	0	7
	3	2.3809	0	2	1	1
	6	2.7619	1	1	1	2
					Mean	3.33
					SD	3.21
H-*DHLI*	1	3.762	3	0	0	7
	4	3.810	3	0	0	6
	5	3.619	1	1	1	2
					Mean	5.00
					SD	2.65

Those participants who failed to locate the target or did not attempt trials were more likely to report a lower SEQ score indicating a more complicated experience completing the task. Overall, participants in the L-*DHLI* group reported that they found this activity more challenging than the H-*DHLI* group, who found the activity more comfortable to complete [$M_{L\text{-}DHLI}SEQ=3.3$, *(SD=3.21) vs* $M_{H\text{-}DHLI}SEQ=5.0$ *(SD=2.65), p=.526;* $d_{Cohens}=0.429$ *intermediate effect*[544]].

8.6.2 EVALUATION METHOD 2. CLOSED CARD SORT

Two data sets were created from cards associated directly to menu headers or disassociated from the primary menu and related to the second-level content. The first dataset contained cards directly associated with three top menu headers, 'At the End', 'Specific Groups' and 'Using Online Information' directly linked to level 2. Analysis of this dataset demonstrates differences between developers' content placement with information architecture and how participants viewed the relationship between content and content groups (Table 8.10).

Table 8.10 *DHLI* Group sorting outcomes for concepts with associated menu items – At the End, Specific Groups and Using Online Information

Current top-menu descriptor	Concept (card) descriptor	Selected menu categories	Identified correct category	% Agreement between *DHLI* groups
At the End	Things to think about dying at home	• For Patients • For Families • *At the End**	Low *DHLI*	3 (50.0)
At the End	What happens after death	• *At the End** • For Carers • Specific Groups	Low/High *DHLI*	4 (66.67)
Specific Groups	Importance of families and community groups	• For Families	Low/High *DHLI*	6 (100.0)
Specific Groups	Understanding the language of palliative care	• For Carers • For Families • Using Online Information	Neither	5 (83.33)
Using Online Information	Importance of research and evidence	• *Online Information** • Specific Groups	Low/High *DHLI*	5 (83.33)
Using Online Information	Find good sources of information	• For Carers • For Families • *Online Information**	Low/High *DHLI*	4 (66.67)

**=Correct menu categories*

‘Specific Groups’ category concepts, all participants misplaced cards into other menu categories. Discussions by all participants querying the definition of ‘Specific groups’ highlighted the uncertainty around this term. For participants, conceptually, ‘*Importance of families and community groups*’ belongs within the ‘For Families’ section (100% agreement for all 6 participants). ‘*Understanding the language of palliative care*’ was placed into three categories (‘Using Online Information’, ‘For Families’ and ‘For Carers’), reflecting 83.33% agreement across 5 participants. Other concepts (cards) related to the menu headings, ‘Using Online Information’ and ‘At the End’ were found to have differing degrees of variation in placement within categories, with 4-5 participants across *DHLI* groups reaching an agreement for concepts ‘*What happens after death*’, ‘*Importance of research and evidence*’ and ‘*Find good sources of information*’. ‘*Things to think about dying at home*’ was placed correctly more often by members of the L-*DHLI* group, with 50% agreement that conceptually placed this card in the ‘For Patients’ menu within both L-*DHLI* and H-*DHLI* groups.

The second dataset presents cards and categories ‘disassociated’ from a first level menu item and related to the second level section headers. This analysis provided an opportunity to discover how participants group concepts with seven of the top menu buttons on the section Home page. This reflected the actual user experience of the developer’s ‘inferred navigation’ pathway within the Patients and carer section of the website. Table 8.11 summarises associations between second-level sections concepts, categories selection, and agreement level across these *DHLI* groups. The level of agreement ranged between 50% (*n*=3 participants in agreement) and 100% (*n*=6 where all participants agree) on the placement of cards in the category/ies chosen. All six participants displayed 100% agreement on placing six cards into ‘For Patients’ and ‘For Carers’ groups. The greatest variation was observed in the sorting of ‘*Different types of medicines*’, ‘*Voluntary Euthanasia and* ‘*Voluntary Assisted Dying (VAD).*’

‘*Managing Symptoms*’ and ‘*When does end of life care begin*’ also had 100% agreement but for a two-category (‘For Carers’ or ‘For Families’) or three category sorts (‘For Families’, ‘For Patients’ or ‘At the End’). Participants used the ‘Unsure’ category for three concepts: the ‘*Importance of finding the right person to talk to*’, the ‘I*mpact of looking after someone*’, and ‘*Navigating the health system*’ twice by participants in the L-*DHLI* group and once by members of H-*DHLI* group. Auxiliary concepts (*) in Table 8.11 were sorted into 2, 3 or 4 different categories with 50-100% agreement across groups. Participants placed these concepts into different categories in diffuse patterns that were not specific to *DHLI* levels.

Table 8.11 Summary of closed card sorting for concepts not associated with 'Menu button options' on the section header page

		Menu Categories chosen for 'Uncategorised 2nd Level Concepts.'		% Agree / groups
2 level Header	**Concept (Card) Descriptor**	**Low *DHLI***	**High *DHLI***	
Living with Illness	*Importance of finding the right person to talk to*	2 Finding Services, 1 UNSURE	1 For Patients, 1 For Families, 1 F/Serv.	3 (50.0)
About Palliative Care	*Ways of finding information about services*	2 For Families, 1 Finding Services	2 Finding Services, 1 Online information	3 (50.0)
Other	*Voluntary Assisted Dying (VAD)**	1 For Patients, 1 For Families, 1 Specific Groups	2 For Patients, 1 At the End	3 (50.0)
Other	*Voluntary Euthanasia**	2 At the End, 1 Specific Groups	2 For Patients, 1 At the End	3 (50.0)
Other	*Navigating the health system**	1 For Carers, 2 Finding Services	2 For Carers, 1 UNSURE	3 (50.0)
How to Care	*Impact of looking after someone*	2 For Carers, 1 UNSURE	2 For Carers, 1 Family	4 (66.67)
Practical Caring Resources	*Different types of medicines*	For Patients, 1 Carers, 1 At the End	1 For Patients, 1 Carers, 1 Online Information	4 (66.67)
Practical Caring Resources	*How do you say goodbye to someone who is dying*	3 For Families	1 For Families, 2 At the End	4 (66.67)
Living with Illness	*Communication and being honest and open*	Two possible categories: For Carers or UNSURE		5 (83.33)
How to Care	*Accepting help when offered*	Two possible categories: For Patients or Carers		5 (83.33)
Other	*Explanation of what palliative care is**	Two possible categories: For Patients or Families		5 (83.33)
Living with Illness	*Dealing with Government departments*	Two possible categories: For Carers or Finding Services		5 (83.33)
Living with Illness	*Wills, Advance care planning and Advance directives*	Two possible categories: For Patients or Families		5 (83.33)
About Palliative Care	*Accessing services*	Two possible categories: For Families or Finding Services		5 (83.33)
Practical Caring Resources	*Supporting carers to care*	For Carers		5 (83.33)
Living with Illness	*Expected costs of care*	For Families		5 (83.33)
Bereavement, Grief and Loss	*Supporting children during grief*	For Families		5 (83.33)
How to Care	*Difficulties of being a carer*	For Carers		6 (100.0)
Living with Illness	*Prognosis and Quality of life*	For Patients		6 (100.0)
Living with Illness	*Emotional roller coaster for Carers*	For Carers		6 (100.0)
About Palliative Care	*Organising and keeping track of care*	For Carers		6 (100.0)
Bereavement, Grief and Loss	*Recognising grief and sadness*	For Families		6 (100.0)
Living with Illness	*Managing symptoms*	Two possible categories: For Carers or Families		6 (100.0)
Other	*When does end of life care begin**	Three possible categories: For Patients or Families or At the End		6 (100.0)

***Auxiliary cards**

Therefore, diverse audiences may experience difficulties navigating these concepts due to varying expectations of finding these cards within a site's architecture. SynCaps software[577] was used to generate the visual relationships between concepts to illustrate relationships' strength and explore differences or similarities in sorting behaviours between *DHLI* groups. Relationships are illustrated within Figures 8.2A and 8.2B presenting high and L-*DHLI* group dendrograms.

There were differences between the number of nodes/branches created, five compared to 4 for low and H-*DHLI* groups. The second node (node-2) on L-*DHLI* dendrogram three concepts directly explain interactions with health systems or services (*'Importance of finding the right person to talk to'*, '*Navigating the health system*' and '*Dealing with Government departments'*) perhaps reflecting 'real-life' experiences dealing with these organisations.

Three carer concepts had shared associations shown by clade equidistance in node-1 in dendrograms of both *DHLI* groups. '*Difficulties of being a carer*', *'Emotional roller coaster for carers'* and '*Organising and keeping track of care*' were shared between groups whilst the L-*DHLI* group also grouped *Supporting carers to care* within this branch. The remaining concepts in this node were related to practical aspects or roles of carers compared with node-1 for H-*DHLI,* which presents a diverse range of concepts reflecting care at a service or system level and demonstrating a close relationship between '*Understanding the language of palliative care*' and '*Find good sources of information*'*.* Although dendrograms were visually different, analysis of *DHLI* group proximity matrices using the Mantel Test found these were similar, positively correlated (*r(48)=0.515, p<.001; large effect*[544]). '*Importance of research and evidence*' demonstrated a different relationship to other concepts regardless of *DHLI* level, shown in node-5 and node-4 for both low and high *DHLI* groups. Complementary concepts related to research and evidence described an 'action' of finding information, relating to information to support care and the other to locate services.

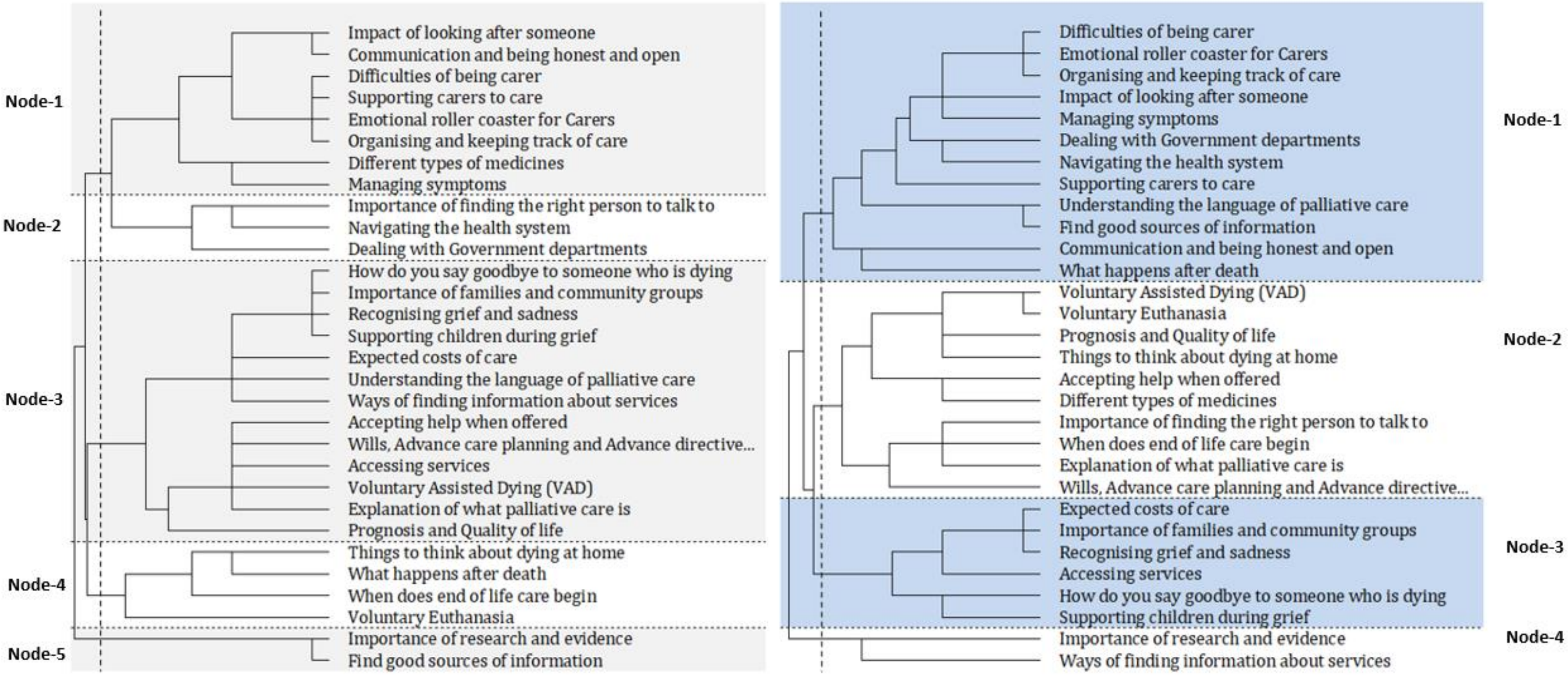


Figure 8.2A Low *DHLI* group dendrogram for CCS

Figure 8.2B High *DHLI* group dendrogram for CCS

Figure 8.2A and 8.2B *DHLI* Group dendrograms from CCS activity

L-*DHLI* participants required significantly greater time to complete the card sorting activity, averaging 752.67 seconds (*SD=178.48*, 12 mins 54 secs) when compared to participants in the H-*DHLI* group who averaged 404.0 seconds (*SD*=2.83, 7 mins 13 secs) [$t(4)=3.527, p=.024; d_{Cohens} =0.02$ *small effect*[544]]. Both groups reported this activity relatively easy to complete [$SEQ_{L\text{-}DHLI}$ =4.0 (*SD=2.0*) vs $SEQ_{H\text{-}DHLI}$ =5.50 (*SD=.71*)]. Table 8.12 summarises completion time and ease of completion SEQ.

Table 8.12 Time to complete and level of ease in completion SEQ for CCS activity

	Participant	***DHLI* score**	**Completion time (secs)**	**Ease of completion SEQ**
Low *DHLI*	2	2.4285	702	4
	3	2.3809	605	6
	6	2.7619	951	2
	Mean	2.524	752.67	4.0
	SD	0.208	178.48	2.0
High *DHLI*	1	3.7619	402	6
	4	3.8095	406	5
	5	3.619	320	3
	Mean	3.786	404.0	5.50
	SD	0.03	2.83	0.71

8.6.3 Evaluation method 3. First-click analysis

Data was collected from sequential first-click tasks from all six participants (three per participant, nine per group). After completing sessions, all data was downloaded and analysed for timed completion, success and failure rates and ease of activity completion SEQ. Table 8.13 presents all data and supplementary calculated data variables for each task of this activity.

Task 1 was a task-based scenario whose correct path was the ‘Using Online Information’ menu button. All three H-*DHLI* group participants were selected correctly and completed a task on average faster than members of the L-*DHLI* group.

Table 8.13 Task scores and timed variables for first-click analysis activity for low and high *DHLI* groups

	Overall activity group performance	**Low *DHLI***	**High *DHLI***	***p* value**
	Mean *DHLI* score (*M* ±*SD*)	2.524±0.208	3.730±0.099	*0.001*
	Mean successful % tasks (*M* ±*SD*)	55.33±38.68	77.33±19.63	0.429
	Mean SEQ Ease of Completion (*M*±*SD*)	5.33±1.15	6.0±0.0	0.423
Task Number	Group Effectiveness (%)	66.67%	77.77%	
1. You visited a close relative at home who is currently receiving palliative care for an illness that cannot be cured. In your conversation, your relative told you that they were thinking of starting a new treatment that they found online that is reported to help and even cure their condition. You are worried that they have been tricked into finding and believing false or misleading health information. **[Flesch-Kincaid Readability Grade Score = 11.6]** *Find some information to show them to help give clues to work out safe, high-quality information on the Internet*	**Task time (secs)**	16.05±2.01	7.98±3.69	*0.029*
	Success:Failure	1:2	3:0	0.400*
	Time efficiency (goals per sec)	0.022	0.149	0.069
	Task effectiveness %	33.33	100.0	
	SEQ Ease of completion	5.33±2.082	6.67±0.577	0.345
	SEQ Level of confidence correct choice	4.670±2.517	6.67±0.577	0.251
2. You live in a medium-sized country town a good 4-5 hours from the nearest capital city. Your next-door neighbour lives alone and has asked you to look after his garden as he has been told that things are not going very well with his health. He will need to go to the city to see a specialist. As he does not drive, you are worried about the uncomfortably long bus trip that he would have to take. **[Flesch-Kincaid Readability Grade Score = 7.3]** *You would like to suggest some alternatives and find information about helping him organise transport to the city for his treatment.*	**Task time (secs)**	30.14±17.45	6.70±2.90	0.142
	Success:Failure	3:0	3:0	
	Time efficiency (goals per sec)	0.174	0.049	0.091
	Task effectiveness (%)	100.0	100.0	
	SEQ Ease of completion	4.67+1.528	6.00+1.00	0.275
	SEQ Level of confidence correct choice	4.670+1.528	6.33+0.577	0.152
3. A close friend has been told that there is no further treatment available for their illness and that it is time to prepare for what lies ahead. You have had a chance to talk about what they would like and their wishes. Your friend has said they would like to die at home, but you are unsure if this is a reality as you are worried about their partner. **[Flesch-Kincaid Readability Grade Score = 7.9]** *Find some information that may help your friend and their family to decide if dying at home is a practical or realistic option for their situation.*	**Task time (secs)**	17.93±13.38	27.37±10.09	0.385
	Success:Failure	2:1	1:2	1.000*
	Time efficiency (goals per sec)	0.077	0.010	0.399
	Task effectiveness %	66.67	33.33	
	SEQ Ease of completion	6.00±1.00	5.33±0.577	0.374
	SEQ Level of confidence correct choice	5.00±1.00	4.67±0.577	0.643

* Data was analysed using two-tailed Pearson's Chi-squared analysis using Phi and Cramer's V nominal association.

Flesch-Kincaid Readability Score considers words per sentence and syllables per words[598] and indicates the US education school grade levels required to comprehend the written text.

This difference was statistically significant at $p<0.05$ level [$M_{H\text{-}DHLI}$ *=7.98 seconds (SD=3.69)* vs $M_{L\text{-}DHLI}$ *=16.05 (SD=2.01), t(4)=3.330, p=.029;* $\eta^2=0.0097$ *small effect*[544]] and the H-*DHLI* group were increasing more time and task efficient in completing the task. L-*DHLI* group participants were also more likely to self-report lower confidence levels in selecting 'correctly' corresponding with a lower level in ease of completion than H-*DHLI* members. This disparity could be due to the higher comprehension levels required to understand the scenario given the increased readability level impacting measures of efficiency, confidence and ease. In Task 2, participants located information regarding services for their neighbour, where the correct path was selecting 'Finding Services' from the menu. All six participants completed the task. Participants in the H-*DHLI* group completed this task more efficiently, although task effectiveness was measured equally.

Ease of task completion was rated on average more difficult than Task 1 for L-*DHLI* group participants, although the confidence level of choosing 'correctly' was similar. Conversely, the H-*DHLI* group reported high ease and confidence in completing Task 2, similar to completing the first task. The final task was assessed as the most difficult, eliciting the lowest confidence levels for H-*DHLI* group members compared to higher self-reported levels by L-*DHLI* group participants. Task 3 invited participants to find information to help friends evaluate living situations' suitability to safely care for someone dying at home. Task 3 invited participants to find information to help friends evaluate living situations' suitability to safely care for someone dying at home. On average, task completion for H-*DHLI* participants was three times longer than previous tasks at a 33% success rate. The L-*DHLI* group identified the correct path with 66% success, completed the task similar to the first task and operated at greater efficiency than H-*DHLI* participants. Overall, the H-*DHLI* group were on average more successful at predicting correct paths [$M_{\text{L-}DHLI\text{Success}}$=55.33%, (*SD*=38.68) vs $M_{\text{H-}DHLI\text{Success}}$=77.33%, (*SD*=19.63), *p*=.43; $\eta^2=0.1433$ *small effect*[544]] with greater effectiveness (77.77% compared with 66.67%) and found the activity more comfortable to complete than those participants in the L-*DHLI* group [$M_{H\text{-}DHLIEaseSEQ}$=6.0 vs $M_{L\text{-}DHLIEaseSEQ}$=5.33*, (SD*=1.15*), p*=.42*;* $\eta^2=0.14$ *small effect*[544]].

8.6.4 EVALUATION METHOD 4. SEMI-STRUCTURED INTERVIEW OF UX

The semi-structured interview duration was a 5–10-minute period during each participant's evaluation sessions. Three primary questions were asked each participant; a) technological device preference, b) mode of information presented and c) and features of interface design that assisted search behaviour. Participants provided feedback on each of these topics concerning their behaviours and experiences. Limited feedback was gathered on participants' thoughts of the CareSearch Patients and Carers section due to time constraints and relative lack of user interrogation of the site's inner sub-sections. Due to the narrow focus and quality of descriptions within the website narrative, formal qualitative analysis (such as thematic or content analysis) was not undertaken. Instead, a similar approach was employed to analyse expert and user-based reports of interface issues (as described in Study 3, section 6.8.5.4 and 6.8.8.5, respectively). Appendix 8.4A and 8.4B provides a summary of data captured for *DHLI* groups. Tables also include observations on interactive behaviours and background demographics for each group, including *DHLI* sub-scales. For H-*DHLI* group participants, questions were irrelevant as they propositioned their behaviour to be exemplary, limiting the scope and exploration of query probes.

Other participants were open but self-deprecating regarding their abilities and capabilities to find online information, such as "*I am pretty terrible at working on a computer*" [Participant 3]. This attitude was apparent in participants with the lowest *DHLI* scores (P3 and P6 in the L-*DHLI* group). Discussions focussed on header page structure, including menu structures and images before moving into the second level, focusing on left-hand menus (LH), horizontal drop-down menus (HM), page structure, information flow and types of images used. Interestingly, discussions with H-*DHLI* group members (P1 and P4) were more comprehensive and, although they had similar exposure to the section as other participants, provided more contextual and structural feedback on both features of the site. Participant's suggestions and commentary focussed on information design, internal section structures such as flaws in HM and disassociation of second-level pages with eight menu buttons. These two participants also recognised pragmatic difficulties that some end-users would experience using this site, especially those with different technological skills or content knowledge compared with their own. Issues included complex menu structures (LH and HM), relative ease of making navigation errors, accidentally leaving the section, and getting lost within site.

Acknowledging excess information available for this intended audience (patients, carers, or family members) could cause the sense of being

> *"overwhelmed and perhaps [they] feel pressure to read everything when perhaps they need a little information to start with, then give them an option to read more later when they need it".*

[*H-DHLI* Participant]

In contrast, *L-DHLI* group members, when discussing their thoughts on these features, had their attention easily distracted away from questions posed as they had discovered something new and then felt like they needed to explore this feature. For example, P3 experienced the most significant difficulty navigating the section to complete previous evaluation activities. When the discussion turned to navigation features that felt helpful in their own experience, LH and HM structures were illustrated as a 'type' of a navigation device. P3 was surprised that these were present (had not noticed they were there), and after practising using these menus, they commented that these features would help 'other' people to use. P3 proposed that they would still experience difficulties even after knowing menus were there as

"I am terrible at following instructions" [and pointing to menu hyperlink descriptors] ...
"and reading these on the screen".
[L-*DHLI* Participant]

For P6, even with menu structures highlighted, "*I felt the site was overly difficult to use*", or a "*bit tricky, this one*" [... describing the website]. There were minimal feedback and commentary provided about the website section from L-*DHLI* group members as they found the site far too complex to navigate and failed to understand the structure to begin to explore the content.

8.6.4.1 Influence of device preference on interactions

Observed device preference was directly related to confidence and expertise in navigating a complex and information-heavy website. All four participants who preferred to use a desktop/laptop as their in-principle configuration (for finding, viewing, and reading online information) were observed to work more efficiently independent of their *DHLI* score. These individuals were aware of navigation features, were deliberate in their navigation approach, and understood the fundamentals of how websites are designed in terms of linked pages on different levels of the site. Two participants (P3 and P6), having the lowest measured *DHLI* scores, preferred Apple iPads as their choice of device to browse and interact with online information. These participants justified their tablet choice over a laptop/desktop for ease of use, connectivity, and portability. These participants could not recognise navigation features or landmarks, menu structures or observe relational connections between different web pages or within 'sections' of the CareSearch website. These individuals skipped along the website's surface without knowledge or skills of moving deeper into the site to find the information they were looking for, most likely in fear of getting lost within site and not having the ability to find a way out. However, their observed navigation behaviour seems to be counterintuitive to this fear of virtual disorientation. P3 and P6 were observed systematically moving through all hyperlinks available on a page to try and locate the information required, and even when asked if this was typical online behaviour, both indicated that this was their conventional practice to find information:

> *"if it is not right for you, you would kinda go back and press the next one until you found something" [..that would give you the information you were looking for]."*
>
> [L-*DHLI* Participant]

Conversely, H-*DHLI* participants indicated using the Google search engine if unable to locate the information required in-site. A search engine became a strategic starting point for a systematic search approach to find a targeted piece of information.

Participants either described or were observed undertaking similar behaviours depending on each device of choice and type of tasks performed. Participants of all DHL levels reportedly used their phones to perform quick searches or complete short, uni-purposed activities such as checking timetables or prices requiring minimal steps and interaction with small amounts of information. For more detailed searches, reading or interacting with more complex sites, participants displayed sophisticated approaches to saving or referring to information by self-notification. Approaches included using site bookmarks or sending self-notifications via social messaging or e-mail, including the link to the resource where they would view, read, interact, or print from their preferred device. Older participants had a reportedly higher likelihood of printing information to read later, whilst younger participants felt comfortable reading and comprehending onscreen information.

8.6.5 EVALUATION METHOD 5. SYSTEM USABILITY SCALE (SUS) QUESTIONNAIRE

SUS questionnaire data was exported from Qualtrics[432] and manipulated in Excel,[528] producing a total SUS score for each participant. Performance measures including the time to completion (seconds), Ease of completion was downloaded, and each participant was in low and high *DHLI* groups. Table 8.14 provides participant SUS data and associated calculated measures of satisfaction for each *DHLI* group.

Table 8.14 SUS questionnaire scores for low and high *DHLI* groups

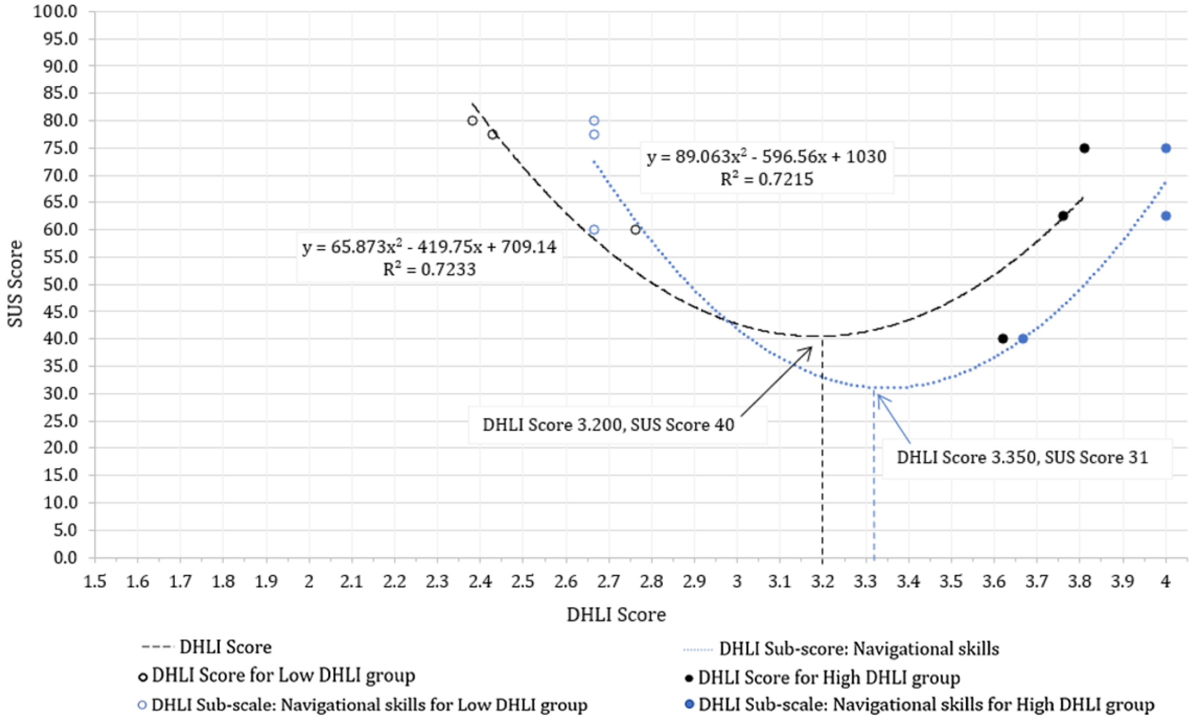
	Participant	*DHLI* score	Completion time (secs)	SUS final	Ease of completion SEQ
Low *DHLI*	**2**	2.4285	182	77.5	6
	3	2.3809	217	80.0	7
	6	2.7619	255	60.0	3
	Mean	2.524	218.0	72.50	5.33
	SD	0.208	36.51	10.90	2.08
High *DHLI*	**1**	3.7619	200	62.5	7
	4	3.8095	185	75.0	7
	5	3.619	238	40.0	6
	Mean	3.730	207.67	59.17	6.67
	SD	0.099	27.32	17.74	0.58

Participants found the SUS questionnaire relatively uncomplicated and easy to complete (SEQ ranged 6-7). Except for an L-*DHLI* group participant who found this questionnaire challenging to complete measuring longest time to completion (255 seconds) and SEQ=3. Average time to complete was similar between low and H-*DHLI* groups [$M_{L\text{-}DHLISUScomplete}$*=218.0 seconds, SD=36.51 vs* $M_{H\text{-}DHLISUScomplete}$ *=207.67 seconds, SD=27.32; t(4)=.392, p=.715;* d_{Cohens}*=0.584 intermediate effect*[544]], and as was SEQ [$M_{H\text{-}DHLISEQ}$*=5.33, SD=2.08* vs $M_{L\text{-}DHLISEQ}$*=6.67, SD=0.58, t(4)=-1.069, p=.345;* d_{Cohens}*=0.282 small effect size*[544]]. Calculated SUS scores varied across participants and between *DHLI* groups. L-*DHLI* group had M_{SUS}=72.50 (*SD=10.90*), and conversely, H-*DHLI* group SUS scores were on average lower (although not significantly *p*=0.329; d_{Cohens}*= 0.269 small effect size*[544]) with M_{SUS}=59.17 (*SD=17.74*).

Overall, participants with H-*DHLI* scores were less satisfied with the site section than the L-*DHLI* group and indicated a lower overall acceptability rating. Conversely, L-*DHLI* participants measured higher satisfaction levels but indicated less practical, real-time interactions with site content and information than H-*DHLI* participants who were highly critical of the overall experience.

This finding prompted further analysis exploring an apparent inverse relationship between *DHLI* status and SUS scores and was visualised explored by graphing these variables against each other. The resultant relationship was described quadratically [equation $y = 65.873x^2 - 419.75x +$

709.14, R^2 = 0.7233; large effect size[544]]. This parabolic line had a vertex (where a change in the level of satisfaction measured by SUS was zero) at *DHLI*=3.200 and SUS score=40. Exploratory graphs discovered which *DHLI* sub-scales displayed a similar relationship as overall *DHLI* score to SUS satisfaction outcomes. Navigation skills subscale was identified as the only sub-scale to have a similar relationship to SUS [equation $y = 89.063x^2 - 596.56x + 1030$, $R^2 = 0.7215$, *large effect size*[544]] with vertex at *DHLI*=3.350, SUS score=31. These two equations are presented visually in proximity to measured outcomes from the two questionnaires in the two *DHLI* groups of participants and displayed in Graph 8.3.



Graph 8.3 Graphical representations of the relationship between SUS satisfaction scores, *DHLI* total scores and navigational skill subscale

The forthcoming discussion will examine the implications for selecting representative participants involved in usability evaluations assessing acceptability and usability of interface designs where the general population is the intended audience.

8.7 DISCUSSION

This study explored performance outcomes and online behaviours of two usability samples stratified by levels of DHL during the evaluation of a palliative care interface. Results suggest the

DHLI scale successfully produces two groups differentiated by significantly different levels of DHL from a sample with similar demographics. Outcomes from five evaluation methods found that participants with low DHL levels perform and behave very differently when interacting online when compared to a technically savvy group of participants with higher DHL levels. Findings suggest there are implications for developers who may choose to utilise this strategy in practice. Stratification by *DHLI* to diversify usability feedback will require developers to select an appropriate UEM for both participants and the area of interest and then manage participant expectations to generate meaningful data to improve universal interface designs.

8.7.1 GROUP DHLI, CHARACTERISTICS AND ONLINE BEHAVIOURS

Participants who completed this stage of the research appreciated opportunities to be involved and at no stage were their *DHLI* score disclosed to them directly, although individuals had an intimation of their skills and abilities. *DHLI* scores from the extremes of the distribution presented common attitudes and behaviours between individuals with similar DHL levels. H-*DHLI* participants were all highly skilled, confident, comfortable, and efficient at using interfaces. Interestingly, technical assistance was provided to *all* participants aged over 60 regardless of the *DHLI* group, both before commencing and during the remote evaluation session. Assistance was commonly solving issues relating to operation and transitions between software, platforms, or screens. Levels of functional computer literacy or 'computer or technical savviness' appeared to be graduated across DHLI distribution. Individuals with the lowest *DHLI* scores experienced the greatest difficulties with being 'savvy' online and having fundamental operation and functional computer skills levels. H-*DHLI* individuals scoring between 3.762 and 3.810, being tech-savvy, required no support or assistance during activities. Individuals with the lowest DHL levels were anxious, had apparent issues with operation and navigation within the Internet and were more likely to 'give up' if the retrieval was unsuccessful or in-site navigation failed. Within the small sample, there is an evocation of the presence of a third group based on observations and performance across activities.

Motivations for participation also varied between groups and across *DHLI* scores. Individuals with high technological skills (across both *DHLI* groups) considered it a significant opportunity to offer altruistic support for research. Alternatively, participants with limited digital skills and discerning comfortability with the Internet welcomed the prospects of receiving tutoring in improving their skills using their devices. For developers, this could be the selling point of recruitment strategies focussed on L-*DHLI* groups. Provision of short skills-based sessions adjunct to the evaluations session could be offered as a trade-off between learning new skills and valuable feedback on improving health interfaces.

In this study, the positive evaluation experienced by L-*DHLI* participants could reflect a significant ‘contribution’ to overall SUS satisfaction scores measured within this group, perhaps subconsciously evaluating the satisfaction of increasing their scholarship (through support and reassurance) instead of rating their usability satisfaction. Overall, SUS scores contradict participants’ narrative reports on website structure and eluded operational or navigational success during evaluation activities (discussed in section 8.72). Technical skills are considered equally important in determining total *DHLI* scores as health literacy and observed differences impacted all activities' performance and ease of completion.

8.7.2 USABILITY EVALUATION METHODS AND INFLUENCE OF DHLI SCORES

An array of usability evaluation activities explored various aptitudes contributing to DHL and digital readiness as described by the total *DHLI* score and seven sub-scales of the *DHLI* questionnaire across participant samples. Performance outcomes (task success or completion) were strongly associated with high DHL. Specifically, *DHLI* sub-scales contributed to different aspects of interaction behaviours, supporting observations from van der Vaart et al.[495] As mentioned previously, there was observed graduation of functional and digital competency with increasing levels of DHL. However, specific user characteristics were not as apparent in their impact on the behaviour of higher DHL participants compared to individuals with lower DHL. For example, unfamiliarity with the interface did not perturb interactions; participants adapted to quickly scan and focus on the information most relevant to their search narrative.[599,600] Simultaneous processing and rapid decision-making of retrieved interface information is perhaps a product of higher literacy levels through practical understandings of interface language[601] and their relational meanings to functional components of interface design. As posited from the findings of the open card sort, this is perhaps a product of semantic versus pragmatic understandings of phrases, combined is a skill set developed from experiential learnings founded on increased exposure to using both the Internet and technology.

Inexperienced participants, intermittent Internet users or individuals with low English proficiency performed characteristic behaviours indicating task effects of an increased cognitive load. Difficulty starting the task, searching for sequential ‘clues’ within navigation devices, getting lost within the interface[141,602,603] and hesitation in taking the next step were commonly observed. Hesitation was contemplative of 'being overly sensitive to being distracted', fear of 'doing something wrong', 'breaking the site', or 'getting lost and not finding their way back' and familiar to older people.[141,602,603] Cognitive burdens[599,600] generated due to imbalances between working, short-term and long-term memory as participants attempted to reconcile experiential learnings to problem solve the task-at-hand. End-users simultaneously model new patterns or establish relationships between concepts[604] to navigate a solution.[605] As discussed in Chapter 7, this behaviour may not be positively influenced by increased exposure or experiences online due to factors influencing fixed levels of DHL, including social background, status, and physical characteristics that decline over time.[141,247] Consequently, outcomes suggest older people with higher DHL may not experience a similar cognitive difficulty as older frequent Internet users who are more likely to maintain cognitive health and function[606] during the ageing process. This finding suggests counterintuitively, older tech-savvy individuals with high DHL may not be ideal candidates to be involved in evaluations. Further research is required to investigate whether gender-specific cognitive function[606] influences DHL levels in digitally active ageing populations.

8.7.3 LEARNABILITY – THE MOST DIFFICULT OF THEM ALL

Overall, self-rated SEQ of completion scores from the learnability UEM indicates all participants found this activity the most difficult to complete, given the capabilities to employ technological skills, including search and navigation, then apply health literacy to discover, locate, and comprehend target information successfully. Learnability, or the extent to which naïve users over repeated exposures[575,576] can learn interfaces, was included in this study as it was considered an 'equivalent' experience for new palliative care users arriving at the site for the first time. New visitors must understand the structure, layout and information architecture with very little *pre-emptive* exposure or support. L-*DHLI* and our older participant (P5) experienced difficulty initially comprehending the task, finding a 'start' point within the interface, searching for sequential 'clues' only to forget what they were initially looking for.

The learnability evaluation method has highlighted the interplay between an individual's user characteristics, observed behaviours, and performance indicators, emphasising the complexity in understanding the causal factors influencing DHL for participants with low DHL. For example, the interaction between low literacy and age was reflected in decision-making behaviours, resulting in uncertainty leading to skipping chunks of text, tunnel vision,[599] re-reading navigation descriptors and content that forces the repetitive selection of hyperlinks.[247,603] These behaviours could also be impacted disproportionally by online inexperience, lack of confidence, and level of online autonomy, especially in individuals who read slower and find website structures more complex.[600,603]

Measures of interface satisfaction were inversely associated with DHL. Unlike other outcomes, the ability to complete the SUS questionnaire was independent of DHL level, and participant characteristics determined both time spent and level of interface engagement, influencing final SUS scores. Higher levels of satisfaction were expressed by low DHL participants who spent relatively short periods evaluating the interface. Scores were likely conflated by feelings of reassurance and reflected an appreciation of learning during a skills-based guided session. High DHL participants were highly critical of the interface and, although offered empathetic predictions of difficulties that users with lower skills or knowledge could experience, offered very few narratives that could inform reiterations to improve user experience. Findings indicate DHL affects levels of successful engagement with interfaces and therefore needs to be considered in the approach to undertaking usability assessments; this is a precursor to which method of evaluation and in which circumstances each are selected.

8.7.4 INTERACTION BEHAVIOUR AND EVIDENCE OF THE THIRD-GENERATION DIVIDE

Recent research indicates a further divide within technically competent populations, between those with developed formal Internet skills: *skills to handle the particular structures of digital media such as menus and hyperlinks* and information skills, *skills to search, select and evaluate information in digital media*[152,551,607,608]; and those individuals who can operationalise the Internet but interactions "*do not lead to beneficial outcomes*"[609(p1609),607,610,611]]. Researchers suggest technological skills within this group are inadequate to manage digital complexities of sites and apps at both a site level and information level within pages.[521,612] Users having a low "*digital interface competence,*"[141(p1)] corresponding with low levels of DHL.[555] Informational complexity is related to the language used within pages, both relating strongly to literacy skills informing health and digital literacy. For L-*DHLI* participants, complex phrases or words applied within functional components at a site level, including menu headers, page titles, and hyperlink descriptors, created barriers to movement through the interfaces. The interface could support all end-users when developers are cognisant of readability levels, use of jargon and inclusion of complicated terminology, length of text, hyperlinks descriptors and menu headers.[612,613] However, developers risk alienating groups of end-users who expect interactive and visually appealing interfaces and therefore, the objective has to be to create universal and interactively *balanced* interfaces for all.

Caution should now apply to identifying and reiterating these types of interface errors detected during usability evaluations. Equal digital interface competence across usability samples should not be assumed. Even within the 'usual groups' of tech-savvy individuals, there are indications that the interplay of characteristics confounds feedback and outcomes. There appears to be a third level of DHL or an intermediate *DHLI* group within the study's small sample, as evidenced by characteristics countering their abilities to interact online successfully. For example, high technical abilities were tempered by low English proficiency, and high-level operational skills and confidence in using devices were countered by the physical and cognitive deficits associated with increasing age. Graduation was observed in participant abilities and attitudes, from a clear definitive set of behaviours and skills at the upper and lower boundaries of *DHLI* distribution, to an opacity of the undefined contribution of technical skills, life experiences and socio-demographic factors influencing intermediate levels of DHL. Findings suggest DHL affects levels of successful engagement with interfaces and therefore needs to be considered in undertaking usability assessments; this is a precursor to which method of evaluation and in which circumstances each are selected. Preliminary indications from this study suggest that further investigation into the benefits of the 'intermediate' DHL levels on the design and evaluations of universal health interfaces are warranted. Future research requires studies with adequately powered sample sizes to detect statistically significant differences between groups of differing DHL levels with confidence. These studies should focus on performance and interactive behaviours and consider functional structures or dynamic aspects of interfaces that could improve the UX of health interfaces for all.

8.7.5 DHL AND SUITABILITY FOR PARTICIPATION IN UEM

Variation in usability evaluation methods undertaken across this study stage has identified several critical observations contextualising outcomes to total *DHLI* scores. Findings based on performance outcomes, satisfaction and comfortability measures suggest a differential approach is required when selecting participants to be involved in usability evaluations - perhaps speaking to more than just success or failures.

At the beginning of any evaluation approach, there is a need to identify and recruit representative individuals to participate. In this approach, developers are required to identify individuals having DHL levels that are conducive to understanding the objective of the method and having the skills to undertake the activities to generate meaningful feedback to reiterate the interface. However, this is not as straightforward as it seems given the differences in the types of feedback generated by high, intermediate and low DHL participants when evaluating across methodologies.

Outcomes from participants with L-*DHLI* may confound reiterative design depending on UEM undertaken as a direct function of literacy, health literacy, technological confidence, ability (digital interface competency) and previous experience. Their feedback is crucial to understanding the real-world interface pinch and pain points for hard-to-reach community groups. However, due to overlapping complexity contributing to higher cognitive loads, the likelihood of generating high quality, meaningful feedback to inform specific reiterations is limited through no fault of the participant nor the developer. Alternatively, H-*DHLI* participants' feedback in some UEMs would be welcomed as this could be considered more critical and extensive[561] due to their level of general literacy, health literacy, online experience and abilities using online resources. In other UEM, because of these higher functioning cognitive skills, H-*DHLI* groups are likely to generate feedback 'glossing' over the real experience of end-users who experience barriers to online interactions.

Participants with intermediate levels of DHL have characteristics differentially impacting interactions depending on socio-cultural factors, their life experiences, and digital abilities. Feedback generated from UEM is likely at the level of interface functionality and reflects their levels of digital competency or the ability to use interface features to achieve the required task successfully. This type of feedback would inform functional components of the interface. However, it may be void of more critical analysis of relationships between content and interface design, interactive features and content or the broader context of the interface within the digital health landscape relative to other resources or services. To better understand this relationship, performance, observations and qualitative - quantitative data across all of the different formative UEMs undertaken across all thesis studies, the suitability of participant *DHLI* levels to the types of usability methods is presented schematically in Figure 8.3. If these observations were shown to be consistent within larger samples across different health resource interface types, the implications arising from this shift in practice are profound for development teams.

8.7.6 IMPLEMENTING A DHL-CENTRED APPROACH FOR EVALUATION

To successfully implement an evaluation approach centred on DHL levels requires previous levels of usability experience to decide on the types of UEM required to generate meaningful feedback to reiterate interface designs. Given the relationship between DHL attributes and performance or behaviours within the interface, the acuity of the feedback generated is influenced by ability, comfortability, and confidence to fully participate in tasks. Therefore, UEMs can be best suited to ranges of participant DHL (Figure 8.3), and importantly, everyone can play a role in evaluating health interfaces.

For participants with L-*DHLI*, characterised by low health literacy, limited digital skills and infrequent use of technology or the Internet, there are opportunities to participate in qualitative UEMs in non-digital formats. Paper-based surveys or questionnaires, being involved in focus groups or interviews can still offer the opportunity to evaluate interfaces. These methods remove the pressure of contending with technology and digital interfaces to convey feedback. Importantly, these participants should not be limited to participatory or co-design approaches to development. L-*DHLI* can provide usability feedback on prototypes (for example, wireframing or paper prototyping), especially if moderation is provided when interacting with a digital interface. Developers also need to be prepared to offer technical support or education to support interactions within the sessions. However, this can also be an enticement within recruitment to engage, particularly with technically averse and embarrassed to show their level of skill.

Intermediate DHL levels are suited to combinations of paper and remote usability evaluations, although assessment of online prototypes or activities involving digital interactions will most likely need to be limited to activities with linear progression; including surveys or questionnaires, closed card sorting, first-click analysis or other UEMs offered within user-friendly platforms.

As these participants can offer incredibly valuable feedback on the functional aspects of the interface, involvement in usability testing would be the key to generating meaningful in-context feedback to improve interfaces for all end-users, including those who are vulnerable, excluded or disadvantaged. For example, digitally excluded seniors are likely to misinterpret common symbols or icons within interfaces designs.[614] Developers could create a universal interactive experience by including user-initiated hover tooltips[615] placed near symbols or icons. Tech-savvy users would ignore these as they are unobtrusive and could be accessed (if or when required) to support navigational or information issues by intermittent or non-frequent users. Tooltips for digitally excluded end-users are always available and can provide orientation and assist with familiarisation to icons or symbols functions.

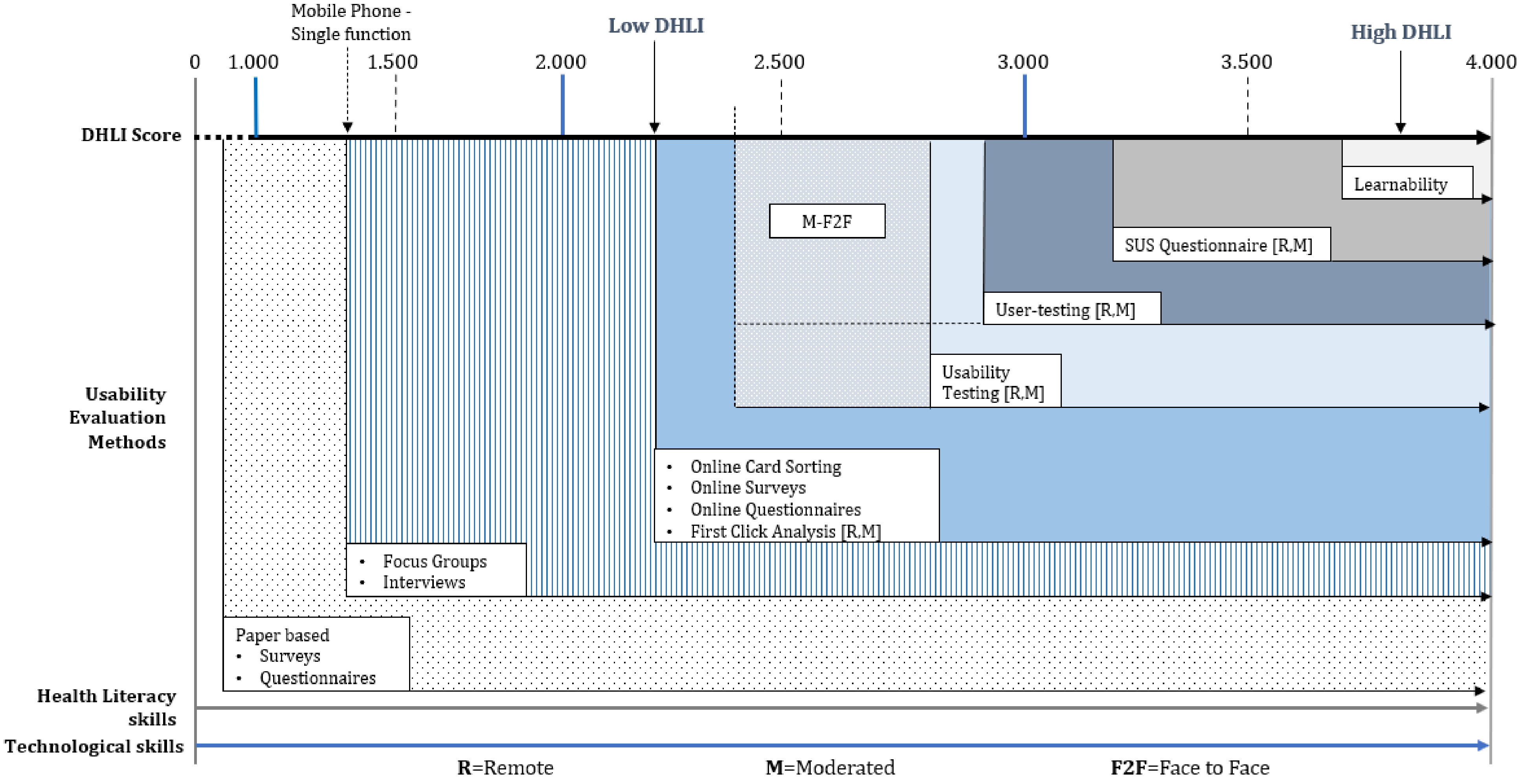


Figure 8.3 Suitability for usability evaluation methods when DHL is applied to stratifying participants

Again, caution is required as participants' characteristics influence each person's abilities, language proficiency, and cultural understanding of the content. Therefore, developers would need to screen participants prior to involvement to ensure individuals have the competencies required to service the method. Intermediate *DHLI* participants could also provide valuable qualitative narratives to inform needs or gap analysis from their lived experiences concerning interactions with health services, domain knowledge and digital capabilities encouraging developers to be inclusive in conceptualising the interface early in the development process. These participants are more likely to provide a realistic interface satisfaction measure than H-*DHLI* and L-*DHLI* participants.

For participants with H-*DHLI*, individuals can provide highly critical feedback on global issues within the interface, complexities between language, interface design, information flow, navigation and the relation between the purpose of the resource, context and content. Due to high executive functioning, cognitive fluidity and memorising experiential learnings from previous interactions, H-*DHLI* are suited to the more complex, cognitively demanding tasks in which their skills can highlight issues hidden from other individuals with lesser DHL. Learnability and usability testing would suit their attributes equally since both activities require health literacy, digital competency and the confidence to interact across all interface aspects. Version testing, or A/B testing, could also suit H-*DHLI,* who can attend to differences in interaction patterns, have the language and understanding to verbalise improvements or deficits in different interface designs that influence interactive success. For developers, H-*DHLI* can also increase the convenience of evaluations as no moderation or facilitation would be required, and all sessions could be held remotely without users experiencing operational or functional issues.

Implementing this approach to evaluation could ease the burden of attempting to recruit to reflect the diversity seen within the general population. By selecting across DHL levels, small numbers of participants could provide meaningful feedback across all interface aspects to be reiterated. In real-world practice, any saving of time or money is beneficial and could increase the likelihood of usability being adopted within development processes, even increasing the capability to undertake multiple rounds of usability with participants of varying levels of DHL before release. Whilst there are great benefits to improving health interfaces for all end-users, there are implications for development teams. Anticipatory awareness of both interface areas, choice of appropriate methodologies and consideration of DHL levels of potential participants, including levels of prior basic health knowledge[573]; an addition to socio-demographic or socio-cultural factors influencing online engagement[139,510,561] is required.

Additionally, the ability to interpret contextualised feedback generated from different methodologies to inform universal interface design is complicated. To progress a DHL-centred approach when developing health interfaces is dependent on the guidance and support being offered to development teams with limited evaluation experience or expertise. How, where and who will provide this guidance then becomes the fundamental question, if as a society, we want to increase access to online health information or services to improve health outcomes[616] for all communities.

8.8 STRENGTHS AND LIMITATIONS OF THIS STUDY

As an exploratory study, the study design was primarily developed to reflect a usability testing sample within an iterative UCD process, where typically, a small, representative sample is involved in evaluating the interface. This was a proof-of-concept study focussing on the potential benefits for non-specialised development teams (and the interface) if DHL could provide a stratification within a testing sample, *n*=6 participants. It is acknowledged that very small samples (*n*=3 in each *DHLI* group) were unlikely to detect statistically significant differences between *DHLI* groups' performance outcomes. The study was underpowered to detect small or subtle differences between groups and could only demonstrate significance when the effect size was large. As the source of participants was drawn from a sub-cohort from Study 4, there were limitations on the spread of DHL levels within interest participants who registered to participate. Studies were conducted with relatively tech-savvy groups and without participation from survey respondents with the lowest *DHLI* scores. Despite the absence of the *very*-low *DHLI* respondents from this study, analysis of between-group performance data indicated non-significant differences of large effect were still evident between low and high *DHLI* groups.

As differences were detected between groups from evaluation data collected across all five UEM undertaken by participants, the feasibility of the *DHLI* as a mechanism to diversify usability evaluation feedback was demonstrated to be of potential value to the evaluation practice of specialised development teams designing health interfaces. Future studies are warranted with researchers examining the influence of DHL using adequate sample sizes to statistically power the study to detect differences between groups with greater certainty. Group sizes would reflect similar participant numbers required for summative usability evaluations, and for example, a large-scale study would require n=102 participants (power=0.8 to detect medium effect sizes between groups[526]). This could prove challenging for future researchers given the difficulties and limitations to recruiting individuals with low *DHLI,* as described in section 7.8. However, the potential implications for universal interface design and usability evaluation practice are worthy of the investment in resources, time and money required.

8.9 CHAPTER SUMMARY

Whilst cautioning on the small sample size and the variability of performance, outcomes indicate a need for developers to be conscious of recruiting for candidate diversity and the feedback characteristics offered through different evaluation methodologies. Strategies to diversify representatives and their feedback have previously been founded on participant prior health knowledge,[573] Internet behaviours and socio-cultural factors.[139,510,561]

A single measure of *DHLI* considers these factors. While not alleviating the difficulties associated with usability evaluation within complex environments, stratification can produce samples predicted to behave differently compared to homogenous tech-savvy participant cohorts undertaking commercial usability studies.[595,617] Observations of behaviour, performance measures and comfort suggest that DHL-contextualised representative samples require a differential approach in the usability evaluation process. There needs to be a conscious effort by developers to recruit for diversity across interactive behaviours, life experiences and cultural backgrounds of potential candidates and subsequent anticipatory awareness and knowledge suitability of evaluation methods suited to *DHLI* samples. A choice of a mixed-method approach to evaluation can maximize variation in feedback generated to meaningfully shape interfaces of health resources for a wide range of patients, carers, and consumers within the community.

Outcomes from this study reflect the complexities of interrelationships between factors influencing DHL levels and their implications for usability evaluations, both as methodologies and a development process. There are complications in disentangling causal factors contributing to participants variations in performance and behaviours within usability evaluation methodologies when DHL is a delineator. There are indications that the *DHLI*, as a screening measure, can produce diverse samples for usability evaluations of health information resources. While this study is exploratory, *DHLI* could allow developers to rapidly identify individuals with DHL levels reflecting the diversity of socio-demographic, socio-cultural, and digital readiness in a relatively small sample or samples for usability evaluations of prototypes.

There was great value in the method and outcomes from this study. Findings indicate functional and behavioural differences were evident between participants with high and low levels of DHL; however, the decision by developers to the involvement of one group over the other is not clear from this exploratory study. However, preliminary findings suggest participants with intermediate levels DHL could offer hidden opportunities to understand what universal design in health looks like for vulnerable, excluded or disadvantaged groups. Future investigations could focus on the feasibility of alternative or innovative strategies to deliver health information and knowledge given the difficulties that hard-to-reach and excluded groups may encounter using interfaces. Strategies could extend from the modality of information delivery (printed, enhanced auditory and visual resources) and the type of information display (infographics or pictorial presentations). In a palliative context, the research could focus on how nurturing virtual communities[339] can support vulnerable, social or digitally excluded groups to improve HL and DHL whilst growing acceptance of death as part of life within a digital environment.

Implementing a DHL-centred approach to evaluation could profoundly change both evaluation and development practice in digital health environments. Easing the time and resource pressures of participant recruitment could stabilise development processes, perhaps increasing the likelihood of usability and accessibility evaluations being integrated into typical practice. Implementation would require guidance and support for developers, especially those with limited usability evaluation experience or expertise, and again, this raises the question of who, where, and how developers of health interfaces source this information to guide practice.

9 THESIS DISCUSSION

Within an evolving health environment, there is an acknowledgement that consumer access to health information has shifted towards a greater reliance on digital resources to support all aspects of consumer information requirements,[477] including health management, disease prevention and access to services. Forced adoption and increased reliance on use of health interfaces can increase the divide between those who can and cannot successfully support their healthcare needs[178] potentially reinforcing digtial marginalisation.[618]

Health interface developers can apply inclusive and universal principles to interface designs, enabling end-users who face barriers to use and access information while also improving the experience for everyone.[13,247] This strategy offers developers a generalist interface solution to maximise participation by many different individuals from the intended audience as possible.[208,247,482] Combined with evaluations of interface usability and accessibility with individuals from the intended audience, it can offer a glimmer of hope for those who experience difficulties accessing and using health technology. Both universal design and usability evaluation share a common thread; to be an effective strategy to improve interface design for everyone requires both to be woven within a UCD approach undertaken within the development process.

9.1.1 THE LIMITATIONS OF UNIVERSAL/INCLUSIVE DESIGN AS AN INTERFACE SOLUTION

This thesis offers a potential solution to increase engagement, participation and successful use of health information interfaces through the application of universal (and inclusive) design. It is important to recognise that inclusive and universal design approaches have limitations for the resultant interfaces developed. Universal and inclusive design cannot solve all of the issues that can or will be experienced within the interface for all end-users, for all contexts and environments of use. Even if universal design approaches are deployed (in full and including evaluations) within a UCD process, it is very likely that a majority of end-users could interact successfully with the interface. However, designs and evaluations are fallible; practice, interpretation of feedback, and designers' perceptions can contribute to interfaces that still exclude end-users through digital design marginalisation.[618]

Interestingly, fully adopting the universal design approach within the process appears limited and constrained by similar factors identified within this thesis. This is unsurprising given the inherent relationships between universal design approach, UCD, usability, UX and accessibility. In an industrial (commercial) context, familiar barriers emerge from the literature: incompatibility of the approach in process,[619] no incentives to adopt,[620] interface designs are a compromise between what can be afforded in the time available, and the designers' approval of self-conceptualised designs that do not require user evaluation.[618]

From a client or funder perspective, evaluation of usability and accessibility adds to the delays and costs involved in applying universal/inclusive design approaches whilst offering little in perceived benefits.[618] However, incorporation and adoption of universal design are driven by *client need and awareness*,[621] where designers are required by contractual agreement to include universal design within the development of a product. Perhaps this indicates the role that the Commonwealth should adopt when funding the development of health interfaces. The adoption of universal/inclusive design into UCD approaches for health interface development are only now emerging along with recognition of the benefits to excluded end-users. Potential risks of digital marginalising could be reduced when practice is informed and supported by guidance and user-research including evaluations are obligatory and are fully costed.

When it comes to developing digital health interfaces for a generalist audience, this is where the complexity lies.

This PhD thesis aimed to explore if comprehensive and structured evaluations could identify interface areas that could improve the UX for end-users. The five studies investigated different factors influencing the likelihood of evaluations undertaken by teams during typical development processes. Explorations are contextualised to the purpose of the interface build, team structures, and the funding of the resource within an Australian research environment. As described earlier within this thesis, the research focussed on the role of funded non-specialised development teams to translate health research outcomes or evidence into online websites, toolkits, apps, or devices.[106] Importantly, being non-specialised does not infer non-expert, rather multidisciplinary teams have expertise in non-technical aspects of development or evaluation. As funded project grants, such development teams are likely to have reduced resources[622] and more limited web development, usability, or digital translation experience than groups with mature (and commercial) UX structures. The technical build for non-specialist teams is commonly outsourced to web designers, developers and software programmers.[344] By understanding the barriers to undertaking evaluations within complex development environments, findings could further inform development and evaluation practice to improve interface design for health technologies for diverse audiences.

This thesis' original contribution is to the scholarship, practice and knowledge informing real-world usability and accessibility evaluation practice during health information resource development. By observing and undertaking usability and accessibility evaluation activities within real-world scenarios, practice complexity was accepted and shaped the current research context. Identification of barriers to evaluation informed recommendations for developers and commissioning funders to improve health interfaces. Innovative studies within this thesis have produced novel findings, including the systematic mapping review of the OHT literature and applying the WDHMC evaluation framework[218] to the CarerHelp Toolkit resource.

Each study provided an understanding of pragmatic evaluation practices undertaken by non-specialised development teams. While findings indicated evaluations were undertaken, studies highlighted the barriers to comprehensive and critical usability and accessibility evaluations. The studies also identified engagement strategies and discovered a novel approach to diversify usability samples, crucial steps in involving individuals in usability evaluations generating diverse feedback to improve the UX of the interface for all users regardless of their characteristics. Importantly, research within this thesis was undertaken within a palliative care context where there is a universal need for consumer information and support as patients, carers, family and community members. This setting and subject domain contributed significantly to contextualising knowledge and scholarship of findings.

As a complex domain for developers, HCP, caregivers and patients, this thesis's palliative care domain focus was not considered a limitation; instead, it provided real-world context for the fundamental need to ensure interfaces were informed by the end-users needs.[469] However, challenges and difficulties experienced across evaluations were not unique to palliative care. The implications and recommendations for practice are widely applicable across development teams and their processes. Moreover, specific feedback generated within one thesis study investigating how to improve the designs of interfaces to support carers and patients in finding and understanding the information provided real-time data to enhance the interface prior to its public release.

The five research studies explored three primary factors influencing evaluation practice within health interface design: the development process, the health content, and the end-user characteristics.

9.2 A SUMMARY OF KEY FINDINGS

The five studies identified several issues and complications for non-specialised developers in designing health interfaces. Findings speak directly to knowledge, abilities and experience that contribute to pragmatic evaluation practice. Collectively, the outcomes from the research demonstrate the inherent difficulties of evaluating health interfaces using a user-centred approach by non-specialised teams in development processes attuned to academic objectives, outcomes, and reporting.[106] Findings indicated an awareness by developers of the essential role that evaluations have in shaping interfaces for audiences. However, there are strong indications of the need for evidence to support developers whose expertise is not in UCD, online development, nor evaluation.

Studies indicated that the likelihood of evaluations undertaken during the development of health interfaces is influenced by the process supporting the activity. Findings suggest that structure, expertise, and previous development team experience are significant if usability or accessibility is successfully implemented within the development process. Although a comprehensive and structured evaluation approach can improve interface design for the intended audience, development teams face issues in the timing of evaluations, choice of UEM, identifying participants or expert evaluators, and interpretation of findings to reiterate interfaces with meaningful improvements. Some of these factors are present regardless of the context and domain of the interface evaluated. However, there are indications that being under-resourced[216,441] and developing within unstable processes can create additional pressures that can lead non-specialised teams to cut corners[440] and neglect evaluations.[117] Difficult and complex subject domains, such as palliative care, add another layer of difficulty for developers when identifying and recruiting participants for evaluations. This finding is duly applicable to identifying participants from other vulnerable groups, including patients or carers, disadvantaged communities or those who are socially or digitally excluded.

For health interfaces to be accessible, providing a valuable and meaningful experience for everyone, findings from the research have also highlighted the barriers to involving participants in evaluations who are diverse in their characteristics. Assumptions of engagement through digital and electronic communication platforms can be unfounded. For development teams applying an inclusive and universal design approach, engaging with hard-to-reach populations requires time and cost-intensive strategies. Findings indicate that collaboration with invested gatekeepers is essential to negotiate access to potential participants. However, time-space recruitment and face to face engagement are essential to provide both reassurance and confidence. Community-based services, public libraries and local Government proved to be a successful locations to access hard-to-reach individuals. However, this approach was inconsistent in identifying potential participants for evaluations. Outcomes found an individual's level of digital health literacy (as assessed by the *DHLI*[516])determined factors influencing digital interactions and engagement with health interfaces.

Identifying representative participants to recruit into usability evaluation samples is arduous. This is partly due to development teams being unable to identify a typical representative user archetype and the challenge of identifying potential caregivers and patients from healthcare services, systems, or the general population. Findings from these studies have identified that *DHLI* is an effective mechanism to stratify participants by offering an approach to diversify feedback generated by usability evaluations. This is a novel approach to shape interfaces to be inclusive, universal in design to support end-users with varying superdeterminants of digital health.[178]

Table 9.1 outlines the key findings from each of the five individual studies undertaken in this thesis.

Research within the thesis was supported by methodological approaches grounded in a pragmatic view of evaluation and interface design. From an epistemological standpoint, involving end-users and exploring their experiences as human actors in their own lives is a powerful and valuable mechanism to reiterate interfaces. Feedback offered is subjective, contextualised and grounded in the real world, offering individualistic perspectives of relationships between the interface design and the real world, personal experience within a societal context.

Table 9.1 Key findings from the five studies undertaken within this PhD

Chapter/Title	**Focus of chapter**	**Key findings**	**Description**
4. Systematic mapping review of the literature describing evaluation practice in OHT development	Current evaluation practice and evidence base to support practice	Evaluations not typical within reported OHT development processes	Indications from descriptions within the literature that evaluations are not commonly undertaken within the development of OHT.
		Peer-reviewed literature is incomplete and variable in descriptions of evaluation practice	Descriptions within the literature are not comprehensive; they are incomplete records of evaluations undertaken across the OHT development process.
		Current evaluation practice is unclear within developers of OHT	Mapping could not provide a definitive state of practice due to the variable and fragmented descriptions provided within the literature.
5. Relationship between accessibility and usability in OHT interfaces pre- and post-release	Pragmatic evaluation practice from published literature and post-release interface design	OHT with low levels of accessibility	High frequencies of general and contrast errors were assessed across all live OHT.
		Relationship between accessibility and UEM	Attending to usability errors from inquiry-based and late evaluations of UEM during OHT development increased the frequency of accessibility errors.
		Knowledge or experience of evaluations in practice inconclusive	The imbalance between attenuation of accessibility errors and reporting of usability outcomes may indicate the developer’s lack of understanding of the pragmatics of evaluating for UX.

6. Structured evaluation and improving the UI – Evaluation of the CarerHelp OHT	Development process, team structure and evaluation practice	Difficulties in undertaking complex usability evaluation within the development process	Instability, lack of funding and experience developing are likely barriers influencing the likelihood of evaluations being adopted as part of typical development processes for non-specialised teams.
		Complex evaluations can improve health interfaces	The interface usability errors identified by caregivers within usability testing and formal reporting to the National Reference Group were fully resolved before release.
		Identifying and recruiting participants for the usability of health interfaces is a complicating factor	Access, identification, and recruitment of participants for evaluations further complicate the development process, particularly when experts and/or end-users are involved as evaluators of health interfaces.
		Evaluation of health interfaces may require non-traditional UEM	Development and feasibility of a novel UEM to support developers undertaking evaluations within academic settings if representative end-users are hard to find.
		Support is needed to assist non-specialised development teams	Requirement for funders to be responsible for ensuring evaluations are undertaken within the development of health interfaces.
7. Engaging hard-to-reach populations for usability evaluations	End-users and participation in evaluations	Reliance on digital or electronic communications platforms for remote UEM creates a biased sample	Communication through digital or electronic communication to invite respondents to participate in a remote online UEM creates a tech-savvy bias within the group.

		A combination of communication strategies are required	Communication strategies require the use of gatekeepers and face to face engagement to establish rapport and invite participation from hard-to-reach groups.
		Engagement for participation in UEM	Time-space sampling at public libraries and local councils using face-to-face engagement successfully recruited hard-to-reach individuals.
		Preference for paper over online participation	Hard-to-reach groups engaged with paper surveys over online surveys.
		Participant characteristics were different between survey return groups	Variables describing socio-demographic, Internet behaviour and technical ability characteristics indicated participants returning paper surveys were from hard-to-reach groups within the community.
		Digital health literacy levels were lower in paper survey returns than online survey returns	DHL levels (as assessed by *DHLI*) identified factors influencing digital interactions and engagement with health interfaces.
8. DHL, user characteristics and usability	End-user characteristics and evaluation outcomes	*DHLI* was a successful mechanism to stratify for diversity within usability samples	Low and High *DHLI* participants performed and were observed to interact differently when undertaking UEM activities.

evaluation methods		DHL level could determine UEM suitability	The acuity of feedback from participants across DHL levels indicates the need to consider the suitability of the evaluation method selected, the type of feedback required, and participant *DHLI* score.
		Intermediate *DHLI* could identify interface issues for vulnerable, excluded, or disadvantaged users	The interplay between the characteristics influencing DHL could indicate the need to evaluate health interfaces with participants of intermediate DHL levels as the complicating factor of digital competency was alleviated within this group.

Usability evaluations, particularly user and expert-based UEM, provided the ability to triangulate errors within the prototype interface using a mixed-method approach of qualitative and quantitative UEM. This approach also highlighted the differences in interactive behaviours of end-users when differentiated by DHL. Thesis research outcomes indicate that a mixed-methods approach can limit guesswork and limit the unknown when reiterating interfaces from representative data. Abductively, reiterations should be reasoned on the evidence generated by evaluations. However, uncertainty in design will always remain, even with triangulation and multiple rounds of iterative test-redesign-retest. Pragmatically, even when gold-standard evaluation practices and methods are deployed, the resolution of errors within interface design is temporal, and solutions are informed by data collected from only a small representative group from the community. Therefore, evaluations remain deductive, and a global interactive resolution to support end-user groups will remain elusive. However, research findings highlight the need to: improve evaluation practice, create UEM, integrate universal design, stabilise development processes, incentivise usability and diversify participants to limit the unknown – to improve UX of health interfaces for all end-users.

9.3 WHY THIS RESEARCH IS IMPORTANT WITHIN THE CURRENT ENVIRONMENT

The transformative digital agendas of Governments are driving change in how communities are now living and working. Research within this thesis has highlighted the difficulties individuals face interacting with digital health interfaces, the digital front doors[623] to searching, finding and using health information and accessing health services and systems. The Internet can offer cost-effective distribution of health information, improve the reach and interconnectivity of services into communities and across populations and improve the budget bottom line by stretching the health dollar further. This forced transition to online engagement with health for many arguably shifts the burdens to individuals, their communities, and supporting organisations. The digital environment adds layers of complexity for those already experiencing poorer health outcomes due to social and digital inequities.[624]

This perceived ambivalence toward those groups who face barriers to information access and use of digital health interfaces was again evident in the Government's response when the COVID-19 pandemic impacted communities in Australia. The combination of a fragmented digital environment and the assumptions of English language proficiency, digital reach, access to digital technology and social media platforms created an information void. The response to inform communities of the risks of virus spread and to provide reassurance at a time of uncertainty experienced multiple failures. As a result, the virus spread amongst vulnerable,[625] digitally excluded,[626] and multicultural communities.[627]

COVID-19 has highlighted the difficulties experienced by these communities and their caregivers[628] when assumptions drive digital engagement to result in groups slipping through informational cracks.[32,625] At a Governance level, digital health transformation requires acceptance of a certain level of risk[629] of exclusion due to digital fragmentation. Development teams, therefore, can step in and do their part when designing for health – to support *everyone* to find and open the door by designing and evaluating inclusive interfaces to improve health outcomes for all.

Unlike much of the literature and guidance available to development teams who design and build health information resources, this thesis focuses on an emerging and increasingly important area of interdisciplinary research at the intersection between UX, user-centred interaction, design evaluation practice and digital health. Thesis research studies focus on evaluations of designs of universal health interfaces; these are created to support the wide-ranging abilities of the end-users of generalist resources. Designing universally encompasses the inclusivity of all end-users, especially individuals having low levels of DHL and HL being fundamental barriers to access and use of health resources[486] in underserved and hard-to-reach populations.[630] Characteristically, such individuals are technically averse, older, from CALD groups within the community, from low socioeconomic areas, live in geographically isolated areas, and have low digital competency and confidence using the Internet or devices. The greatest disparity for individuals is at the intersectionality between two or more characteristics that influence the ability to access and successfully use the information to inform health decisions.

9.4 THE DIFFICULTIES FOR DEVELOPERS DEVELOPING AND EVALUATING HEALTH INTERFACES FOR DIVERSE AUDIENCES

Unlike the complications of identifying and recruiting usability participants, which impact all developers,[441] study findings highlight the difficulties in the process, expertise and experience in developing and evaluating health interfaces for non-specialised development teams. The in-parallel exploration of the evaluation approach undertaken within a development process demonstrated the complexity of programming, recruiting, conducting, analysing and reporting outcomes from usability testing to prompt discussion on modifying interfaces for user needs. Three important points can be drawn from these results:

1. Knowledge of usability evaluation practice is essential.
2. Previous experience managing digital projects is critical.
3. If neither expertise nor experience is present, then evidence to support both development and evaluation practice is fundamental to ensure the timing is right, UEM choice is optimal, and feedback informs meaningful improvements to the interface.

All three points of conjecture are not easily solved without investment in building capacity, re-envisaging funding structures or organisational[631] transformation of development processes (discussed later in this chapter). In offering potential solutions to improve universal health interfaces, understanding how the collision between academic health research, digital health technology, UX and HCI have impacted multidisciplinary teams to undertake evaluations within development processes is required. As an emerging area of research, the application of the UCD approach within the development of health information technologies, health systems, platforms and devices is gaining interest[632] due to the advantages iterative evaluations can offer in designing interfaces to users requirements.[633] For large organisations with mature usability teams in a funding rich environment, the use of the UCD approach is familiar, and for those with embedded technological skills, the use of an agile approach to development is second nature.[634] As a software engineering or HCI approach to project management and development, agile is flexible, reiterative, user-focussed, and user feedback continuously informs iterative change to the interface.[439] It is this versioning approach[102] that is seen to challenge the traditional health research paradigm[217,635] which is driven by the clinical evidence hierarchy to mitigate risks.[636] The usability/UX experts, programmers, designers, marketing and content developers work with end-users seamlessly across all areas of development.[637] Reporting of outcomes is internally focused and informs developers of errors or issues to shape the interface further. However, agile is considered a risk if development teams are time-poor [638] and/or do not have previous experience .[104]

For small multidisciplinary teams, the environment and context for development are far removed from the ideal described previously. Funded through grants, non-specialised teams collaborate with technical professionals to fill the void in the skills required to develop online. Mann et al.[106] has observed that for these teams, it is challenging to balance the agile, iterative processes required for UCD projects and align them with the objectives, reporting and management of academic research. Projects grounded in academic research employ traditional, linear 'waterfall' management, a method[102,438] that actively competes with the iterative and agile UCD approach. As observed in this thesis's studies, the opportunity for user-, expert- and content-based evaluations diminishes, with project lag and delays having serious downstream repercussions for the design[639] of health interfaces being developed.

Unstable development processes and the resulting inconsistent or variable evaluations were examined in studies of this thesis concerning OHT development. Academic evaluation practice was explored as a potential evidence base to support usability practice. Recommendations from this study support the increasing tide of research encouraging a minimum standard of reporting rigour[89,277,388] when describing outcomes from evaluations—statements of scientific background, methods, results, discussion of the results and limitations.; extending to explicit descriptions of usability methodology in what is seen as a movement toward evidenced-based human factors research.[89,244,277,388] This notion of academic research validity, generalisability, and reproducibility[106] for dissemination externally conflicts with the rapid, formative approach to generating findings within small participant samples. As demonstrated in many of this thesis's evaluation studies, statistical power could not be achieved with the small numbers of participants to reliably demonstrate the statistically significant difference, effect, or generalisability of the method. In some ways, the research within this thesis has demonstrated the complexities and the lack of clarity around current evaluation practice within non-specialised teams, which illustrates the relative immaturity of this field of research and development. Usability as a field of practice is undergoing another evolution, with digital health technologies, software and devices highlighting the importance of designing with the user needs and abilities in mind.[632]

9.4.1 TEAM STRUCTURES AND EVALUATION PRACTICE

The strengths of non-specialised development teams lie within other aspects of development, in the early stages of resource conceptualisation, user requirements or gap analysis, components of participatory design and content development.[640] Industry partners are contracted to support the project with technical expertise, creating an additional layer of complexity within the development process. As discussed earlier, development teams are unlikely to engage with UX professionals in the same capacity as resource-rich traditional development teams. There are two likely scenarios if technical professionals do not arrive interested and readily skilled to undertake usability evaluations. Developers outsource evaluations to UX professionals by subcontracting to UX companies to buy in costly expertise, with no guarantee of previous experience developing within a health domain. Alternatively, evaluations are left to project staff with varying levels of expertise depending on previous experiences. Opportunities are available for staff to gain qualifications; however, there is no standardised UX curriculum (customised to experience and professional requirements across design domains[641-643]); and therefore, it requires a long-term commitment to building practical skills and evaluation capacity within project groups.

In an Australian context, there are limited opportunities for project groups (and in some cases organisations) to build evaluation capacity[644] due to short funding cycles and staff turnover. Perhaps for project leads to grow, in-house evaluation expertise is best achieved by leveraging expertise from other domains.[640] For example, where access, availability, and budget limits leverage to involve experienced HCP or UX professionals, study findings demonstrated the possibility of accessing technical experts with awareness of usability within the overarching academic institutions. This could potentially benefit the project and interface whilst breaking down practice silos[215] common within large organisations[645] to pave the way for future collaborations and partnerships.

Of interest is the perception of the level of usability scholarship held by contracted technical professionals, their enthusiasm to be involved in UEMs, and their previous experience undertaking usability and accessibility evaluations. From in-study discussions with technical professionals internal (Web Developer) and external (LDs) to development processes, knowledge of usability evaluation is limited to the classroom, and practical experience is uncommon, which could explain a reluctance to undertake evaluations. However, the time-intensive nature of UEM,[446] the downstream work required to attend to ongoing changes,[446] leads to questioning the relative value of iterative formative evaluations compared to user testing and is a likely point of contention for developers as well.[466,646]

The benefits external technical expertise can bring to the development of universal health interfaces for non-specialised teams need to be balanced, with not only level of commitment to UCD approaches and iterative evaluation practice, but also the capability to empathise with difficulties and barriers to interactions for end-users[647] (discussed later in this chapter). In many ways, technical experts are less likely to understand the nature and impact of vulnerability, disadvantage or exclusion on the need to search, find and understand health information through digital interactions compared to HCP. Arguably, non-specialist teams reliance on technical experts further compounds lack of evaluation practice; and, surprisingly, accessibility assessment.

In the case of accessibility and requirements for interfaces to be a minimum AA compliance,[171] findings from the studies in this thesis suggest consideration of accessibility may be limited to the reliance on off-the-shelf skins to make interfaces accessible. Accessible compliant packages are commonly purchased by technical experts on behalf of the development team and may be viewed as a viable alternative to automated software to identify areas of concern. However, the interface only remains 'accessible' if development teams and their technical experts remain within the skin parameters and importantly, these parameters do not adjudicate levels of usability of the information, function or operations within the site.

Developers could 'tinker' with components of the interface that contribute to the aesthetics or interactivity to create a more engaging site. Effectively increasing the presence of either of these attributes could improve UX for the majority. However, it can decrease accessibility for others and is contrary to using these skins in the first place. Within standard interfaces, subsequent use of automated tools when evaluating accessibility may contribute to other usability errors. As indicated from thesis studies, non-specialised development teams are unaware of the relationship between usability and accessibility and the impact of the design when attenuating for one without considering the other. Striking a balance in aspects of usability, accessibility and UX within universal health interface designs is difficult for non-specialised development teams. The idea of the 'best interface' in context to team expertise, process and resources is explored later in this chapter.

These differences perhaps reflect the divide between health research understanding of humans concerning health context,[216] it is technical experts (and not UX professionals) who may need additional scholarship; to

1. Ground their understanding of what health systems and services demand of digitally excluded individuals in the real world.
2. Recognise the requirement to contextualise usability evaluation methodologies to account for abilities, access, confidence, comfortability and socio-cultural characteristics.

3. Generate outcomes that can be translated into universal interface health designs for everyone.

9.4.2 CONTENT DELIVERY AND INFORMATION DESIGN

Content delivery was highlighted within the study findings as a major contributor to destabilising the development process managed by non-specialised teams. This outcome is not uncommon to all developers and is the primary cause for delays in delivery within agile, iterative approaches.[434-436] As described within section 6.10.1, content delays were the catalyst for snowballing, an increasing list of activities being on hold when waiting for components to be completed as time progresses, and release dates quickly approaching. Delays pressurise development processes, and for non-specialised teams, it is not identification, synthesis or appraisal of evidence that creates the issues (as this is a strength of academically-bound multidisciplinary research teams). Instead, it translates from research or clinical evidence into meaningful, appropriate and informative content for digital interfaces. For developers, digital content writing considers audience demographics, marketing, search engine optimisation,[648] aligning content with information design principles[649] and user-centred interface design and evaluation approaches. Information is more than just the content[650] and encompasses aesthetics, visual imagery, audio, space, time and behaviours.[651,652] Visual literacy as a facet of visual design is an emerging area of research[652] to improve information experience for individuals with low health literacy,[651] including hard-to-reach groups, such as older individuals, lower SES, and ESL,[651] or those with complex, high or medical needs.[653]

Assessing information for readability and understandability or undertaking expert or user-based evaluations will identify issues with language, content, jargon, terminology and perceived tone used within the interface. These are unlikely to improve health literacy in end-users. However, these evaluations can increase end-users accessibility of the interface, including findability, searchability and usability[654] as critical qualities of universal interface designs for diverse audiences. Identifying and recruiting suitable evaluators will remain a complicating factor in development; however, unlike usability, the studies found that content evaluation was relatively simple using automated tools. Adjustments could easily be made in-situ and were not time dependant. Hence, this was not a limitation within the process.

9.4.3 END-USERS AND EVALUATION PRACTICE

Across all studies of user-centred evaluations undertaken within this thesis, identification and recruitment of end-users and experts as participants in the assessment of health interface was *challenging*. Whilst not impossible, difficulties faced by non-specialised development teams are familiar to those experienced by all teams recruiting participants for evaluations[441] where identifying and recruiting end-users added time and complications to already stretched development processes. Study outcomes provided a pragmatic understanding of the context surrounding why developers inadvertently exclude[247] community groups, recruiting readily accessible users over those who are hard-to-reach.

Study findings suggest designing for health interfaces for generalist audiences is further complicated by the need to consider user need, requirements and environment of use, and characteristics of access, use, knowledge, life experiences, and levels of adoption or adversity of technology.[164] Non-specialist development teams are acutely aware of the end-user being the centre of the design and development processes and the need to involve end-users in generating and evaluating interface designs. Non-specialist development teams typically involve HCP across facets of the development approach. If resources permit, responsibility for evaluation recruitment can remain with the development team or be transferred to technical experts or UX experts who appropriate contracted control of evaluations. In both the case for recruitment for generalist resources or a specific resource for a health or medical domain, there lies a conundrum - who *really* knows the diversity of the representative end-users, the multidisciplinary team or technical experts?

One could argue there are no advantages or incentives for technical experts in their typical practice to engage with end-users with diverse characteristics for evaluations, given their audiences are more likely to be characteristically homogenous and have high levels of tech-savviness. Speculatively, inviting end-users with limited health literacy or digital skills may result in feedback that could endanger their interface designs, functions, or aesthetics and risk losing their appeal to their 'tech-savvy' audiences. Findings from the thesis studies indicate tech-savviness would most likely reflect high DHL, and therefore homogenous samples generate critical feedback further to improve interfaces, almost creating a self-fulfilling evaluation cycle for non-diverse archetypal end-users. Alternatively, HCP are experts in the subject domain, and the scope of practice provides an opportunity to match natural life diversity in characteristics and experiences of representatives suitable for evaluations. This ability extends to feeling and expressing empathy for people who face difficulties with their health and living in circumstances that negatively impact health outcomes.[655] For UX experts in UCD, usability, accessibility and interaction design, audience contextualisation within the health domain places HCP at the fore in understanding diverse needs and facilitating access to potential participants.

For technical experts, interactions by individuals with low digital competency, low digital health literacy, and operational experience are variable, inconsistent, and arbitrary compared to their own online experiences. Empathy as a core component of interactive design[656] requires designers and developers to place themselves figuratively into users' shoes in attempting to understand the difficulties, behaviours, and interactions. In the case of generalist health interface development, it is unrealistic for teams to assume to understand how every individual characteristic influence behaviour and performance of interface interactions.

In many ways, end-users' abilities are far worse than imagined[120] or construed within literature descriptions or interviews. The experience of moderating usability sessions for this thesis and observing older, multicultural and technically-averse groups when attending digital skills sessions within the community is supportive of this view. There is a certain level of unease in watching a group of 80-year-olds struggle with mobile technology squinting at small, screened devices solely to access and use a Government portal on health information in order to ensure their aged pension arrives safely.

For health resource development, the empathy-driven design still risks excluding individuals who experience difficulties interacting or accessing the Internet and devices,[138,647] especially in a health context.[657] Older Australians learning to use their mobile phones are examples of a digitally excluded[10] cohort forced to adopt and use technology to access digital health information or services. Again, this raises concerns for the technical experts' role in development and evaluation practice when contracted to collaborate with non-specialist teams.

In the context of palliative care, the studies undertaken demonstrated the extreme complexities involved for non-specialised development teams in navigating health service, stakeholder and advocacy organisations. Understanding the concept of representativeness was a far more straightforward task in targeted audiences, although not as clear cut in diverse, generalist audiences. Representativeness within usability samples for generalist health interfaces could only work within agile approaches to development. Multiple small representative usability samples involved in continuous iterative formative evaluations across the development process could inform reiterations to the interface from different end-user perspectives. Combining the sample participant numbers offer developers the power to generalise feedback and errors to the experiences of the wider untested population.[106] As described previously, non-specialised development processes are unstable, and observations from the studies in this thesis suggest multiple rounds of formative evaluations could not 'fit' within the process aligned with academic research projects due to previously described factors.

Representativeness by non-specialised teams considers participants unique combination of characteristics[247] that inform super social determinants of digital health.[178] Determinants include confidence levels, digital skills and competencies to be autonomous online, attitude toward the Internet being useful to inform health decisions, and the ability to distinguish trustworthiness of the information. Practically, these are more difficult to ascertain within community groups when recruiting for usability evaluations. However, measures of DHL assess factors influencing levels of digital or social inequalities[138] underpinning current digital divides[483,PP] addressing digital competency[609] and access.

Findings identified a *pragmatic key* to generating reiterative feedback representative of natural diversity within general populations. Engaging, recruiting and moderating evaluations with individuals living with digital social inequalities, factors influencing technological use, and health literacy will further challenge developers of health interfaces. Individuals with low digital health literacy compared to tech-savvy cohorts are high maintenance in terms of resource investment. Recruitment for usability evaluations requires 1) time and money, 2) presence at physical locations to provide information and reassurance, and 3) patience and ability to simultaneously provide tuition to improve digital competency before and during sessions.

Exploring participants' DHL further substantiates arguments against developers' use of homogenous samples for usability evaluations. Thesis research indicates that the application of the *DHLI*[516] could be a mechanism to create heterogeneity to diversify critical feedback. For non-specialised development teams, the *DHLI* could allow a judicious and efficient selection of participants to shape universal interfaces during unstable and under-resourced processes. Given

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[PP] Digital divide at three levels: First – access and affordability of Internet, Second – Level of digital readiness (health literacy and technological ability), Third – Level of interaction through digital competency and technological confidence and skill.

the importance of representativeness within usability samples, w*hat pragmatically constitutes the 'best results' from usability activities for generalist health interfaces?*

'Best results' for interfaces are modifications supporting contextual use by intended audiences balancing the pragmatics of manipulation[51] (practicality, function and usability) with hedonistic characteristics[45] (stimulation, identification and evocation), consequently evoking feelings of appeal, satisfaction and pleasure within the user. Content within highly organised or functional designs is more likely to be remembered by end-users than aesthetically pleasing interfaces where end-users are likely to recall only the interactive features.[658] Further, end-users perception and judgement of interface information quality are highly contextualised to the domain's perceived level of seriousness.[658] This suggests that highly engaging and visually appealing health interfaces may be counterintuitive to the objective of these resources where end-users expect and trust information within interfaces with high levels of usability. The relational influences of function, interactivity or dynamics and visual aesthetics is critical when designing for optimal engagement. However, the disconnect between designers/developers and end-users when considering interface visual aesthetics[659] could compromise designs optimised for support digitally or socially excluded end-user groups. Accessibility as a consideration within universal interface design[660] could potentially complicate these designs further. For developers of generalist health interfaces, what point is a design balanced between the project's and/or funder needs (salient, attractive, persuasive, engaging and marketable) and the needs for the end-users (being usable, accessible, meaningful, satisfying)?

From a technical view, offsetting the design to accommodate the needs of the few can compromise the overall design function and appeal, delivering a paternalistic interface[216] that can further marginalise some end-user groups.[661] One approach is to return to the concept of representativeness by undertaking iterative evaluations with end-users who are not at the extremes of the digital health literacy instrument scale.[516] Participants with an intermediate level of digital health literacy represent end-users facing the third digital divide[609] with operational digital competencies, including the confidence to use technology, but still experience barriers to successfully using health interfaces. By progressively layering interactivity to enhance the final interface, developers design[662-664] can provide diverse audiences with the ‘best’ experience. Developers can increase interface functionality from essential components (as required by all end-users - accessibility compliance, plain language to aid translation, alt-text, visual design, navigational cues and basic HTML code) to optional and more complex interactive features (e.g., personalisation or communication). By considering this design technique, developers can account for end-users inequities of use and the complications of UX due to older software and technologies.[662] In practice, developers considering approaches to deliver an intermediate level interface for diverse audiences could benefit a hierarchy of user-based evaluation approaches aligning to increasing complexity of integration of interactives and DHL suitability levels for UEM.

Importantly, interface designs reiterated from evaluation feedback does not offer development teams a single, definitive solution to support all the combinations of user characteristics influencing interactions. Interface designs approximate the best solution informed by feedback generated by a specific end-user sample when using a version of the interface within the process. Continual cycles of summative and formative evaluations can continually improve interface features to suit the needs and abilities of the intended audiences. Non-specialised development teams do not have a sustainability plan embedded within their funding structures that could increase the likelihood of usability and accessibility evaluations across the life of the interface. As funding is grant-based, evaluations to continually improve use or demonstrate success are not rewarded nor incentivised within the process. Therefore, grant funding structures negate the advantages or benefits the UCD approach can offer non-specialised development teams (and its end-users) when developing health interfaces. In considering recommendations to improve evaluation practice for non-specialised development teams, it is essential first to consider the thesis research limitations.

9.5 LIMITATIONS OF THE THESIS RESEARCH

The focus of evaluations within the specific development setting of non-specialised development teams denotes findings from the studies conducted for this thesis. Not all may be generalisable across all subject or content domains, UX field or within the discipline of usability engineering. The research within this thesis focuses on the subject (content) domains of health and medicine and informs investigators or researchers creating resources from research or evidence.

It is essential to acknowledge that development experience, evaluation expertise, ready or unimpeded access to end-users, and unfettered access to resources would still generate interfaces that are not universally suited to all end-users across all contexts and environments of use. This is a limitation of development, evaluation, design approaches and processes. Pragmatically, interface designs themselves are open to developer and designer bias. Designs could be hijacked by self-centred beliefs, personal preferences or perceptions of use and access. In the case of user-based evaluations, interpretation of feedback can be subjective or framed within a developer-centric[117] conceptual framework. The resultant interface does not represent their contextualised lived experience with the content or the overall information experience for end-users. Universal or inclusive design within a UCD approach can minimise this limitation to design and increase the likelihood of increasing access and use to all end-users[31], including those who face barriers to access and use.

Members of multidisciplinary teams may have limited experience or skills in development or evaluation. Levels of experience or expertise in the development of evaluation cannot be quantified, and it was a difficult concept to demarcate between what characteristics are required to classify a development team as being 'experienced' or 'specialised'. Factors considered included team composition, the overall number of years of usability evaluation experience, previous involvement in developing health interfaces, digital translation skills, or previous experience in designing and building resources. The literature is definitive on the composition of traditional development teams[198]; however, it lacks clarity on composition, specialisations or experience influencing evaluation maturity. Applicability of thesis findings depends on the subject domain of the resource and is relevant to Project Leads, managers, researchers, academics, or other members who feel their multidisciplinary development teams lack the required skills, experience, and resources.

There is also recognition that these findings are limited to the development of static Internet health interfaces and not to connected health interventions such as m-Health. Programmers naturally develop these interfaces within agile UCD environments as continuous connectivity and reliance on rapidly evolving software or device specifications[101] are required. An essential aspect of this research is to reiterate the significance, inform practice and increase both usability and accessibility of health interfaces for diverse end-user groups. Not constrained by definitions or measures of specialisation or experience, research findings can still inform evaluations undertaken by non-specialised development teams during the development of health interfaces.

Research findings from this thesis highlighted the challenges and complexities experienced by development teams to establish end-user groups for involvement in usability evaluations to explore the interface and generate feedback to inform reiterations. The issue does not lie with acknowledging the need to account for diversity but rather in establishing representative heterogenous end-user groups to reconcile the disparate user characteristics required to shape health interfaces. Within thesis studies, recruitment strategies applied to identify participants were not guaranteed to recruit for the studies successfully. Successful engagement required negotiating with gatekeepers[455] to reach open (digitally excluded populations) or targeted (palliative care caregivers[455]) cohorts or directed invitations to participate in the case of expert evaluators. Different strategies and sources of participants were explored to ensure the numbers of participants were adequate for the evaluation methodologies.

However, recruitment has to be more than just making up the numbers. Targeting specific characteristics to diversify feedback is critical, although how this is practically reflected within small formative evaluation samples is confounding. The research within this thesis was exploratory in nature, and in many cases, these studies were a proof of concept or method. The participant-centric research and subsequent designs of Study 4 and Study 5 assessed the feasibility and potential value of the method, activity or strategy concerning pragmatic development and evaluation practice. Small sample sizes are acknowledged as a limitation of these participant focussed studies. However, small, subtle or nuanced differences in the between-group comparisons were not detected because the sample size was small and statistically underpowered.[66,391] This is not an unusual outcome from feasibility or proof-of-concept studies where small samples indicate the potential value and validate investment in further research.

Results suggest that strategies, methods, and approaches to involving hard-to-reach groups in evaluations were feasible within typical processes and practices. These could also potentially offer development teams a valuable strategy of recruitment and a DHL-centred approach to evaluation to optimise universal designs of UI for audiences. The next step for future researchers is to repeat these studies with increased participant numbers to have adequate statistical power to detect slight differences between groups. An appropriately powered study will allow researchers to capture the capabilities of 1) recruitment strategies to identify hard-to-reach individuals within the community to participate in usability evaluations and 2) the implementation of the DHL approach to evaluation in practice to increase UX of health interfaces for all end-users.

Thesis investigations indicated the use of the *DHLI* as a feasible mechanism to stratify end-users by DHL. Optimally, developers would align the required feedback with the appropriate UEM and suitable end-users with levels of DHL that could offer meaningful feedback during multiple rounds of iterative evaluations. Given the pragmatic complexity of development processes for non-specialised teams, there is the relative value to involve experts (subject-domain and heuristic) within the approach. Alternate perspectives generate feedback to triangulate error identification within the interface. However, participation in evaluations is still reliant on successful strategies to recruit evaluators, end-users and experts, and is a limiting step in evaluating interfaces. In the case of undertaking bare minimum evaluation within the development, study findings suggest that as a necessity, end-users and subject domain experts are crucial sources of evaluation feedback to inform designs of health interfaces for diverse audiences potentially. Importantly, undertaking evaluation with one of these evaluator groups outweighs the risks of not undertaking any formative assessment of usability or accessibility. No evaluations within development processes place health interfaces at risk of being unusable, inaccessible, and irrelevant to audiences who have the most to gain through successful interactions with health service and information interfaces.

9.6 IMPLICATIONS AND RECOMMENDATIONS

Interdisciplinary development and evaluation of digital health interventions have been aptly described as working within a ‘parallel’ universe, seeing a convergence of health research[216] and HCI cultures, practices and mutual understandings of processes to inform user-centred health interface designs”. Difficulties, barriers[214,665] and strategies to recognise the value of each discipline’s research, knowledge,[666] processes and practice are shared globally.[216] The tension between HCI and health research underpins the environment for this thesis's research, in which academically attuned health research funded project teams were applying HCI user-centred approaches to develop health interfaces. Multidisciplinary collaborators and contracted partners add to the complexity. Sharing a common goal of ensuring the health interface meets the needs and requirements of the intended users does not necessarily reflect the collective expertise, knowledge and practice to produce the interface design required. Evaluation and accessibility evaluations can offer the reassurance of designs meeting the needs of end-users in the context of their abilities, backgrounds and lived experiences.[667] When teams are not evaluation ready or not in processes where evaluations can be operationalised, how can practice be improved, and who is responsible or accountable within this complex development structure?

9.6.1 THE IMPLICATIONS FOR COMMISSIONING FUNDERS

9.6.1.1 Responsibility versus accountability

In the thesis's social, digital and health context, the responsibility for evaluation to optimise health interface design for a diverse audience can lie with either the non-specialised development team or the commissioning funder - a Government or non-Government organisation (NGO). From the outset, both the funder and developer have a vested interest in the product's success, and therefore one would assume a need to undertake formative and summative evaluations.

For developers, success is measured by use, reach and engagement with the intended audience. Adopting and integrating health information resources into services or communities builds reputation and trust and provides an academic providence for future grants and research. Evaluations can improve the end product acceptability, use and relevance to end-users whilst decreasing costs and time associated with potential downstream re-engineering of the interface due to poor or unsuitable interface design.[668] For commissioning funders, evaluations ensure functionality, advocacy, build creditability and longevity of the health resource within the online environment. Digital endurance ultimately can create savings on two fronts, first, by reducing costly post-release interface redesigns, and second, by avoiding new investments to duplicate or regenerate abandoned resources that have left a virtual 'hole' in the digital landscape due to funding shortfalls.

This proposition suggests a demarcation should be observed between assuming overall responsibility for evaluations and accountability for individual components of the development-evaluation approach.

9.6.1.2 Development teams need accountability

Development teams are accountable for the development process and evaluations of the interface designs when influential factors impacting practice are known and controlled. Contractual agreements between multidisciplinary partners and the funder to compulsorily tie evaluations to project milestones promotes accountability by developers to undertake and report outcomes from usability and accessibility evaluations. However, funders recognise that evaluation milestones can only be met when the development process is stable and adequate support of evaluation practice is available. As the commissioner of the product, Governments and NGOs are ultimately responsible for the quality, usefulness and availability of digital health interfaces produced. Perhaps there needs to be a conceptual shift from a 'techno-utopian' view, adopting a 'techno-critical' approach[669] by governance to address the complexities of developing health interfaces pragmatically.

9.6.1.3 Commissioning funders have a responsibility

Assuming responsibility implies an appreciation of the importance of evaluations to the health interface whilst accepting the value the approach adds to the interface designed for diverse audiences. In an Australian context, findings from Commonwealth-supported digital health resources highlight major deficits in usability and UX for health consumers.[569,670-673] It is difficult to argue against the business case for embedding usability into development when such large budgets are in play. For funders, the savings or returns are not immediately reconcilable from a potential 70% return on investment for every dollar spent on usability,[668] and the consequent reduction in resource burdens across development. Perhaps a more prudent selling point is to focus on the downstream benefits of evaluations on the health outcomes of the end-users. Evaluations can improve end-user UX by decreasing interface pain and pinch points and improving interaction effectiveness, efficiency, and satisfaction. Further, successful interactions with health interfaces can support those with the greatest social, health and technology needs.

Interface designs guided by universal and inclusive design principles can be shaped with end-user differences in mind when evaluations consider the diversity of the audience. 'Everyone interfaces'[207] increases the opportunities for a large number and proportion of end-users to participate and improve health outcomes. So, given the advantages universal interfaces can offer end-users, how can commissioning funders to get involved and support evaluation practice to support improved access and use of health interfaces within communities?

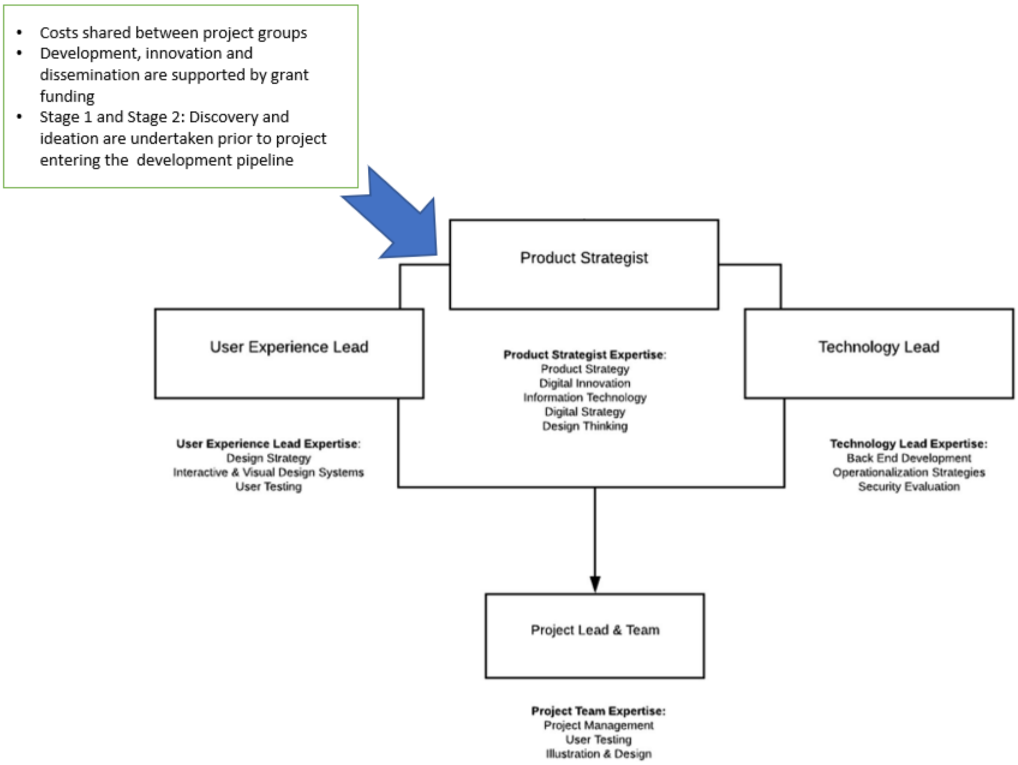
Opportunities abound for Governments and NGOs to contribute to evaluation practice over and above just commissioning the products, including providing a national or international platform for disseminating interfaces in which they are invested.[213] Findings from studies can inform roles and responsibilities funders could offer developments to improve UX of universal interface designs by increasing the likelihood of evaluations being adopted into typical processes, removing their discretionary objectivity. Thesis findings will add to the emerging research from Australia and overseas to improve models and expand recommendations for interdisciplinary development of health interventions. Research findings have highlighted the multidisciplinary and contractual partners' structure as factors influencing evaluations within non-specialised teams.

Commissioning funders can support evaluation practice by investing in the following:

1. Evidence and pragmatically based evaluation guidance for developers -
   Develop an evidence-based resource for information to advise evaluation practice for non-specialised teams and for teams expanding their practice scope into developing and evaluating innovative health interfaces.[214] Unlike present web-based resources available to developers, any new resource would require contextualised, specific guidance for developing health information interfaces—an area currently under-supported by funding bodies. Reported evaluations from projects would contribute to the evidence base, effectively creating a repository to identify practice deficiencies to further scholarship. Evidence Standards Framework for Digital Health Technologies,[335] and usability.gov[196] resource could offer a base off to build.
2. Reconceptualise project length and funding for health research with a digital artefact-
   By re-conceptualising the three-year project funding cycle for health resource development projects, resources become more sustainable, and an increase in longevity increases the opportunity to continually evaluate and improve the interface over the post-release period. In an Australian context, development teams can plan if funding was provided over a fixed term versus being assessed by ongoing need. In an Australian context, a funding period greater than three years would be ideal as research funding, and priorities coincide with election cycles, making prospects of continuing funding unpredictable. Funders could be amenable to a five-seven-year funding round given this is the same period required to conduct a four-stage clinical trial in a medical research setting. A five-year cycle[213] could increase advocacy, reach, engagement, and trust with audiences whilst decreasing duplication[448] and waste across funding rounds by implementing rounds of summative and formative evaluations to ensure interface currency, quality and relevance to the audience. Evaluations could include benchmarking to ensure quality markers are being met by design over time.
3. Support collaborations between technical experts and non-specialist teams to improve the process through research -
   Encourage collaboration and research between technical experts (front end developers, designers, software engineers, programmers) to improve processes specifically for health

interface development within UCD and agile environments. Examples include using the disciplined agile delivery (DAD) methodology,[469] translating research into agile development (TRIAD) method,[674] the three-phase methodology for connected technologies[101] and the four-stage IDEA framework.[675]

4. Transform development and evaluation practice by centralising expertise and creating a pipeline for digital health interfaces - change how non-specialised development teams can access and utilise technical experts, usability/UX/IXD specialists, designers, and marketing professionals by centralising skills and creating a multidisciplinary digital development team with a development pipeline. The Government or NGO funds digital development teams to support academic health researchers to translate findings or evidence into digital health artefacts. Research project funds pay for interface development and evaluations, leaving multidisciplinary teams to specialise in their area of expertise, neither development nor evaluation practice. An example of a centralised approach to development and evaluation is the Digital Design Lab[344] in New York (schematically represented in Figure 9.1).



- Costs shared between project groups
- Development, innovation and dissemination are supported by grant funding
- Stage 1 and Stage 2: Discovery and ideation are undertaken prior to project entering the development pipeline

Figure 9.1 The embedded expertise within the centralised development and evaluation pipeline of the Digital Design Lab[344]

[p.13. Mann DM, Chokshi SK, Lebwohl R, Mainiero M, Dinh-Le C, Driscoll K, Robinson S, Egger H. Building digital innovation capacity at a large academic medical center. npj Digital Medicine. 2019;2(1):13. CC License https://creativecommons.org/licenses/by/4.0/. Primary image not modified; information added for context).]

Considering accountability and responsibility could increase the regularity of evaluations within health interface development; however, the difficulties and complications to identify and recruit appropriate end-users for involvement in usability evaluations would remain.

9.6.1.4 What about accountability by usability/UX professionals?

In many ways, UX/usability professionals are also required to take on a leadership role in developing universal health interfaces. UX (and UX professionals) are now embedded within health services, offering empathetic and creative problem-solving abilities[676] as a crucial mechanism to improve communication, information sharing and integration within health services. Arguably, UX professionals can play an equivalent valuable role in developing health information interfaces, working within the nexus between academic institutions, HCP, patients, consumers, and developers.[677] Leadership in this space would involve democratising professional knowledge[678] to improve the development and evaluation practice within non-specialised teams. Just as UX has been able to balance the needs of patients, HCP and institutions within health systems, the same opportunities exist within multidisciplinary or interdisciplinary teams. In this sense, UX professionals do not have the authority to make large-scale decisions,[677] however they have the skills to balance and negotiate political, business, development, health and consumer agendas to improve the interface for the end-user. In project-driven development programs, these same skills could be deployed to navigate the competing interests or political agendas of academic institutions, their partners, and affiliated organisations.

Strengthening these relationships can further drive the acceptance of UX beyond the fields of science or engineering. Thereby perhaps encouraging policy makers and leaders of health and aged care services to adopt UCD, evaluations and universal design into typical practices to improve UX of interfaces for staff, clinicians and patients. Accepting this leadership role within these teams would also require UX professionals to fully participate in the academic process. Contributing to scientific publications can alleviate some of the burdens of dissemination and further contribute to the scholarship of UX knowledge to inform and improve practice for all development teams. At some level, we are all responsible for ensuring health interfaces are accessible and usable for everyone, including those already marginalised within our communities.

9.6.2 A PRAGMATIC WISH LIST - TO IMPROVE EVALUATION PRACTICE

From the thesis findings, the following requirements and resources could support non-specialised teams to embed evaluations within their typical development processes when designing universal health interfaces:

- Adequate funding to support process and evaluations across the life of the digital health interface, funding tied to milestones to encourage uptake of evaluations at timepoints informing the continual reiterative redesign of interfaces to maintain the currency relevance to intended end-users.
- Reconceptualise funding cycles for projects with a digital health interface artefact to improve the opportunities to maintain resources, increasing community awareness, reach and engagement.
- Readily accessible guidance to adopt and embed UCD approaches, including evaluations, within complex academically-focussed research funded projects where health interfaces are an artefact.
- Research funding of projects to continually design and develop processes supporting equally the requirements of HCI and health research to improve health interfaces.
- Access to organisational development pipelines[344] removes the need to partner with inexperienced technical experts to address barriers to improving processes from innovation to marketing digital health interfaces to the community.
- Acknowledgement that digital health interventions are more than just integration across health platforms, electronic Health Records and services.[182] The general population are cognisant of the accessibility, searchability, relevance and importance of high-quality health information and m-Health in supporting decisions about their health. Development and evaluation of digital health interfaces should be supported appropriately.
- Recognition of the value evaluations brings to UX design of universal and inclusive health interfaces for end-users. By assigning tangible value to evaluation approaches, impresses the significance, the need and the support by funders for non-specialised

teams to undertake assessments of accessibility and usability across the interface lifecycle.

9.6.3 THE IMPLICATIONS FOR DEVELOPERS OF PALLIATIVE CARE INTERFACES

Findings from these PhD studies identified two areas of development for non-specialised development teams that were further complicated when undertaking evaluations of palliative care interfaces – the subject domain and recruitment of participants.

As a specialised area of health, patients, caregivers, and HCP have misconceptions of what palliative care is[586] and what this approach to care can offer patients[679] and their caregivers when faced with a life-limiting diagnosis. The findings from this thesis suggest that exposure to palliative care, the palliative care approach, terminology and experience with the multidisciplinary team approach to care provided context to user evaluations which informed usability feedback. However, the previous experience did not guarantee that end-users would understand all palliative care conceptual relationships, navigation structures, menus, and language within the interface. In many ways, feedback generated from usability evaluations with palliative care naïve end-users were equally informative. This was observed when working with LDs involved in thesis studies providing feedback on the palliative care interface as educational professionals, offering valuable feedback from a palliative care naïve perspective. Their life experiences were dotted with experiences of death and dying. Participants could not always *put a name* to the type of care of relatives, friends, colleagues, and acquaintances received.[680] However, (naïve) palliative care narratives of experiences of death and dying created contextualised interactions generating meaningful feedback. What is less certain is the discrete differences in interface design that could support carers, patients and families' specific needs contextualised to their socio-cultural backgrounds, abilities and life experiences. The involvement of palliative care naïve end-users within evaluations instead of representative or surrogates is an area requiring further research.

9.6.3.1 Can everyone be a potential participant for evaluations of palliative care interfaces?

Findings from these studies indicate that those closely involved in palliative caregiving should be prioritised for recruitment by developers. Priority is not due to specific socio-demographic or end-user characteristics. Characteristics are grounded in their experiential relationships with HCP, health services, and systems that inform their feedback. From this perspective, caregivers and families can offer altruistic support via shaping palliative care interface information during evaluations to benefit others in the same situation.

Engagement, identification, access and recruitment of palliative care participants demanded the development team's time and resources. Gatekeeping[453-455] by HCP was a common barrier, as was lack of availability[456] often due to caring commitments.[451] Caregiver participation was more likely if palliative care was received within health services associated with specialist palliative care settings than community-based palliative care recipients. Involvement in evaluations was not an indication of increased availability due to increased levels of support between settings. Rather, leveraging relationships between multidisciplinary development team members and service gatekeepers were key to unlocking access to potential participants, both patients and caregivers. This highlights the specific issue for developers of collaborating with end-users who have an established relationship with the content domain and/or context of use versus involving those with a casual or a more generalised association to resource content. Whilst access to contextually tied end-users can increase ease of involvement; general end-users can offer development teams the ability to understand the level and type of information required within the community and uncover engagement pathways.

Positive experiences with health services, staff and HCP, were also noted as a common reason for participating in what was typically an uncomfortable experience for caregivers. The study findings showed the value surrogates could bring to usability evaluations when recruiting *ideal* representatives for the resource is unsuccessful. Surrogate end-users are, by definition, those with shared attributes of 'real' end-users, whose risks are managed concerning their differences.[462] The universal nature of death and dying is a unifying attribute when considering the suitability for involvement in usability evaluations of palliative care interfaces. In this context, thesis studies found that caregiver surrogates (bereaved carers) can provide valuable feedback powered by the hindsight of their caring experiences. Ideally, surrogates should have lived experience or have worked with palliative care patients. Suitability for participation could include hospital or hospice volunteers,[681] health service support groups, retired or trainee HCP or allied health professionals.[682]

Developers evaluating palliative care interfaces involving surrogates for patients or caregivers should be aware of the diversity in characteristics of participants relative to those of the wider audience. When considering the heterogeneity of carers with the community,[372] age should not be an assumed limiter to participate in evaluations. Study findings indicate that participants' age is not necessarily the primary factor influencing identifying issues within the interface. Rather consideration of digital competency[141] and technical ability within participants is crucial to identifying errors and given that DHL emerged as a critical indicator of online success,[495] developers should recruit for diversity within their samples. Perhaps this also needs to be a practice consideration for developers creating palliative care interfaces for staff and clinicians. Findings from thesis Study 1 suggest the under-reporting of evaluations could reflect assumptions of homogeneity in access and use within HCP and professional staff in aged and acute palliative settings. Professional health staff are equally heterogenous in their abilities, life experience and socio-cultural backgrounds as nurses, who reportedly are more likely to be involved in evaluations of OHT. Awareness of ‘professional status’ bias toward assumptions of tech-savviness could improve health interfaces in multidisciplinary settings by ensuring all staff representatives are involved in evaluations. Thesis findings have demonstrated that an alternative perspective offered by user groups can improve palliative care interfaces, and pragmatically both aged and acute care settings are reflective of supporting diverse audiences.

Further, recruitment strategies must extend to groups within the community who regularly experience difficulties accessing and using health interfaces. Individuals who are technically averse or have low technical abilities should be invited, along with those from low socioeconomic groups, culturally diverse populations, and isolated geographic locations. Given that both digital exclusion and death do not follow economic or social contours, there is an imperative to ensure information about palliative care, death and dying is easy to find, access and understand for everyone in the community. Evaluation of usability and accessibility are the keys.

9.7 DIRECTIONS FOR FUTURE RESEARCH

Findings from the research in this thesis should contribute to the forthcoming technological revolution of health. This will culminate in the convergence of machine learning,[635] and design approaches to create adaptive user-centred interfaces[683] with layered digital solutions[562] integrating all aspects of an individual’s health.

For example, outcomes could inform the development of a machine learning-supported Internet browser plug-in, automatically augmenting the interface to a design supporting the specific needs or requirements of the end-user. Informed by data capture from social network sites, the software could adjust critical aspects of the interface to improve UX, including information flow, modify the language to increase translation capabilities, increase visual or graphic representations and simplify the language used as landmarks or links for navigation. However, to establish the roles of developers, funders and end-users within this new digital health milieu, further research is required to extend the understanding of the relationship between systems, technology and digital health literacy. The studies in this thesis have become the catalyst for further exploration of the significant findings, especially given this ongoing agenda of forced adoption to access and use health interfaces to support "*tech-equity*"[562(p301)] across the population.

The studies undertaken in this thesis have been exploratory, investigating aspects of evaluation practice within development teams, especially those with limited experience or usability expertise. Thesis studies employed novel approaches to understanding current practice, development processes and application of a measure of DHL to diversify feedback. In all future research, study designs need to be statistically powered with large sample sizes to be able to detect small differences between participant's performances within the interface and their variations in their characteristics. This will enable researchers to fully capture the capability and applicability of the methods to development and evaluation practice. As a result, many different activities could extend these findings to inform development and evaluation practices in development teams to improve universal interfaces. Future research could include the following activities:

1. Fundamentally, there is a need to comprehend the scope of evaluation practice in projects commissioned to create health interfaces for the community. Canvassing current project funded development teams could provide valuable information on evaluation scholarship knowledge and practice behaviours within an Australian context. This information could form the basis to recognise the gaps in knowledge and practice and assist in designing education packages to inform development teams of the 'why', 'how', and 'when' to apply evaluations during development. Research training programs[213] could involve usability experts teaching, explaining, and training developers or peer-to-peer networking between groups to collaborate and share methodologies, participants, or design frameworks.
2. Activities investigating stable development processes are the key to ensuring opportunities for usability and accessibility evaluations can occur. The revised development framework created from the research undertaken in Study 3 (Figure 6.4) could be an appropriate place

to begin for non-specialised development teams. Research investigating the applicability of this framework in the development of health interfaces could inform further improvements to a structured yet comprehensive process to provide every opportunity for developers to complete usability and accessibility evaluations. This framework would provide researchers with both process and outcome evaluations of the success of this process on the interface design for generalist audiences.

3. There are prospects in investigating the roles of participants in evaluations during the development process – representative end-users and expert evaluators. The current research demonstrates that identifying and recruiting participants is challenging within complex and pressurised development processes. Research survey panels offer researchers an on-demand sample of potential participants who can be preselected based on personal social, political, geographic, and behavioural characteristics. The ability to select characteristics to match end-user context, requirements and need for use could provide developers with a readily available and time and cost-effective source of participants to undertake remote UEM.

Consequent to the findings of the influence digital competency has in facilitating an individual's successful interactions with health interfaces; there is an urgent need to investigate further the relationship between user characteristics, online behaviour and digital health literacy. Future research requires a series of studies (which are adequately statistically powered with participant numbers to detect small differences between groups) to improve the understanding of DHL as a concept and the interplay of how an individual's characteristics influence interactions across socio-demographic divides and digital inequities. There is a need to primarily understand the *DHLI* assessment and how this differs between cohorts and within communities in determining the implications of high and low scores for individuals. For example, what is a 'high' or 'low' *DHLI* score and are *DHLI* scores equivalent to the same behaviours or performance outcomes across communities given the unequal influence of characteristics on DHL?

4. Understanding individuals with low DHL levels require expanding recruitment strategies and applying time-space sampling to engage with potential participants within community organisations. Public libraries and local councils were valuable focal points of community engagement, highlighting a need to increase the distribution of organisations involved to potentially recruit participants with characteristics not identified within the current study cohort, such as geographically isolated communities, Indigenous peoples, and CALD

populations. The distribution of *DHLI* levels within crowdsourcing networks[684] would also be an interesting investigation, given the significance of identifying individuals to diversify feedback from evaluations. Stratification and selection based on DHL levels would add value to investigations of revised development processes, especially if recruitment is streamlined and becomes less time-intensive for non-specialised teams. This approach could inform evaluations for health interfaces for specialised domains or audiences is an area of future interest.

5. The role of skill-building is another area of research to investigate if DHL levels are fixed, temporal or transient in nature due to the influence of digital competencies, socio-demographic and Internet behaviours. Outcomes could inform subsequent programs to improve HL and DHL,[11] end-users functional aptitudes and competencies, and highlighting potential interface designs to support access to health information.
6. From the thesis research, the involvement of socially or digitally excluded and hard-to-reach communities is crucial to understanding user characteristics' influence on success levels within health interfaces. Further research activities are required to investigate the influence of DHL on performance and behaviours during evaluations to generate feedback to improve interfaces for all users. Studies require engagement, recruitment, and participation of individuals from these community groups in usability evaluations. Exploring these interactions using UEM increases the ability to design universal interfaces to support people who face barriers to access and use health information and improve inadvertent UX for everyone else.

The additional exploration of the out-of-scope research data reported within this thesis and not aligned with the core objectives of this body of research.

7. Further examination of the survey response data collected within Study 4 is essential to understanding health literacy and computer anxiety predictors concerning *DHLI* scores. Multivariate statistical analysis would investigate the correlations between socio-demographic characteristics and descriptors of Internet use and online behaviour on the eHEALS and SCAS (when participant scores are treated as outcome variables).

10 THESIS CONCLUSION

For many in the population, access to knowledge is enabled by using the Internet and connected technologies.[1] There is a need to sustain the considerable gains to individuals, health services and systems by the availability of health information being online. The ability for individuals and their families to proactively manage their health could provide benefits beyond the individual themselves. Economic savings and increased capacity to provide care are potential benefits for health systems and services if individuals access and use digital health information to improve health outcomes.[616]

Evaluations of usability and accessibility by development teams can support increased access and use of health information by improving UX of interface designs.[188] Integrating usability testing and post-release evaluations provides valuable participant-based feedback, increasing the applicability and acceptability of the health interface to end-users. Iterative improvements through improved awareness and usability approaches could further consolidate these gains.

Applying universal and inclusive design principles[207] can further guide development teams to improve interfaces for *all end-users,*[247] including socially or digitally excluded individuals who belong to vulnerable groups[31] or are disadvantaged and are already likely to experience poorer health outcomes. However, development processes managed by non-specialised teams are unstable. The identification then subsequent recruitment of representatives for involvement in evaluations, restrictive budgets, lack of resources and limited evaluation expertise in teams not experienced in online development all combine to decrease opportunities for usability and accessibility to be undertaken during the development of health interfaces.

Given the prominence and persistence of the digital divide[685] and social inequities, the push for the forced adoption of technology and the Internet further supports the fundamental need for developers to consider diversity within their evaluations. For development teams, evaluations of usability and accessibility can only occur when high fidelity interfaces are stable,[636] requiring well-resourced processes and participants who are readily available to generate feedback from programmed activities to inform modifications to improve the interface.

Five studies within this thesis have explored the primary question of the influence of structured and comprehensive evaluation during development to improve the UX of health interfaces. Observations of practice through the peer-reviewed literature, explorations of development processes and conducting evaluations have highlighted the real-world barriers for non-specialist development teams. Implications from the challenges, difficulties, and complications directly impact the likelihood of crucial evaluations to shape health interfaces.

For these teams, the peer-reviewed literature offered no evidence to inform evaluation practice, improve the methodological rigours or aid in interpreting feedback to inform meaningful improvements to interface design. Team composition was vital to increase the probability of usability or accessibility evaluations being normalised within the development. Previous experience in undertaking an evaluation approach within the development and resolving issues meaningfully was fundamental to improving the UX of interface design for health resources.

An understanding of the relationship between digital health literacy and user characteristics for the first time acknowledges where the *"conditions in which people live, learn, work and play .... can affect health and produce disparities,"*[162(p1416)] can also affect levels of success when interacting with health interfaces. Functional capabilities and digital competency, including confidence, comfortability and the ability to gauge trustworthiness, are critical skills required by those who face barriers to accessing and using health interfaces. Underlying socio-cultural factors will continue to impact digital inequities; unlike previous decades, the divide is no longer at the level of access or digital readiness; instead, the divide is at the level of digital competency within the interface.

The dynamic nature of the online environment and the evolution of new devices, platforms, technology and software will continue to challenge developers to evaluate interfaces for diverse audiences. Until commissioning funders to stop asking health researchers to be "*all things to all people*"[275(p4)] in providing development and evaluation expertise to health interface design, non-specialised development teams will remain accountable for usability and accessibility evaluations.

The ecosystem for development teams is a critical factor in determining the normalisation of evaluations within complex processes. Governments as funders can enrich and improve this environment[213] for non-specialised development teams. Due to the disparity in evaluation scholarship within and across development teams, a 'one size fits all' approach will not necessarily increase adoption. In an Australian context, the Commonwealth has an opportunity to integrate a differentiated approach to assist development teams to integrate evaluations into typical practice. Support could extend to (developing and) providing access to evidence to support the practice of under-skilled professionals and to fund development teams to incorporate evaluations within their processes adequately. Governments could foster evaluation practice by incentivising usability and accessibility assessments. Arguably, this could result in an increasing adoption of evaluation and routine reporting of outcomes; possibly encouraging a shift in practices of interdisciplinary development teams to normalise usability and accessibility evaluations within their processes.

For example, development teams who complete evaluations could be rewarded with priority grant funding to maintain their health interfaces into the future. Encouraging cooperative behaviours to work effectively[213,214,665] between all collaborators can increase the likelihood evaluations can improve the UX of health interfaces. Patronage should extend to individuals who are internal or external to the development team, groups who cross multidisciplinary or interdisciplinary boundaries, and within collaborators or contractors to the project. Finally, Governments could genuinely transform the digital development of health interfaces by offering structured delivery and equal access to evaluation expertise. This step acknowledges the value of evaluation recognised as a key for all end-users to have a meaningful experience with health interfaces.

There is still much work to counter the utopian view of digital health interventions, platforms, information and technologies. Increasing adoption and use of health information interfaces require a commitment to support, encourage and insist development teams improve their evaluation practice. As ‘digital health providers’, there is a need to: *Build* the knowledge base, create awareness of evaluations and increase local expertise to support development. *Facilitate* networking opportunities for specialist and generalist evaluators to share their expertise. *Establish* and enhance the process governance for usability evaluations, including documentation of activities and the outcomes or effect of the feedback on the interface. *Support* exploration to identify or develop methods and mechanisms to support inclusive design. *Encourage* communities and researchers to collaborate to increase usability participation of those who represent the diversity of Australia.

11 APPENDICES

APPENDIX 1. ADDITIONAL INFORMATION RELATING TO THE INTRODUCTORY CHAPTER

Appendix 1.1 WCAG (2.1) Guidelines and Principles for Accessibility

Principle	**Guideline**
Perceivable	1 Provide text alternatives for non-text content. 2 Provide captions and other alternatives for multimedia. 3 Create content that can be presented in different ways, including by assistive technologies, without losing meaning. 4 Make it easier for users to see and hear content.
Operable	• Make all functionality available from a keyboard. • Give users enough time to read and use the content. • Do not use content that causes seizures. • Help users navigate and find content. • Make it easier to use inputs other than the keyboard.
Understandable	• Make text readable and understandable. • Make content appear and operate in predictable ways. • Help users avoid and correct mistakes.
Robust	• Maximize compatibility with current and future user tools.

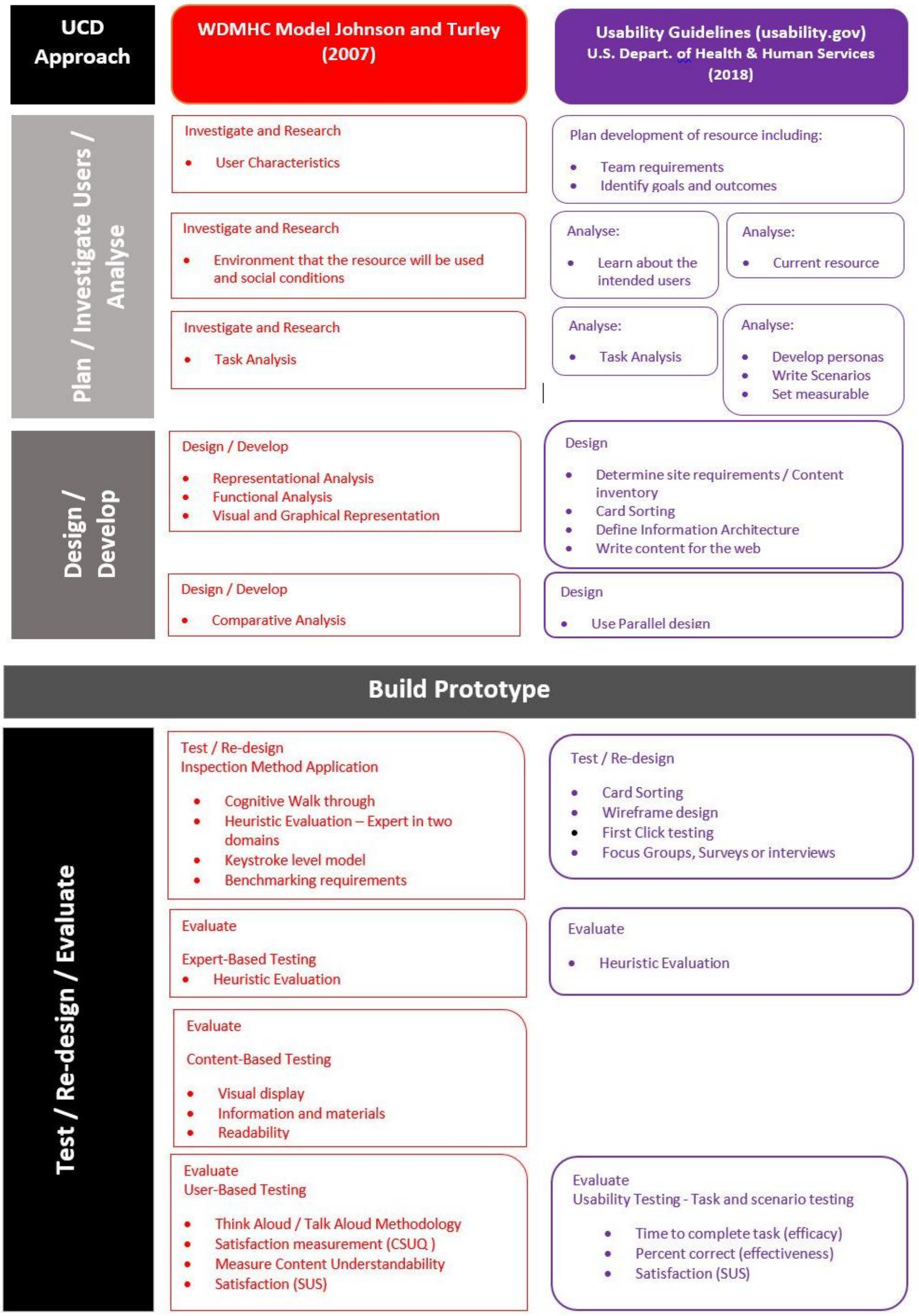
(adapted from Abou-Zahra (2018) [33])

APPENDIX 2. ADDITIONAL INFORMATION RELATING TO THE GUIDELINES, MODELS AND FRAMEWORKS CHAPTER

Appendix 2.1 US Human and Health Service research-based web design and usability guidelines (www.usability.gov guidelines) topics and strength of evidence descriptors [196,197]

US HHS Human and Health Service research-based web design and usability guidelines (www.usability.gov guidelines)	
Guideline Topics – Usability and Accessibility	
1: Design process and evaluation	10: Links
2: Optimizing the user experience	11: Text Appearance
3: Accessibility	12: Lists
4: Hardware and software	13: Screen-based controls (Widgets)
5: The home page	14: Graphics, images, and multimedia
6: Page layout	15: Writing web content
7: Navigation	16: Content organization
8: Scrolling and paging	17: Search
9: Headings, titles, and labels	18: Usability testing
Strength of evidence rating summary	
5 – Strong research support	• Cumulative and compelling, supporting research-based evidence • At least one formal, rigorous study with contextual validity • No known conflicting research-based findings • Expert opinion agrees with the research
4 – Moderate research support	• Cumulative research-based evidence • There may or may not be conflicting research-based findings • Expert opinion • Tends to agree with the research, and • A consensus seems to be building
3 – Weak research support	• Limited research-based evidence • Conflicting research-based findings may exist - and/or a mixed agreement of expert opinions
2 – Strong expert opinion support	• No research-based evidence • Experts tend to agree, although there may not be a consensus • Multiple supporting expert opinions in textbooks, style guides, etc. • Generally accepted as a ’best practice’ or reflects ’state of practice’
1 – Weak expert opinion support	• No research-based evidence • Limited or conflicting expert opinion

Appendix 2.2 Mapping domains with user-centred approach (UCD), Web Development Model for Health Consumers (WDHMC) framework[218] and US Human and Health Service research-based guidelines[197] usability.gov



UCD Approach	WDMHC Model Johnson and Turley (2007)	Usability Guidelines (usability.gov) U.S. Depart. of Health & Human Services (2018)
Plan / Investigate Users / Analyse	Investigate and Research • User Characteristics	Plan development of resource including: • Team requirements • Identify goals and outcomes
	Investigate and Research • Environment that the resource will be used and social conditions	Analyse: • Learn about the intended users Analyse: • Current resource
	Investigate and Research • Task Analysis	Analyse: • Task Analysis Analyse: • Develop personas • Write Scenarios • Set measurable
Design / Develop	Design / Develop • Representational Analysis • Functional Analysis • Visual and Graphical Representation	Design • Determine site requirements / Content inventory • Card Sorting • Define Information Architecture • Write content for the web
	Design / Develop • Comparative Analysis	Design • Use Parallel design
Build Prototype		
Test / Re-design / Evaluate	Test / Re-design Inspection Method Application • Cognitive Walk through • Heuristic Evaluation – Expert in two domains • Keystroke level model • Benchmarking requirements	Test / Re-design • Card Sorting • Wireframe design • First Click testing • Focus Groups, Surveys or interviews
	Evaluate Expert-Based Testing • Heuristic Evaluation	Evaluate • Heuristic Evaluation
	Evaluate Content-Based Testing • Visual display • Information and materials • Readability	
	Evaluate User-Based Testing • Think Aloud / Talk Aloud Methodology • Satisfaction measurement (CSUQ) • Measure Content Understandability • Satisfaction (SUS)	Evaluate Usability Testing - Task and scenario testing • Time to complete task (efficacy) • Percent correct (effectiveness) • Satisfaction (SUS)

APPENDIX 4. ADDITIONAL INFORMATION RELATING TO THE SYSTEMATIC MAPPING REVIEW CHAPTER

Appendix 4.1 Modified search strategy for literature databases

a) PubMed

((evaluat* or summative or formative or qualitative or focus group* or analytics or quantitative or interview* or survey* or questionnaire* or feedback or usefulness or usage or usability or user testing or accessibility or utility or applicability or medical informatics) AND (on line or online or website or internet or web) AND (tool box* or toolbox* or toolkit* or tool kit*)) NOT Medline[sb]

b) CINAHL (EBSCO)

#	Query	Results
S1	(MH "Surveys") OR (MH "Interviews+")	233,915
S2	(MH "Evaluation Research+")	44,033
S3	(MH "Qualitative Studies")	72,076
S4	(MH "Program Evaluation")	23,864
S5	(MH "Medical Informatics")	1,806
S6	(MH "Questionnaires")	231,581
S7	TI (evaluat* OR summative OR formative OR “focus group*” OR analytics OR qualitative OR quantitative OR interview* OR survey* OR questionnaire* OR feedback OR usefulness OR usage OR usability OR "user testing" OR accessibility OR utility OR applicability OR informatics) OR AB (evaluat* OR summative OR formative OR “focus group*” OR analytics OR qualitative OR quantitative OR interview* OR survey* OR questionnaire* OR feedback OR usefulness OR usage OR usability OR "user testing" OR accessibility OR utility OR applicability OR informatics)	684,407
S8	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7	867,810
S9	"on line" OR online OR website OR internet OR web	169,509
S10	"tool box*" OR toolbox* OR toolkit* OR "tool kit*"	2,548
S11	S8 AND S9 AND S10	140

c) SCOPUS

((TITLE (evaluat* OR summative OR formative OR "focus group*" OR analytics OR qualitative OR quantitative OR interview* OR survey* OR questionnaire* OR feedback OR usefulness OR usage OR usability OR "user testing" OR accessibility OR ut) OR ABS (evaluat* OR summative OR formative OR "focus group*" OR analytics OR qualitative OR quantitative OR interview* OR survey* OR questionnaire* OR feedback OR usefulness OR usage OR usability OR "user testing" OR accessibility OR ut))) AND ((TITLE ("on line" OR online OR website OR internet OR web) OR ABS ("on line" OR online OR website OR internet OR web))) AND ((TITLE ("tool box*" OR toolbox* OR toolkit* OR "tool kit*") OR ABS ("tool box*" OR toolbox* OR toolkit* OR "tool kit*"))) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "SOCI") OR LIMIT-TO (SUBJAREA , "NURS") OR LIMIT-TO (SUBJAREA , "HEAL") OR LIMIT-TO (SUBJAREA , "PSYC") OR LIMIT-TO (SUBJAREA , "DENT")) AND (LIMIT-TO (LANGUAGE , "English"))

d) Web of Science

TOPIC: (evaluat* OR summative OR formative OR “focus group*” OR analytics OR qualitative OR quantitative OR interview* OR survey* OR questionnaire* OR feedback OR usefulness OR usage OR usability OR "user testing" OR accessibility OR utility OR applicability OR informatics) AND TOPIC: ("on line" OR online OR website OR internet OR web) AND TOPIC: (("tool box*" OR toolbox* OR toolkit* OR "tool kit*"))

Refined by: WEB OF SCIENCE CATEGORIES: (HEALTH CARE SCIENCES SERVICES OR GERIATRICS GERONTOLOGY OR INFECTIOUS DISEASES OR MEDICINE GENERAL INTERNAL OR PHARMACOLOGY PHARMACY OR PSYCHOLOGY OR NURSING OR NUTRITION DIETETICS OR GERONTOLOGY OR PSYCHOLOGY CLINICAL)

e) ProQuest

(ab(evaluat* OR summative OR formative OR "focus group*" OR analytics OR qualitative OR quantitative OR interview* OR survey* OR questionnaire* OR feedback OR usefulness OR usage OR usability OR "user testing" OR accessibility OR utility OR applicability OR informatics) OR ti(evaluat* OR summative OR formative OR "focus group*" OR analytics OR qualitative OR quantitative OR interview* OR survey* OR questionnaire* OR feedback OR usefulness OR usage OR usability OR "user testing" OR accessibility OR utility OR applicability OR informatics)) AND (ab("on line" OR online OR website OR internet OR web) OR ti("on line" OR online OR website OR internet OR web)) AND (ab("tool box*" OR toolbox* OR toolkit* OR "tool kit*") OR ti("tool box*" OR toolbox* OR toolkit* OR "tool kit*"))

evaluat* OR summative OR formative OR “focus group*” OR analytics OR qualitative OR quantitative OR interview* OR survey* OR questionnaire* OR feedback OR usefulness OR usage OR usability OR "user testing" OR accessibility OR utility OR applicability OR informatics

"on line" OR online OR website OR internet OR web "tool box*" OR toolbox* OR toolkit* OR "tool kit*"

LIMITED to *HEALTH* DATABASES

Appendix 4.2 Inclusion and exclusion criteria for publications identified in the primary search process

Inclusion Criteria

All publications, articles or conference proceedings were included if any of the following criteria were met:

- Studies that describe an online toolkit - the AHRQ[300] definition guided inclusion, therefore, to be a 'toolkit' must have:
    - an evidence base that guides the content and is mentioned within the study literature
    - more than one tool; where a 'tool' is an instrument to assist the user to complete specific tasks and can be a quiz, survey, online module, or checklist are related to the goal of the toolkit
    - an objective for the user to change a behaviour or practice based on evidence-based guidelines, standards or recommendations that underpin the resources, information, and tools provided in the toolkit.
      This should also be described within the study literature.
- The online toolkit supporting users within the health domain (including public health, medicine, allied health, including social work, psychology, physiotherapy, and occupational therapy)

Exclusion criteria

Reported studies that have at least one of the following criteria were excluded, papers:

- describing 'hard' or 'paper' based toolkits that are available and includes studies where an online resource such as a website is a mechanism to request or access a physical copy of the toolkit
- reporting usability evaluation methods of health-related products or online systems, including:
    - medical devices
    - hospital systems
    - personal or electronic health records systems
    - health system-related competencies or quality
    - analytical systems or software or programs
    - web-based or mobile applications
    - library information systems or databases
    - social media platforms or products relating to health information
    - medical imaging, including MRI and CT scans or radiography.
- describing web-based information resources such as websites or online education sites hosting a single tool (such as learning modules or webpages) and portals
- with introductory papers for special issues of books, conferences, or workshops
- reporting the same studies in different sources (duplicates of studies)

Appendix 4.3 Data descriptors, extraction variables and definitions for a systematic mapping study

Mapping review question	Data descriptor (source reference) definition	Extracted variables (V.)
DemQ1	Demographics of the paper	V. Authors, Country of research, Journal, Reference, Year of study
	1b) Type of study described within the reference	V1 Conceptualisation or development of content
		V2. Feasibility or acceptability
		V3. Intervention study with OHT as an intervention
		V4. Outcome measures of OHT post-release
		V5. OHT Implementation Protocol
DevQ2	Description of Toolkit Use (Barac et al.[250]) Q2a) Setting of Use – settings that the toolkit would be intended to support practice, behaviour or knowledge)	V. Acute clinical, Rehabilitation Allied health, Primary care, Aged care, Community at home, Schools
	Q2b) Intended user group	V. Clinicians, Allied health specialities, Nurses (Aged, Primary, Acute), Community (specific groups or general), students, academics or researchers
	Q2c) Toolkit components	V. Downloadable documents or forms, quizzes, surveys, online modules, tip sheets, assessment guides and checklists
DevQ3	Toolkit knowledge translation goal or objective [Barac et al.[250]] Toolkits can be developed with an underlying knowledge translation goal that guides content, tools and resource choice or goals.	V1. Educating or sharing knowledge
		V2. Informing policy
		V3. Aid decision-making
		V4. Changing a behaviour
		V5. Improving clinical practice
DevQ4	Evidence base for toolkit development [Barac et al. [250]]	V1. Evidence base was described in detail (referenced or mentioned in the text)
		V2. Evidence base was not included in the description of the toolkit development V3. Reviews (Systematic, critical analysis, literature, umbrella), Case Studies, Clinical Trials, Survey, Focus groups, Stakeholder interviews, Expert panels, Theories or Conceptual frameworks, Evidence-based guidelines, Formal reports, Best practice approaches, Specialist discussions
DevQ5	Evaluation of the effectiveness of the toolkit [Barac et al.[250]]	V1. Evaluation of the toolkit was reported in the study – Overall toolkit was evaluated relative to the objectives outlined in the study

		V2. Evaluation of the toolkit was reported in the study – Specific toolkit components were evaluated relative to the objectives outlined in the study
		V3. No evaluation of the toolkit was reported in the study
EvalQ6	Toolkit evaluation type [Barac et al.[250]]	V1. Process evaluation completed and reported in the study – testing and monitoring the process of use
		V2. Outcome evaluation completed and reported in the study – evaluation and assessment of the changes influenced by the use of the toolkit reported by users
		V3. Process and outcome evaluation completed and reported in the study – can assess usefulness, satisfaction and positive effects relative to objectives
UEQ7	Origin of UEM applied [Fernandez et al.[59]]	V1. New - researchers modified an existing UEM or developed a new UEM to assess their toolkit
		V2. Existing - researchers applied previously validated UEMs used within the field of usability engineering
		V3. None – no reference or application of UEM described in the experimental method
UEQ8	Referencing standards within evaluation description used in the study	V1. Usability Standards – definition based on the International Standards Organisation (ISO) standards applicable to usability [such as ISO 9241-210:2010 [309] or ISO 9241-11] or mention Usability Guidelines (HHS www.usability.gov website)
		V2. Accessibility standards – provide a description or references source of accessibility guidelines used (such as W3C Accessibility Guidelines (WAI/WCAG) or details www.w3c.org website) in the experimental methods
		V3. No standards referenced in the paper
UEQ9	Stage of product process UEM applied [IEEE[309]]	V1. Requirements / Research – evaluation methods that input into the requirements for the online including case studies, use cases, use scenarios, personas, focus groups identifying needs and requirements of intended users, environmental studies or field research observing user behaviours.
		V2. Design / Development – evaluations applied too early to intermediate versions of the product such as wire frames or prototypes to investigate function, interface, or navigation of the resource Evaluations applied during this stage are most likely focused on identifying interface usability issues through analytical and empirical methods. UEMs include card sorting, dialog models, paper prototypes, heuristic evaluation, cognitive walkthrough.
		V3. Implementation – evaluation method conducted on the final version of the online product prior to release Evaluations applied during this stage are most likely focused on identifying usability issues through empirical methods as a final 'check' before release. UEMs are often empirical and can be formative or summative in approach.

		V4. Post-release / Post Implementation – evaluation methods applied post-release are often summative and can include measures of effectiveness or satisfaction and often include usage data generated from log data.	
		V5. Mixed Stage or Multiple Evaluations across stages – Evaluations applied across different stages of product cycle where a single UEM can be applied to multiple iterative versions of the product across stages or different UEMs applied to a product at different stages of development	
UEQ10	Class of UEM applied to the online toolkit, Classifications of UEM developed by Ivory and Hearst[310]	V1. Testing – evaluations involving moderator or facilitator observing users interacting with the online resource to determine usability issues (UEMs include think-aloud protocol, remote testing, log file analysis)	
		V2. Inspection – evaluations conducted by experts against a set of rules for deployment (UEMs include Heuristic evaluations, cognitive walkthroughs or guideline reviews)	
		V3. Inquiry – evaluations involving users that specifically probe for opinions, suggestions, preferences or feelings (UEMs include focus groups, interviews, surveys, questionnaires)	
		V4. Simulation – evaluations conducted by system-based algorithms that simulate user behaviour or analyses usage data	
		V5. Analytical modelling – involves predictions by evaluators based on an engineering approach using models (UEMs include cognitive task analysis and GOMS)	
UEQ11	What type of UEM was employed [Fernandez et al.,[59] Fernandez et al.,[269] Farrell et al.,[62] Ellsworth et al.[295]]	V1. Survey	V9. Interviews
		V2. Goals, Operator, Methods and Selection (GOMS)	V10. Focus Groups
		V3. Think Aloud Protocol	V11. Card Sorting
		V4. Cognitive Walkthrough	V12. Brainstorm
		V5. Heuristic evaluation	V13. Personas / Use Cases
		V6. Task analysis	V14. Field observations
		V7. KLM	V15. TURF / UFuRT
		V8. Teach / Reverse Teach	V16. Metrics analysis (log data)
UEQ12	Evaluation type completed by UEM [Fernandez et al.,[59] Fernandez et al.,[269] Nielsen,[54] Abou-Zahra[33]]	V1. Manual – evaluation protocol that a human evaluator conducts (method can be computer-aided) (UEMs include interviews, think-aloud protocols, questionnaires)	
		V2. Automatic – describes a tool (software) that conducts all or the majority of the evaluation and the data produced requires interpretation by an evaluator	
UEQ13	What type of feedback is provided to the developer from the UEM [Fernandez et al.,[59] Fernandez et al.,[269] Nielsen,[54] Abou-Zahra[33]]	V1. Yes – Evaluation method provided guidance or inference for improvements in design based on the usability issue identified	
		V2. No – Evaluation method generated a list of usability issues	

UEQ14	14a) UEM Protocol	V1. UEM protocol described within the paper to full extent or in brief
		V2. UEM protocol was mentioned, but no detail was provided or not mentioned at all
	14b) UEM Participants - Users	V1. Number and archetype of users involved in UEM provided within the paper
		V2. No description of the users involved
	14c) UEM Participants - Evaluators	V1. Description of the role and evaluator characteristics included in the paper
		V2. No description of the evaluators provided in the UEM protocol
	14d) UEM Participants - Experts	V1. Description of the expert's characteristics included in the paper
		V2. No description of the experts provided in the UEM protocol
AccQ15	15a) Accessibility Evaluation method	V1. Automated - describes a tool (software) that conducts all or the majority of the evaluation and the data produced requires interpretation by an evaluator (examples include 508 checker (Formstack), A-Tester (Evaluta), Accessibility Developer Tools (Google Accessibility)
		V2. Manual – evaluation protocol that is conducted by a human evaluator including experts (method can be computer-aided)
		V3. User-based observation – Accessibility evaluation conducted with the user and associated assistive technologies either remotely or in house
	15b) What type of feedback is provided to the developer	V1. Yes – Evaluation method provided guidance or inference for improvements in design based on the accessibility issue identified
		V2. No – Evaluation method generated a list of usability issues
	15c) Stage of product process UEM applied (IEEE 2017)	V1. Requirements / Research
		V2. Design / Development
		V3. Implementation
		V4. Post-release / Post Implementation
		V5. Mixed Stage or Multiple Evaluations across stages
FunQ16	Reported funding source	V1. Government (Federal, Commonwealth, State or Provincial)
		V2. Corporate (Organisation) or Private funding
		V3. No Funding description provided

Appendix 4.4 Literature excluded after retrieval and screening of full text (*n*=26)

Not toolkit (AHRQ definition) *n*=20	**Author and publication reference**
Hard copy or paper copy of the toolkit (not online version)	Sturgiss 2017[686] Wigwe 2016[687] Yates 2015[688]
Information or communication Portal/Platform/Dashboard	Adeponle 2016[689] Brown 2018[690] Dykes 2014[691] Goldsmith 2009[692] Katapodi 2018[693] Strand 2017[694]
Not toolkit - a collection of individual tools/resources	Adams 2016[695] Belot 2017[696] Kahn 2016[697]
PDF toolkit disseminated via a website	Arbour-Nicitopoulos 2013[698] Arbour-Nicitopoulos 2017[699] Kuperman 2013[700] Macaller 2011[701] Nagykaldi 2010[702] Naz 2016[703] Schippke 2017[704]

Toolkit (by AHRQ definition) *n*=6	**Author and publication reference**
Non-health or service improvement (system Level) online toolkit	Allen 2012[705] Caldwell 2008[706] Ganz 2018[707] McGilton 2016[708] Muir 2008[709] Stav 2011[710]

Appendix 4.5 Full citations of articles, conference proceedings and thesis included within systematic mapping review

	Author	Country	Year	Journal	Reference
C1 [315]	Babul, S., Pike, I.	Canada	2017	British Journal of Sports Medicine	Babul S, Pike I. The online concussion awareness training tool (catt) Br J Sports Med 2017;51:A72
A1 [322]	Champion, K.E., Chapman, C., Newton, N.C., Brierley, M.E., Stapinski, L., Kay-Lambkin, F., Nagle, J., Teesson, M.	Australia	2018	JMIR Mental Health	Champion, K.E. A Web-Based Toolkit to Provide Evidence-Based Resources About Crystal Methamphetamine for the Australian Community: Collaborative Development of Cracks in the Ice. JMIR Mental Health 2018;5(1):e21
A2 [319]	Duggleby, W., Ghosh, S., Struthers-Montford, K., Nekolaichuk, C., Cumming, C., Thomas, R., Tonkin, K., Swindle, J.	Canada	2017	Oncology Nursing Forum	Duggleby, W. et al. Feasibility Study of an Online Intervention to Support Male Spouses of Women with Breast Cancer. Oncology Nursing Forum 2017;44(6):765-775
A3 [317]	Duggleby, W., Ploeg, J., McAiney, C., Peacock, S., Fisher, K., Ghosh, S., Markle-Reid, M., Swindle, J., Williams, A., Triscott, J. A., Forbes, D., Jovel Ruiz, K.	Canada	2018	Journal of Medical Internet Research	Duggleby, W. et al. Web-Based Intervention for Family Carers of Persons with Dementia and Multiple Chronic Conditions (My Tools 4 Care): Pragmatic Randomized Controlled Trial. Journal of Medical Internet Research 2018; 20(6):e10484p.1
C2 [316]	England, R., Shreeve, P.	United Kingdom	2018	BMJ Supportive and Palliative Care	England R, Shreeve, P.109 Developing an on-line toolkit to support end of life care. BMJ Supportive & Palliative Care 2018;8:A49-A50.
A4 [323]	Ezzat, A.M., Schneeberg, A., Huisman, E.S., White, L.D., Kennedy, C., Levesque, L.A., Scott, A., Hoens, A.M.	Canada	2017	Disability and Rehabilitation	Ezzat, A.M. et al. A cross-sectional evaluation examining the use of the Achilles tendinopathy toolkit by physiotherapists in British Columbia, Canada. Disability and Rehabilitation 2017; 39(7):671-676
A5 [324]	Farndon L., Robinson V., Nicholls, E., Vernon, W.	United Kingdom	2016	Journal of Foot and Ankle Research	Farndon, L. et al. If the shoe fits: development of an on-line tool to aid practitioner/patient discussions about 'healthy footwear' Journal of Foot and Ankle Research (2016) 9:17
A6 [325]	Fine, P.G., Bradshaw, D.H., Cohen, M.J., Connor, S.R., Donaldson, G., Gharibo, C., Gidal, B.E., Muir, J.C., Tselentis, H.N.	United States	2014	Pain Medicine	Fine, P.G. et al. Evaluation of the performance improvement CME paradigm for pain management in the long-term care setting. Pain Medicine 2014;15(3):403-9
A7 [326]	Gallagher, A., Curtis, K., Dunn, M., Baillie, L.	United Kingdom	2017	International Journal of Older People Nursing	Gallagher, A. et al. Realising dignity in care home practice: an action research project. International Journal of Older People Nursing. 2017;12(2):e12128
A8 [320]	Gannon, M., Qaseem, A., Snow, V., Snooks, Q.	United States	2011	Journal of Primary Care and Community Health	Gannon, M. et al. Pain management and the primary care encounter: opportunities for quality improvement. Journal of Primary Care and Community Health 2011; 2(1):37-44

A9[321]	Gannon, M., Qaseem, A., Snow, V., Snooks, Q.	United States	2011	American Journal of Medical Quality	Gannon, M. et al. Using online learning collaboratives to facilitate practice improvement for COPD: an ACPNet pilot study. American Journal of Medical Quality. 2011; 26(3):212-9
A10[327]	Gulati, A., Harwood, C.A., Rolph, J., Pottinger, E., McGregor, J.M., Goad, N., Proby, C.M.	United Kingdom	2015	Journal of the European Academy of Dermatology and Venereology	Gulati, A. et al. Is an online skin cancer toolkit an effective way to educate primary care physicians about skin cancer diagnosis and referral? Journal of the European Academy of Dermatology & Venereology. 2015;29(11):2152-9
A11[328]	Han, C., Voils, C.I., Williams, J.W., Jr.	South Korea	2013	Community Mental Health Journal	Han, C., Voils, C.I., Williams, J.W., Jr. Uptake of Web-Based Clinical Resources from the MacArthur Initiative on Depression and Primary Care. Community Ment Health J (2013) 49:166-171
A12[329]	Hitzig, S.L., Noreau, L., Balioussis, C., Routhier, F., Kairy, D., Craven, B.C.	Canada	2013	Disability and Rehabilitation	Hitzig, S.L. et al. The development of the spinal cord injury participation and quality of life (PAR-QoL) tool-kit. Disability and Rehabilitation. 2013; 35(3):1408-14
T1[314]	Kading, V.M.	United States	2016	Thesis for Doctor of Nursing Practice	Kading, V.M. Evaluation of a nurse practitioner developed toolkit on health care provider knowledge of perinatal depression. Thesis Doctor of Nursing Practice, New Mexico State University. 2016.
A13[330]	Lobban, F., Robinson, H., Appelbe, D., Barraclough, J., Bedson, E., Collinge, L., Dodd, S., Flowers, S., Honary, M., Johnson, S., Mateus, C., Mezes, B., Minns, V., Murray, E., Walker, A., Williamson, P., Wintermeyer, C., Jones, S.	United Kingdom	2017	BMJ Open	Lobban, F. et al. Protocol for an online randomised controlled trial to evaluate the clinical and cost-effectiveness of a peer-supported self-management intervention for relatives of people with psychosis or bipolar disorder: Relatives Education And Coping Toolkit (REACT). 2017;7(7):e016965
A14[331]	Nicolaidis, C., Raymaker, D., McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., Gerrity, M., Kripke, C., Platt, L., Baggs, A.	United States	2016	Journal of General Internal Medicine	Nicolaidis, C. et al. The Development and Evaluation of an Online Healthcare Toolkit for Autistic Adults and their Primary Care Providers. Journal of General Internal Medicine 2016;31(10):1180-9.
A15[332]	Parker, D.R., Eaton, C.B., Ahern, D.K., Roberts, M.B., Rafferty, C., Goldman, R.E., McCool, F.D., Wroblewski, J.	United States	2013	BMC Family Practice	Parker, D.R. et al. The study design and rationale of the randomized controlled trial: translating COPD guidelines into primary care practice. BMC Family Practice 2013;14:56.
A16[318]	Ploeg, J., McAiney, C., Duggleby, W., Chambers, T., Lam, A., Peacock, S., Fisher, K., Forbes, D. A., Ghosh, S., Markle-Reid, M., Triscott, J., Williams, A.	Canada	2018	Journal of Medical Internet Research	Ploeg, J. et al. A web-based intervention to help caregivers of older adults with dementia and multiple chronic conditions: Qualitative study. Journal of Medical Internet Research 2018;1(1):e2p.2
A17[333]	Sinclair, L.B., Taft, K.E., Sloan, M.L., Stevens, A.C., Krahn, G.L.	United States	2015	Maternal and Child Health Journal	Sinclair, L.B. et al. Tools for improving clinical preventive services receipt among women with disabilities of childbearing ages and beyond. Maternal and Child Health Journal. 2015;19(6):1189-201

A18 [334]	Starkey, M., Wiest, D., Qaseem, A.	United States	2016	American Journal of Medical Quality	Starkey, M. et al. Improving Depression Care Through an Online Learning Collaborative. American Journal of Medical Quality 2016;31(2):111-7.

A = Journal article in peer reviewed journal
C = Conference Proceeding
T = Thesis

Appendix 4.6 Type of UEM undertaken within each development stage as described within reviewed literature

Type UEM	D/D	I	MS or ME	PR/PI	Total (% Total)
Algorithms	-	-	-	-	0
Analytics (website)	-	-	A1, A10	A17, C2	4 (16.0)
Brainstorm	-	-	-	-	0
Card sorting	-	-	-	-	0
Clinical vignette	-	-	-	A4	1 (4.0)
Cognitive task analysis	-	-	-	-	0
Cognitive walkthrough	-	-	-	-	0
Field observations	-	-	A5	-	1 (4.0)
Focus groups	A13	-	A5, A10	-	3 (12.0)
GOMS	-	-	-	-	0
Guideline review	-	-	-	-	0
Heuristic	-	-	-	-	0
Interviews	A13	-	-	A16	2 (8.0)
KLM	-	-	-	-	0
Log file analysis	-	-	A1, A10	A17, C2	4 (16.0)
Personas/use cases	-	-	-	-	0
Remote testing	-	-	A1	-	1 (4.0)
Survey or questionnaire	-	A2, T1	A1, A10	A4, A11, A14, C1	8 (32.0)
Task analysis	-	-	-	-	0
Teach/reverse teach	-	-	-	-	0
Think aloud protocol	-	-	-	-	0
TURF / UFuRT	-	-	-	-	0
User testing	-	-	-	A11	1 (4.0)

D/D = Design or development stage
I = Implementation stage
MS or ME = Mixed stage or multiple evaluations
PR/PI= Post implementation or post-release stage

Appendix 4.7 Funding source of publications and relative characteristics of usability evaluations undertaken by 14 developers of OHT within this review

			Funding source [FUNQ16]			
Mapping Question			Gov	C / P / O	NF	**Total**
UEQ12	UEM Process	Manual	A13, A14, A16, T1	A2, A5, A11	A4, C1	10
		Automatic	-	A17	C2	2
		Both	A1	-	A10	2
UEQ13	Useful feedback provided to developers	Yes - Evaluation method provided guidance or inference for design improvements	A1, A3, A13	A5, A11	C2	6
		No - Evaluation method generated list of usability issues (not applied)	A16, T1	A2	A10	4
		Not described	A14	A17	A4, C1	4
UEQ15	Users as participants	User number / archetype	A1, A3, A14, A16, T1	A2, A5, A11	A4, A10, C1	11
		No descriptions of users	A13	A17	C2	3
	Experts as participants	Expert number / archetype	A1	A5	-	2
		No descriptions of experts	A3, A13, A14, A16, T1	A2, A11, A17	A4, A10, C1, C2	12
	Evaluators as participants	Evaluator number / archetype	A16	-	-	1
		No descriptions of evaluators	A1, A3, A13, A14, T1	A2, A5, A11, A17	A4, A10, C1, C2	13

Gov = Government funding, C / P / O = Corporate, private or organisational funding source
NF = No funding source provided within the literature

Appendix 4.8 Descriptions of OHT development processes and frameworks for evaluation of OHT reviewed within the literature

RESULTS

From a total of 21 publications, 12 authors (57.1%) reported no strategy for knowledge translation as a development concept or as an approach for encouraging the user to learn or change behaviour or practice. Although these developers did not explicitly describe a KT strategy for these OHT, perhaps KT was an artefact of the development process rather than an intended process that informs OHT structure and/or function. Nine publications described strategies within the content (42.9%), categorised as

a) applying Knowledge to Action (KTA) strategy to frame the development of OHT content
  - Two studies:
    - A12 - reporting conceptualisation or development of OHT
    - T1 - OHT Intervention study including outcomes

b) utilising 'toolkit as intervention' strategy as an opportunity to increase user knowledge, support the clinical practice or provide support to community-based end-users
  - Seven studies:
    - OHT intervention studies (A2, A9, A10)
    - OHT outcome measures post-release (A4, A11)
    - conceptualisation or development of OHT (A7, A17)

Gallagher *et al.* (A7, 2017) undertook action research to develop content through a participatory design model and was not applied as a framework for evaluation.

All 21 publications included a description of the overall objective of the OHT. This was regardless of whether a KT strategy was included in the content. OHT objectives and KT strategy applied within publications are presented in Table A4.8.1.

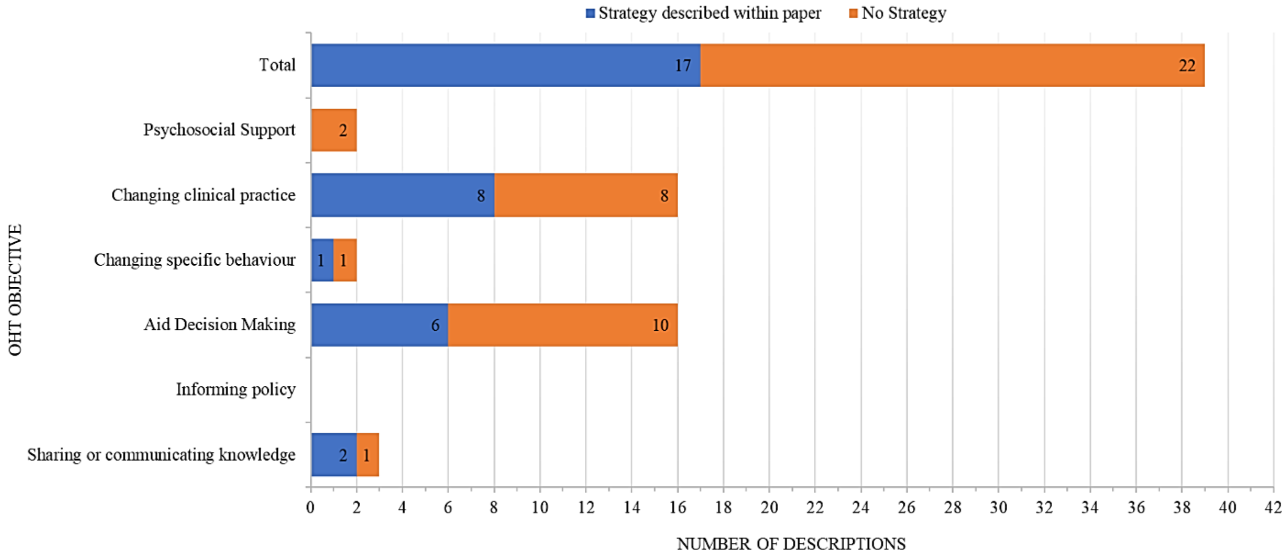
Aiding decision-making and changing clinical practice were the primary study objectives for publications included in this review and were stated within the papers regardless of whether KT strategies were described within study descriptions.

Table A4.8.1. OHT objectives and KT strategy as described in retrieved publications

	Objective of OHT reported					
KT Strategy	Sharing / communicating knowledge	Informing policy	Aid decision-making	Changing specific behaviour	Changing clinical practice	Psychosocial support
Strategy described within the paper (*n*=9)	A12, A17	-	A4, A9, A10. A12, A17, T1	A2	A4, A7, A9, A10, A11, A12, A17, T1	-
No Strategy (*n*=12)	A13	-	A1, A3, A5, A6, A8, A14, A15, A18, C1, C2	A1	A1, A6, A8, A14, A15, A18, C1, C2	A3, A16
Total (%Total)	3 (14.29)	0	16 (76.19)	2 (9.52)	16 (76.19)	2 (9.52)

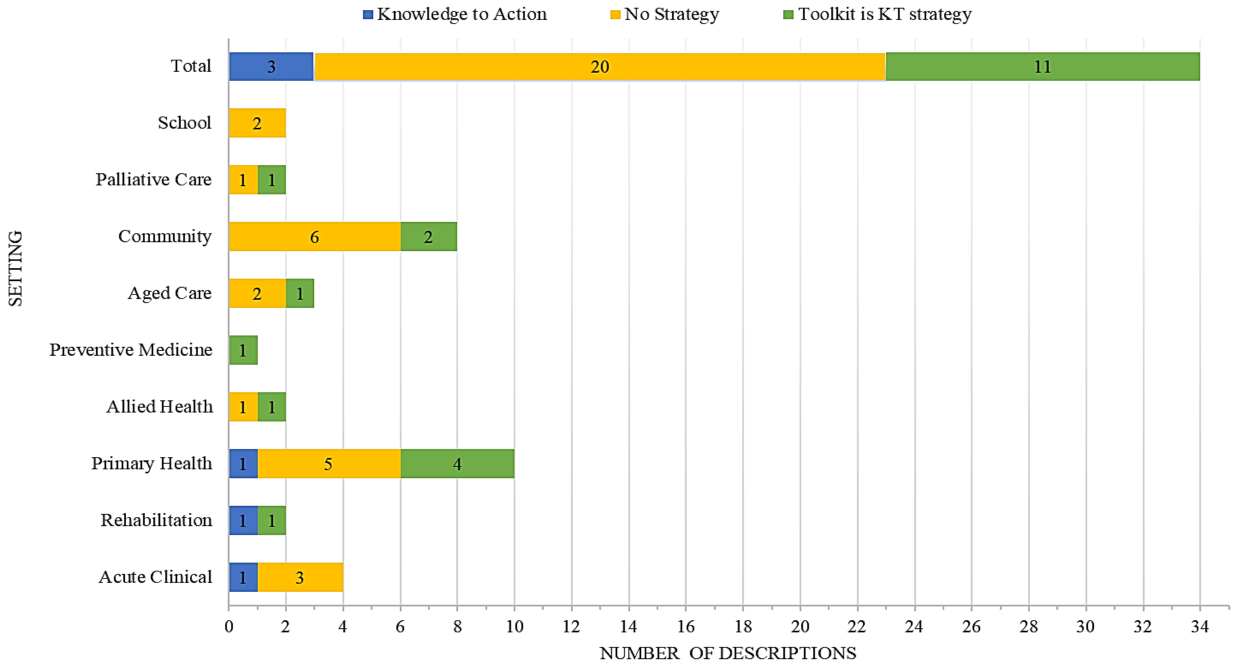
Studies can be classified into one or more categories; the summation of the percentages is, therefore, greater than 100

Changing clinical practice was an objective that was reported equally between those papers providing a KT strategy and those reporting no strategy. Two studies reported the OHT objective as changing a specific behaviour (A1, A2), whilst two described psychosocial support as an objective (A2, A16). No authors reported an objective to inform policy. Graph A4.8.1 presents OHT objectives and KT strategy.



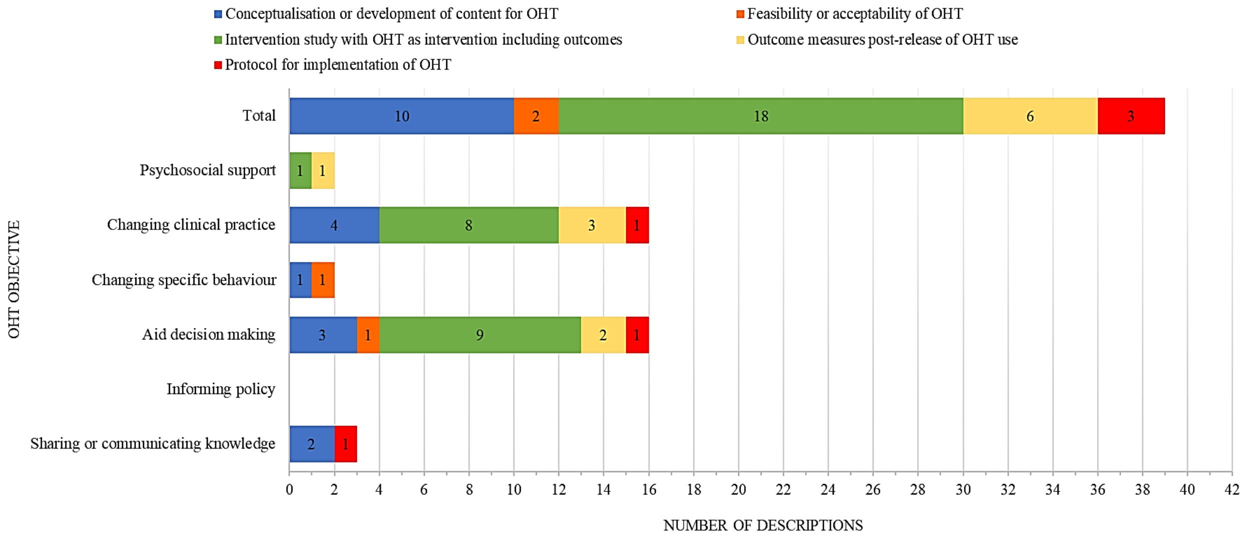
Graph A4.8.1. Publication OHT objective and KT strategy description

Further analysis found that for OHTs whose settings of use are in primary health or for use within the community setting, authors were more likely to describe no KT strategy do not describe KT strategy within the publication. However, an equal number of papers reported KT strategies for intended users within the primary health care setting. Those authors describing the application of a KTA strategy were within both rehabilitation (A12) and primary health (T1). A summary of the relationship between described OHT knowledge translation strategies and setting of use are presented in Graph A4.8.2.



Graph A4.8.2. OHT knowledge translation strategies and setting of use as described in OHT publications

Graph A4.8.3 displays the relationship between OHT objective and study type described in reviewed publications (studies can be classified into one or more categories; the summation of the percentages is greater than 100).



Graph A4.8.3. Publication OHT objective and the study type described

Nineteen developers described an evidence base for OHT development (90.5%), with only authors not providing a basis for the content within the OHT (T1 and A16). Types of OHT study reported and supporting evidence base descriptions within the publication cohort are displayed in Table A4.8.2.

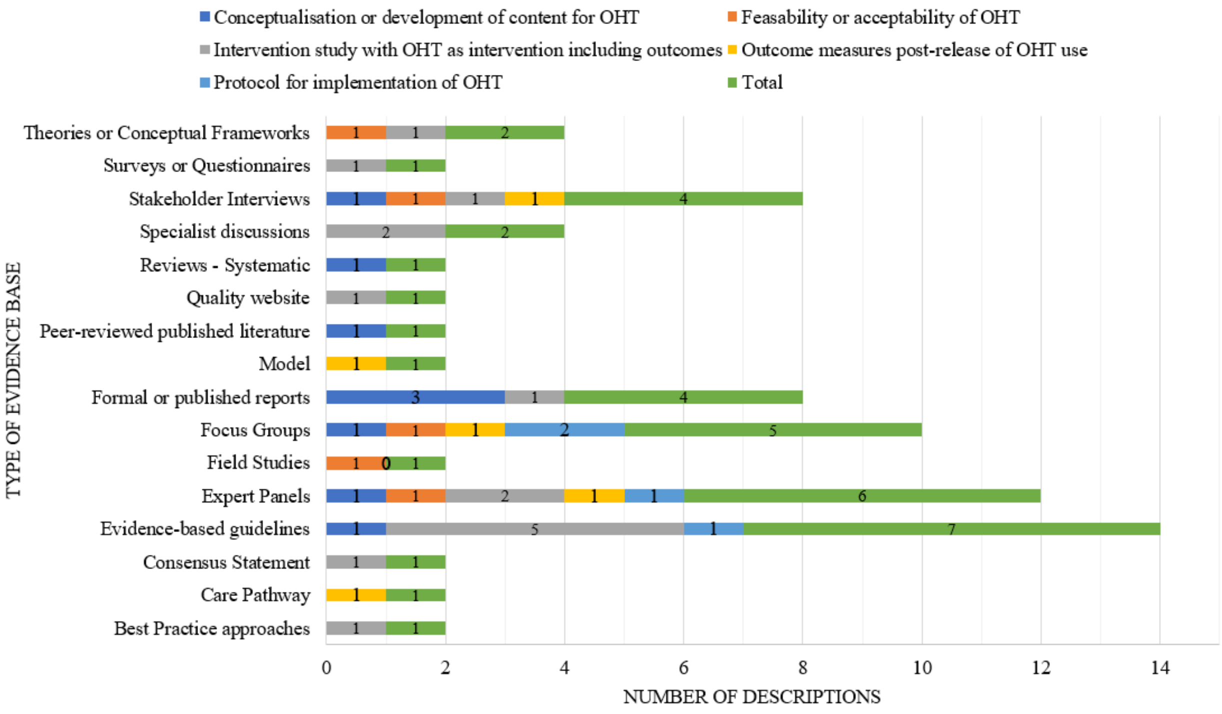
Table A4.8.2. Publication study type and evidence base description for OHT development

Article type	Evidence base is not described within publication	Evidence base is described within article	**Total (%Total)**
OHT Conceptualisation or development	-	A1, A7, A12, A17	4 (19.05)
Feasibility or acceptability of OHT	-	A2, A5	2 (9.52)
OHT Intervention study with outcomes	T1	A3, A6, A8, A9, A10, A14, A18, C1	9 (38.10)
OHT Outcome measures post-release	A16	A4, A12, C2	4 (19.05)
OHT Implementation Protocol	-	A13, A15	2 (9.52)
Total (%Total)	2 (9.52)	19 (90.48)	

When considering the evidence base that underpins OHT development, 12 of 19 publications reported using an EB used a pre-existing or documented evidence source (such as a published report or document, clinical guidelines, evidence guidelines, peer-reviewed literature). Seven reported applying information gained from invested stakeholders through inquiry-based activities (such as interviews, focus groups or expert panels). Table A4.8.3 summarises the diverse evidence base sources used to develop OHTs reported within retrieved literature. The most commonly sourced evidence was EB guidelines (33%), expert panels (28%) and focus groups (24%). No authors reported using clinical guidelines and observed the absence of reviews (including umbrella, scoping, critical analysis etc.). Evidence-based guidelines most commonly supported OHT development in those studies reporting intervention approaches to evaluation; authors also applied a diverse range of EB including, for example; consensus statements (C1), theories or frameworks (A9), best practice guidelines (A6), expert panels (A3, A6) and the use of a quality website (A8). Graph A4.8.4 displays the class of evidence base reported concerning the published OHT evaluation study type.

Table A4.8.3. Different types of evidence described for the basis of OHT development

Type of Evidence Source	**Publication**	**Total (%Total)**
Reviews - Critical Analysis	-	0
Reviews - Literature (Scoping etc.)	-	0
Reviews - Systematic	A12	1 (4.76)
Reviews - Umbrella	-	0
Best practice approaches	A6	1 (4.76)
Care pathway	C2	1 (4.76)
Clinical guidelines	-	0
Consensus statement	C1	1 (4.76)
Evidence-based guidelines	A6, A8, A9, A10, A15, A17, A18	7 (33.33)
Expert panels	A2, A3, A4, A6, A7, A13	6 (28.57)
Field studies	A5	1 (4.76)
Focus groups	A4, A5, A7, A13, A15	5 (23.81)
Formal or published reports	A1, A7, A8, A17	4 (19.05)
Model	A11	1 (4.76)
Peer-reviewed published literature	A1	1 (4.76)
Quality website	A8	1 (4.76)
Specialist discussions	A3, A14	2 (9.52)
Stakeholder interviews	k, A7, A14	4 (19.05)
Surveys or Questionnaires	A14	1 (4.76)
Theories or conceptual frameworks	A2, A9	2 (9.52)



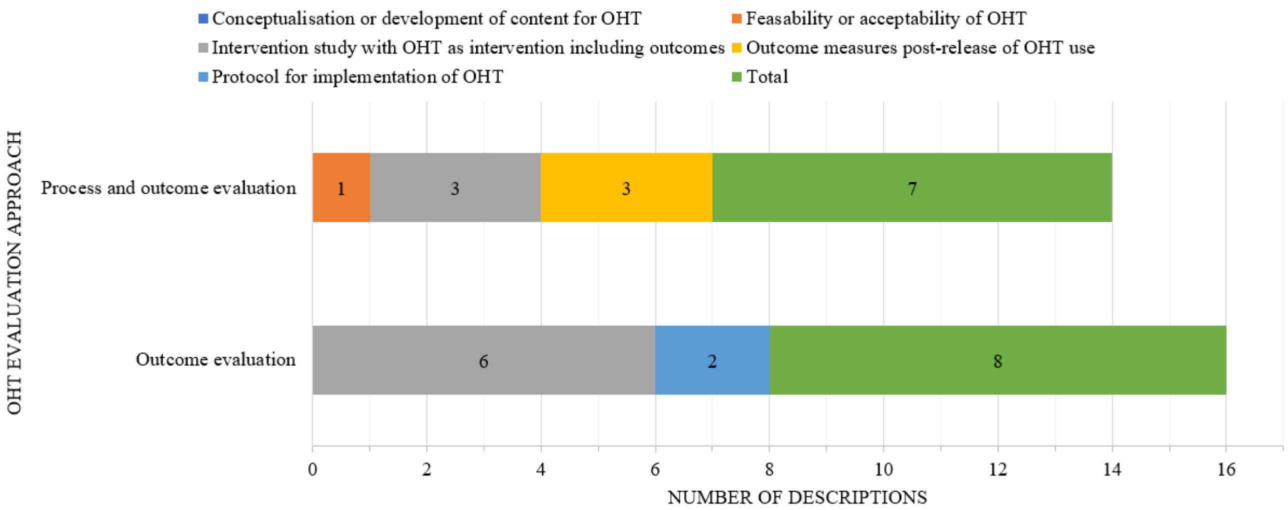
Graph A4.8.4. Type of evidence described by reported OHT study type

Further analysis of data extracted found that overall, 15/21 studies (71.4%) reported OHTs were evaluated relative to objectives outlined in the publications, all OHT intervention studies were found to have completed overall OHT evaluation (refer to Table A4.8.4). This was similar for two protocol implementation studies (A13, A15), which were completed as an overall evaluation of the toolkit as a complete resource. 6 of 21 articles (25.6%) retrieved had no evaluation of the overall OHT resource described within their publications. Four of these studies were focused on conceptualisation or development processes of the OHT in the early prototype phase (A1, A7, A12, A17), and this was not unexpected as evaluation of OHT effectiveness should be completed on the final prototype or post-release product. No authors reported within their studies evaluation process relating to individual components of the OHT concerning the objectives stated. Two authors, Duggleby et al. (2017) and Ploeg et al. (2018), provided sequential publications describing the development and implementation of the My Tools 4 Care toolkit.

Table A4.8.4. Publication study type and reported evaluation of the OHT as a complete resource

Article type	No evaluation of the toolkit was reported	Overall toolkit was evaluated relative to objectives outlined	**Total (% Total)**
OHT Conceptualisation or development	A1, A7, A12, A17	-	4 (19.05)
OHT Feasibility or acceptability	A5	A2	2 (9.52)
OHT Intervention study	-	A3, A6, A8, A9, A10, A14, A18, C1, T1	9 (42.86)
OHT Outcome measures post-release	C2	A4, A11, A16	4 (19.05)
OHT Implementation Protocol	-	A13, A15	2 (9.52)
Total (% Total)	6 (25.57)	15 (71.43)	21

Of 15 studies that completed an overall evaluation of OHT effectiveness, eight developers (38.1%) evaluation approaches assessed overall changes in user knowledge, behaviour, or practice as a result of OHT use. Authors applied this evaluation method for those studies where the OHT is the intervention (A3, A6, A8, A9, A10, A14, A18, C1) or concerning OHT implementation (A13, A15). Conversely, seven developers (33.3%) chose to apply a process and outcome evaluation within their development cycle. This type of evaluation investigates 'internal' processes of the mechanisms that influence how users interact with facets of the OHT and the effect on evaluation outcomes (measures of usefulness or satisfaction or descriptions of positive effects on the user interaction). Extracted data found that this evaluation approach was applied across all pre- and post-release study types [feasibility (A2), OHT intervention (A10, A14, T1), and OHT Outcome measures post-release (A4, A11, A16)] except for implementation protocols and early development or conceptualisation OHT evaluation publications. This data is graphically represented in Graph A4.8.5.



Graph A4.8.5. Effectiveness of OHT evaluation approach in those publications reporting evaluations (*n*=15) and literature study type

DISCUSSION of results

1. Describing OHT development processes

While the relationship between developers and individuals was most commonly reported, examples of alternative partnerships that supported development were also evident. Gallagher et al. (A7, 2017) utilised a rigorous participatory action research methodology to engage nurses to generate an OHT to change practice around providing dignity in care for the residents in four aged care facilities. This egalitarian partnership formed between the developers and a specific group of nurses,709 who contributed to both the research as experts and as a conduit to engage residents, generated a specific contextualised OHT and empowered and encouraged nurses to take leadership roles to ensure change occurs. Participatory or co-design development process engages developers and stakeholders or end-users in a partnership where each has equal input into research and development of the final product. Nicolaidis et al. (A14, 2016) undertook a community based participatory research process whereby end-users (people living with autism, their family carers or HCP) and academics were involved in all AASPIRE OHT development stages, including research design, participation as research subjects and experts, analysis of the data and dissemination of the results. Researchers believe there are distinct advantages of employing participatory design in the development of products, including giving consumers a voice, particularly in groups of disenfranchised or marginalised in society, encouraging empowerment and the creation of contextualised, high-value, efficient and effective artefact.[711,712] Conversely, this equal partnership can comprise design (as end-users are not experts,[336,713] be time-consuming due to scheduling and availability and consequently produce lengthier (and more costly) implementation period between development and release.[15]

2. Frameworks for OHT development and evaluation

Usability evaluation is an important process that measures and elicits feedback that can influence how end-users access, understand, engage, and measure how effective intended integrated-KT strategies are in achieving the objective of the OHT created.

Application of frameworks or models to the development and evaluation process guides developers to undertake a defined process exploring and extracting relevant evidence, translating evidence into well designed online content (including learning activities, tools or resources), and measuring the influence or impact of the OHT outcomes on intended audiences. For OHT to be effective modulators of change or inform end-users (as defined by the objectives stated within the publications of this review), it is pragmatic that developers apply a framework that supports knowledge translation and evaluation across the UCD process from ideation to post-release. Knowledge translation (KT) is a “dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge” to improve health outcomes.[714] KT can occur within complex interactions between knowledge users (end-users) and researchers, which may vary in intensity, complexity and level of engagement.[714,715] KT strategies, therefore, provide a framework to guide researchers and developers in both creation and implementation of initiatives in the online environment; KT approaches such as the Knowledge to Action framework (KTA) incorporate evaluation, specifically identifying user needs and encouraging sustainability of knowledge.[340,716]

Of the twenty-one publications analysed for this review, only four authors included descriptions of KT frameworks to support knowledge and content creation for the OHT. Gallagher et al. (A7, 2017) described the utilisation of the action research framework, which provided a rigorous collaborative process to co-develop evidence and knowledge to support practice in aged care. Nicolaidis et al. (A14, 2016) completed a participatory research process within an autism community to promote actionable knowledge produced through relationships and collaborative practice.[717] Two authors provided details of using the Knowledge to Action (KTA) framework to scaffold knowledge, identify barriers or gaps in practice, develop content and learning opportunities and measure effectiveness. Whilst there is congruence between these frameworks to promote translation of knowledge to experiential learnings, both action and participatory research aims to improve large scale population health by changing practice.[718] This is compared with other processes that focus on smaller cohorts with specific needs or behaviours, such as HCP caring for people with spinal cord injury (Hitzig et al. 2013, A12) or nurse practitioners caring for mothers with perinatal depression (Kading 2016, T1). There were also mixed levels of reporting of the evaluation of OHT effectiveness within the publications reviewed. Hitzig et al. (A12, 2013) applied KTA to their development processes but did not report if this was a practical resource, whilst Kading (T1, 2016) described measures of efficacy on learning when OHT operates as the intervention.

Perhaps an argument is that integrated KT (iKT) frameworks[71] should be integrated into OHT development processes. iKT approaches involve engaging end-knowledge users and stakeholders as collaborative partners from the outset of development.[719,720] iKT compliments the fundamental UCD process by providing an evaluation structure and underlying design principles for translating evidence to inform practice. This becomes imperative for OHT that are multifaceted or have complex components to the iterative redesign of the prototype to determine which of the activities are ‘working’ and which are not when implemented within a specific end-user group. Of the publications identified within this review, 71.4% (15 of 21) studies described measures of the effectiveness of the OHT against objectives presented and notably, all of these studies measured effectiveness of the whole OHT and not components individually (not components nor specific features of the OHT that contribute to effectiveness), suggesting a lack of formal process or time constraints placed on development. Researchers acknowledge the difficulties of identifying appropriate frameworks for KT for eHealth applications,[721] implementation approaches and tools for measuring change. Glasgow et al. (2014) propose that could be due to the process and duration of research framework design in contrast to the rapid technological changes in platforms, systems, devices, software and interactive capabilities of both hardware and software.

There is also evidence of no ongoing measures of the effectiveness of the OHT post-release; this has been identified as a flaw with the lack of evaluation frameworks for other eHealth applications, programs and platforms. This observation could reflect the current linear funding and reporting models constrained by elongated time frames between grant application, environmental and stakeholder scans of need, development and build, testing release and publishing cycle.[721] Therefore, post-release evaluations are often not completed due to the funding cycle and the rapidly changing technological environment that electronic health resources are integrated into.

For OHT to modulate changes in behaviour or practice or inform their users, the influence of content design on potential learning of end-users is a function of a) creating learning objectives that guide content development, (b) establishing evaluation methods for measuring learning and importantly, (c) shaping content to the needs of the user.[722] As such, instructional or educational designers ideally have a significant role in developing online health information resources, particularly in planning information flow, content layout, and designing high quality, effective learning activities that can be measured to ascertain the effectiveness of strategies.[723] None of the authors of the studies explored within this review described an interaction with an instructional designer to tailor or construct their online content. Interestingly, best practice recommendations for the development of online information within the rehabilitation literature imply impotence for developers of online KT resources to engage with an instructional designer (as part of the team) and apply instructional design processes that guide the development of these artefacts to enhance practice change.[340]

Researchers encourage the application of the ADDIE model,[340,723,724] an instructional design process guiding (A)nalysis, (D)esign, (D)evelopment, (I)mplementation and (E)valuation of online content. ADDIE has been previously adapted to account for contextualised factors for online engagement.[340,722,725] Importantly, KTA, ADDIE and UCD are synergistic models that encourage evaluation - outcome evaluation of effectiveness in the case of KTA and ADDIE [340] and formative evaluation of interface usability undertaken during the UCD process. Realistically, developers of online health toolkits should endeavour to utilise each of these models within their development processes as each assesses different aspects of online resources, the effectiveness of the strategies and success of translation using interface features and iterative re-design of the resource ensuring use and access.

Appendix 4.9 Bubble plot representation of mapping variables by study objectives

The mapping review questions were developed to provide a framework for exploring the objectives of the study. The findings from the review process have been organised and displayed into bubble plots providing a visual map of the data extracted and their direct relationship to the objectives. The objectives and related mapping review questions are tabulated below, with the resultant bubble plots provided in subsequent pages.

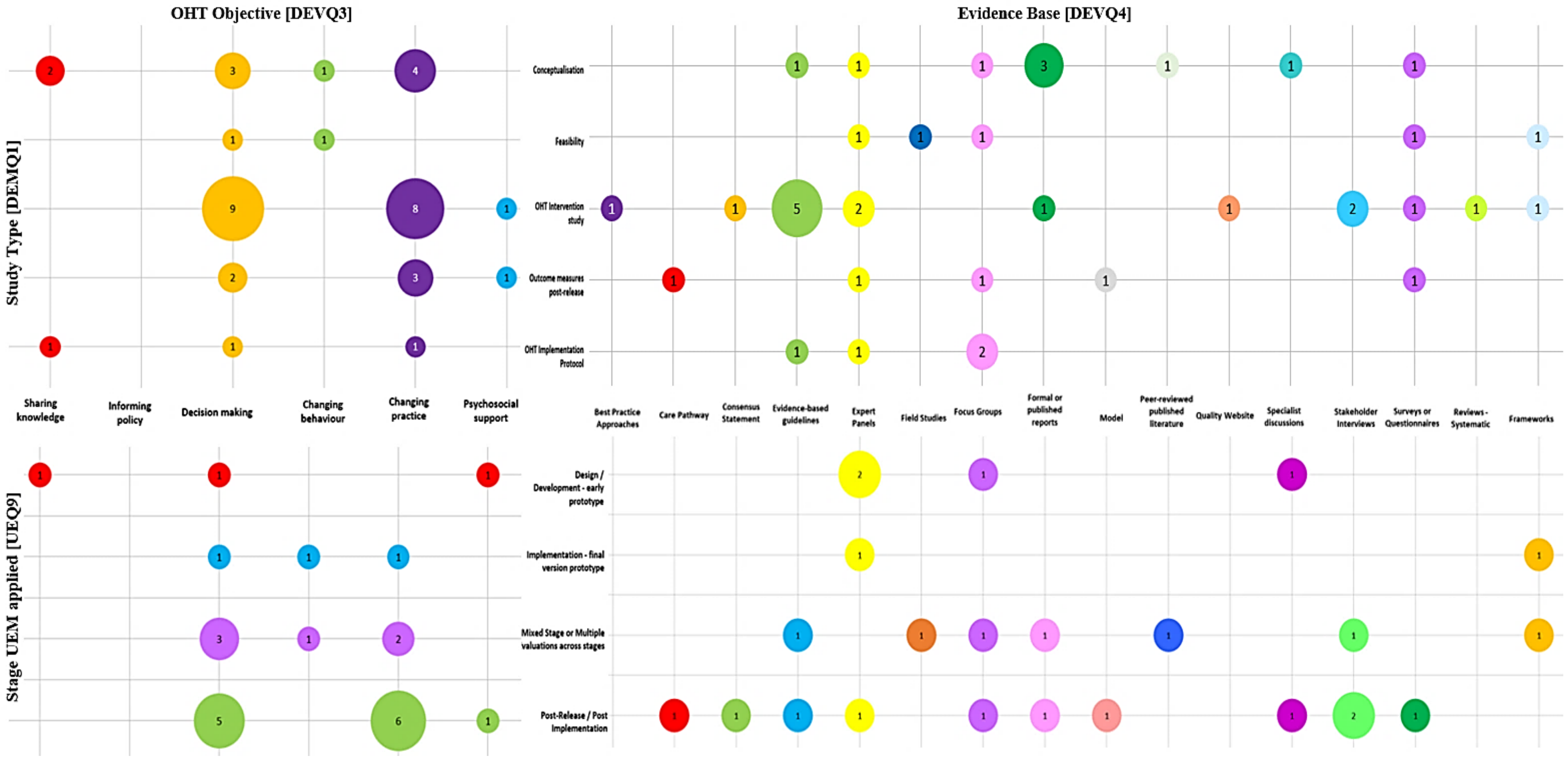
Table A4.9.1 Study objectives as mapped within literature and presented graphically as bubble plots

Study Objective	Question	Bubble Plot	Mapping Variables
1	*To map within the literature the quality and comprehensiveness of the published reports of both rationales for toolkit development and the evaluation methods applied to the development and implementation process*	**Graph A4.9.1**	Study Type [DEMQ1] x OHT Objective [DEVQ3] x Evidence Base [DEVQ4] x Stage of Development UE applied [UEQ9]
		Graph A4.9.2	Class of UEM [UEQ10] x Stage of Development UE applied [UEQ9] x Study Type [DEMQ1] x Setting of use [DEVQ2]
		Graph A4.9.3	Funding Source [FUNQ16] x Evaluation reported [UEQ5] x Year of study [DEMQ1] x Study Type [DEMQ1]
2	*To identify and measure the frequency of the different classes and types of usability evaluation methods undertaken at the different stages of the product lifecycle.*	**Graph A4.9.4**	Evaluation reported [UEQ5] x Stage of Development UE applied [UEQ9] x Evaluation Outcomes [UEQ6] x Class of UEM [UEQ10]
		Graph A4.9.5	Evaluation reported [UEQ5] x Setting of use [DEVQ2] x Class of UEM [UEQ10] x Funding Source [FUNQ16]
3	*To identify and measure the frequency of the different classes and types of usability evaluation methods undertaken at the different stages of the product lifecycle.*	**Graph A4.9.6**	Class of UEM [UEQ10] x Funding Source [FUNQ16] x Audience [DEVQ2] x OHT Objective [DEVQ3]
4	*To observe the proficiency of the reporting approach of developers to publishing usability and accessibility* evaluation methodologies within the literature compared to the proposed standards of reporting by evaluation experts.*	**Graph A9.4.7**	Class of UEM [UEQ10] x Stage of Development UE applied [UEQ9] x Study Type [DEMQ1] x Setting of use [DEVQ2]
5	*To explore the use of standards for accessibility* and usability to inform iterative changes in the development and implementation lifecycle of the online health toolkit.*	**Graph A4.9. 8**	Application of UE Feedback [UEQ13] x Stage of Development UE applied [UEQ9] x Audience [DEVQ2] x OHT Availability [ONLQ1]
		N/A*	Accessibility described in paper [UEQ15] x Funding [FUNQ16] x Study Type [DEVQ2] x Accessibility Change Indicator in available OHT [ONLQ16]

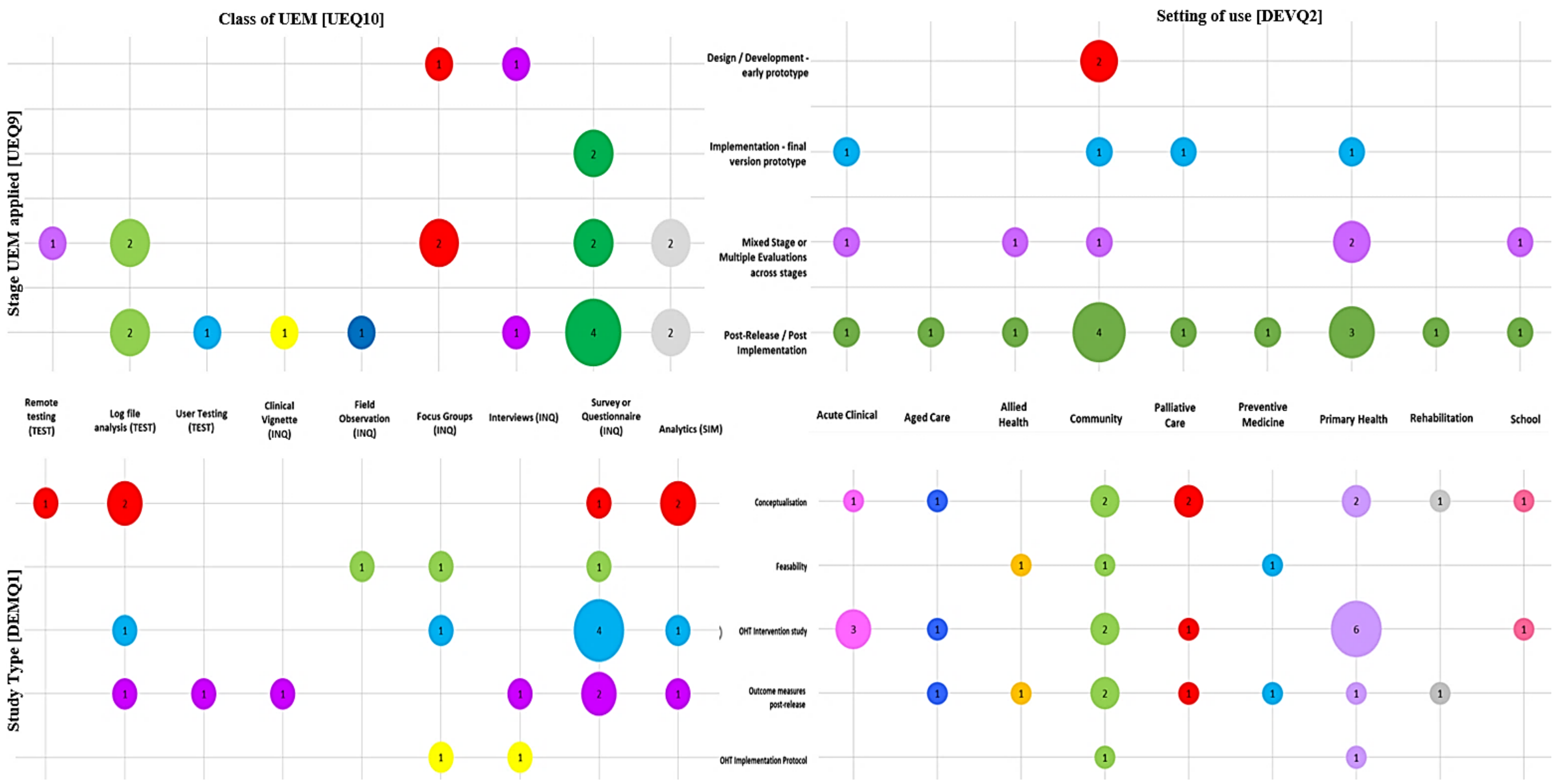
6	*To examine the published literature to determine the user or expert feedback was collected to inform single or multiple iterative improvements during the development or implementation of OHT*	**Graph A4.9.9**	UEM Feedback [UEQ12] x Stage of development of UEM applied [UEQ9] x Process of evaluation UEM [UEQ13] x Role of humans in UEM process [UEQ14]

** This review found no Referencing Standards [UEQ8] described in any of the included literature and found no authors described accessibility evaluation undertaken during development [UEQ15]. This finding was the impotence to investigate how accessibility is applied in 'live' online toolkits identified from the literature in this review and how this compares to descriptions within the concomitant reports.

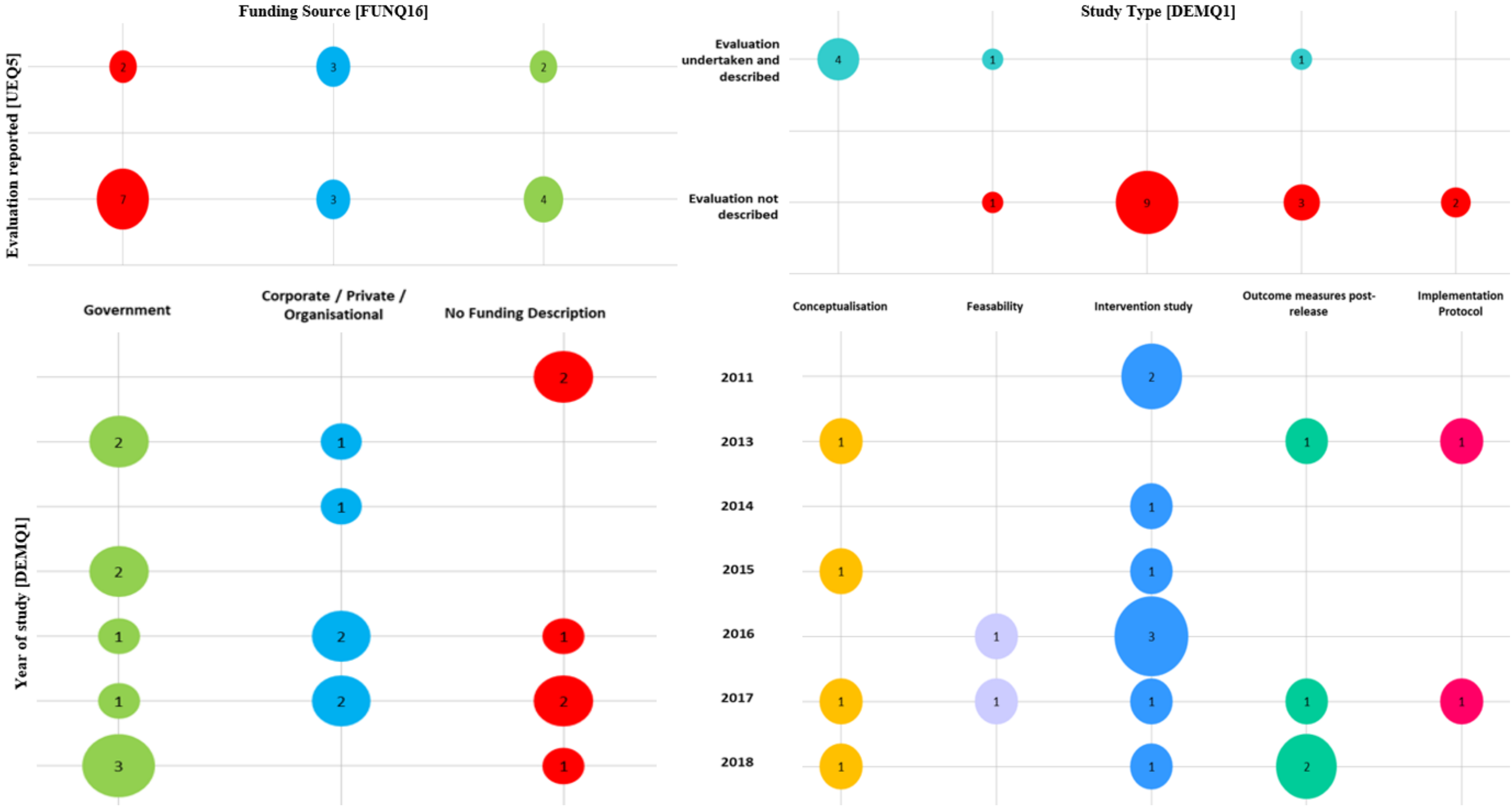
Mapped study objective 1



Graph A4.9.1 Study Type [DEMQ1] x OHT Objective [DEVQ3] x Evidence Base [DEVQ4] x Stage of Development UE applied [UEQ9]

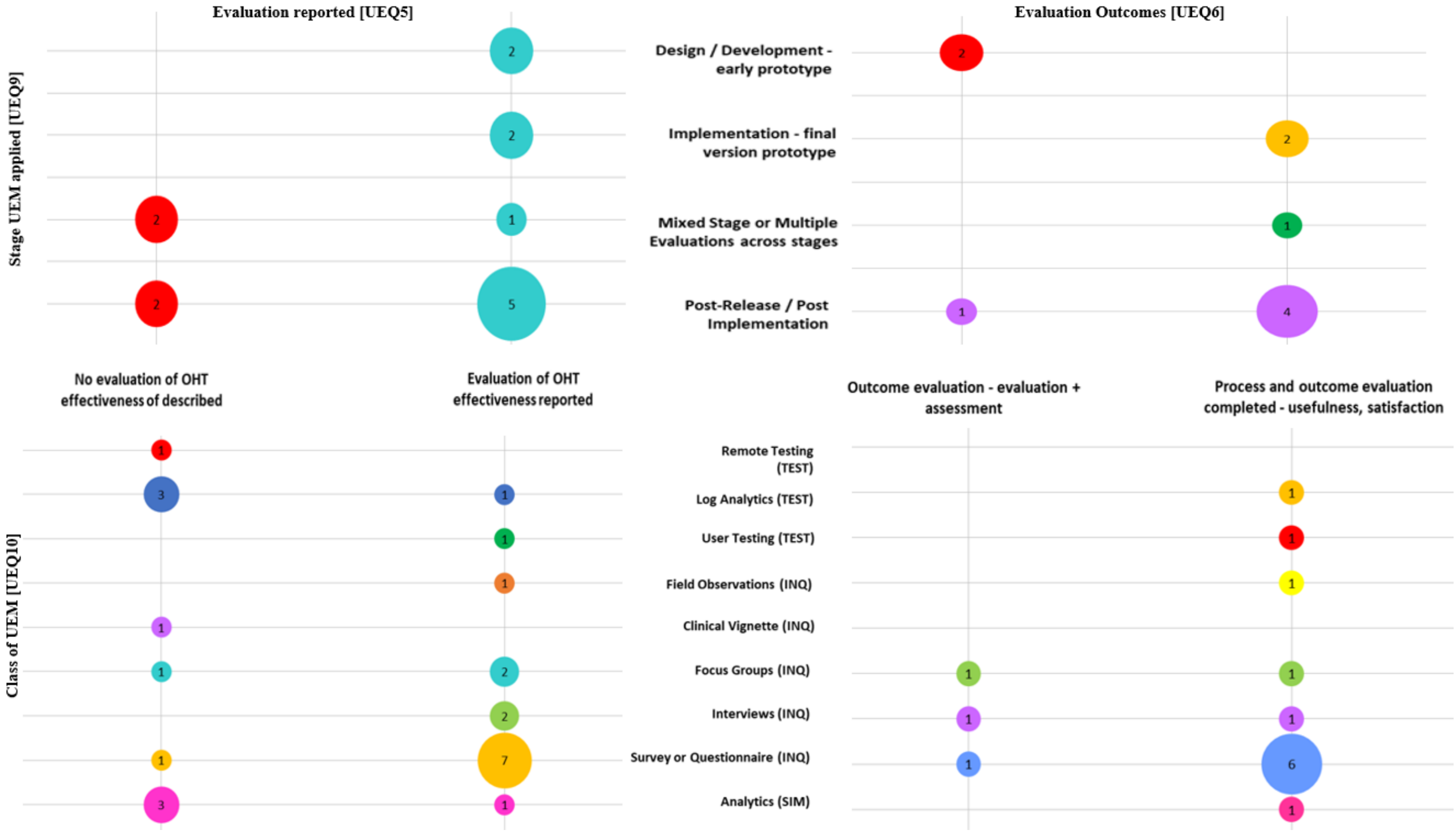


Graph A4.9.2 Class of UEM [UEQ10] x Stage of Development UE applied [UEQ9] x Study Type [DEMQ1] x Setting of use [DEVQ2]



Graph A4.9.3 Funding Source [FUNQ16] x Evaluation reported [UEQ5] x Year of study [DEMQ1] x Study Type [DEMQ1]

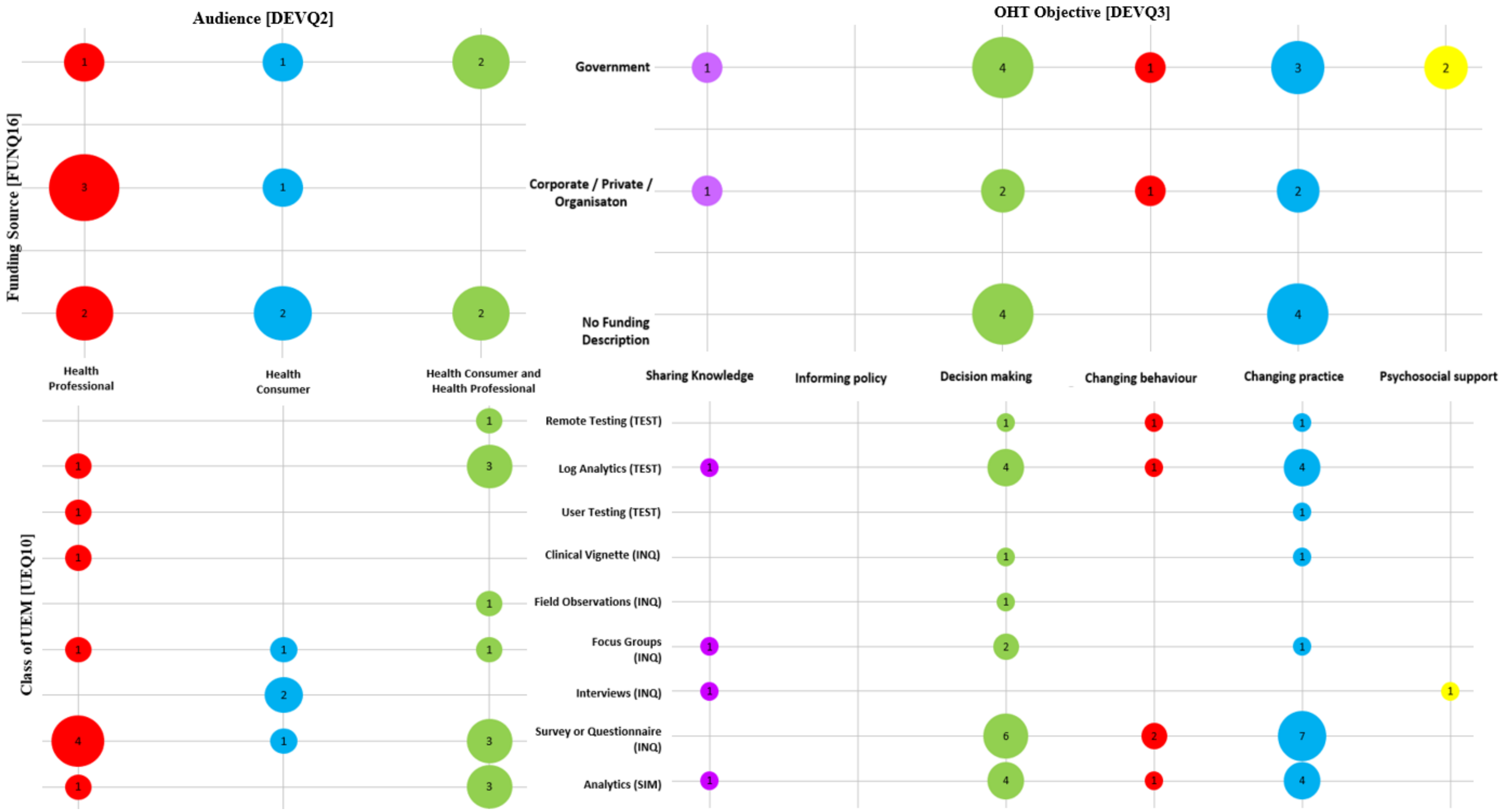
Mapped study objective 2



Graph A4.9.4 Evaluation reported [UEQ5] x Stage of Development UE applied [UEQ9] x Evaluation Outcomes [UEQ6] x Class of UEM [UEQ10]

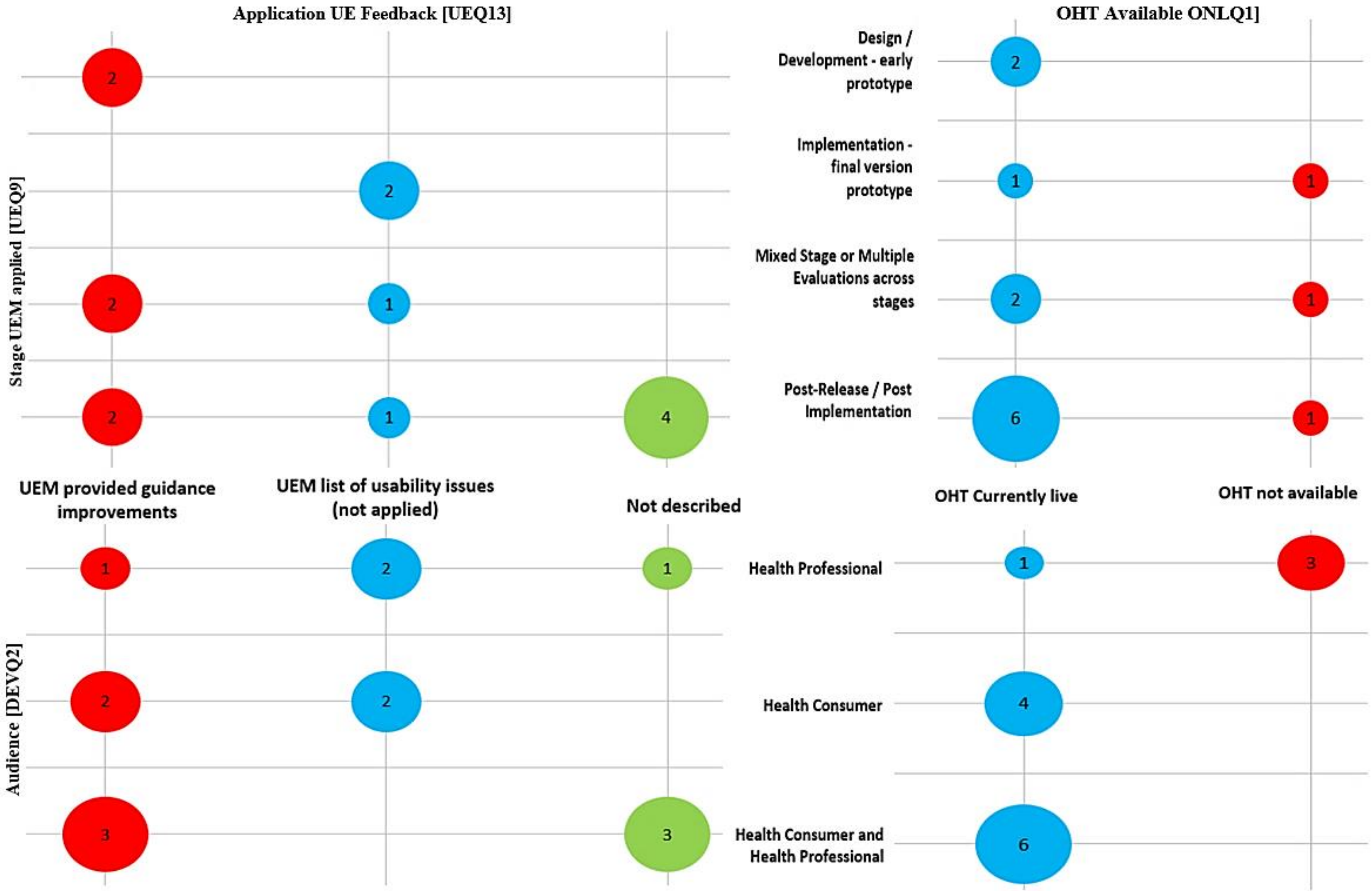
Graph A4.9.5 Evaluation reported [UEQ5] x Setting of use [DEVQ2] x Class of UEM [UEQ10] x Funding Source [FUNQ16]

Mapped study objective 3



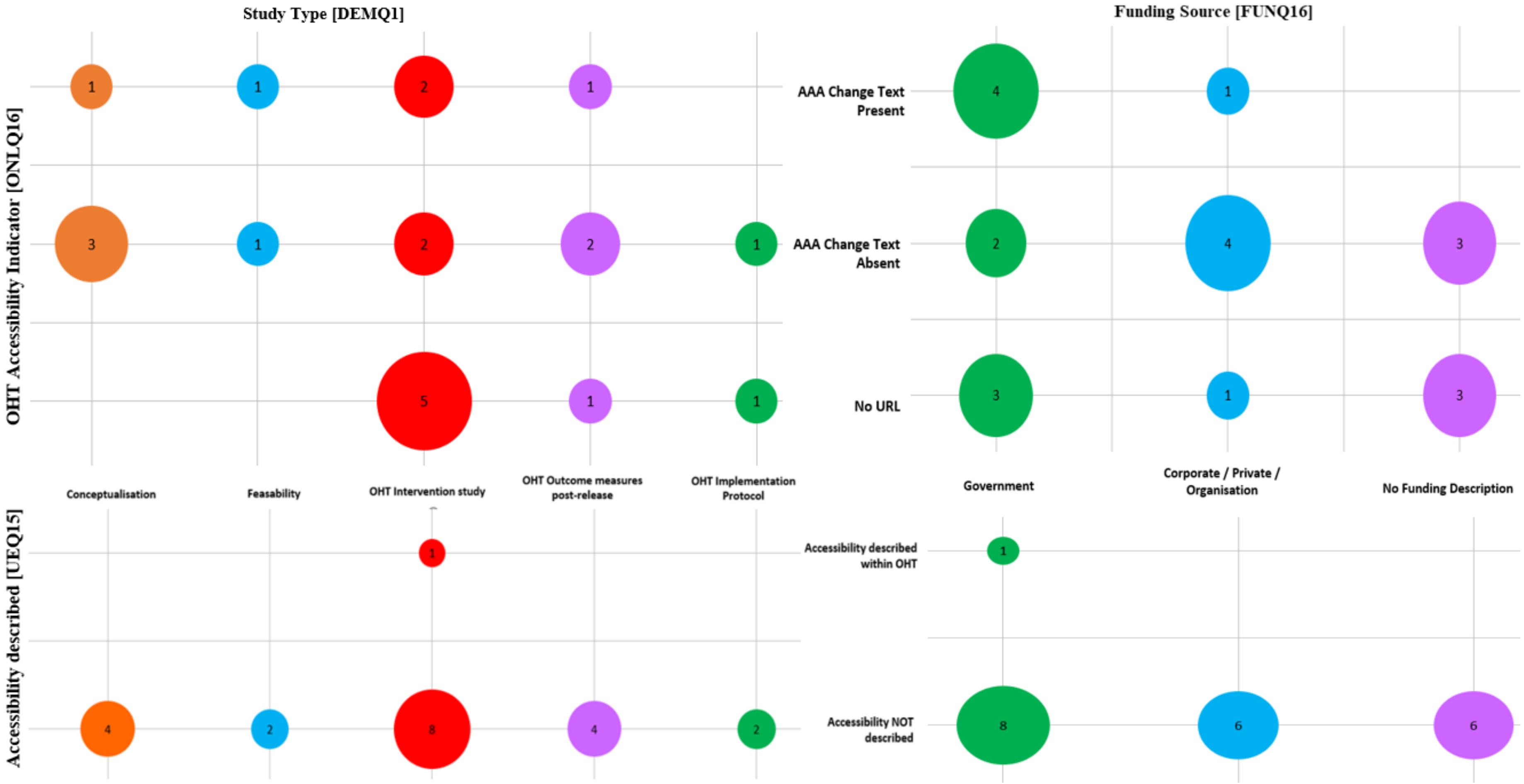
Graph 6. Class of UEM [UEQ10] x Funding Source [FUNQ16] x Audience [DEVQ2] x OHT Objective [DEVQ3]

Mapped study objective 4



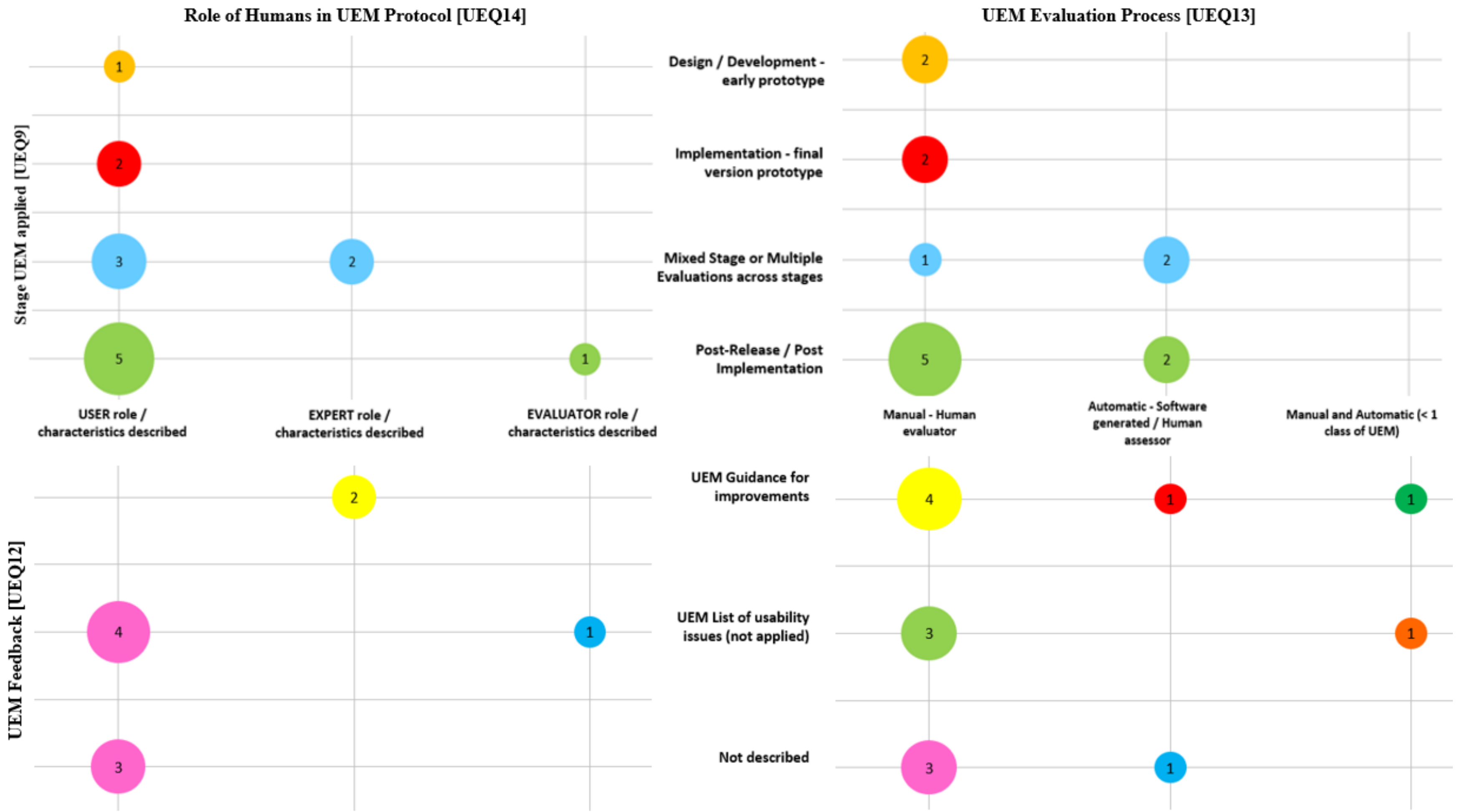
Graph A4.9.7 Graph Application of UE Feedback [UEQ13] x Stage of Development UE applied [UEQ9] x Audience [DEVQ2] x OHT Availability [ONLQ1]

Mapped study objective 5



Graph A4.9.8 Accessibility described in paper [UEQ15] x Funding [FUNQ16] x Study Type [DEVQ2] x Accessibility Change Indicator in available OHT [ONLQ16]

Mapped study objective 6



Graph A4.9. UEM Feedback [UEQ12] x Stage of development of UEM applied [UEQ9] x Process of evaluation UEM [UEQ13] x Role of humans in UEM process [UEQ14]

APPENDIX 5. ADDITIONAL INFORMATION RELATING TO THE MAPPING ACCESSIBILITY AND USABILITY WITHIN LIVE THE OHT CHAPTER

Appendix 5.1 Data variables collected from currently available live OHT from studies reported in the primary literature of this review

	OHT Characteristics	Data Descriptor	Data Variable
ONLQ1	Toolkit URL	URL	URL
ONLQ2	Described within OHT	Evidence base for Toolkit	V1. Description not present
			V2. Description present
ONLQ3	Described within OHT	Content development process	V1. Description not present
			V2. Description present
ONLQ4	Described within OHT	Expert involvement in the process	V1. Description not present
			V2. Description present
ONLQ5	Described within OHT	An evaluation process was undertaken during the development	V1. Description not present
			V2. Description present
ONLQ6	Described within OHT	Publications related to the development	V1. Description not present
			V2. Description present
ONLQ7	Described within OHT	Accessibility evaluation	V1. Description not present
			V2. Description present
ONLQ8	Described within OHT	HonCODE accreditation	V1. Description not present
			V2. Description present
ONLQ9	Operational Online Environment	Availability online	V1. Freely accessible (www)
			V2. Local or Private VPN
ONLQ10	Web1.0 or Web2.0	Features of OHT that are Web 1.0 or Web2.0	V1. Web1.0
			V2. Web2.0

ONLQ11	Web1.0 features	Limited interactivity and static information characterised by hyperlinks only to external resources	V1. Static information - a hyperlink to secondary sources only
			V2. Other Web2.0 features present
ONLQ12	Web2.0/Web1.0 shared features	Interactivity (social media)	V1. No option for online communication
			V2. Links/Icons to Social Media
			V3. Online interaction with experts
		Interactivity (Creating or editing content)	V1. No option for creating or editing content
			V2. Creating and editing content features available
ONLQ13	Responsive design	Responsivity to different screen sizes	V1. Non-responsive skin
			V2. Responsive skin
ONLQ14	Device agnostic	Agnostic to operating systems and devices	V1. Not agnostic
			V2. Agnostic
ONLQ15	aAA Change text size indicator	Indicator of accessibility	V1. Not visible in the skin
			V2. aAA or equivalent visible in the skin
ONLQ16	WebAIM WAVE Analyser	Accessibility errors found on 'Home page' of OHT	*Errors - Home page
			*Contrast Errors - Home page
		Accessibility errors found on randomly selected 'inside page' of OHT	*Errors - Inside page
			*Contrast Errors - Inside page

*Measurement is taken from evaluation software

Appendix 5.2 Summary descriptions of all OHT from the literature identified within the review process (*n*=21)

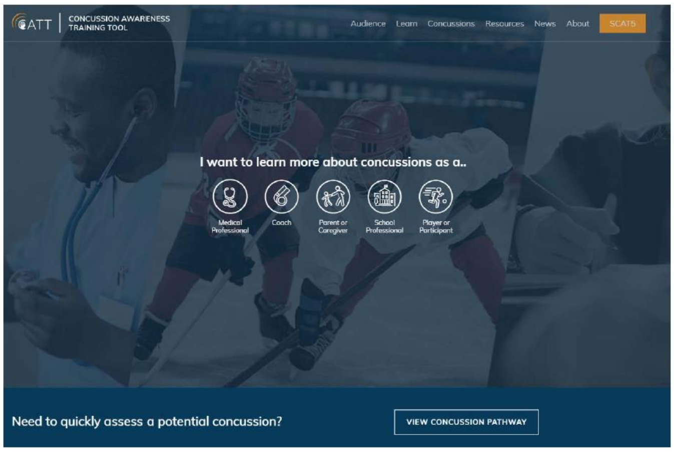
Author (Year) Country, Funding	Name of OHT [URL]	Intended audience	Currently available online	Web1.0 or Web2.0	Social media/ Creating, editing content / Online interaction with experts	Responsive design / Device agnostic
Babul S, Pike I. (2017) Canada, No Funding Statement (C1)*	CATTonline [https://cattonline.com/]	Health consumer and Health Professional	Freely accessible (www)	Web 2.0	Social media	Responsive design / Device agnostic
Champion, KE et al. (2018) Australia, Government Funding (A1)*	Cracks in the Ice [https://cracksintheice.org.au/]	Health consumer and Health Professional	Freely accessible (www)	Web 2.0	Social media	Responsive design / Device agnostic
Duggleby, W. et al. (2018) Canada, Corporate/Private or Organisation Funding (	Males Transition Toolkit (MaTT) [https://www.malespousetoolkit.ca/]	Health consumer	Freely accessible (www)	Web 2.0	Creating and editing content	Responsive design / Device agnostic
Duggleby, W. et al. (2018) Canada, Government Funding (A3)*	My Tools 4 Care [https://www.mytools4care.ca/]	Health consumer	Freely accessible (www)	Web 2.0	Creating and editing content	Responsive design / Device agnostic
England R, Shreeve P.(2018) United Kingdom, No Funding Statement (C2)*	Derbyshire End of Life Care [https://derbyshire.eolcare.uk/]	Health consumer and Health Professional	Freely accessible (www)	Web 2.0	Creating and editing content	Responsive design / Device agnostic
Ezzat, A.M. et al. (2017) Canada, No Funding Statement (A4)*	Achilles tendinopathy toolkit (ATT) [https://www.physio-pedia.com/Achilles_Tendinopathy_Toolkit]	Health Professional	Freely accessible (www)	Web 1.0 - Static Information - a hyperlink to secondary sources only	Social media	Responsive design / Device agnostic

Farndon et al. (2016) United Kingdom, Corporate/Private or Organisation Funding (A5)*	If the Shoe Fits [www.sheffield.ac.uk/ podiatrytoolkit]	Health consumer and Health Professional	Freely accessible (www)	Web 1.0 - Static Information - a hyperlink to secondary sources only	Social media	Responsive design / Device agnostic
Fine, PG et al. (2014) United States, Corporate/Private or Organisation Funding (A6)*	ACHLPICME - Pain in LTCF [http://www.achlpicme.org/ltc/CMEInfo.aspx]	Health Professional	Freely accessible (www)	Web 1.0 - Static Information - a hyperlink to secondary sources only	None	Not responsive /Device agnostic
Gallagher, A. et al. (2017) United Kingdom, Corporate/Private or Organisation Funding (A7)*	ENACT [http://dignitytoolkitsurrey.org/index.html]	Health Professional	Freely accessible (www)	Web 1.0 - Static Information - a hyperlink to secondary sources only	None	Responsive design / Device agnostic
Gannon, M. et al. (2011) United States, No Funding Statement	Unknown [No URL]	Health Professional	No - Local or private VPN	No URL	No URL	No URL
Gannon, M. et al. (2011) United States, No Funding Statement	Unknown [No URL]	Health Professional	No - Local or private VPN	No URL	No URL	No URL
Gulati, A. et al. (2015) United Kingdom, No Funding Statement	Unknown [No URL]	Health Professional	No - Local or private VPN	No URL	No URL	No URL
Han, C., et al. (2013) South Korea, Corporate/Private or Organisation Funding	Unknown [No URL]	Health Professional	No - Local or private VPN	No URL	No URL	No URL
Hitzig, S.L. et al. (2013) Canada, Government Funding (A12)*	PAR-QoL [http://parqol.com/]	Health Professional	Freely accessible (www)	Web 2.0	Online interaction with experts	Responsive design / Device agnostic

Kading, V.M. (2016) United States, Government Funding	Unknown [No URL]	Health Professional	No - Local or private VPN	No URL	No URL	No URL
Lobban, F. et al. (2017) United Kingdom, Government Funding (A13)	REACT [https://www.reacttoolkit.co.uk/]	Health consumer	No – Toolkit trial site only	Web 2.0	Online interaction with experts	Responsive design / Device agnostic
Nicolaidis, C. et al. (2016) United States, Government Funding (A14)*	AASPIRE [https://autismandhealth.org/]	Health consumer and Health Professional	Freely accessible (www)	Web 2.0	Creating and editing content	Responsive design / Device agnostic
Parker, D.R. et al. (2013) United States, Government Funding	Unknown [No URL]	Health Professional	No - Local or private VPN	No URL	No URL	No URL
Ploeg, J. et al. (2018) Canada, Government Funding (A16)*	My Tools 4 Care [https://www.mytools4care.ca/]	Health consumer	Freely accessible (www)	Web 2.0	Creating and editing content	Responsive design / Device agnostic
Sinclair, L.B. et al.(2015) United States, Corporate/Private or Organisation Funding (A17)*	AMCHP Disabilities Toolkit [http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/WomensHealthDisability/Pages/default.aspx]	Health consumer and Health Professional	Freely accessible (www)	Web 2.0	Social media	Not responsive /Device agnostic
Starkey, M. et al. (2016) United States, Government Funding	Unknown [No URL]	Health Professional	No - Local or private VPN	No URL	No URL	No URL

*Screenshot of the Home page of freely accessible toolkits can be found in Appendix 15
A= Published article, C= Conference Proceeding, T= Thesis

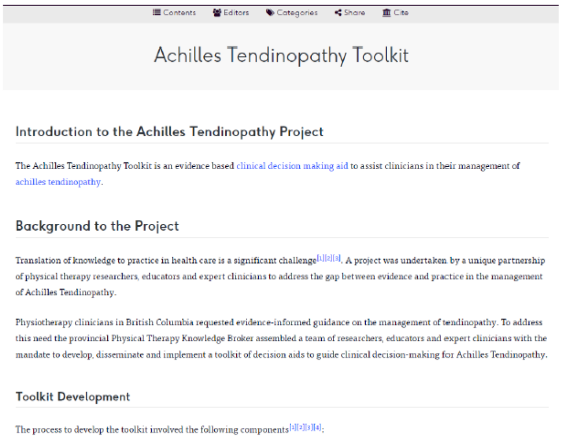
Appendix 5.3 Examples of the home pages of live OHT identified from publications



I want to learn more about concussions as a..

Need to quickly assess a potential concussion?

C1. Babul and Pike 2017 'CATT Online' Toolkit



Achilles Tendinopathy Toolkit

Introduction to the Achilles Tendinopathy Project

The Achilles Tendinopathy Toolkit is an evidence based clinical decision making aid to assist clinicians in their management of achilles tendinopathy.

Background to the Project

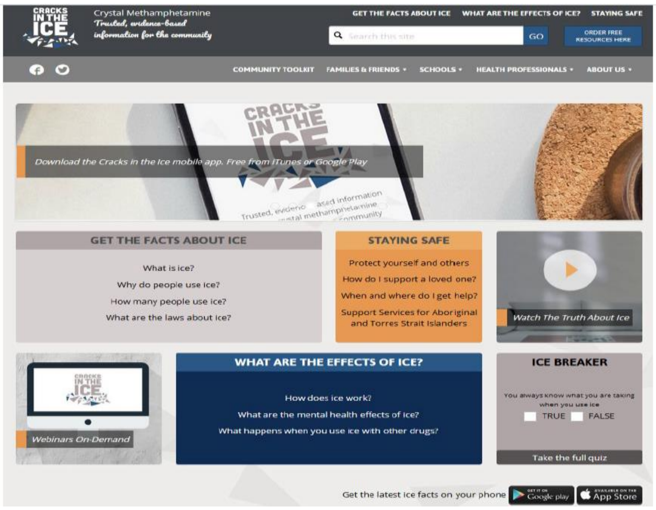
Translation of knowledge to practice in health care is a significant challenge[1][2][3]. A project was undertaken by a unique partnership of physical therapy researchers, educators and expert clinicians to address the gap between evidence and practice in the management of Achilles Tendinopathy.

Physiotherapy clinicians in British Columbia requested evidence-informed guidance on the management of tendinopathy. To address this need the provincial Physical Therapy Knowledge Broker assembled a team of researchers, educators and expert clinicians with the mandate to develop, disseminate and implement a toolkit of decision aids to guide clinical decision-making for Achilles Tendinopathy.

Toolkit Development

The process to develop the toolkit involved the following components[1][2][3][4]:

A4. Ezzat et al. 2017 'ATT' Toolkit



Download the Cracks in the Ice mobile app. Free from iTunes or Google Play

You always know what you are taking when you use ice

Get the latest ice facts on your phone

A1. Champion et al. 2018 'Cracks in the Ice' Toolkit

Welcome to the online Footwear Choice Toolkit. This toolkit has been designed to support health professionals in their role in advising patients on the subject of healthy footwear.

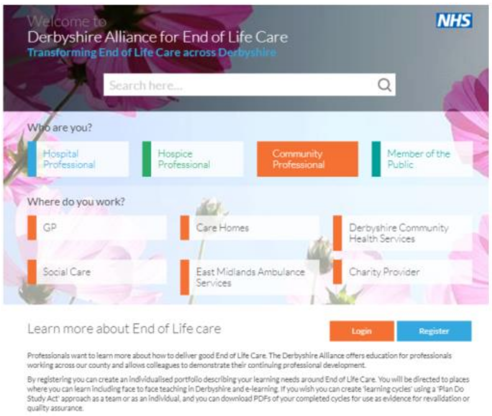
Navigate to the relevant sections of the website here

"That confusion between something that's beneficial to your health but also part of your clothing, your dress and how you feel about your appearance... that's the kind of weighing scales on which all footwear intervention balances"

LYNN, PODIATRIST

A partnership between University of Sheffield and Sheffield Teaching Hospitals NHS Foundation Trust, Podiatry Service

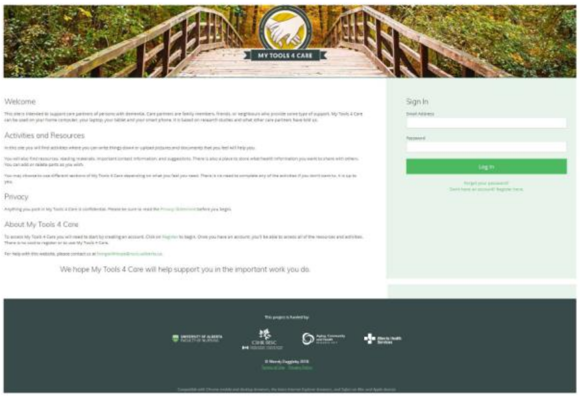
A5. Farndon et al. 2016 'If the Shoe Fits' Toolkit



Professionals want to learn more about how to deliver good End of Life Care. The Derbyshire Alliance offers education for professionals working across our county and allows colleagues to demonstrate their continuing professional development.

By registering you can create an individualised portfolio describing your learning needs around End of Life Care. You will be directed to places where you can learn including face to face teaching in Derbyshire and e-learning. If you wish you can create 'learning cycles' using a 'Plan Do Study Act' approach as a team or as an individual, and you can download PDFs of your completed cycles for use as evidence for revalidation or quality assurance.

C2. England and Shreeve 2018 'End of Life Care' Toolkit



We hope My Tools 4 Care will help support you in the important work you do.

A3. Duggleby et al. 2018 and A16. Ploeg *et al* 2018 'My Tools for Care' Toolkit

REACT is an online study to compare the effectiveness of a Relatives Education And Coping Toolkit (REACT) with an online Resource Directory. Half the people in the study will receive the REACT toolkit, and half will receive the Resource Directory.

The REACT study is no longer recruiting. If you would like to be informed of study results please check back on this site in Summer 2018. For more information please click here.

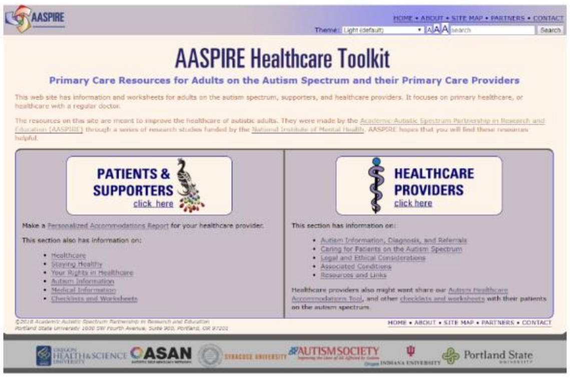
Please only continue with registration if you feel you're able to commit to this.

We would like to invite you take part if the following applies to you:

- Aged 16 and over
- Living in the UK
- A good knowledge of written and spoken English language

If you are interested, please click the 'Start Registration' button above.

A13. Lobban et al. 2017 'REACT' Toolkit



AASPIRE Healthcare Toolkit

Primary Care Resources for Adults on the Autism Spectrum and their Primary Care Providers

This web site has information and worksheets for adults on the autism spectrum, supporters, and healthcare providers. It focuses on primary healthcare, or healthcare with a regular doctor.

The resources on this site are meant to improve the healthcare of autistic adults. They were made by the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) through a series of research studies funded by the National Institute of Mental Health. AASPIRE hopes that you will find these resources helpful.

Make a Personalized Accommodations Report for your healthcare provider.

This section also has information on:

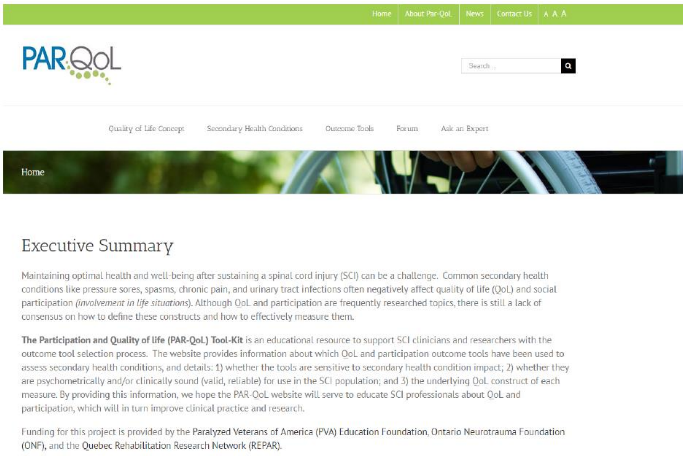
- Healthcare
- Staying Healthy
- Your Rights in Healthcare
- Autism Information
- Medical Information
- Checklists and Worksheets

This section has information on:

- Autism Information, Diagnosis, and Referrals
- Caring for Patients on the Autism Spectrum
- Legal and Ethical Considerations
- Associated Conditions
- Resources and Links

Healthcare providers also might want share our Autism Healthcare Accommodations Tool, and other checklists and worksheets with their patients on the autism spectrum.

A14. Nicolaidis et al. 2016 'AASPIRE' Toolkit



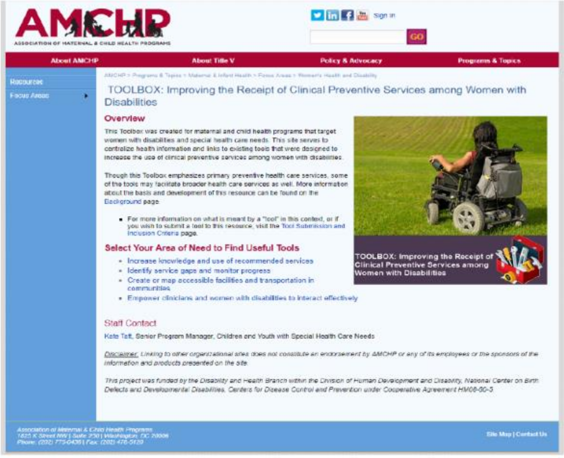
Executive Summary

Maintaining optimal health and well-being after sustaining a spinal cord injury (SCI) can be a challenge. Common secondary health conditions like pressure sores, spasms, chronic pain, and urinary tract infections often negatively affect quality of life (QoL) and social participation *(involvement in life situations)*. Although QoL and participation are frequently researched topics, there is still a lack of consensus on how to define these constructs and how to effectively measure them.

The Participation and Quality of life (PAR-QoL) Tool-Kit is an educational resource to support SCI clinicians and researchers with the outcome tool selection process. The website provides information about which QoL and participation outcome tools have been used to assess secondary health conditions, and details: 1) whether the tools are sensitive to secondary health condition impact; 2) whether they are psychometrically and/or clinically sound (valid, reliable) for use in the SCI population; and 3) the underlying QoL construct of each measure. By providing this information, we hope the PAR-QoL website will serve to educate SCI professionals about QoL and participation, which will in turn improve clinical practice and research.

Funding for this project is provided by the Paralyzed Veterans of America (PVA) Education Foundation, Ontario Neurotrauma Foundation (ONF), and the Quebec Rehabilitation Research Network (REPAR).

A12. Hitzig et al. 2013 'PARQoL' Toolkit



TOOLBOX: Improving the Receipt of Clinical Preventive Services among Women with Disabilities

Overview

This Toolbox was created for maternal and child health programs that target women with disabilities and special health care needs. This site serves to centralize health information and links to existing tools that were designed to increase the use of clinical preventive services among women with disabilities.

Though this Toolbox emphasizes primary preventive health care services, some of the tools may facilitate broader health care services as well. More information about the basis and development of this resource can be found on the Background page.

- For more information on what is meant by a "tool" in this context, or if you wish to submit a tool to this resource, visit the Tool Submission and Inclusion Criteria page.

Select Your Area of Need to Find Useful Tools

- Increase knowledge and use of recommended services
- Identify service gaps and monitor progress
- Create or map accessible facilities and transportation in communities
- Empower clinicians and women with disabilities to interact effectively

Staff Contact

Kate Taft, Senior Program Manager, Children and Youth with Special Health Care Needs

Disclaimer: Linking to other organizational sites does not constitute an endorsement by AMCHP or any of its employees or the sponsors of the information and products presented on the site.

This project was funded by the Disability and Health Branch within the Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention under Cooperative Agreement

A17. Sinclair et al. 2015 'AMCHP' Toolkit

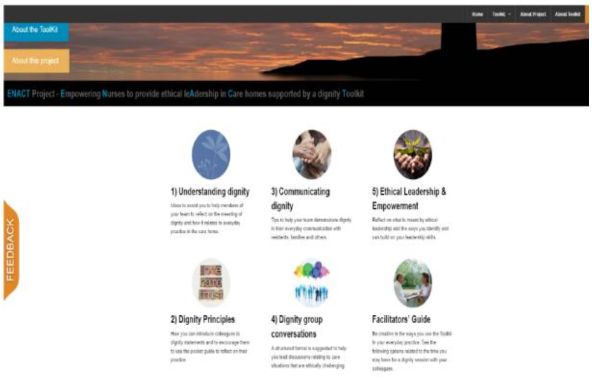
Toolkit: Enhancing the Management of Neuropathic Pain in the Long-term Care Setting

This toolkit provides strategies and templates to help long-term care facilities and their clinicians implement a performance improvement project. The goal of this project is to help clinicians accurately and appropriately manage residents with persistent pain. The toolkit includes the following components:

1. Introduction
2. Algorithm and instructions for toolkit implementation |
3. Sample data collection form and performance measures/calculation instructions
4. PowerPoint slides used during Stage B clinical in-service meetings
5. List of resources available for Stage B intervention |
6. Published manuscript- *Pain Medicine*

The information included in this toolkit was prepared by The Academy for Continued Healthcare Learning (ACHL) and faculty members as outlined in the Introduction.

A6. Fine *et al.* 2014 'Pain in Long Term Care Setting' Toolkit



ENACT Project - Empowering Nurses to provide ethical leAdership in Care homes supported by a dignity Toolkit

1) Understanding dignity
Ideas to assist you to help members of your team to reflect on the meaning of dignity and how it relates to everyday practice in the care home.

3) Communicating dignity
Tips to help your team demonstrate dignity in their everyday communication with residents, families and others.

5) Ethical Leadership & Empowerment
Reflect on what is meant by ethical leadership and the ways you identify and can build on your leadership skills.

2) Dignity Principles
How you can introduce colleagues to dignity statements and to encourage them to use the pocket guide to reflect on their practice.

4) Dignity group conversations
A structured format is suggested to help you lead discussions relating to care situations that are ethically challenging.

Facilitators' Guide
Be creative in the ways you use the Toolkit in your everyday practice. See the following options related to the time you may have for a dignity session with your colleagues.

A7. Gallagher et al. 2017 'Dignity in Care' Toolkit

Appendix 5.4 In-site descriptions of OHT development [ONLQ2-8] categorised by publication study type [DEVQ2]

	Description within online OHT (*n*=14)						
	Evidence base for Toolkit [ONLQ2]	Content development process [ONLQ3]	Expert involvement [ONQL4]	Evaluation during development [ONLQ5]	Development articles [ONL6]	Accessibility evaluation [ONLQ7]	HonCODE [ONLQ8]
Conceptualisation / development of content	A1, A7, A12, A17	A1, A7, A12, A17	A1, A7, A17	-	A1, A7, A12	-	-
OHT Feasibility or acceptability*	A5	A5	A5	A5	A5	-	-
OHT Intervention study*	A14, C1	A6, A14	A6, C1	-	A6, A14, C1	A14	-
OHT Outcome measures post-release*	A4	A4	A4	A4	-	-	-
OHT Implementation protocol*	-	-	-	-	-	-	-

*Developers of A2 (Feasibility), A3 (Interventions), A16, C2 (Outcome measures) and A13 (Implementation Protocol) did not provide online content supporting these aspects of OHT development as described within reviewed publications

Appendix 5.5 Live OHT characteristics and accessibility errors [general and contrast] as measured by the WAVE Accessibility tool

					Usability evaluation (UE)	Accessibility indicator	WAVE Accessibility Checker [http://wave.webaim.org]			
	Author (Year)	**OHT name**	**Intended audience**	**Web1.0 or Web2.0**	**Described in publication**	**In Skin 'aAA' Indicator present**	**Errors - HP**	**CE - HP**	**Errors - 2nd level page**	**CE - 2nd level page**
C1	Babul S, Pike I. 2017	CATTonline	HC, HCP.	2.0	UE	No	37	34	7	25
A1	Champion, K.E. et al. 2018	Cracks in the Ice	HC, HCP	2.0	UE	No	6	22	8	12
A2	Duggleby, W. et al. 2018	MaTT	HC	2.0	UE	Yes	*	*	*	*
A3	Duggleby, W. et al. 2018	My Tools 4 Care	HC.	2.0	UE	Yes	2	9	*	*
C2	England R, Shreeve P. 2018	Derbyshire End of Life Care	HC, HCP	2.0	UE	No	2	10	4	6
A4	Ezzat, A.M. et al. 2017	ATT	HCP	1.0	UE	No	15	3	14	3
A5	Farndon et al. 2016	If the Shoe Fits	HC, HCP	1.0	UE	No	1	5	1	6
A6	Fine, P.G. et al. 2014	ACHLPICME	HCP	1.0	Not described	No	4	2	**	**
A7	Gallagher, A. et al. 2017	ENACT	HCP	1.0	Not described	No	15	16	4	6
A12	Hitzig, S.L. et al. 2013	PAR-QoL	HCP	2.0	Not described	Yes	^	^	^	^
A13	Lobban, F. et al. 2017	REACT	HC	2.0	UE	No	4	1	10	10
A14	Nicolaidis, C. et al. 2016	AASPIRE	HC, HCP	2.0	UE	Yes	5	2	16	6
A16	Ploeg, J. et al. 2018	My Tools 4 Care	HC	2.0	UE	Yes	2	9	*	*
A17	Sinclair, L.B. et al. 2015	AMCHP	HC, HCP	2.0	UE	No	^^	^^	^^	^^

HC= Health Consumers HCP = Healthcare Professionals CE=Contrast Errors HP=Home page
*Password Protected Access unable to analyse ^ Website dark, WAVE analyser unable to read archived version ** Pages open as Pop-up window unable to analyse^^ Website URL too long for WAVE analyser to read
Nicolaidis et al. (2016) mentions accessibility within OHT due to the unique needs of their intended audience/use

Appendix 5.6 Stage of development UEM applied [UEMQ9], accessibility errors identified using WAVE Analyser [ONLQ16] of live OHT, class of UEM employed [UEQ10] as reported within reviewed publications

Stage of Development UEM applied [UEMQ9]	**Class of UEM** [UEMQ10]	**ONLQ16**					**Total accessibility errors by class (Mean/publication)**
		Publication number	Errors - Home page	CE - Home page	Errors - 2nd level page	CE - 2nd level page	
D/D	Inquiry - Focus groups	A13	4	1	10	10	25 (25.0)
	Inquiry - Interviews						
I	Inquiry - Survey or questionnaire	A2#	-	-	-	-	
MS or ME	Simulation - Analytics	A1	6	22	8	12	48 (48.0)
	Testing - Log analytics	A1	6	22	8	12	48 (48.0)
	Testing - Remote testing						
	Inquiry - Focus groups	A5	1	5	1	6	60 (30.0)
	Inquiry - Survey or questionnaire	A1	6	22	8	12	
PI/PR	Testing - Log analytics	A17*, C2	2	10	4	6	22 (22.0)
	Inspection - Clinical vignette	A4	15	3	14	3	213 (71.0)
	Inquiry - Interviews	A16	2	9	^	^	
	Inquiry - Survey or questionnaire	A4, A14, C1	57	39	37	34	
	Simulation - Analytics	A17*, C2	2	10	4	6	22 (22.0)

*A17 – WAVE Analyser unable to process URL #A2 OHT on password-protected secure site - WAVE Analyser unable to process

^ A16 - Password Protected Access unable to analyse

PR/ PI = Post-Release / Post Implementation D/D = Design / Development - early prototype MS or ME across stages = Mixed Stage or Multiple Evaluations across stages

I = Implementation - final version prototype

Appendix 5.7 Type of UEM [UEM11] employed during stages of development [UEMQ9] and accessibility errors identified using WAVE Analyser [ONLQ16] of live OHT, as reported within reviewed publications

Type UEM [UE11]	**Stage** [UE9]	**Publication number**	**ONLQ16**				**Total accessibility errors by class (Mean/publication)**
			Errors - Home page	CE - Home page	Errors - 2nd level page	CE - 2nd level page	
Testing - Remote testing	MS or ME	A1	6	22	8	12	48 (48.0)
Testing - Log analytics	MS or ME	A1	6	22	8	12	70 (35.0)
	PR/PI	A17*, C2	2	10	4	6	
Inspection - Clinical vignette	PR/PI	A4	15	3	14	3	35 (35.0)
Inquiry - Focus groups	D/D	A13	4	1	10	10	38 (19.0)
	MS or ME	A5	1	5	1	6	
Inquiry - Interviews	D/D	A13	4	1	10	10	36 (18.0)
	PR/PI	A16	2	9	0	0	
Inquiry - Survey or questionnaire	I Final	A2#	-	-	-	-	195 (48.75)
	MS or ME	A1	6	22	8	12	
	PR/PI	A4, A14, C1	57	39	37	34	
Simulation - analytics	MS or ME	A1	6	22	8	12	70 (35.0)
	PR/PI	A17*, C2	2	10	4	6	

PR/PI = Post-Release / Post Implementation D/D = Design / Development - early prototype MS or ME across stages = Mixed Stage or Multiple Evaluations across stages I = Implementation - final version prototype

#A2 OHT on password-protected secure site - WAVE Analyser unable to process

*A17 – WAVE Analyser unable to process URL

APPENDIX 6. ADDITIONAL INFORMATION RELATING TO THE COMPREHENSIVE EVALUATION OF THE CARERHELP TOOLKIT CHAPTER

Appendix 6.1 Ethics approval for Study 3 from Flinders University SBREC– Project 8347

From: Human Research Ethics
Sent:
To:
Subject: 8347 ETHICS approval notice (13 June 2019)
Attachments:

Importance: High

Dear Amanda,
Your conditional approval response for project 8347 was reviewed by the interim Chairperson of the Social and Behavioural Research Ethics Committee (SBREC) and was **approved.** The ethics approval notice can be found below.

APPROVAL NOTICE

Project No.: **8347**

Project Title: Applying a website development model to evaluate usability of the Carers Toolkit, a new type of online palliative care information resource

Principal Researcher: Ms Amanda Adams

Email:

Approval Date: 13 June 2019

Ethics Approval Expiry Date: **28 February 2023**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

PARTICIPANT DOCUMENTATION

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

ANNUAL PROGRESS / FINAL REPORTS

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* an annual progress report must be submitted each year on the **13 June** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval web page.

Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

If the project is completed *before* ethics approval has expired, please ensure a final report is submitted immediately. If ethics approval for your project expires please either submit (1) a final report; or (2) an extension of time request (using the modification request form).

First Report due date:	**13 June 2020**
Final Report due date:	**28 February 2023**

STUDENT PROJECTS

For student projects, the SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

MODIFICATIONS TO PROJECT

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes/modifications include:

- change of project title;
- change to research team (e.g., additions, removals, researchers and supervisors)
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes to information/documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

CHANGE OF CONTACT DETAILS

If the contact details of researchers, listed in the approved application, change please notify the Committee so that the details can be updated in our system. A modification request is not required to change your contact details; but would be if a new researcher needs to be added on to the research / supervisory team.

ADVERSE EVENTS AND/OR COMPLAINTS

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that affects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Executive Officers, Social and Behavioural
Research Ethics Committee
Research Development and Support

Proactively supporting our Research

Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001

Appendix 6.2 Newest Vital Sign[396] health literacy screening tool

a) Label

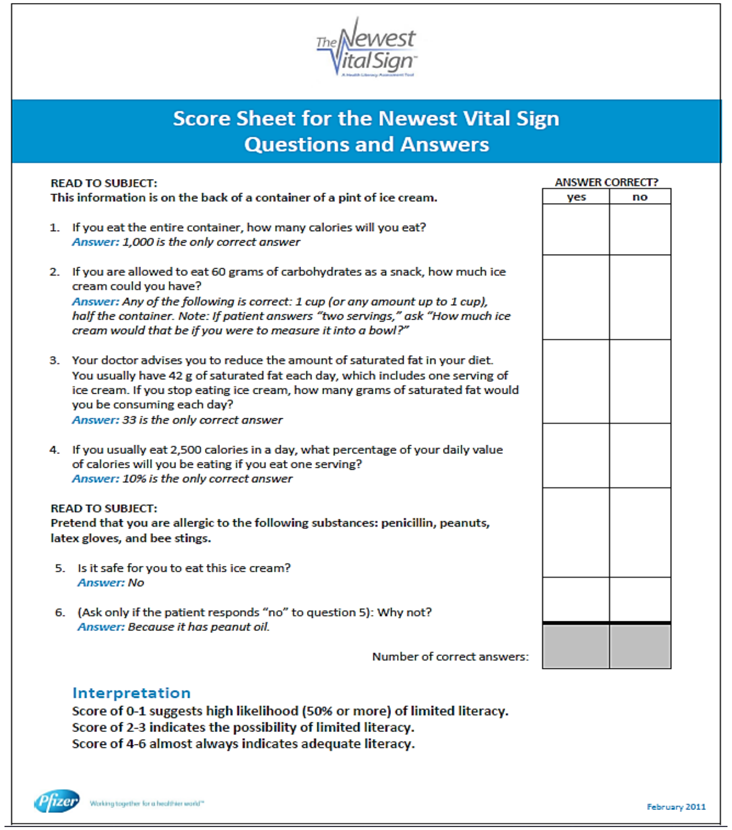
Nutrition Facts

Serving Size	½ cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
	%DV
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

b) Scoring Sheet



Score Sheet for the Newest Vital Sign
Questions and Answers

READ TO SUBJECT:
This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?
   Answer: 1,000 is the only correct answer
2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?
   Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl?"
3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?
   Answer: 33 is the only correct answer
4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?
   Answer: 10% is the only correct answer

READ TO SUBJECT:
Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?
   Answer: No
6. (Ask only if the patient responds "no" to question 5): Why not?
   Answer: Because it has peanut oil.

Question	ANSWER CORRECT? yes	ANSWER CORRECT? no
1		
2		
3		
4		
5		
6		
Number of correct answers:		

Interpretation

Score of 0-1 suggests high likelihood (50% or more) of limited literacy.
Score of 2-3 indicates the possibility of limited literacy.
Score of 4-6 almost always indicates adequate literacy.

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February 2011

Appendix 6.3 Usability Testing - three Single Ease Questions (SEQ)

a) Ease of use

	Very Difficult 1	2	3	4	5	6	Very Easy 7
1. Overall, this task was							

b) Level of confidence

	Low 1	2	3	4	5	6	High 7
2. How confident are you that you completed the activity fully							

c) Level of satisfaction

	Low 1	2	3	4	5	6	High 7
3. What was your level of satisfaction after doing this activity							

Appendix 6.4 CSUQ Questionnaire[403] (Version 3)

	Strongly Agree 1	2	3	4	5	6	Strongly Disagree 7	N/A
1. Overall, I am satisfied with how easy it is to use this online toolkit								
2. It is simple to use this online toolkit								
3. I am able to complete my work quickly using this online toolkit								
4. I feel comfortable using this online toolkit								
5. It was easy to learn to use this online toolkit								
6. I believe I became productive using this online toolkit								
7. The online toolkit gives error messages that clearly tell me how to fix problems								
8. Whenever I make a mistake using the online toolkit, I recover easily and quickly								
9. The information (such as online help, on-screen messages and other documentation) provided within this online toolkit is clear								
10. It is easy to find the information I needed								
11. The information provided to within the online toolkit is effective in helping me complete my work								
12. The organisation of information in the online toolkit screen is clear								
13. The interface of this online toolkit is pleasant								
14. I like using the interface of this online toolkit								
15. This online toolkit has all of the functions and capabilities I expect it to have								
16. Overall, I am satisfied with this online toolkit								
The interface included those items include those items that you use to interact with the system and includes the keyboard, mouse, microphone and screen, including the graphics and language								

The CSUQ questionnaire above has been adapted to evaluate online toolkits, where the term '*system*' in Lewis' CSUQ Version 3[403] has been updated to reflect resource type ('*online toolkit*'). This modification in terminology has been shown not to influence the psychometric validity or reliability of the questions,[402,406] providing users with clarity and increasing understanding of the questionnaire.

Appendix 6.5 Suitability Assessment of Materials (SAM) Score sheet including factors and categories [418]

Scores	
2 points – Superior rating	0 points – Not suitable rating
1 point – Adequate rating	N/A – if a factor does not apply to this material

Factor	**Score**	**Comments**
1. Content		
a) Purpose is evident		
b) Content about behaviours		
c) Scope is limited		
d) Summary or review is included		
2. Literacy demands		
a) Reading grade level		
b) Writing style, active voice		
c) Vocabulary uses common words		
d) Context is given first		
e) Learning aids given by 'road signs'		
3. Graphics		
a) Cover graphics shows purpose		
b) Type of graphics		
c) Relevance of illustrations		
d) List, tables etc. explained		
e) Captions used for graphics		
4. Layout and Typography		
a) Layout factors		
b) Typography		
c) Sub Headings ('chunking') used		
5. Learning Stimulation, Motivation		
a) Interaction used		
b) Behaviours are modelled and specific		
c) Motivation – self-efficacy		
6. Cultural Appropriateness		
a) Match in logic, language, experience		
b) Cultural image and examples		
Total SAM Score		
Total Possible Score		
Percentage Score (%)		

Appendix 6.6 Post-release online survey for carers who completed usability testing

Start of Block: Survey Instruction

Evaluation of User Experience of the Carers Toolkit

Thank you for your participation in this research study.

There are two activities to complete in this online survey.

The first will ask you about your experiences using the Toolkit by rating how satisfied you were with your interaction and how easy you found the Toolkit was to use. This survey is the same that you completed at the end of your evaluation session in August.
This activity will take you approximately 5 minutes to complete.

The second activity asks you to provide your feedback describing if you think the developer has changed parts of the Toolkit to improve carer's experience using the Toolkit concerning your issues or problems that you identified during the sessions in August.

All responses are voluntary, although your feedback will help us understand the development of relevant and useful online health resources for consumers.
This activity will take you approximately 10 minutes to complete.
You may find it helpful to have the Carer Toolkit open at the same time as you complete the survey.
You can access the Carer Toolkit by following this link: https://www.carerhelp.com.au/
This research has been reviewed by the Flinders University SBREC (Project Number 8347) and will contribute to a PhD project in the College of Nursing and Health Sciences at Flinders University.
If you have any questions about this questionnaire, please contact

Clicking the 'I agree to participate' button below indicates that you are willing to participate in the research by completing the questionnaire.

By agreeing, you are aware that your participation is voluntary and that you may choose not to participate or to withdraw at any time. *All electronic data collected will be confidential and de-identified for academic purposes only and stored securely.*

○ I agree to participate on the understanding that my participation will not be anonymous, on the basis that I will be asked to provide my last name

○ I do not want to participate

Skip To: End of Survey If Clicking the 'I agree to participate' button below indicates that you are willing to participate... = I do not want to participate

End of Block: Survey Instruction

Start of Block: Block 3

Please provide your *last name*

This will allow us to compare the information you gave us during the evaluation of the early prototype in August to how you view the Carers Toolkit now.

____

End of Block: Block 3

Start of Block: CSUQ questions

Satisfaction of the User's Experience of the Carers Toolkit

Please answer the following questions on how you found your experience using the Carers Toolkit. This is the same questionnaire you completed after using the Toolkit prototype in your usability session in August.

For each question, select a number from 1 to 7 that corresponds to how you strongly agree or disagree with each statement about how easy the Carers Toolkit was to use and how you felt interacting with the toolkit interface.

The interface includes items you use or see to interact with the system and relate to the keyboard or mouse or speakers and the on-screen display, including content, language or images.

There are 16 questions in this section, and they should take approximately 5 minutes to complete.

Q1 Overall, I am satisfied with how easy it is to use this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q2 It is simple to use this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q3 I am able to complete my work quickly using this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q4 I feel comfortable using this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q5 It was easy to learn to use this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q6 I believe I became productive using this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q7 The online toolkit gives error messages that tell me how to fix problems

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q8 Whenever I make a mistake using the online toolkit, I recover easily and quickly

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q9 The information (such as online help, on-screen messages and other documentation) provided within this online toolkit is clear

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q10 It is easy to find the information I needed

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q11 The information provided within the online toolkit is effective in helping me complete my work

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q12 The organisation of information in the online toolkit screen is clear

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q13 The interface of this online toolkit is pleasant

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q14 I like using the interface of this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q15 This online toolkit has all of the functions and capabilities I expect it to have

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q16 Overall, I am satisfied with this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

End of Block: CSUQ questions

Start of Block: Feedback

Carer Toolkit End-User Feedback

The following questions will ask you to provide your thoughts on how the final version of the Toolkit that you view today differs from the prototype version that you interacted with in August during usability testing.

Some of the issues that carers involved in the usability evaluation of the Toolkit in August found include:

- Issues with the Home Page including not enough information of what is in the Toolkit, lack of a menu, difficulty in finding the menu and search function and descriptions on the page
- The language used in the Toolkit was sometimes insensitive or inappropriate, including labels of activities and descriptions on the content pages
- Difficulties locating resources found in the Carers Library
- Problems locating essential practical tools or pieces of information within the pages
- Obstacles affecting navigation through the Toolkit

Five questions ask you to provide your feedback on the features and information found in the final version of the Toolkit that may or may not have been improved based on the feedback you provided in August. We would like you to explain the reasons for your answers as this will allow us to explore your experiences with the Toolkit as a carer using this resource.

The final question asks how likely you are to recommend the Carers Toolkit to a friend or family member.

You can choose to answer as many questions as you like, or you can choose not to answer any of these questions.

There are six questions in this section, and they should take approximately 10 minutes to complete.

Q17.1 Do you think that the final version of the Toolkit you have used today improves the prototype version of the Toolkit you used in August?

○ Yes

○ No

Q17.2 Please tell us why you think this

____

____

Q18.1 Do you think that the issues or problems that you identified during your evaluation of the prototype in August have been fixed in the final version of the Toolkit?

○ Yes – the majority have been fixed

○ Not sure – there are some which I can see that has not been fixed, but some others have

○ No – the majority of the issues or problems are still in the Toolkit

---

Q18.2 Can you provide up to 3 examples that support your choice – please explain why you think that these have or have not been fixed in the final version of the Toolkit

Example 1:

____

Q18.3 Example 2:

____

Q18.3 Example 3:

____

Q19.1 Do you think modifications made to the Toolkit since you last viewed it in August have improved your experience accessing the information?

○ Yes

○ No

Q19.2 Please explain your answer why you think this

____

Q20.1 Do you think that the evaluation process you have been involved with, that is, looking and providing feedback at both stages of development of the toolkit, is a valuable process to be involved with?

○ Yes

○ No

Q20.2 Please explain your answer

____

Q21.1 Do you think your feedback has made a difference in how the Toolkit looks, feels and works now?

○ Yes

○ No

Q21.2 Please explain your answer

____

Q22 Based on your user experience, on a scale from 0-10, how likely are you to recommend The Carer Toolkit to a family member, friend or colleague?

○ 0

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10

End of Block: Feedback

End of Survey Message

Thank you for your valuable feedback and your participation in this research study.

Your involvement has been greatly appreciated.

Appendix 6.7 Post-release online survey for pre-registered users

---

Start of Block: Survey Instruction

Evaluation of User Experience of the Carers Toolkit

Thank you for your participation in this research study.

There are two activities to complete in this online survey.

The first will record your level of satisfaction with your experience using the Carer Toolkit and will take approximately 7 minutes to complete.

The second activity asks you to provide feedback on how the Carer Toolkit functions, any problems or issues you may find during your visit, and if the Carer Toolkit provided the information you were looking for.

These responses are voluntary but will provide valuable information on how developers can better produce online health information resources to support carers in the community.

This activity will take you approximately 8 minutes to complete.

You can access the Carer Toolkit by following this link: https://www.carerhelp.com.au/

This research has been reviewed by the Flinders University SBREC (Project Number 8347) and will contribute to a PhD project in the College of Nursing and Health Sciences at Flinders University.
If you have any questions about this questionnaire, please contact

Clicking the 'I agree to participate' button below indicates that you are willing to participate in the research by completing the questionnaire.

By agreeing, you are aware that your participation is voluntary and that you may choose not to participate or to withdraw at any time. All electronic data collected will be anonymous, stored securely, and used for academic purposes only.

○ I agree to participate - continue to the online questionnaire

○ I do not want to participate

Skip To: End of Survey If Clicking the 'I agree to participate' button below indicates that you are willing to participate... = I do not want to participate

End of Block: Survey Instruction

Start of Block: Carer Status

Are you currently:

○ The primary carer for a relative or friend who is living with advanced disease

○ A bereaved carer

○ Neither of the above

End of Block: Carer Status

Start of Block: CSUQ questions

Satisfaction of the User's Experience of the Carers Toolkit

Please answer the following questions on how you found your experience using the Carers Toolkit.

For each question, select a number from 1 to 7 that corresponds to how you strongly agree or disagree with each statement about how easy the Carers Toolkit was to use and how you felt interacting with the toolkit interface. The interface includes items you use or see to interact with the system and relate to the keyboard or mouse or speakers and the on-screen display, including content, language or images.

There are 16 questions in this section, and they should take approximately 5 minutes to complete.

Q1 Overall, I am satisfied with how easy it is to use this online toolkit:

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q2 It is simple to use this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q3 I am able to complete my work quickly using this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q4 I feel comfortable using this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q5 It was easy to learn to use this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q6 I believe I became productive using this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q7 The online toolkit gives error messages that tell me how to fix problems

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q8 Whenever I make a mistake using the online toolkit, I recover easily and quickly

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q9 The information (such as online help, on-screen messages and other documentation) provided within this online toolkit is clear

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q10 It is easy to find the information I needed

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q11 The information provided within the online toolkit is effective in helping me complete my work

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q12 The organisation of information in the online toolkit screen is clear

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 6

○ Strongly Agree 1

○ N/A

Q13 The interface of this online toolkit is pleasant

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q14 I like using the interface of this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q15 This online toolkit has all of the functions and capabilities I expect it to have

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

Q16 Overall, I am satisfied with this online toolkit

○ Strongly Disagree 7

○ 6

○ 5

○ 4

○ 3

○ 2

○ Strongly Agree 1

○ N/A

End of Block: CSUQ questions

Start of Block: Feedback

Carer Toolkit End-User Feedback

The following questions will ask you to provide your feedback as a carer on your interaction with the Carer Toolkit.

There will be two questions that will ask you if the Toolkit meets your information needs as a carer and if the information within the toolkit was what you expected to find.

There will also be questions asking you to provide feedback on the Carer Toolkit interface, focusing on issues or problems you may have encountered during your visit.

The interface includes items you use or see to interact with the system and relate to the keyboard or mouse or speakers and the on-screen display, including content, language or images.
We would like you to describe in as much detail as needed and include references to pages within the toolkit. This will allow us to locate and modify any problems that you may identify.

You can choose to answer as many questions as you like, or you can choose not to answer any of these questions.

There are eight questions in this section, and they should take approximately 10 minutes to complete.

Q17 Do you think your experience within the Carers Toolkit meets your information needs as a carer caring in the community?

○ Yes

○ No

Q18 Please provide your feedback

____

Q19 Did your experience of the information found within the Carers Toolkit meet your expectations of what you thought you might find before your visit?

○ Yes

○ No

Q20 Please provide your feedback

____

Q21 Did you have any problems or issues with the content, how the toolkit looks, hyperlinks, resources within the toolkit or language of the toolkit pages when you last visited?

○ Yes

○ No

Q22 Please provide your feedback

____

Q23 When visiting the Carers Toolkit, did you think the information was presented so that it was easy to find?

○ Yes

○ No

Q24 Please provide your feedback

____

Q25 Did you find the information easy to access and understand?

○ Yes

○ No

Q26 Please provide your feedback

____

Q27 Does the menu structure make sense to you?

○ Yes

○ No

Q28 Please provide your feedback

____

Q29 Did the toolkit features that help you move around to take you where you expected to go? This can include hyperlinks, images or pictures and text.

○ Yes

○ No

Q30 Please provide your feedback

____

Q31 Based on your user experience, on a scale from 0-10, how likely are you to recommend The Carer Toolkit to a family member, friend or colleague?

○ 0

○ 1

○ 2

○ 3

○ 4

○ 5

○ 6

○ 7

○ 8

○ 9

○ 10

End of Block: Feedback

End of Survey Message

Thank you for your valuable feedback and your participation in this research study.

Your involvement has been greatly appreciated.

Report of Usability Test Findings of the Australian Carers Toolkit

Prepared by:
Amanda Adams
(PhD Candidate, Flinders University)

26 August 2019

TABLE OF CONTENTS

EXECUTIVE SUMMARY

SUMMARY OF FINDINGS

Overall, the participants found the Carers Toolkit to be a generally useful and relevant online resource that will be acceptable to the targeted audience. Participants found the content to be extremely valuable especially the practical tools and guidance supporting care during the intermediate stages before the terminal phase. The majority of issues identified by this usability evaluation were related to the navigation into and around the internal pages of the Toolkit, including text descriptors and landmarks whilst the language used in the prototype was highlighted as a problem for some carers.

STRENGTHS

- The way the Toolkit looks provided a pleasant experience to carers with the colours and drawn images being well received, particularly in the Carers Pathway to sensitively portray pictorial representations of the stages of caring.
- Carers easily learned the Toolkit structure (menu and information design) after their initial visits to the site, and carers were pleased with the simplicity of the design.
- Resources and tools within the Toolkit were found to be of great relevance to carers and all identified information that would have been helpful during their caring experiences.
- Carers involved in this evaluation all provided positive feedback on the need of the resource, were moderately satisfied with their experience using the prototype, and recommended the resource to other carers, particularly early in their caring experience.

TO BE IMPROVED

This design does not lead people quickly and easily through the Toolkit to find specific information, especially when arriving at the Home Page. In particular:

- It is unclear how visitors can move from the Home Page into the correct sections of the Toolkit if they are not shown what is in the Toolkit when arriving
  - Lack of visible menu or poorly described navigation buttons provides difficulty to older people or people with limited technological skills or experience to recognise not traditional functions of newer designs; this includes the ≡ menu button and icons that change colour when hovering but have no function.
  - The steps moving into the Toolkit pages are not clearly described or landmarked, especially concerning the Carers Pathway page
  - Key information was missed due to the structure of content on the pages as visitors with poorer technological skills and experience do not always look everywhere on a page for information
  - Balancing the language to be acceptable to all carers regardless of the stage of caring will be important in providing a satisfying experience for users

---

DEFINITIONS USED IN THIS REPORT

The Toolkit or prototype: The Carers Toolkit website

Interface: Can describe all information on the screen, the device and associated hardware such as mouse, printers and integration across different software.

STUDY OUTLINE

1.1 TEST DATES: 8th – 15th August 2019

1.2 LOCATION: Rehabilitation and Palliative Care Building, Flinders Medical Centre, Adelaide

1.3 PURPOSE OF TEST: Identify usability issues and feasibility of Carers Toolkit prototype to be addressed in the redesign

1.4 AREAS TESTED: General usage of finding information and overall impressions of the Carers Toolkit

1.5 TEST FACILITATOR: Amanda Adams

METHODOLOGY

Six people participated in the study. Participants were given tasks to perform and asked to use the think-aloud protocol. Test sessions lasted an average of 70 minutes.

INDEX OF FINDINGS

For easy reference, the findings in this report are identified as **High**, **Med**(ium), **Low**, or ***Good*** and appear as follows:

1. **GOOD: The design was simple, and users understood it. Keep it.**
2. **HIGH: The design or feature caused extreme confusion or frustration; the problem has a large impact on task flow.**
3. **MED: The design or feature caused some confusion.**
4. **LOW: The design or feature caused little confusion or frustration; the feature is not in a high priority area of the site.**

Recommendations look like this. One recommendation may address several usability issues.

> *Quotes from participants look like this*

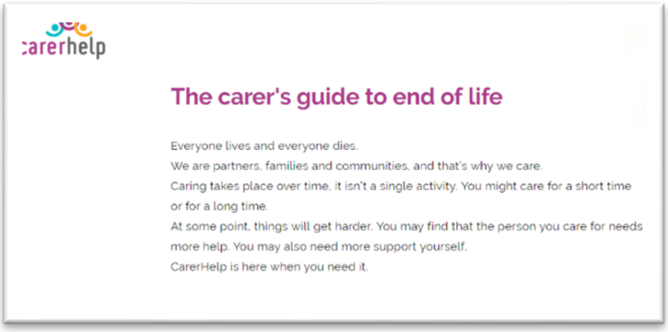
LIST OF FINDINGS

DETAILED FINDINGS

3.1 HOME PAGE (https://www.carerhelp.com.au/tabid/5611/Default.aspx)

1 HIGH: IT IS UNCLEAR ON WHAT INFORMATION THE TOOLKIT HAS TO OFFER NEW VISITORS TO THE SITE

Participants commented that the text on the home page (HP) provided little guidance on the practical guidance that is provided within the toolkit. Over half described the text as "project speak" and provided no real information on carers should go further into the toolkit; this was noted as being particularly important as this information is in prime view of users arriving at the site.



The carer's guide to end of life

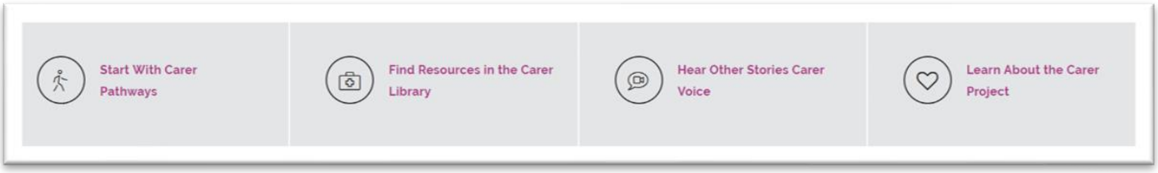
Everyone lives and everyone dies.
We are partners, families and communities, and that's why we care.
Caring takes place over time, it isn't a single activity. You might care for a short time or for a long time.
At some point, things will get harder. You may find that the person you care for needs more help. You may also need more support yourself.
CarerHelp is here when you need it.

→ Modify the text to include how the toolkit can help carers and include descriptions of this resource's practical support to help users with decision-making.

2 HIGH: LACK OF NAVIGATION CUES PRODUCED INDECISION IN CARERS TRYING TO LOCATE THE CORRECT PATH INTO THE TOOLKIT FROM THE HOME PAGE

Carers were moving into the internal sections of the Toolkit from the HP, primarily using the four "navigation buttons" at the bottom of the first screen. Observations showed that even though carers knew that either 'Carers Voice' or 'Carer Library' was not the correct option for finding specific information, they were willing to accept 'incorrect pathways' in order to access the internal menu system at the top of the screen of all other pages.
Acceptance of this behaviour should be cautioned due to the conditions of usability testing, as 'regular' carers may not be so forgiving when trying to navigate to the correct section via multiple incorrect clicks and leave the site unsatisfied.

→ Need to include brief descriptions in the 'buttons' that will give the user more sense of what they will find in each section, providing improved guidance into the Toolkit to decrease frustration levels.



3 **HIGH:** IT IS DIFFICULT TO KNOW THE SECTIONS THAT ARE WITHIN THE TOOLKIT FROM THE NAVIGATION AND LANDMARK CUES ON THE HOME PAGE

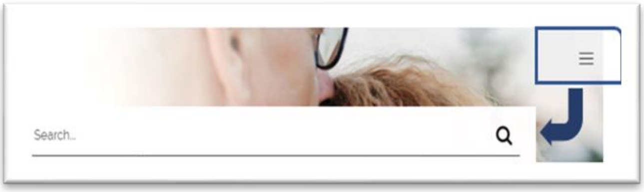
Features on the HP that assist users in formulating a pathway to specific information within the Toolkit include four ‘navigation buttons’ and a menu associated with the website's skin (top LH corner – ‘Hamburger’ icon ≡). Participants were found to use the ‘navigation’ buttons the majority of the time to access the internal pages, but these only describe four of the internal sections and do not reference the content sections (Being an EoL Carer, Being Prepared, Caring for the Dying and After Care).

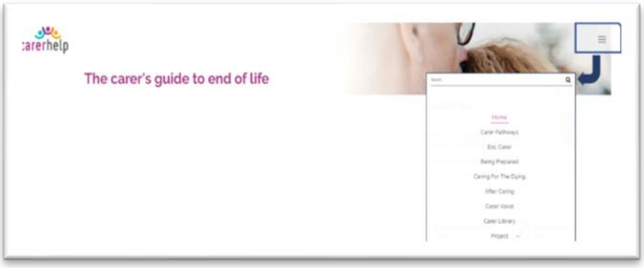
> *[I am] "more likely to find a search thing and search for a particular word rather than clicking through pages. Cause I would probably get the sh**s clicking through things really quickly. Because when you are stressed out and caring for someone and you are doing all that, the last thing you want to do is to sit here and click click click. I just prefer to have at my fingertips so to speak - I think most people, even having the menu right at the start more visible and easier to access" [would help].*
>
> *(Carer 1)*

This structure contributes to the incorrect pathways observed (as described above) and increased frustration as carers were often surprised and overwhelmed at the amount of content they found once they got past the HP. Interestingly, only 1 of the participants used the ≡ menu on the HP to navigate into the Toolkit. This carer could be considered an ‘expert’ in technological skills and abilities and was familiar which this structure due to her browsing on a smartphone. All other participants were shown the ≡ on the HP during the session, but all still used the buttons to navigate the Toolkit.

→ Due to the demographics of carers (generally older with intermediate to low levels of technological experience and ability), users will not readily adapt to the menu.
→ There is still a need to provide information about what is in the toolkit, and the implementation of a visible menu could solve this issue. Where design limitations exist (vertical or horizontal menu are not possible), other visual cues could be implemented, including increasing the number of ‘navigation buttons’ to include the other sections or using an image or text to funnel users to a specific starting point such as the ‘Carers Pathway’ page.

4 **MEDIUM:** A VISIBLE SEARCH FUNCTION ON THE HOME PAGE WOULD DECREASE THE LEVEL OF FRUSTRATION OBSERVED WHEN TRYING TO FIND SPECIFIC INFORMATION IN TOOLKIT SECTIONS





The search field option is "hidden" in the ≡ menu, a feature that most participants did not see or did not know what this button did. Participants were asked if this feature was something they were used to seeing; one participant of the six knew what this icon did and used this to navigate into the Toolkit. The remaining five commented that the ≡ menu was 'new' to them and that they were used to seeing a structured and visually apparent menu running either horizontally or vertically on the page with drop downs. Users could learn to use this function, but this would take several visits to get used to, and this should not be assumed across all users.

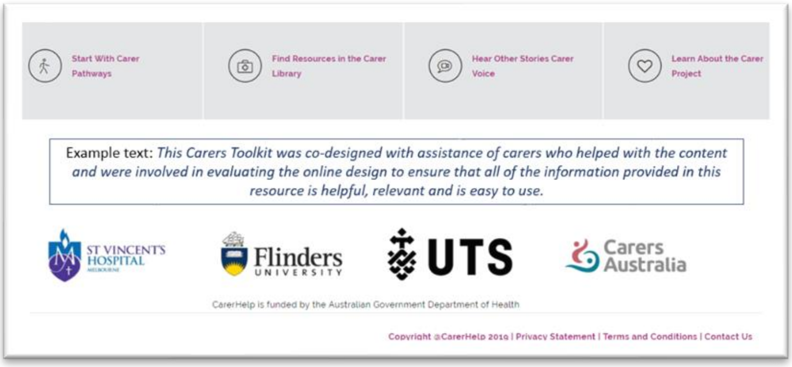
→ If the ≡ menu remains the formal navigation and search tool on the Toolkit, a possible solution would be to include a 'Getting Started' page or 'Hints' section on the Home Page, which could help your users transition to this menu type.

5 MEDIUM – LOW: Quality indicators are hidden below the fold, and more information on the hp about how carers contributed to the process of development could increase users sense of authenticity and provide reassurance that this information is relevant

Participants were asked to locate indicators of quality and trust within the Toolkit. All six located the institutional logos at the bottom of the page also the statement of funding. Only half of the participants located the 'About the Project' page and thought that this was valuable information that should be included on the HP.
All participants verbalised the importance of knowing that this Toolkit has been developed and evaluated in co-operation with carers and thought this information could provide an increased sense of reassurance that content is written from the carer's point of view.

> *"I would think on the very first page there needs to a background on who was involved in how this was developed, which would provide greater indication to people that it is trustworthy and has been researched properly. Not something that has just been made up off of the top of someone's head".*
>
> *(Carer 2)*

→ Add a sentence to the Home Page, perhaps just below the navigation buttons, that includes a statement that cares were involved in a participatory relationship with the project team to develop the content and assist with the Toolkit's evaluation to ensure that the website is easy to use.



Example text: *This Carers Toolkit was co-designed with assistance of carers who helped with the content and were involved in evaluating the online design to ensure that all of the information provided in this resource is helpful, relevant and is easy to use.*

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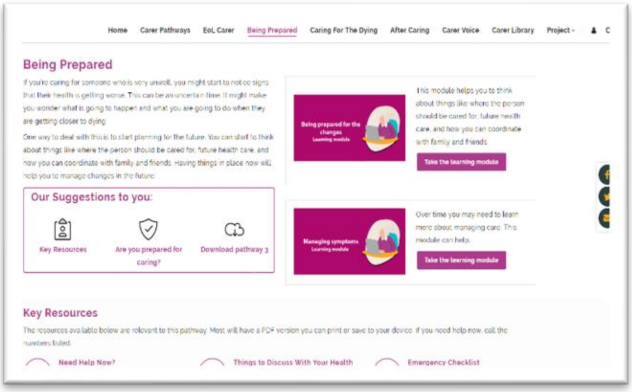
3.2 CONTENT PAGES

- Being an EoL Carer (https://www.carerhelp.com.au/tabid/5612/Default.aspx)
- Being Prepared (https://www.carerhelp.com.au/tabid/5613/Default.aspx)
- Caring for the Dying and After Caring (https://www.carerhelp.com.au/tabid/5614/Default.aspx)
- After Caring (https://www.carerhelp.com.au/tabid/5577/Default.aspx)

> *"I am terrible at scrolling….*
> *This is better [pointing to key resources]. If I was looking for this [Managing Symptoms link] … This is a practical thing that would be helpful, and resources are great. These are the things you do on a day to day basis. Learning modules may be great to do when you have time".*
>
> *(Carer 6)*

6 **HIGH:** 'KEY RESOURCES' WERE COMMONLY MISSED DURING VISITS TO THESE CONTENT PAGES AS PARTICIPANTS DID NOT SCAN BELOW THE FOLD

A common trait of participant searching behaviour was observed in the initial tasks undertaken by all carers, where content below the fold of the first screen was not viewed. 'Key Resources' were regularly missed, especially in the first or second activity when the site was relatively 'new' to the participants. This section of the page was often discovered by accident, but after the user was aware of the page structure, these were regularly



Being Prepared

If you're caring for someone who is very unwell, you might start to notice signs that their health is getting worse. This can be an uncertain time. It might make you wonder what is going to happen and what you are going to do when they are getting closer to dying.

One way to deal with this is to start planning for the future. You can start to think about things like where the person should be cared for, future health care, and how you can coordinate with family and friends. Having things in place now will help you to manage changes in the future.

Our Suggestions to you:

This module helps you to think about things like where the person should be cared for, future health care, and how you can coordinate with family and friends.

Over time you may need to learn more about managing care. This module can help.

Key Resources

The resources available below are relevant to this pathway. Most will have a PDF version you can print or save to your device. If you need help now, call the numbers listed.

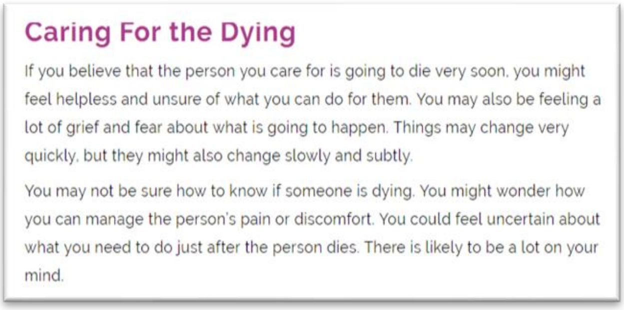
viewed as they were considered the most practical and useful for carers from the content on the page.

→ Recommend changing information flow of content pages to reflect participants view of 'Key Resources' being at the top of the page (in plain view or direct line of sight) if this section is considered to reflect the principle objective of the Toolkit. Would suggest moving the 'Key resources' to the position where the learning module sits alongside the descriptor of the purpose and outline of the content found on the page.

→ This comment is relevant to the Learning Module section below.

7 **HIGH:** LANGUAGE WITHIN THESE PAGES WERE FOUND TO BE IMPERSONAL AND PATRONISING THAT PROVIDED A FRUSTRATING EXPERIENCE FOR SOME CARERS

The language and tone within these pages will require a balance between using realistic and 'hard' language whilst maintaining a personal and supportive tone that will cater for those carers who are going to be an EoL carer in the near future but projecting a realistic and practical tense for carers who are currently "living the experience".



Caring For the Dying

If you believe that the person you care for is going to die very soon, you might feel helpless and unsure of what you can do for them. You may also be feeling a lot of grief and fear about what is going to happen. Things may change very quickly, but they might also change slowly and subtly.

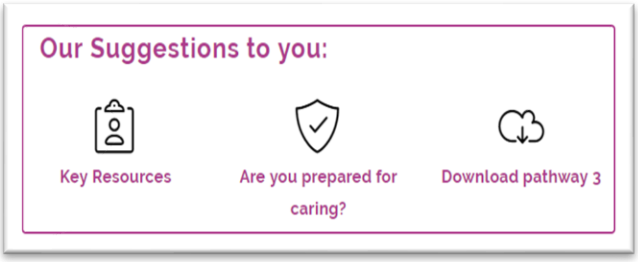
You may not be sure how to know if someone is dying. You might wonder how you can manage the person's pain or discomfort. You could feel uncertain about what you need to do just after the person dies. There is likely to be a lot on your mind.

Participants found the text describing the page (top of the page) to be "project speak" and "fluffy" in nature. Comments suggest that this text needs to be harder and alerts carers to the practical information that can be found within each page – that is, carers need to know what is on the page for them to use.

→ Recommend updating text to be less non-descript, that is, sharpen the language around the page's purpose and content and provide a 'harder' narrative about how this content/resources will help carers at [a specific] stage of caring. Participants suggested not sugar coating the realities of the process, particularly around the practical aspects of caring for a loved one who is dying.

8 **GOOD:** 'OUR SUGGESTIONS TO YOU' PROVIDED A MIX OF ACTIVITIES THAT CAN PROVIDE INFORMATION PRESENTED IN DIFFERENT MODES

All participants found the 'Our Suggestions to You' helpful and useful but indicated that other key resources could be included in this box, perhaps pulled from the 'Key Resources' section.
Although it is noted that descriptors for some of these resources were not detailed enough or specific to what the carer will find when opening the link.

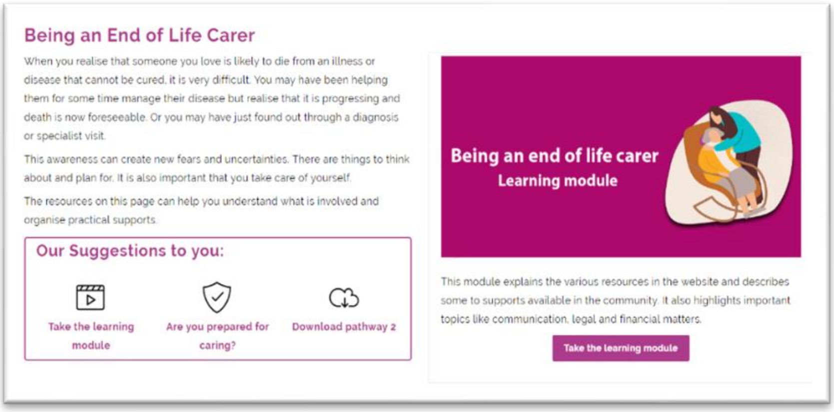


→ Suggest including some information about the legal process and access to documents in the 'Our suggestions to you' section on the 'Being Prepared' and 'Caring for the Dying' sections. Language activity descriptors would also need updating as the use of 'Take this' and 'Learn this' was not well received, along with non-precise wording linking activity hyperlinks and what is expected when activated.

3.3 LEARNING MODULES

9 HIGH: CONTENT DEEMED TO BE IMPORTANT TO CARERS THAT WILL ASSIST WITH CARING NEEDS SHOULD BE PRIORITISED ON PAGE POSITION TO BE IN IMMEDIATE EYE LINE FOR USERS TO VIEW ON OPENING THE PAGE

All participants commented that the learning modules were an interesting and useful mode of providing information in a different format contrasting to information in a written or visual format. Providing a note of caution was advised so that participants would only view these in a 'real-life scenario' if they had time and space to think and 'take in the information'. Realistically, for all these carers, this would be an under-utilised resource as this sample group suggest that they would not use these to access information for practical solutions or support for their caring needs. This contrasted with the 'Key Resources', which all participants found relevant, immediately recognised as a useful tool and something that would help them care at that stage in their journey.



Being an End of Life Carer

When you realise that someone you love is likely to die from an illness or disease that cannot be cured, it is very difficult. You may have been helping them for some time manage their disease but realise that it is progressing and death is now foreseeable. Or you may have just found out through a diagnosis or specialist visit.

This awareness can create new fears and uncertainties. There are things to think about and plan for. It is also important that you take care of yourself.

The resources on this page can help you understand what is involved and organise practical supports.

Our Suggestions to you:

Take the learning module

Are you prepared for caring?

Download pathway 2

Being an end of life carer
Learning module

This module explains the various resources in the website and describes some to supports available in the community. It also highlights important topics like communication, legal and financial matters.

Take the learning module

> *"I think being a carer is more emotional than this. I would do this if this was part of my job and part of the hard bit about caring is that you have already start to lose your relationship with your loved one, if you are a carer, that relationship starts to change. When you are being a carer and not a wife, or a daughter or whatever, I think that this [pointing to the learning module text] really highlights this.*
> *Not very personal, I am not taking a course. I am looking after someone.*
> *This is a personal journey that is already eroding a relationship ... Not breakdown, but the dynamics change and that is part of looking after someone that is dying. And to have things like modules and stuff like that makes even more depersonalising" [experience].*

→ See comments referring to the ‘Key Resources’ in the Content section above

10 **HIGH:** LANGUAGE AND LINK DESCRIPTORS PROVOKED FRUSTRATED AND IRRITATED REACTIONS FROM CARERS TO THE IMPERSONAL AND EDUCATIONAL APPROACH DEMONSTRATED BY THESE DESCRIPTIONS

Descriptive language around the learning modules evoked highly emotional feedback from over half of the participants. Carers reported that this language – such as “Learn …” or “Take the Learning module” depersonalises their lived experience, as they are not students in a professional learning situation where they will achieve a certificate on completion. This language highlights the painful realisation that their relationship with the person they are caring for has changed. The caring role requires the need for carers to be removed, operating in an almost job-like manner and being devoid of emotion to provide care to their loved ones.

> *“I am not a student; I am a carer” ………… “Why would I want to learn it when I am living it?”*
>
> *(Carer 6)*

→ Recommend changing the language used within the labels of the text relating to the learning modules on all of the pages. This was an aggravation for over half of the participants and would require a personal, contextual narrative that does not imply or highlight the carers' experience. Consider changing these to Information Modules or Information course to remove the unintentional student-teacher dialogue within the Toolkit.

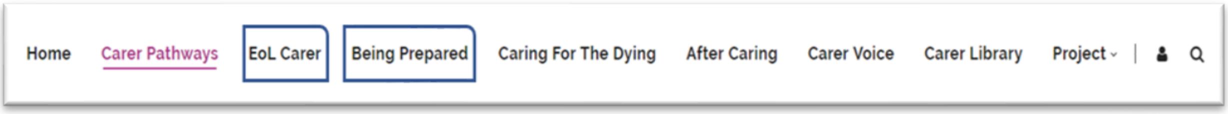
11 **GOOD:** INCLUSION OF LEARNING MODULES PROVIDE A DIFFERENT STYLE OF PRESENTING INFORMATION PROVIDING AN EXPERIENCE THAT WILL BENEFIT LEARNERS WHO ARE LOOKING FOR THE ‘WHOLE’ PICTURE

All participants recognised that some carers would use these modules but suggested their use will be concerning time, the type and specifics of the information required, the ability for carers to stop the module and return to where they were up to if they get called away.

3.4 OTHER FEEDBACK

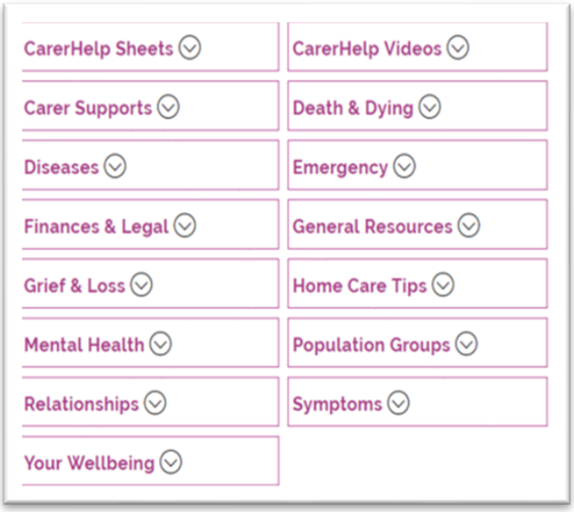
12 LOW: SECTION HEADERS MAY NEED TO BE REVIEWED AS THESE WERE FOUND TO BE NON-DESCRIPT

Examples: ’Being Prepared’ (for what) and Being an EoL Carer (what does EoL stand for?)



→ Could include a webpage or downloadable PDF that could provide some guidance on the language and features of the Toolkit to assist non-technological users whilst supporting carers who are not health-literate or familiar with medical jargon. This resource could also include hints on the menu and search functions or highlight key tools or resources that could be useful/relevant.

13 MEDIUM-HIGH: ADDITIONAL INFORMATION ON LEGAL ISSUES AND PALLIATIVE CARE IDENTIFIED AS SOME KEY INFORMATION NEEDED IN THE TOOLKIT THAT IS CURRENTLY MISSING



One of the tasks that were asked of the participants was to locate the directory of palliative care services from within the Toolkit, two carers were able to find this reference in the Carers Library, but all six commented that both the process of accessing and the importance of what palliative care services can offer was extremely important.

Participants were also asked to locate a reference to the ‘Making Healthcare Decisions for Someone Else’ reference in the Carers Library, in which none of the six was successful. This task led to a discussion on if, why and where information about the legalities of being prepared for dying. All six highly recommended some information be provided within the Toolkit as this issue was one of the more difficult to negotiate as the caring process advanced toward death and that there were serious implications for carers if not initiated early.

→ Palliative care information will be relevant and important additional information for the Toolkit, recommend including a PDF or section within the ‘Being Prepared’ providing further information on roles and assistance that palliative care services provide to carers (not from the view of the dying person). The Carer Library page would also benefit from the inclusion of a palliative section with a hyperlink to relevant resources

→ Legal information was also highlighted as an information deficiency within the Toolkit. This could sit within the 'Being Prepared' key resources or 'Our suggestions for you' and be included as a separate section within the Carer Library (already updated).

3.5 CARER PATHWAY (https://www.carerhelp.com.au/tabid/5635/Default.aspx)

14 GOOD: CARER PATHWAY WAS PROVIDED A COMMON SENSE AND STRAIGHTFORWARD PATHWAY THAT CARERS CAN IDENTIFY WHERE THEY ARE IN THE CARING TRAJECTORY

15 LOW-MEDIUM: DESCRIPTIONS WITHIN THE CARER PATHWAY CAUSED SOME CONFUSION AS THEY PROVIDED NO SENSE OF WHAT A CARER WILL FIND WITHIN EACH SECTION OF THE PATHWAY

> *"All of these pathways descriptions are not very explanatory of what information you are going to be able to see if you open that pathway up - There is nothing here that tells me if there is anything that could help me for practical decisions".*
>
> (Carer 6)

Carer Pathways

There are 2.6 million carers in Australia. Carers can provide physical, emotional, social or financial support. If someone has a life-limiting illness, they are likely to have specific care needs and this is the role of CarerHelp. The pathways below remind that carers are different and may be a different points in caring.

Pathway 1: Being a carer

Many people provide regular and ongoing care and help to a family member, friend or a neighbour. This may involve a few hours a week or all day every day, depending on the level of support needed. People often provide care when someone is older, seriously or has a disability. We have provide a set of resources that can be useful for all carers.

Pathway 2: Being an end of life carer

If you are caring for someone who is seriously ill or has an ongoing condition, you may come to realise that the person you are caring for will die from this illness or condition. This can be quite a difficult moment. We have a set of resources that can help you understand what is happening and how to take care of yourself and the person you are caring for.

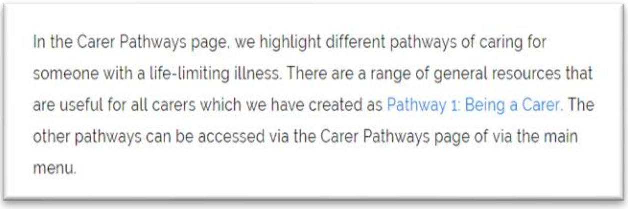
Pathway 3: Being prepared

When death becomes nearer, you may want to understand more about how to manage care that is more challenging and how to work with the health care team. You also need to make sure that you look after yourself and have sufficient support. We have created a set of resources specific to getting prepared to provide care at the end of life.

Suggest modifying text descriptors for each of the pathways within this page to describe better the information found within each pathway and include a brief outline of the practical tools/resources found within the pages.
This will enhance users decision-making process to choose the correct pathway whilst providing specific guidance to others on resources or tools available.

16 MEDIUM: HOW DOES THE CARER PATHWAY PAGE FIT WITHIN THE NAVIGATION STRUCTURE/INFORMATION FLOW OF THE TOOLKIT AS THERE WAS SOME CONFUSION OF ITS ROLE IN THE WEBSITE

All participants found this page to be useful, but it was observed that there was a disconnection in where and how the users integrate this pathway into their interactive experience. There was some uncertainty about what they were supposed to do once they landed on this page from HP.



In the Carer Pathways page, we highlight different pathways of caring for someone with a life-limiting illness. There are a range of general resources that are useful for all carers which we have created as Pathway 1: Being a Carer. The other pathways can be accessed via the Carer Pathways page of via the main menu.

→ Recommend adding some narrative on the Home Page that describes how to use the Carer Pathway, especially if this will be used as a ‘gateway’ page influencing the flow of information and user paths through the Toolkit.
This could also be added to the ‘Getting Started’ webpage/PDF if implemented [there is some information in the Carer Library that accurately describes its function]

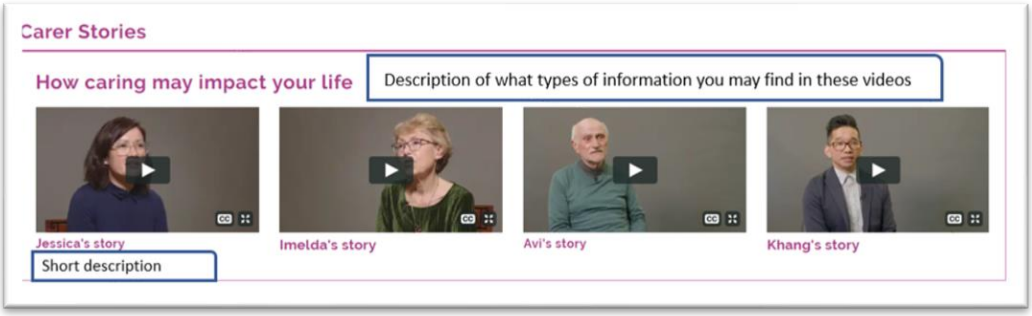
3.6 CARER VOICE (https://www.carerhelp.com.au/tabid/5749/Default.aspx)

17 GOOD: This format for exploring carers experience was acknowledged as a good option for carers to get the whole picture, especially on what to expect.

Many carers explained that whilst this was a good option for some carers, particularly for those starting on the carers journey, this would be a resource that they may find very useful and inciteful to support expectations. Two-thirds of the carers undertaking evaluations said in no uncertain terms that they would not view these as they do not want to hear about other people experiences as they have both enough to deal with, and watching these would provide little comfort to their caring experience.

18 HIGH: DESCRIPTORS PROVIDED NO INFORMATION ON WHAT IS COVERED IN EACH VIDEO

Participants commented that they would like to know what information could be found in the videos; this was important, mainly when time is an issue. A short description of the topics covered in each video will enhance the user's decision-making processes as to which video to see and reduce the chance of wasting time on topics that are not needed.



→ Text descriptors will be crucial to guide users on which video will suit users' needs and provide a sense of reassurance that carers could systematically view these to build on their knowledge or support the expectations depending on where in the caring trajectory they are.

19 LOW-MEDIUM: NEED TO INCLUDE INFORMATION ABOUT COMPLEX ILLNESS AND CARING JOURNEYS FOR CARERS AS THESE ARE UNPREDICTABLE AND DON'T ALWAYS FOLLOW THE CARING PATHWAY

Two of the participants had experienced caring for loved ones with complex illnesses toward the end of their lives and found a lack of information for carers in this not uncommon situation. There were suggestions of additional resources that would provide some support and comfort to carers in this situation as there is a lack of information on the broader palliative care sector, particularly around uncertainty and the impacts on carers.

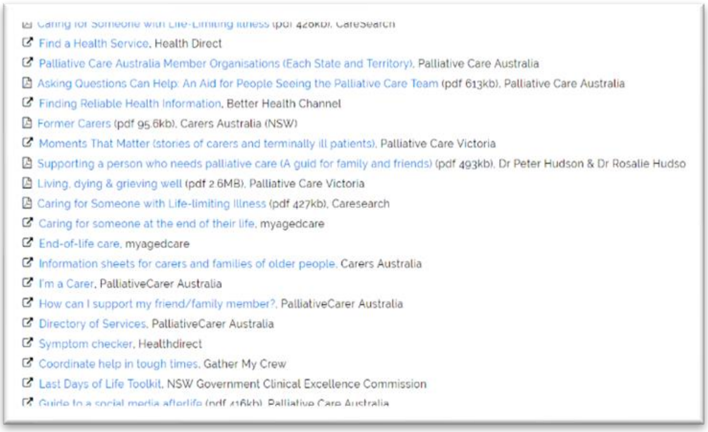
> *"The thing I find really difficult is that my husband is not the normal case .... So I don't know whether to prepare myself and I need a large hospital bed in my lounge room or whether that is the course we will take ... I don't know which path. For me it is not a normal pathway that he has got ... This is interesting information, but I just don't know what is in front of me and is what I find most difficult is that I can't plan".*

→ An option to include information for those carers who do not necessarily fall into the pathway categories would be of great assistance, especially as there is limited information to be found for carers and provided by health professionals. Therefore, there is a high likelihood that these carers will actively be seeking specific information on what to expect and what to do.

3.7 CARER LIBRARY (https://www.carerhelp.com.au/tabid/5615/Default.aspx)

20 HIGH: ALTHOUGH THERE WERE SECTION HEADERS FOR GUIDANCE, THERE WAS DIFFICULTY IN FINDING INFORMATION IN EACH OF THE SECTIONS OF THE LIBRARY

All participants found their experience within the Carers Library as being "muddled", "overwhelming", and "confusing", with all carers making use of the section headers to navigate down the page to the identified group of resources. They were still unable to find the required information, spending immense time browsing randomly to find the hyperlink in either the correct section or the incorrect section.
This led to frustration and cessation of the tasks due to user fatigue.

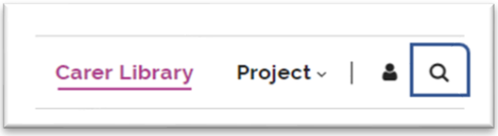


Caring for Someone with Life-Limiting Illness (pdf 426kb), CareSearch
Find a Health Service, Health Direct
Palliative Care Australia Member Organisations (Each State and Territory), Palliative Care Australia
Asking Questions Can Help: An Aid for People Seeing the Palliative Care Team (pdf 613kb), Palliative Care Australia
Finding Reliable Health Information, Better Health Channel
Former Carers (pdf 95.6kb), Carers Australia (NSW)
Moments That Matter (stories of carers and terminally ill patients), Palliative Care Victoria
Supporting a person who needs palliative care (A guid for family and friends) (pdf 493kb), Dr Peter Hudson & Dr Rosalie Hudso
Living, dying & grieving well (pdf 2.6MB), Palliative Care Victoria
Caring for Someone with Life-limiting Illness (pdf 427kb), Caresearch
Caring for someone at the end of their life, myagedcare
End-of-life care, myagedcare
Information sheets for carers and families of older people, Carers Australia
I'm a Carer, PalliativeCarer Australia
How can I support my friend/family member?, PalliativeCarer Australia
Directory of Services, PalliativeCarer Australia
Symptom checker, Healthdirect
Coordinate help in tough times, Gather My Crew
Last Days of Life Toolkit, NSW Government Clinical Excellence Commission
Guide to a social media afterlife (pdf 416kb), Palliative Care Australia

→ This section could be considered a repository of information for all aspects of caring at the end of life, but the current organisation structure has been observed to be confusing and the sheer amount of resources overwhelming. Recommend re-ordering resources both between sections and within sections to enhance the user experience in finding information.
Suggest alphabetising the sections or resources within the sections or alternative order them in another manner but provide some structure.

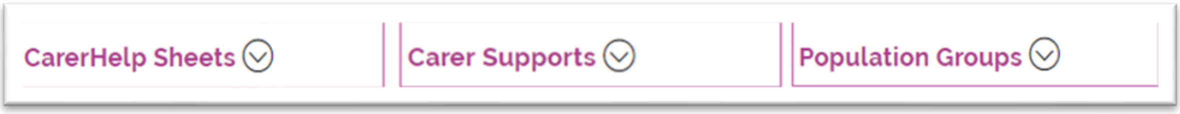
21 MEDIUM: SEARCH FUNCTION WOULD BE HELPFUL TO FIND INFORMATION IN THE CARER LIBRARY IN A MORE DIRECT AND EFFECTIVE MANNER

There were several attempts at locating a search function within the Library page to assist searching as the section headers were often vague or non-specific (included terms such as 'Populations', 'CarerHelp ' and particularly 'Carer Support', which provided references to resources that were not matched to the header). Participants also suggested that additional sections, including Palliative Care, Legal and Financial, Assistance with Processes. Observation of search behaviour also found that no participants attempted or used the search function in the horizontal menu bar once in the Carer Library.



→ Recommend re-organisation of the sections and sub-headings within sections should assist users to locate the resources more easily. Could feature the search function in the horizontal menu (internal pages) within the Getting Started page (if developed).

→ Section text labels should be reviewed, and user-centric language applied to headers as carers will not understand medical jargon or terms commonly directed at health care professionals.



22 LOW-MEDIUM: RESOURCES TO SUPPORT CARERS OF PEOPLE LIVING WITH COMPLEX ILLNESSES TO HELP WITH UNCERTAINTY OF CARING TRAJECTORY

Two of the participants had experienced caring for loved ones with complex illnesses toward the end of their lives and found a lack of information for carers in this not uncommon situation. There were suggestions of additional resources that would provide some support and comfort to carers in this situation as there is a lack of information on the broader palliative care sector, particularly around uncertainty and the impacts on carers.

Participants suggested additional resources that could assist carers looking after complex and challenging conditions that do not follow the identified pathway, particularly as this is a real issue and very distressful as they do not have enough information and reassurance from healthcare professionals of what is going to happen and when. Carers experienced distressing incidents relating to the repeated ambulance and hospital admissions and perhaps a medical or condition template that carers could complete, which could be handed to the attending HCP, reducing the repeated "story-telling", which is distressing and upsetting for the carer.

→ A resource would assist these under-serviced groups of carers that could be added to the 'Carer Library' or 'Being Prepared' section of the Toolkit

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3.8 LANGUAGE AND VISUAL REPRESENTATION

23 HIGH: INFORMATION DISPLAYED IN THE TOOLKIT WAS HARD TO READ AND LIGHT IN CONTRAST TO THE BACKGROUND

Four of the six participants found the text and hyperlinks difficult to read due to the font size, and the hyperlinks were too light in contrast to the background. This observation could be attributed to the demographics of the usability group with age and visual decline prevalent in this group of carers and could be extrapolated to the larger carer population. None of the four augmented the screen for improved readability.

→ Recommend increasing the text size to a minimum of 12-13pt and changing the font colour of the hyperlinks to a darker blue.

24 HIGH: BALANCE IN LANGUAGE AND TONE WILL BE IMPORTANT FOR THIS GROUP OF USERS, PARTICULARLY AS THERE WILL BE VARIATION IN SELF-IDENTIFICATION OF WHERE CARERS ARE IN THE CARING TRAJECTORY, LEVELS OF PREPAREDNESS-ACCEPTANCE-LIVED EXPERIENCE AND TYPES OF INFORMATION REQUIRED BASED ON THE LEVEL OF SUPPORT BEING RECEIVED IN THE COMMUNITY

Through think-aloud methods, observations of carers interacting with the Toolkit has provided a useful insight into the delicate balance between “being gentle” or “fluffy” and being “hard” or “practical” or “telling it like it is” depending on individual carers. Overwhelmingly, carers suggested that there was no point in being gentle or overly delicate because of the lived experience and all the hard stuff that goes with caring, the death and the grieving after death. With this view, there may need to be a consideration to the likely real-life situations that some of the carers will be experiencing that may prompt or are happening to give context to their information seeking and tailor the language to meet their needs.

→ Choice of tone and language should be applied consistently across the Toolkit and into the resources developed by the Project Team.

4. APPENDIX: TECHNICAL REPORT

4.1 USABILITY SESSION SUMMARY

A combination of observation and Think Aloud protocol was undertaken to gather both visual and verbal feedback on the interaction of the participants with the Toolkit as they completed the eight tasks.

Participants were given 5 minutes to complete the task. The activity was stopped when the target information was located, the participant gave up, or 5 minutes had passed.

Participants were also asked to provide feedback on other features, information or problems they may have encountered during the session

All issues, problems and feedback were analysed for levels of severity as guided by Nielsen’s Severity rating tool (level of severity [number of participants experiencing the problem, level of frustration recovery, frequency of the issues and the influence of the problem on critical tasks]and the time and resources required to modify the problem in the interface).

4.2 TASK SCENARIOS, TASK CHARACTERISTICS, TASK SUMMARY & PARTICIPANT LIST

4.2.1 TASK SCENARIOS

Tasks were developed from the six key objectives identified by the developers of the Carers Toolkit:

1. **An understanding of what to expect when someone is dying**
2. **Access to high-quality information and resources that support them in the carer role**
3. **Better communication with the health care team, family and friends**
4. **A greater sense of control over their role**
5. **Greater wellbeing**
6. **Knowledge of the services available to carers**

A task explored each objective with a specified goal being an action or targeted information within the Carers Toolkit.

Test participants were given eight tasks in this study, one at a time:

1. You need some information on how to manage restlessness and confusion in the person you are caring for
2. Locate an indicator that helps *you* to know that this toolkit resource is trustworthy and provides quality information
3. 3A) You need to build a list of the ever-growing issues and problems that you need to discuss with the GP, palliative care team and specialists to take with you when you visit them or to have it handy when they are visiting your home
4. 4A) You have some self-doubt about whether you can care for your loved one, find some information that will help you to make this decision and to aid with discussions
5. You have always been an organised person and finding your way after caring feels messy and full of insecurities.
   Find some information that could help you build a map to assist you in planning for the future.
6. Find information on how to locate palliative care services in your local area
7. 4B) Find some information that will help you to make decisions for the person you are caring for legally
8. 3B) Your fridge and cupboard are covered in paper with various names and numbers to call in case of emergencies or if something unexpected happens.
   Find something to organise this information.

4.2.2 PARTICIPANTS IN THE STUDY

Six people participated in the study. All participants have experienced caring for loved ones with a life-limiting condition who were living at home.

Carer	Gender	Age	**Frequency of Web Usage(1)**	**Internet Use(2)**	**Self-Assessment of Technical Ability(3)**	**Device option(4)**	**Health Literacy Level (NVS)ˇ**	**Overall Satisfaction with Prototype (CSUQ)#** **OS:** Overall Satisfaction **USE:** Usefulness **INFOQUAL:** Information Quality **INTERQUAL:** Interface Quality
1	F	36	Daily	• View News or Current Affairs • View Entertainment / Streaming programs (Netflix etc.) or YouTube • Social Media or Networking • To pay bills or complete banking transactions • Looking for information from websites or Apps	An Expert who is confident in finding and using online information	• Laptop Computer • Mobile Phone	6	**OS: 3.43** **USE:** 3.33 **INFOQUAL:** 3.75 **INTERQUAL:** 3.25
2	F	73	Daily	• To pay bills or complete banking transactions • Looking for information from websites or Apps	Having Intermediate skills who is mostly confident	• Laptop Computer • Mobile Phone	6	**OS: 5.86** **USE:** 6.20 **INFOQUAL:** 5.00 **INTERQUAL:** 6.50
3	F	71	Daily	• View News or Current Affairs • View Entertainment / Streaming programs (Netflix etc) or YouTube • Social Media or Networking • To pay bills or complete banking transactions • Looking for information from websites or Apps	Having Intermediate skills who is mostly confident	Mobile Phone	6	**OS: 4.73** **USE:** 4.83 **INFOQUAL:** 4.60 **INTERQUAL:** 4.75
4	F	66	Weekly	• View News or Current Affairs • Social Media or Networking • To pay bills or complete banking transactions	Avoider of everything online	Desktop Computer	5	**OS: 2.93** **USE:** 3.00 **INFOQUAL:** 3.60 **INTERQUAL:** 2.00

				• Looking for information from websites or Apps				
5	F	67	Daily	• View Entertainment / Streaming programs (Netflix etc) or YouTube • Social Media or Networking • To pay bills or complete banking transactions • Looking for information from websites or Apps	Having Intermediate skills who is mostly confident	Mobile Phone	6	**OS:** 3.87 **USE:** 4.00 **INFOQUAL:** 4.20 **INTERQUAL:** 3.25
6	F	63	Daily	• View News or Current Affairs • View Entertainment / Streaming programs (Netflix etc) or YouTube • Social Media or Networking • To pay bills or complete banking transactions • Looking for information from websites or Apps	Having Intermediate skills who is mostly confident	• Laptop Computer • Tablet (for example: iPad) • Mobile Phone	6	**OS:** 2.87 **USE:** 3.00 **INFOQUAL:** 2.80 **INTERQUAL:** 2.75

Frequency of Web Usage(1): a) Daily, b) Once or Twice a Week, c) Weekly, d)Once or Twice a Month, e) Rarely or hardly ever

Internet Use(2): a) View News or Current Affairs, b) View Entertainment / Streaming programs (Netflix etc) or You Tube, c) Social Media or Networking (Facebook etc), d) Pay bills or complete banking transactions, e) Looking for information from websites or Apps

Self-Assessment of Technical Ability(3): a) Avoider of everything online – you would prefer to find a 'real' person to help, b) Novice or Learner or Beginner, c) Having Intermediate skills who is most confident, d) Expert who is confident in finding and using online information

Device option(4): a) Smart TV, b) Desktop Computer, c) Laptop Computer, d) Tablet (for example: iPAD), e) Mobile Phone

NVS (Newest Vital Sign)ˇ: interpreted as scores of [0-1] high likelihood of limited health literacy, [2-3] possibility of limited literacy and [4-6] almost always indicates adequate literacy

Overall Satisfaction of Use (CSUQ)#: Average scores from 15 item scale (measured 7-point Likert scale 1 = Strongly Agree to 7 = Strongly Disagree)

4.2.3 TASK CHARACTERISTICS

Participants were given 2 minutes to browse the Carer Toolkit prior to the tasks being undertaken.

Objective - Task Number	**Completion Rate*** % Success (Success:Failure)	**How Easy was it to complete the task** Self- Assessed (average score *n*=6) Very Difficult (1) – Very Easy (7)	**How confident are you that you completed the activity fully?** Self- Assessed (average score *n*=6) Low (1) – High (7)	**What was your level of satisfaction after completing this task?** Self- Assessed (average score *n*=6) Low (1) – High (7)
1 –1	67.7% (4:2)	4.33	5.00	4.83
2 –2	100.0% (6:0)	6.00	6.17	6.50
3A –3	50.0% (3:3)	4.00	3.33	3.50
4A –4	67.7% (4:2)	5.83	5.83	6.0
5 –5	33.3% (2:4)	4.67	5.33	5.33
6 –6	33.3% (2:4)	3.00	4.67	4.67
4B –7	0% (0:6)	4.00	6.00	5.67
3B –8	100.0% (6:0)	6.33	6.67	6.67

*Participants were given a maximum of 5 minutes to complete the task. The task was considered a success if the user could locate the information within the period. Task failure was if the user was unable to find the information in the allotted time, if the task was stopped due to the user giving up or if the user nominated that they would have stopped looking and left the Toolkit to search for this information via a different mechanism (such as performing a ‘Google Search’).

4.2.4 TASK SUMMARY

Objective - Task Number	**Target / Specified Action or Information**	**Comments**	**Completion Rate*** % Success (Success:Failure)
1 –1	Locate information about symptoms and management of these toward the end of life (information located in the 'Symptoms' section of the Carer Library (https://www.carerhelp.com.au/tabid/5615/Default.aspx#PS) or Confusion and Terminal Restlessness PDF found on the 'Caring for the Dying' webpage (https://www.carerhelp.com.au/tabid/5614/Default.aspx)	• All but two carers could locate some information on managing the symptoms of confusion (delirium) and restlessness in the dying person. • 1 of the 5 carers found the information in the 'Caring for the Dying' section of the website; others found this information in the Carer Library under 'Symptoms.' • 1 carer found some information in Managing Symptoms LM, 1 searched the CL but then would have moved to do a 'Google Search' as could not find any reference to confusion or restlessness. • No participants referred to the Symptom Management videos in the Caring for the Dying section. • Users searching within the CL for this information were frustrated, commenting that too much information was muddled within sections, and the page was overwhelming.	67.7% (4:2)
2 –2	Find indicators of trust and quality, could include institution logos, privacy or funding statements, 'About the Project' webpage (https://www.carerhelp.com.au/tabid/5675/Default.aspx)	• All six participants could locate an indicator of quality and trust • 1 participant located the institutional logos on the Home Page • 4 users located the 'About the Project' page and noted the funding and organisations involved • 2 carers referred to the Privacy Statement, and one checked the e-mail address for consistency	100.0% (6:0)
3A –3	Locate and download the 'Things to discuss with your healthcare team' document on the 'Being Prepared' webpage (https://www.carerhelp.com.au/tabid/5613/Default.aspx)	• Only 3 of the 6 carers could locate this item in the TK • 1 carer was able to navigate directly to this PDF using the horizontal menu; the other two used the Carer Pathway page but only after trying to find the document in the CL or CV page • Indicates issues with the HP, search functions and general menu structures due to the navigation problems of the users	50.0% (3:3)
4A –4	Find and download the My Plan for Moving Forward PDF found within the 'After Caring' webpage (https://www.carerhelp.com.au/tabid/5577/Default.aspx)	• 4 carers were able to find this PDF on the 'After Caring' webpage • 1 carer used the 'Hamburger Menu' on the HP, the other 3 used either the 'Carer Pathway' or 'Carer Library' buttons on the HP to enter the site as	67.7% (4:2)

		there were no other viable options – they then used the horizontal menu within site to navigate to the page • 1 carer found the after caring video on the Carer Voice page and thought that there might be some information within this resource that may help bereaved carers	
5 –5	Complete the Carer Preparedness Scale found on 'Being an End of Life Carer' webpage at https://www.carerhelp.com.au/tabid/5742/Default.aspx	• 2 of the 6 carers were able to find this tool within the 'Being an EoL Carer' page • 2 carers gave up looking for this tool after not being able to find it in the sections that they thought it may have been • 2 carers located the 'Tips for Carers' PDF in the key resources section but bypassed the link to the tool on the same page • All six carers had the opportunity to use the tool. All thought this was a useful tool for some carers and should be prominent in the Being an EoL Carer and Being Prepared pages as the caring journey does change with increasing complexities, a good tool to re-assess your capabilities. • All thought the premise of the tool and its output was a great idea and liked that you could print or e-mail the results.	33.3% (2:4)
6 –6	Find the Palliative Care Australia Services Directory Link in the CL under General Resources and 'Tools and Resources' sections https://www.carerhelp.com.au/tabid/5615/Default.aspx#GR	• 2 of the participants were able to locate the link in the CL • All participants were perplexed as to why there was no mention of palliative care or accessing palliative care in the TK • All commented on the importance of palliative care in the role of supportive care, particularly for those with limited knowledge of services available, when and how to engage with this support • All participants would like to see references to palliative care services and their role in support of the carer (from this aspect, not so much for the person dying), especially concerning networking with organisations or service providers	33.3% (2:4)
4B – 7	Locate some information on the legal requirements of making decisions for someone else (found at 'Making Healthcare Decisions for Someone Else' on https://www.carerhelp.com.au/tabid/5615/Default.aspx#GR	• None of the participants located this information during the test, although all 6 carers directed their search to the 'Sorting out financial matters' section in the 'Being Prepared' (https://www.carerhelp.com.au/tabid/5613/Default.aspx) webpage • All 6 carers emphasized the importance of this information and stressed that legal information should not be hidden in the CL but should sit alongside the financial matters in the key resources section.	0% (0:6)

3B – 8	Find the 'Emergency Checklist' found on the 'Being Prepared' webpage or in CL (https://www.carerhelp.com.au/tabid/5613/Default.aspx) or the 'Who to Call List' on the 'Caring for the Dying' webpage (https://www.carerhelp.com.au/tabid/5614/Default.aspx)	• All 6 carers were able to find the 'Emergency Checklist' PDF and were able to open this document • None of the carers located the 'Who to Call List' in the Caring for the Dying section. • 4 carers found this document in the 'Being Prepared' page using the horizontal menu on the inside pages after using the buttons on the HP • 2 carers found this document in the CL in the 'CarerHelp' resource section, using the 'Carer Library ' button on the HP • All participants thought this was a useful and relevant resource that all carers could use and liked that you could print this out to use	100.0% (6:0)

HP = Home Page, CL = Carer Library, LM = Learning Module, CV = Carer Voice, TK = Carers Toolkit

Appendix 6.9 Usability errors reported to development team within usability report and level of resolution within interface post-release

Nielsen's Severity Rating	Error type identified in usability report	Error present - Not resolved	Error present [instances/minor modifications] - Semi-resolved	Error absent - Fully resolved
High	Accessibility	0	0	1
	Information flow	0	1[#]	3
	Language	0	1[*]	2
	Navigation	0	1[~]	2
	Total (%Total)	0	3 (15.79)	8 (42.11)
High-medium	Specific content	0	0	1
	Total (%Total)	0	0	1 (5.26)
Medium	Accessibility	0	0	1
	Information architecture	0	1[ˇ]	0
	Navigation	0	0	2
	Total (%Total)	0	1 (5.26)	3
Low-medium	Specific content	1[^]	0	1
	Total (%Total)	1 (5.26)	0	1 (5.26)
Low	Menu	0	0	1
	Total (%Total)	0	0	1 (5.26)
	Total (%Total)	1 (5.26)	4 (21.04)	14 (73.68)

[^]Carer Library - Specific content for complex illnesses not added to the Toolkit
[#]Content Pages - LM still visible, 'Key Resources' (deemed to be of more importance) were moved up the page to be more prominent position, [*]Content Pages - Language across improved content to be more concise and more direct to the user's context of care, [~]Home Page - Horizontal menu allows users to open drop-down menus to see the pages within the TK. No other visual cues can be seen on the Home Page. [ˇ]Carer Pathway - Improved descriptions on Home Page and within the Carer Pathway page provides better clarity on where the pathway fits within the user experience. Not enough detail in the Home page descriptor and too much information on the Carer Pathway page.

Appendix 6.10 Content-based Evaluation - Calculated SMOG and SAM measures for readability and understandability of Carer Toolkit page content

Page Path / Name (URL)	**SMOG Grade**	**Content** Mean (*SD*)	**Literacy demand** Mean (*SD*)	**Graphics** Mean (*SD*)	**Layout and typography** Mean (*SD*)	**Learning and simulation** Mean (*SD*)	**Cultural appropriateness** Mean (*SD*)	**SAM score (%)**
Home Page	4.24	1.0 (1.0)	1.40 (0.89)	2.0 (0)	2.0 (0)	1.0 (0)	2.0 (0)	78.13
Carer Pathway	6.19	1.33 (0.58)	1.80 (0.44)	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	90.63
Being and EoL Carer	7.62	2.0 (0)	1.80 (0.45)	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	97.06
Being Prepared	2.83	1.67 (0.58)	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	97.06
Caring for the Dying	3.87	2.0 (0)	1.80 (0.44)	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	97.22
After Caring	3.87	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	100
Carer Voice	6.56	2.0 (0)	1.60 (0.55)	2.0 (0)	2.0 (0)	2.0 (0)	2.0 (0)	94.44
Carer Library	4.94	2.0 (0)	1.25 (0.96)	1.6 (0.9)	1.33 (1.15)	2.0 (0)	2.0 (0)	79.41
About the Project	8.27	1.33 (1.15)	1.50 (0.58)	N/A	1.67 (0.58)	N/A	2.0 (0)	79.17
About the Project / Project Team	5.05	**	**	**	**	**	**	**
About the Project / National Reference Group	*	**	**	**	**	**	**	**
About the Project / Evaluation	4.51	**	**	**	**	**	**	**
About the Project / Contact Us	3.00	**	**	**	**	**	**	**
Mean (*SD*)	**5.08 (1.74)**	1.70 (0.61)	1.70 (0.56)	1.93 (0.44)	1.86 (0.48)	1.92 (0.28)	2.0 (0)	**90.35 (9.0)**

[1]Content Components [Purpose, Content Topics, Scope, Summary/Review Statement], [2]Literacy Demand Components [Reading Grade Level, Writing Style, Vocabulary, Context, Advance Organisers], [3]Graphics Components [Cover Graphics, Type of Illustrations, Relevance of Illustrations, Lists or Tables or Graphs or Charts, Captions], [4]Layout and Typography Components [Layout, Typography, Sub-Headings], [L]Learning and Stimulation Components [Interaction, Modelling of Behaviours, Motivation], [6]Cultural Appropriateness Components [Cultural Match and Cultural Images and Examples]

Appendix 6.11 Scoring components of Suitability Assessment of Materials (SAM) assessment of Toolkit page content

	Content[#]			Literacy demand					Graphics					Layout and typography			Learning simulation and motivation			Cultural appropriateness			
Page Name	Purpose	Cont. topics	Scope	Read. grade level	Writing style	Vocab	Context	Advance org.	Cover Graphic	Type of Illus.	Relev. of Illus.	Lists, Tables etc.	Capt.	Layout	Typogr.	Sub-head.	Interact	Model behav.	Motiv.	Cult. match	Cult image and exam.	**Calc. : poss. total**	**% SAM**
Home Page	1	0	2	2	2	2	0	1	2	2	2	N/A	2	2	2	N/A	N/A	N/A	1	2	N/A	25:32	**78.13**
Carer Pathways	1	1	2	1	2	2	2	2	N/A	2	2	N/A	N/A	2	2	2	N/A	N/A	2	2	2	29:32	**90.63**
Being an EoL Carer	2	2	2	1	2	2	2	2	N/A	2	2	N/A	2	2	2	N/A	2	N/A	2	2	2	33:34	**97.06**
Being Prepared	1	2	2	2	2	2	2	2	N/A	2	2	N/A	2	2	2	N/A	2	N/A	2	2	2	33:34	**97.06**
Caring for the Dying	2	2	2	1	2	2	2	2	2	2	2	N/A	2	2	2	N/A	2	N/A	2	2	2	35:36	**97.22**
After Caring	2	2	2	2	2	2	2	2	N/A	2	2	N/A	2	2	2	N/A	2	N/A	2	2	2	34:34	**100**
Carers Voice	2	2	2	1	2	2	2	1	2	2	2	N/A	2	2	2	N/A	N/A	2	2	2	2	34:36	**94.44**
Carer Library	2	2	2	0	2	1	N/A	2	2	2	2	0	2	2	2	0	N/A	N/A	2	2	N/A	27:27	**79.41**
About the Project	2	0	2	1	2	1	2	N/A	N/A	N/A	N/A	N/A	N/A	1	2	2	N/A	N/A	N/A	2	2	19:24	**79.17**
Mean	1.67	1.44	2.00	1.22	2.00	1.78	1.75	1.75	2.00	2.00	2.00	0.00	2.00	1.89	2.00	1.33	2.00	2.00	1.88	2.00	2.00		**90.35**
SD	0.5	0.9	0.0	0.7	0.0	0.4	0.7	0.5	0.0	0.0	0.0	0.0	0.0	0.3	0.0	1.2	0.0	0.0	0.4	0.0	0.0		**9.0**

[#] Summary / Review was removed from the table as this variable was not present in the web page structure

Cont.=Content, Read.=reading, Vocab=Vocabulary, org.= organisation, Illus.=Illustrations, Capt.=Captions, Typogr.=Typography, Sub-head.=Sub-headings, behave.=behaviour, Motiv.=Motivation, Cult.=Cultural, exam=examination

Appendix 6.12 Calculated SAM measures for readability and understandability of OHT PDF resource content

PDF Name	**Content** Mean (*SD*)	**Literacy demand** Mean (*SD*)	**Graphics** Mean (*SD*)	**Layout and typography** Mean (*SD*)	**Learning and simulation** Mean (*SD*)	**Cultural appropriateness** Mean(*SD*)	**SAM Score (%)**
Financial Matters	1.25 (0.96)	1.50 (1.0)	1.33 (1.15)	1.67 (0.58)	1.50 (0.71)	2.0 (0)	75.00
Caring for the Dying Person	1.75 (0.50)	1.75 (0.50)	1.0 (1.20)	2.0 (0)	2.0 (0)	2.0 (0)	84.21
When Grief Doesn't Go Away	1.25 (0.96)	1.50 (1.0)	1.33 (1.15)	1.67 (0.58)	1.0 (1.41)	2.0 (0)	72.22
Caring for your relationships and keeping children involved	1.50 (0.58)	1.50 (1.0)	1.33 (1.15)	1.67 (0.58)	2.0 (0)	2.0 (0)	80.56
Pathway 1: Being a Carer	2.0 (0)	1.75 (0.50)	1.50 (1.0)	2.0 (0)	2.0 (0)	2.0 (0)	92.11
Pathway 2: Being an EoL Carer	2.0 (0)	2.0 (0)	1.33 (1.15)	2.0 (0)	2 (0)	2.0 (0)	94.44
Pathway 3: Being Prepared	1.75 (0.50)	1.50 (0.60)	1.50 (1.0)	2.0 (0)	2 (0)	2.0 (0)	86.84
Pathway 4: Caring for the Dying Person	1.50 (1.0)	2.0 (0)	1.33 (1.15)	2.0 (0)	1.50 (0.71)	2.0 (0)	86.11
Pathway 5: After Caring	1.50 (1.0)	2.0 (0)	1.33 (1.15)	2.0 (0)	1.50 (0.71)	2.0 (0)	86.11
After the Death	1.25 (0.96)	1.75 (0.50)	1.0 (0)	1.67 (0.58)	1.50 (0.71)	2.0 (0)	75.00
Checklist for Moving Forward	1.5 (0.58)	1.75 (0.50)	1.33 (1.15)	2.0 (0)	2.0 (0)	2.0 (0)	86.11
Medication template and Handling of medications	1.25 (0.96)	2.0 (0)	0	1.33 (1.15)	1.50 (0.71)	2.0 (0)	70.59
Making Use of Services	1.50 (1.0)	2.0 (0)	1.0 (1.4)	2.0 (0)	2.0 (0)	2.0 (0)	88.24
Tips for Staying Well	1.25 (0.96)	2.0 (0)	1.67 (0.58)	2.0 (0)	2.0 (0)	2.0 (0)	88.89
Setting Up Health Care Team and Support Services	1.25 (0.96)	1.5 (0.6)	1.0 (1.4)	2.0 (0)	1.50 (0.71)	2.0 (0)	76.47
Injections and Syringe Drivers	1.25 (0.96)	1.75 (0.5)	1.0 (1.4)	2.0 (0)	2.0 (0)	2.0 (0)	82.35
What to Do in an Emergency	1.50 (1.0)	2.0 (0)	2.0 (0)	1.33 (0.58)	1.50 (0.71)	2.0 (0)	85.29
Mean (*SD*)	1.49 (0.76)	1.78 (0.51)	1.27 (0.93)	1.84 (0.42)	1.74 (0.51)	2.0 (0)	**82.97 (7.0)**

Appendix 6.13 Error frequencies identified by Healthcare Professionals and Learning Designers within the prototype

		HCP experience (Years)			**S-R TA**			**LD experience (Years)**				**S-R TA**	
		6-10	11-15	16-20	Int	Exp	Total	1-5	11-15	16-20	< 21	Expert	Total
		n=2	*n*=1	*n*=1	*n*=1	*n*=3	77	*n*=2	*n*=3	*n*=1	*n*=1	*n*=7	202
Errors Identified (%Total)		44 (57.1)	17 (22.1)	16 (20.8)	16 (20.8)	61 (79.2)		54 (26.7)	44 (14.7)	71 (35.2)	33 (16.3)	202 (100)	
Ave error/user		22	17	16	16	20.3	**Total (%)**	27	22	71	33	28.86	**Total (%)**
Type of Error	Accessibility	0	0	0	0	0	0	0	0	1	2	3	3 (1.5)
	Inform architect.	3	0	1	1	3	4 (5.2)	1	2	0	2	5	5 (2.5)
	Inform flow	6	1	2	2	7	9 (11.7)	15	9	7	6	37	37 (18.3)
	Interaction	0	0	1	1	0	1 (1.3)	2	2	5	0	9	9 (4.5)
	Navigation	8	3	1	1	11	12 (15.6)	7	8	12	2	29	29 (14.4)
	Pedagogy	2	0	0	0	2	2 (2.6)	0	0	1	0	1	1 (0.5)
	Recovery	0	0	0	0	0	0	0	0	2	4	6	6 (3.0)
	Site platform	1	2	0	0	3	3 (3.9)	8	6	10	1	25	25 (12.4)
	Specific content	22	11	10	10	33	43 (55.9)	18	16	28	15	77	77 (38.1)
	Utility	2	0	1	1	2	3 (3.9)	2	0	4	0	6	6 (3.0)
	Visual Repres.	0	0	0	0	0	0	1	1	1	1	4	4 (2.0)
Nielsen's Severity Rating	High (1)	0	0	0	0	0	0	2	5	5	2	14	14 (6.93)
	High - Med (1-2)	4	1	1	1	5	6 (7.8)	0	1	0	2	3	3 (1.49)
	Medium (2)	15	2	3	3	17	20 (26.0)	14	18	24	12	68	68 (33.7)
	Med - Low (2-3)	9	6	7	7	15	22 (28.6)	3	6	10	2	21	21 (10.4)
	Low (3)	16	8	5	5	24	29 (37.7)	35	14	32	15	96	96 (47.52)

S-R TA=Self-Assessment of Technical Ability a) Avoider of everything online – you would prefer to find a 'real' person to help, b) Novice or Learner or Beginner, INT= Having Intermediate skills who is mostly confident, d) EXP=Expert who is confident in finding and using online information

HCP=Healthcare Professional LD=Learning Designer Visual Repres.=Visual Representation Inform architect.=Information architecture

		HCP experience (Years)			**S-R TA**			**LD experience (Years)**				**S-R TA**	
		6-10	11-15	16-20	Int	Exp	Total	1-5	11-15	16-20	< 21	Expert	Total
		n=2	*n*=1	*n*=1	*n*=1	*n*=3	77	*n*=2	*n*=3	*n*=1	*n*=1	*n*=7	202
Errors Identified (%Total)		44 (57.1)	17 (22.1)	16 (20.8)	16 (20.8)	61 (79.2)		54 (26.7)	44 (14.7)	71 (35.2)	33 (16.3)	202 (100)	
Ave error/user		22	17	16	16	20.3	**Total (%)**	27	22	71	33	28.86	**Total (%)**
Area of toolkit	Site	4	0	1	1	4	5 (6.5)	2	2	6	3	13	13 (6.4)
	Menu	0	0	0	0	0	0	2	0	2	0	4	4 (2.0)
	Home	6	1	3	3	7	10 (13.0)	7	8	11	7	33	33 (16.3)
	Carer Pathway	6	5	2	2	11	13 (16.9)	12	7	8	5	32	32 (15.8)
	Being Prepared	3	3	0	0	6	6 (7.8)	2	1	4	3	10	10 (5.0)
	Being a Carer	0	0	0	0	0	0	1	0	0	0	1	1 (0.5)
	Being EoL Carer	3	0	2	2	3	5 (6.5)	5	4	7	2	18	18 (8.9)
	Caring for Dying	1	0	3	3	1	4 (5.2)	4	1	4	3	12	12 (5.9)
	Learning Module	8	3	2	2	11	13 (16.9)	7	10	17	2	36	36 (17.8)
	After Caring	4	3	0	0	7	7 (9.1)	3	1	2	1	7	7 (3.5)
	Carer Library	6	0	3	3	6	9 (11.7)	1	6	5	4	16	16 (7.9)
	Carer Voice	1	2	0	0	3	3 (3.9)	6	4	5	2	17	17 (8.4)
	About Project	2	0	0	0	2	2 (2.6)	2	0	0	1	3	3 (1.5)

S-R TA=Self-Assessment of Technical Ability a) Avoider of everything online – you would prefer to find a 'real' person to help, b) Novice or Learner or Beginner, INT= Having Intermediate skills who is mostly confident, d) EXP=Expert who is confident in finding and using online information
HCP=Healthcare Professional LD=Learning Designer

Appendix 6.14 Unique and coexisting (overall) errors identified by reviewer groups

	Errors identified by reviewer groups							
	HCP (*n*=4)		**LD (*n*=7)**		**USE (*n*=6)**		**Experts* (*n*=11)**	
Error Type	**#U**	**ˇO**	**#U**	**ˇO**	**#U**	**ˇO**	**#U**	**ˇO**
Accessibility	0	0	3	3	2	2	3	3
Information	4	4	3	5	0	0	5	9
Information flow	6	9	24	37	4	9	28	46
Interaction	1	1	6	9	0	0	7	10
Navigation	8	12	17	29	4	16	23	41
Pedagogy	2	2	1	1	0	0	2	3
Recovery	0	0	3	6	0	0	3	6
Site platform	3	3	17	25	2	6	19	28
Specific content	16	43	28	77	6	21	37	120
Utility	2	3	2	6	0	0	3	9
Visual representation	0	0	3	4	0	0	3	4
Total errors	42	77	107	202	18	54	133	279
% Total - Unique [*N*=167]	25.15		64.07		10.78		88.08^	
%Total - Overall errors [*N*=333]		23.12		60.66		16.22		83.78
Mean error by reviewer	10.50	19.25	15.29	28.86	3.00	9.00	12.09	25.36
Mean error across interface	3.82	7.00	9.73	18.36	1.64	4.91	12.09	25.36

HCP=Healthcare Professionals, LD = Learning Designers, USE=Users (Carers)
*Expert Reviewer Group are the collective of LD (*n*=7) and HCP (*n*=4) participants
#**U**=Unique errors are exclusive within the interface and refer to an exact problem that can be a source of amalgamation of similar errors within the toolkit.
ˇ**O**=Overall errors are all issues or problems identified within the interface and do not consider exclusivity of occurrence
* %Total calculated for Expert group *N*=151 unique errors within the interface for this group when combined

Appendix 6.15 Exclusive and mutually inclusive errors identified within the interface by the reviewer group

	Interface Errors identified by reviewer groups													
	HCPˇ (*n*=4)		LDˇ (*n*=7)		USEˇ (*n*=6)		HCP+LD* (*n*=11)		HCP+USE* (*n*=10)		LD+USE* (*n*=13)		HCP+LD+USE* (*n*=17)	
Area of interface	Uniq.	Over.	Uniq.	Over.	Uniq.	Over.	Uniq.	Over.	Uniq.	Over.	Uniq.	Over.	Uniq.	Over.
Accessibility	0	0	3	3	0	0	0	0	0	0	2	2	0	0
Information architecture	2	2	1	1	0	0	2	6	0	0	0	0	0	0
Information flow	4	5	20	25	3	3	2	14	0	0	2	8	0	0
Interaction	1	1	5	8	0	0	1	1	0	0	0	0	0	0
Navigation	4	6	13	20	1	3	3	8	1	7	2	13	0	0
Pedagogy	1	1	0	0	0	0	1	2	0	0	0	0	0	0
Recovery	0	0	3	6	0	0	0	0	0	0	0	0	0	0
Site platform	2	2	12	18	0	0	1	2	0	0	4	12	0	0
Specific content	8	10	20	33	4	5	7	65	1	14	0	0	1	14
Utility	1	1	1	4	0	0	2	4	0	0	0	0	0	0
Visual representation	0	0	3	4	0	0	0	0	0	0	0	0	0	0
Total errors	23	28	81	122	8	11	19	102	2	21	10	35	1	14
% Total - Unique [*N*=143]	16.08		56.64		5.59		13.29		1.40		6.99		0.70	
%Total - Overall errors [*N*=333]		8.41		36.64		3.30		30.63		6.31		10.51		4.20
Mean error/reviewer	5.75	7.00	11.57	17.43	1.33	1.83	1.73	9.27	0.20	2.10	0.77	2.69	0.06	0.82
Mean / interface	2.09	2.55	7.36	11.09	0.73	1.00	1.73	9.27	0.18	1.91	0.91	3.18	0.09	1.27

HCP=Healthcare Professionals LD = Learning Designers USE=Users (Carers) Uniq.=Unique errors Over.=Overall errors
ˇ Number of exclusive errors identified by reviewer groups which are unique to each group
* Number of mutually inclusive errors identified by more than one reviewer group, these errors are unique to each group of reviewers

Appendix 6.16 Content-specific errors identified by expert-based review group (SME-HCP and LD)

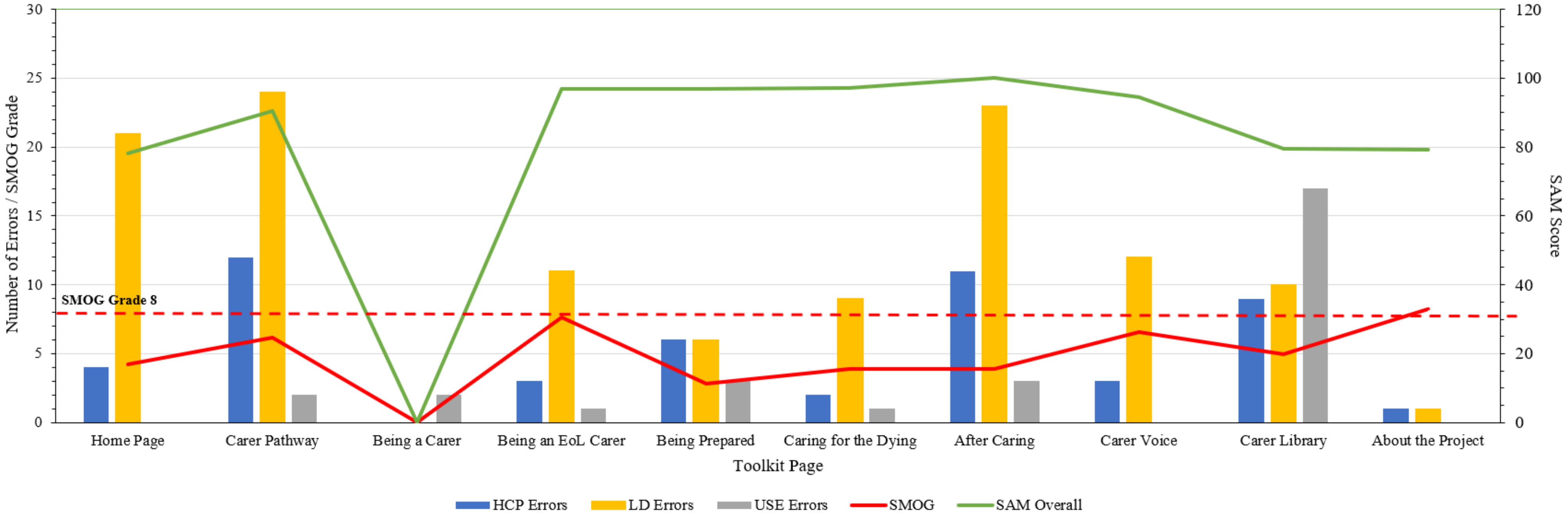
	Content errors identified		
Content error groups: Error definition / examples	**HCP** (*n*=4)	**LD** (*n*=7)	**Total**(%)*
1. Evaluation: Positive or negative comments, judgements or preferences "I don’t like the statement ‘caring for someone dying is a major task'" [ERPC4] "Way too much information and duplication … by this time I have given up as it feels like a maze" [ERLD5]	6	6	12 (10.0)
2. Grammatical: Spelling or grammatical corrections "People often provide care when someone is older, seriously or has a disability. Think the work ill is missing from seriously" [ERPC2] "Last sentence 'provide' should be 'provided' " [ERLD3]	3	8	11 (9.17)
3. Knowledge statement problem with specific content knowledge "Not sure that ‘caring for someone who is dying is the end of a journey of caring’. The dying part is the most intense and most profound and this statement has it over with before the experience has concluded. I would focus on the profound elements of caring for someone dying not the end of the caring role" [ERPC2] "Our other modules” on about slide four but they are not consistent. Why are some listed in a module but not in others? I may worry I am missing information I need to know?" [ERLD7]	3	1	4 (3.33)
4. Problem identification: Explicit reference to an issue or problem "I think language is okay, but there are just too many words" [ERPC4] "...appropriate to also insert a link here to take the users back to the first page, rather than telling them to go to and use the menu (where is that?) to get back to the main page." [ERLD4]	8	12	20 (16.367)
5. Resources and activities: Explicit reference to embedded resources or learning activities "Need to make sure that this toolkit provides information for carers on how to improve and sustain person’s quality of life when at home" [ERPC4] "CarerHelp Sheets and Videos may require some description because they are specific to the site ..not readily apparent what these maybe" [ERLD4]	9	13	22 (18.33)

*Error totals calculated and presented in the subsequent table SME-HCP=Subject matter experts – Healthcare Professionals LD=Learning designers

	Content errors identified		
Content Error Groups: Error Definition / Examples	**HCP** (*n*=4)	**LD** (*n*=7)	**Total** (%)
6. Revision statement: Explicit text statement with the intent to change current to an ideal state "Dying is poorly recognised generally. I think it should be assumed that people using it are seeking assistance for a dying loved one. Maybe a reference that dying can occur over a period of time and is characterised by consistent deterioration would be better upfront…If the person you are caring for is dying, then this resource will help you to prepare for the likely changes that will occur in the future." [ERPC2] "Caring for someone who is dying is the end of a journey of caring ... – could be something like: 'Caring for someone dying also means that your role of carer will come to an end after the person has died. These resources help you be prepared for dealing with the end of life care " [ERLD5]	1	21	22 (18.33)
7. Strategies: Explicit reference to underlying strategies or need to apply strategies to content "Not enough information on how this toolkit will help carers – carers will ask, "how is this going to help me?" [ERPC3] "… my conclusion is that the Carer Pathways is the entry point that links off to everything else. Maybe these needs explaining more as the starting point, and if you're returning to the site, you can use the other menus to navigate if you know where you want to go." [ERLD7]	4	9	13 (10.83)
8. Text knowledge: Comments or statements from reviewers on learnings from the text "There are too many words on this page – I don't think carers will like being told how to feel…" [ERPC4] "… " You might care for a short time or for a long time" could also mean care in the context of how long you personally 'care' about the situation rather than the length of time you may have to provide a level of care." [ERLD1]	9	7	16 (13.33)
Total (%Total)	43 (35.8)	77 (64.2)	120
Mean error / reviewer (*SD*)	10.8 (3.1)	11.0 (5.9)	

*Error totals calculated and presented in the subsequent table SME-HCP=Subject matter experts – Healthcare Professionals LD=Learning designers

Appendix 6.17 Relationship between evaluation measures of content (SMOG Grade and SAM Score) and usability errors identified by reviewer groups across pages of the Toolkit



Appendix 6.18 Recommendations for commissioners of online health resources

1. The requirement that all funding bodies include a line in project budgets for usability evaluation to be completed. Researchers/Organisations would include costings for usability within all proposals for funding, which could include 'in-house' evaluation or to an external contractor to be completed during the development period

2. Usability evaluation is a compulsory component of the development of all online health resources and, as such, should be included in proposed management timelines presented to the funding body.

3. Usability evaluation to be considered compulsory inclusion in project timelines to be formally reported against funding milestones both during development and post-release periods.

4. In parallel, accessibility should also be considered compulsory, and although it is already a legal requirement, developers should comply with minimum accessibility standards as determined by WCAG/WAI to WCAG AA level by the funding body.

5. Commissioning funders to support sunsetting provisions within funding agreements to recognise the importance of consumers having continuous access to familiar, trusted, high-quality online health resources.

6. Sunsetting provisions to be included with critical post-release evaluations directly assessing summative evaluations of consumer engagement, use and learnings. Developers should be encouraged to re-evaluate usability/access to ensure that the resource meets the intended audience's needs and the opportunity to identify new or changing user groups to reiterate the resource to better service further the new audience.

7. As part of funding agreements, developers should be encouraged to publish development and evaluation methodologies within peer-reviewed publications or in 'white' papers to be made publicly available. This recommendation would increase the evidence base to guide developers on practising usability evaluation within their development cycles.

8. Commissioning bodies should prompt developers to include information within their resources describing how consumers were involved in the development and evaluation processes contributing to the final version of the resource. These statements provide reassurance, validation, and authority that resources are developed with the end-user in mind and individuals involved in shaping the content and design.

9. The government funding body should develop an online resource that could provide specific guidance and information for developers of online health resources in an Australian context. This site could incorporate models for development, evaluation methodologies, resources on usability and accessibility (referencing those pre-existing resources that are already considered gold-standard internationally), information on gaining access to different stakeholders and organisations and ethical implications of working with consumers across the health sector. This resource could also be a repository for developers to upload reports or other documents associated with the funding agreements – these would be of great value

to assist other development teams in undertaking rigorous development and evaluation processes.

Appendix 6.19 Recommendations for Project Leads and Managers

1. Development and evaluation of online health resources is a lengthy process – plan for two rounds of evaluation pre-release in your timeline up to hard release pushing your development timeline out by six weeks throughout the process.
2. Include an expenditure line within budget for two rounds of usability evaluation during development – costs include recruitment and reimbursement of experts and users, recruitment of additional personnel, and purchase of technological expertise to modify the interface. Costs concerning post-release evaluation should also be included and adjusted for the type of methodology employed.
3. Guarantee a three-year sustainability plan within the budget which covers maintenance, evaluation, and hosting fees .
4. Prepare a sunsetting plan to ensure that the resource could 'live on' within another organisation post-funding if evaluation outcomes support continuation or cease hosting arrangements.
5. Embed KT strategies and evaluation into conceptual designs of OHT at the beginning of the process and be aware of peer-reviewed literature available to support your development/design.[340]
6. Be open to flexibility with your management style, be aware that traditional 'waterfall' methodologies may not complement but impede technological development processes. Be prepared to implement hybrid management strategies that complement software development approaches (such as water-scrum-fall).
7. Ensure that collaborating partners have the experience, knowledge and capabilities to deliver on intended components for the online resource before reaching a formal agreement. Be clear on expectations on partner involvement and production of tangible products that will contribute to the online resource.
8. Components of development will actively compromise timelines placing constraints on intended or programmed processes. Implement timelines and ensure collaborating partners are aware of difficulties for the product if deliverables are not completed by required milestones.
9. Ensure that your team composition has a diverse range of skills and abilities that extend into the digital environment. Engage or contract digital services to an external organisation if internal web design support is unavailable but be aware that software programmers, architects, designers have a different skill set to web designers and that recruitment of a graphic designer may be required to assist with the look and feel of the interface.
10. Engage with experts and identify a heuristic (double expert), if possible, to assist with evaluation. If a heuristic expert is unavailable, investigate collaboration with both content and educational design experts to assist in undertaking an expert review of the resource.

11. Be aware of impending difficulties in the process and be prepared for contingencies but remember not to shortcut usability evaluation or accessibility assessment as there are implications for your user's ability to use and access the resource.

12. Be aware that accessing specific user groups or individuals to participate in evaluations require ethical support from committees or boards within medical or health organisations, primarily if results from the process are disseminated internally or externally to the project.

13. Reporting development process, evaluation methodologies and outcomes within peer-reviewed or formal literature or disseminated externally.

14. Provide a description or examples of how users were involved in the development and evaluation process within your online resource – supports authority that resource was built for users with valuable contributions by user groups within different phases.

15. Ensure that you have knowledge of the minimum level of compliance for accessibility as required by commissioning bodies (AA minimum WAI/W3C standard). Remember, there are legal ramifications for non-compliance, and it is good practice to implement accessibility as this assists all users.

16. Do not expect your technology professional to be an expert in undertaking usability or to solve your usability or accessibility issues. There is a high likelihood of having little practical experience of undertaking or finding practical solutions to user-identified issues in the interface.

17. Engage with stakeholders early in the process; this includes organisations, peak bodies and health services interested in utilising the resource for their patients, consumers, or professionals.

18. Be aware that organisations, services, health professionals or user groups may not use your resource for the intended purpose. Be prepared for unexpected feedback that may force a re-think of the development goals, interface design, or creation of another to complement new resources for a different audience or objective.

Appendix 6.20 Recommendations for web development teams

1. Acknowledge that interface design specific to information-based health resources should function and appear differently than commercial sites.

2. Be aware of resources that support modification of the interface for accessibility and usability, including websites, peer-reviewed literature and government-supported repositories.

3. Ensure accessibility for your resource attains a W3C minimum AA standard by using freely available online tools and programs to assist in evaluating issues within interfaces.

4. Be prepared to utilise resources that could support developing interfaces. This includes physical resources or human expertise that may come from collaboration or partnering with other developers or designers.

5. 'Be flexible' with designs and be aware that even minor changes altering interface appearance or functionality could have implications on how users interact with the resource.

6. Be prepared to shelve 'the newest' or 'the prettiest' features, as these do not always translate to functional or relevant features for users, particularly for less technological savvy or older audiences. These widgets or applications do not always meet accessibility standards.

7. Remember that web developers are not the audience for the resource, do not make assumptions on the abilities of your users or the environment that they access the resource or device preference.

8. Design for and evaluate all device types; users have preferences for devices depending on information need and purpose of interacting.

9. Present different prototype designs to the development team to increase awareness of what is currently available and include other OHT resources to display both 'good' and 'bad' interface designs.

10. Be prepared to interact with users, which includes asking and listening to feedback, ensure that you access usability evaluation report (if available) to place context around suggested changes inferred from the development team.

APPENDIX 7. ADDITIONAL INFORMATION RELATING TO THE IDENTIFYING AND RECRUITING HARD-TO-REACH POPULATIONS CHAPTER

Appendix 7.1 Ethics approval for Study 4 and 5 from Flinders University SBREC– Project 8627

From: Human Research Ethics
To:
Subject: 8627 SBREC approval notice (11 June 2020)
Date: i
Attachments:

Dear Amanda,

Your conditional approval response for project 8627 was reviewed by the Chairperson of the Social and Behavioural Research Ethics Committee (SBREC) and was **approved.** The ethics approval notice can be found below. Please also note the important information regarding COVID-19 Virus below.

ResearchNow – Ethics and Biosafety

Please note that this project will need to be transferred to the new online system for human ethics (called 'ResearchNow – Ethics and Biosafety') **before any modifications** or annual progress reportscan be submitted. To transfer your project to the new online system, please refer to the instructions at the bottom of this approval notice.

-

COVID-19 Virus Considerations

The minimisation of risk and harm to human research participants is paramount, in line with the National Statement on Ethical Conduct in Human Research, where risk is defined as a potentialfor harm, discomfort or inconvenience, including physical harms including injury, illness or pain.
Flinders researchers must operate at this time with a heightened consideration of doing no harm.

Where possible, avoid face-to-face testing and consider rescheduling face-to-face testing or undertaking alternative distance/online data or interview collection means. Ethics approval for amodification to your protocol may need to be sought for these changes.

Avoid contact with vulnerable people, such as Aboriginal and Torres Strait Islander, elderly and immune-deficient people and people with disabilities or certain mental health problems. New permission to access these populations in the current climate must be sought from the appropriateinstitution.

For fieldwork and collaborations with Aboriginal and Torres Strait Islander Communities, please note that the Northern Land Council and the Northern Territory Government are halting any non-essential travel to these communities.
Note that the AIATSIS Guidelines for Ethical Research in Australian Indigenous Studies, requires ongoing consultation and negotiation with Aboriginal organisations and communities as to their wishes and responses to research.
Avoid entering hospitals, hospices, aged care facilities, medical centres etc.

People with mental health problems may be prone to infection (e.g., eating disorders), whileothers are prone to fears about infection (e.g., OCD, anxious cohorts). Maintain strict health and mental health strategies. Honours, Masters and HDR projects should be reassessed in the light of this advice.
Where participants do attend a data collection session:

Contact participants prior to data collection activity by phone or email to confirm they have no COVID-19 symptoms or are not in a required period of self-isolation.

Ensure all equipment is cleaned in line with the appropriate techniques to avoid the spreadof COVID-19 disease. Safe practices such as ensuring social separation and hand washing must be applied

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APPROVAL NOTICE

Project No.: **8627**

Project Title: Investigating impact of digital readiness on usability evaluation outcomes within an online palliative care information resource

Principal Researcher: Ms Amanda Adams

Email:

Approval Date: 11 June 2020 Ethics Approval Expiry **28 February 2021**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers

listed for all research to be conducted overseas.

- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

ANNUAL PROGRESS / FINAL REPORTS

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* an annual progress report must be submittedeach year on the **11 June** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval web page.

Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms ofethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please either submit (1) a finalreport; or (2) an extension of time request (using the modification request form).

First Report due date:	**11 June 2021**
Final Report due date:	**28 February 2021**

Student Projects

For student projects, the SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data

MODIFICATIONS TO PROJECT

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, researchers and supervisors)
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted toensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

If the contact details of researchers, listed in the approved application, change please notify the Committee so that the detailscan be updated in our system. A modification request is not required to change your contact details; but would be

ADVERSE EVENTS AND/OR COMPLAINTS

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

INSTRUCTIONS TO TRANSFER PROJECT TO ONLINE SYSTEM

ResearchNow Ethics & Biosafety is the new online platform for human research ethics at Flinders University. It can be accessed via Okta (add the “ResearchNow Ethics & Biosafety” chicklet to your dashboard) and allows researchers to apply for human research ethics approval, including modifications, online.

We note that your current project will expire after 31 December 2020. As you may be aware, all current projects approved under the old system that do not expire on/or before 31 December 2020 will need to be transferred into the new online system. Therefore, we would like to requestthat you complete the short HREC Transfer Project Form. To transfer your project, please

- login to ResearchNow Ethics & Biosafety through your Okta dashboard. ResearchNow Ethics & Biosafety will need to be added to your Okta dashboard via the "+ Add Apps" green button (top right) in the first instance.
- Ensure you are on the "Home page", you will see "Work Area" at the top of this page.Select the "Create Project" tile from the left hand "Actions" menu.
- A pop-up appears. Type in the "Project Title" and in the "Main Form" drop-down select"HREC Transfer Project Form".
- Click "Create" and save your project application form.
- Select "Project Information" under "Questions", complete the form and submit it.
-

During the transfer, you can also modify your existing project. Please feel free to contact us if youhave any questions about the transfer process.

-

Please note: *Both Executive Officers are currently working from home to assist with the management of COVID-19 and to ensure everyone’s safety and wellbeing Flinders University. During this time we will still able to be contacted by email and our business phone numbers provided below. We are also available on Cisco Jabber and Zoom for meetings. Thank you.*

Executive Officers, Social and Behavioural Research Ethics
Committee Research Development and Support |
human.researchethics@flinders.edu.au
Flinders University
Sturt Road, Bedford Park, South Australia, 5042GPO Box 2100,
Adelaide, South Australia, 5001

Flinders University
Research Development and Support
Proactively supporting our Research

- -

mornings)

Appendix 7.2 Permission to use DHLI in thesis research

From:
To:
Cc:
Subject: RE: PhD Researcher request to use the Digital Health Literacy Instrument in study
Date:
Attachments: image001.png

Dear Amanda

Thank you kindly for your e-mail and interest in the DHLI.

Please find attached a copy of the instrument in English, you are welcome to use it without anycharge.

Kind regards, also on behalf of Rosalie van derVaart

Constance Drossaert

Dr C.H.C.Drossaert | Vakgroep Gezondheid, Psychologie & Technologie | Universiteit Twente | Faculteit Behavioral, Management and Social Sciences | Postbus 217 | 7500 AE Enschede | kantoor: Cubicus, kamer C143 | email: | URL:

Centre for eHealth
& Wellbeing Research

From: Amanda Adams
Sent:
To: Drossaert, C.H.C. (BMS)
Subject: PhD Researcher request to use the Digital Health Literacy Instrument in study

Dear Associate Professor Drossaert,

I am a PhD candidate working in the College of Nursing and Health Sciences at Flinders University in South Australia in palliative care. I am undertaking research investigating how levels of digital health literacy influence end-user perceptions of usabilityand access when interacting with online health information resources. This study will explore how aspects of interface design can improve the user experience for those individuals within a population who face barriers to successfully using and accessing online health information. Barriers to use and access are more likely to be related to end-users characteristics that define how, when and where this interaction occurs; influential factorsinclude age, gender, socioeconomic status, geography, education, language, ethnicity and technological abilities.

While researching this project's background, I found your Digital Health Literacy Instrument in JMIR (https://www.jmir.org/2017/1/e27/) and I think this would be the idealtool to assess levels of digital health literacy within my intended survey population. I wouldlike to seek permission to use your instrument within my study and if agreeable, could you please provide an English version of the DHLI that I can incorporate into my research (or alternatively direct me to a copy that I can access), that would be most appreciated.
I will of course, attribute and reference the DHLI appropriately within my thesis, and withinany presentations or journal articles that will result from this study.

Please let me know if you would like further information, I would be very happy to discussfurther.

Thank you for your help, and I appreciate your time.I look forward to hearing from your soon.

Kind regards,
Amanda Adams

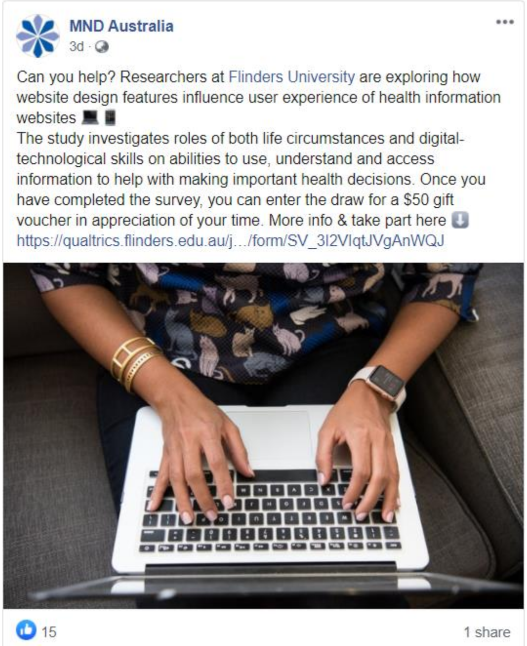
Amanda Adams
PhD Candidate
CareSearch Palliative Care Knowledge Network | Research Centre for Palliative Care, Death and Dying| Caring Futures Institute
COLLEGE OF NURSING AND HEALTH SCIENCES | FLINDERS UNIVERSITY
Rehabilitation and Palliative Care Building, FMC 4W330, GPO Box 2100, Adelaide SA 5001

Flinders
UNIVERSITY
College of Nursing
& Health Sciences

Appendix 7.3 Levels of assistance provided by organisations approached to distribute study information

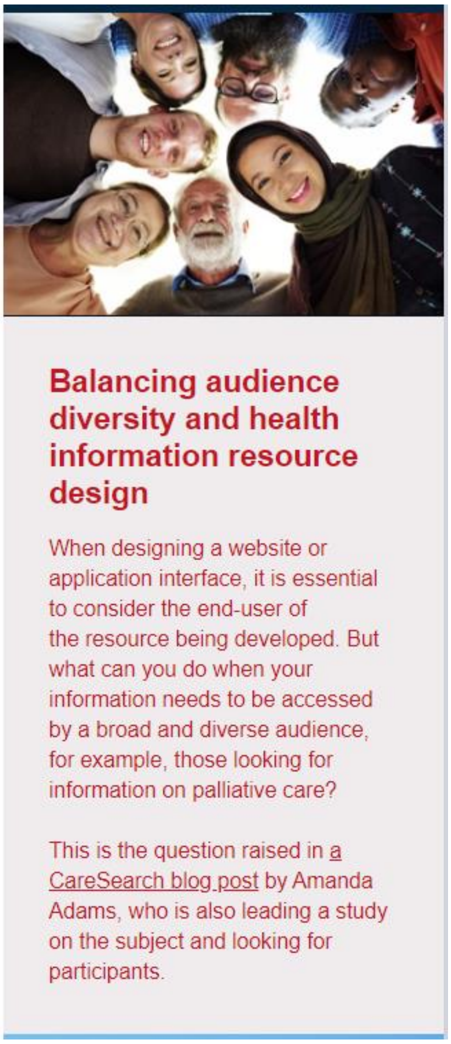
Could not assist further		**No follow up after in-principle support**		**No response**	
Organisation name	Comment	Organisation name	Comment	Organisation name	
Broken Hill Public Library	Not permitted to place non-council messages on networks	Onkaparinga Libraries	No further communication after initial support offered	Barmera Berri Public Library	Victor Harbor Public Library
Mitcham Public Library	Not permitted to place non-council messages on networks	Marion Council Libraries	No post in the e-newsletter	Roxby Downs Public Library	Carers Australia
				Cummins Public Library	Lions Club of Australia
Australian Network on Disability	Stakeholder organisation only	Good Things Foundation Australia	No further communication after initial support offered	State Library of South Australia / English Language Improvement Service (ELIS)	Australian Council of Social Service (ACOSS) and South Australian Council of Social Service (SACOSS)
Rotary Australia	Stakeholder organisation only	Australian Seniors Computer Club	No further communication after initial support offered	Port Augusta Public Library	APRA Active Over 50's
People with Disability Australia	Survey not fully accessible for all disability types	State Library of South Australia / English Language Improvement Service (ELIS)	No further communication after initial support offered	Whyalla Public Library	Country Women's Association
				Jamestown Public Library	Rotary Australia
Federation of Ethnic Communities Councils of Australia	Survey not translated out of English into other languages	MS Australia	No further communication after initial support offered	Cleve Public Library	Community Centres SA
				Lameroo Public Library	Quorn Public Library

Appendix 7.4 Examples of study distribution messages from organisations



MND Australia
3d ·

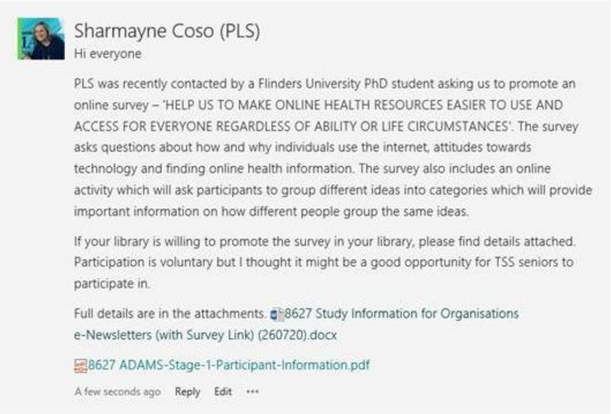
Can you help? Researchers at Flinders University are exploring how website design features influence user experience of health information websites 💻📱
The study investigates roles of both life circumstances and digital-technological skills on abilities to use, understand and access information to help with making important health decisions. Once you have completed the survey, you can enter the draw for a $50 gift voucher in appreciation of your time. More info & take part here ⬇️
https://qualtrics.flinders.edu.au/j…/form/SV_3I2VIqtJVgAnWQJ



Balancing audience diversity and health information resource design

When designing a website or application interface, it is essential to consider the end-user of the resource being developed. But what can you do when your information needs to be accessed by a broad and diverse audience, for example, those looking for information on palliative care?

This is the question raised in a CareSearch blog post by Amanda Adams, who is also leading a study on the subject and looking for participants.



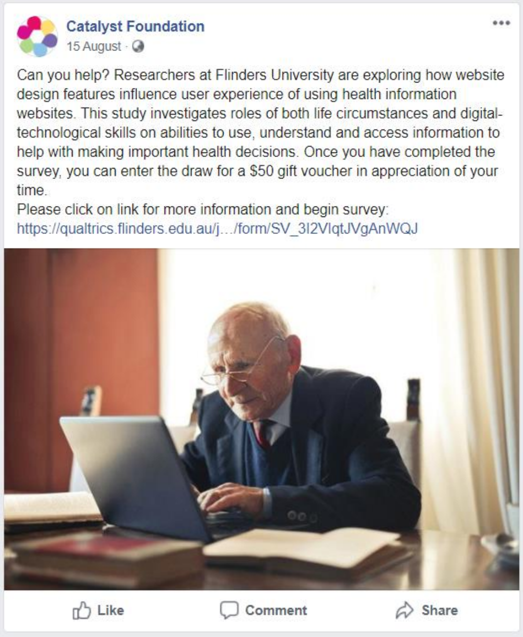
Sharmayne Coso (PLS)
Hi everyone

PLS was recently contacted by a Flinders University PhD student asking us to promote an online survey – 'HELP US TO MAKE ONLINE HEALTH RESOURCES EASIER TO USE AND ACCESS FOR EVERYONE REGARDLESS OF ABILITY OR LIFE CIRCUMSTANCES'. The survey asks questions about how and why individuals use the internet, attitudes towards technology and finding online health information. The survey also includes an online activity which will ask participants to group different ideas into categories which will provide important information on how different people group the same ideas.

If your library is willing to promote the survey in your library, please find details attached. Participation is voluntary but I thought it might be a good opportunity for TSS seniors to participate in.

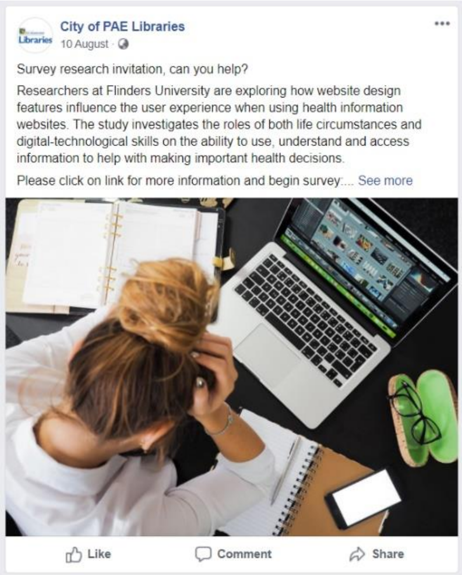
Full details are in the attachments. 8627 Study Information for Organisations e-Newsletters (with Survey Link) (260720).docx

8627 ADAMS-Stage-1-Participant-Information.pdf



Catalyst Foundation
15 August ·

Can you help? Researchers at Flinders University are exploring how website design features influence user experience of using health information websites. This study investigates roles of both life circumstances and digital-technological skills on abilities to use, understand and access information to help with making important health decisions. Once you have completed the survey, you can enter the draw for a $50 gift voucher in appreciation of your time.
Please click on link for more information and begin survey:
https://qualtrics.flinders.edu.au/j…/form/SV_3I2VIqtJVgAnWQJ



City of PAE Libraries
10 August ·

Survey research invitation, can you help?

Researchers at Flinders University are exploring how website design features influence the user experience when using health information websites. The study investigates the roles of both life circumstances and digital-technological skills on the ability to use, understand and access information to help with making important health decisions.

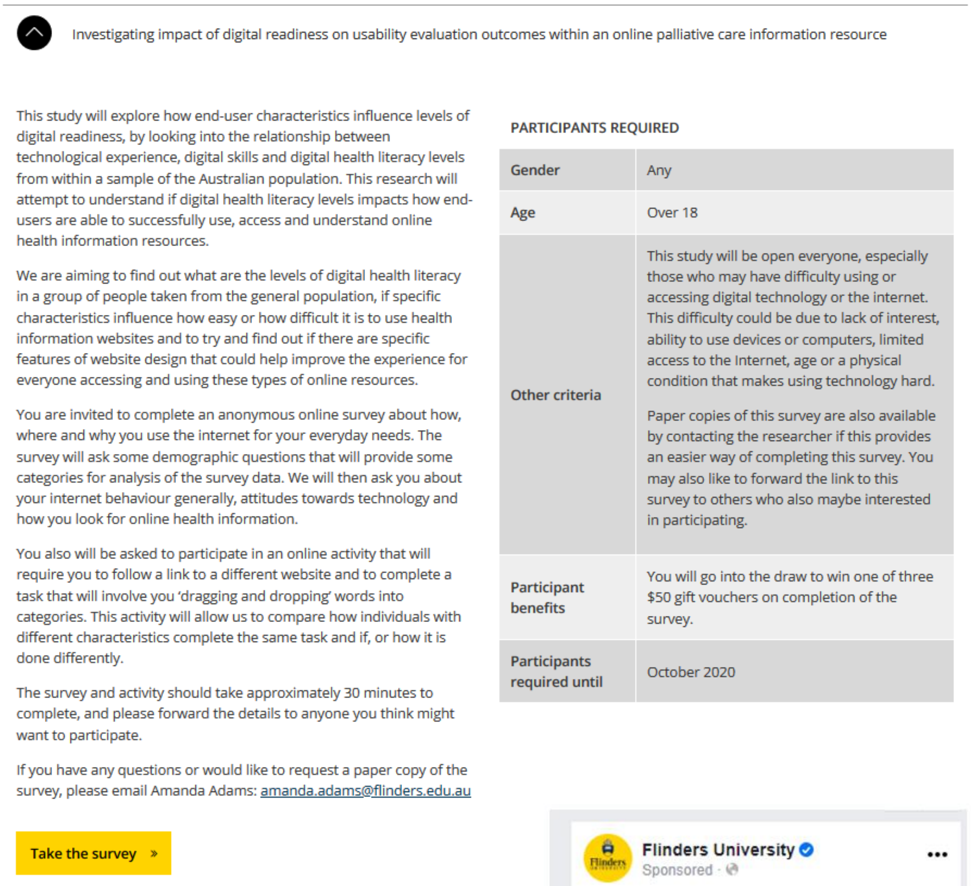
Please click on link for more information and begin survey:... See more

CareSearch @CareSearch · Aug 2

PhD research study seeks online survey respondents from Aust. community especially those finding technology & Internet difficult to explore relationship bn digital health literacy levels & website design: bit.ly/OnlineInfoSurv...

CARESEARCH.COM.AU

Balancing audience diversity and health information resource design



Investigating impact of digital readiness on usability evaluation outcomes within an online palliative care information resource

This study will explore how end-user characteristics influence levels of digital readiness, by looking into the relationship between technological experience, digital skills and digital health literacy levels from within a sample of the Australian population. This research will attempt to understand if digital health literacy levels impacts how end-users are able to successfully use, access and understand online health information resources.

We are aiming to find out what are the levels of digital health literacy in a group of people taken from the general population, if specific characteristics influence how easy or how difficult it is to use health information websites and to try and find out if there are specific features of website design that could help improve the experience for everyone accessing and using these types of online resources.

You are invited to complete an anonymous online survey about how, where and why you use the internet for your everyday needs. The survey will ask some demographic questions that will provide some categories for analysis of the survey data. We will then ask you about your internet behaviour generally, attitudes towards technology and how you look for online health information.

You also will be asked to participate in an online activity that will require you to follow a link to a different website and to complete a task that will involve you 'dragging and dropping' words into categories. This activity will allow us to compare how individuals with different characteristics complete the same task and if, or how it is done differently.

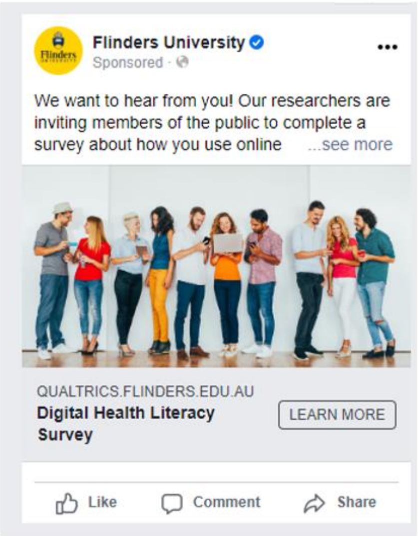
The survey and activity should take approximately 30 minutes to complete, and please forward the details to anyone you think might want to participate.

If you have any questions or would like to request a paper copy of the survey, please email Amanda Adams: amanda.adams@flinders.edu.au

Take the survey »

PARTICIPANTS REQUIRED

Gender	Any
Age	Over 18
Other criteria	This study will be open everyone, especially those who may have difficulty using or accessing digital technology or the internet. This difficulty could be due to lack of interest, ability to use devices or computers, limited access to the Internet, age or a physical condition that makes using technology hard. Paper copies of this survey are also available by contacting the researcher if this provides an easier way of completing this survey. You may also like to forward the link to this survey to others who also maybe interested in participating.
Participant benefits	You will go into the draw to win one of three $50 gift vouchers on completion of the survey.
Participants required until	October 2020



Flinders University
Sponsored ·

We want to hear from you! Our researchers are inviting members of the public to complete a survey about how you use online ...see more

QUALTRICS.FLINDERS.EDU.AU

Digital Health Literacy Survey

Appendix 7.5 Survey – Online version

Start of Block: Welcome and Study Information

WELCOME
Welcome and thank you for your interest...

Please take some time to read the following information about the researcher conducting this study.

To move to the next screen, please use the arrows at the bottom of the page.

JS

Letter of Intro
Hello,

I would like to introduce Amanda Adams to you. Amanda is a PhD candidate in the College of Nursing and Health Sciences at Flinders University. https://www.flinders.edu.au/college-nursing-health-sciences

Amanda is researching publication and producing a doctoral thesis on how evaluation influences the accessibility and usability of online health information resources. This online survey will seek to explore how individuals with differing experiences, abilities and Internet access influence levels of digital health literacy. Digital health literacy is the ability to find, understand and apply online health information to inform your health decisions.

We are interested in feedback from all community members, that is, everyone who accesses and uses the Internet as part of their everyday life. You are also invited to participate if you are an individual who may find the Internet and technology difficult to use or hard to access – this may be due to your ability, broadband access or technological devices, where you live, language spoken, or you do not like to use computers or the Internet.

Amanda will invite you to assist with this project by agreeing to complete an online survey and activity covering certain aspects of this topic. No more than 30 minutes will be required. Be assured that any information provided will be treated in the strictest confidence, and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

If you have any enquiries or concerns regarding this project, please contact me at the address above, by telephone or e-mail

Yours sincerely,
Professor Jennifer Tieman

College of Nursing and Health Sciences
Flinders University

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 8627). For more information regarding ethics approval of the project, the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

Please read the participant information provided below; this explains the study in detail and what you will be asked to do if you choose to participate.

Once you have read this information, please move to the next screen where you can choose to consent and continue the study or choose not to participate.

JS

INFORMATION SHEET

Stage 1 - Online Survey and Activity

Title: Investigating the impact of digital readiness on usability evaluation outcomes within an online palliative care information resource

Researcher:
Ms Amanda Adams
College of Nursing and Health Sciences
Flinders University

Supervisor(s):
Prof Jennifer Tieman
College of Nursing and Health Sciences
Flinders University

Dr Lauren Miller-Lewis
College of Nursing and Health Sciences
Flinders University

Description of the study

This study is part of a PhD project titled ‘Evaluating the access and value of online health information resources’ exploring the processes development teams use to build online health information resources (websites) and to find out if these influence how people who use these resources (known as 'end-users') perceive their value, relevance or usefulness.

This study will explore how end-user characteristics influence digital readiness levels by looking into the relationship between technological experience, digital skills, and digital health literacy levels within a sample of the Australian population. This research will also understand if digital health literacy levels impact how end-users can successfully use, access, and understand online health information resources.

End-user characteristics influence two important aspects of digital readiness - levels of digital health literacy (the ability to successfully find, understand and apply online health information to help with decisions about one's health); and the skills or abilities to successfully use and interact with the technology or devices including those that help with everyday tasks such as reading, writing and comprehension.

This study will be completed in two stages.

- Stage 1 will investigate how different end-user characteristics influence digital health literacy levels and explore the relationship between these characteristics and the different ways that people categorise health information into groups.
- Stage 2 will explore how individuals with specific levels of digital health literacy use a health website and find out what features help end-users find and understand information. This includes content, navigation, the flow of information, images or visual aspects, and the website's structure.

This stage will be open to eligible participants who complete the survey in Stage 1 of this study and will involve using the CareSearch palliative care website.
This study will explore palliative care themes and use the Patients and Carers section of the CareSearch website to explore these ideas. CareSearch is a freely available, Australian-based online information resource for patients, carers, families, and healthcare professionals looking for palliative care information. Palliative care is a medical approach to care for a person who has a serious illness that cannot be cured.
The information found in this document only describes what is involved in **Stage 1 of this study**.

This project is supported by the College of Nursing and Health Sciences and has the Flinders University Social and Behavioural Research Ethics Committee approval (Project Number 8627).

Purpose of the study
This project aims to find out the levels of digital health literacy in a group of people from the general population. This sample will represent people across the community who access the Internet to find and use online health information. We will also explore if specific characteristics of these people influence how easy or how difficult it is to use health information websites. These characteristics could be where someone lives, their gender, if they can afford mobile phones, computers or the Internet, age, education and whether they like to use technology or the Internet. We are also trying to find out if there are features of website design that could help improve how people experience online information by observing people using a website to find specific pieces of information.

What will I be asked to do?
You are invited to participate in Stage 1 of this study as a member of the general population, are over 18 and currently live in Australia. You will be asked to complete an online survey about how, where and why you use the Internet for your everyday needs.
It is important that you have a good understanding of the English language, as you will need to read and answer different types of questions and follow instructions to move through the survey.

To help us define the many different characteristics that could influence your use and access to the Internet, we will start by asking some demographic questions that will provide some categories for the analysis of the survey data. These will include standard questions about you – such as age, gender, postcode and living circumstances; we will then ask you about your Internet behaviour generally, attitudes towards technology and how you look for online health information. Some questions are multiple-choice; others require you to select answers from a list.

You also will be asked to participate in an online card sorting activity that will require you to follow a link to a different website. This activity will allow us to compare how individuals with different characteristics sort a variety of ideas into categories and if or how it is done differently. You will be asked to 'drag and drop' 50 ideas (or 'cards') into groups; these groups will be created and labelled by you. These cards describe some of the different types of information that people may need when someone they know needs palliative care.
There is no way for researchers to know who you are by your responses in the survey and online card sorting activity. We do not ask for any information that could identify you. Your responses are anonymous.
The survey and activity should take approximately 30 minutes to complete.

At the end of the survey, you will be asked if you are interested in participating in Stage 2 of this study. You will be able to read some information about what is involved and provide a contact e-mail address if you would like to register your interest. The researcher will use this e-mail address to contact you to discuss your participation with you.
Researchers will then analyse your survey data to work out if you are eligible to participate in the second study. In order to contact you to discuss this with you, we will link your survey data with your contact e-mail address. Your survey data will no longer be anonymous.
Your data will remain confidential and will be accessed only by the researchers involved in this study.
Any identifying information will be removed, and researchers will give your data a code so that no one will know that any data can be associated with you.

We also invite participants to consider sending the survey off to friends or relatives who find using technology or the Internet difficult. This can be done by cutting and pasting the link to this survey and sending it to friends or sharing the original message you received regarding this survey (e.g. from a Facebook advertisement).

What benefit will I gain from being involved in this study?
Sharing your information on how you experience online health information on websites will provide us with valuable data and feedback on how we can better design, build, and test our online health resources. We can improve how people with different personal circumstances or backgrounds use and access important health information by designing with people in mind. By providing information about you and your Internet behaviour and observing how you use health, websites will help improve the CareSearch website and provide guidance for other websites to improve how people from the general population experience their resources.

Will I be identifiable by being involved in this study?
We do not need your name, and you will be anonymous. Once the survey and activity have been completed, the only information kept will be demographics and the percentage of people responding to a question in a certain way. All data will remain confidential. All information and results collected during this study will be stored in a secure way, with access restricted to relevant researchers. There is no possible way for any person to be identified from the information provided in this survey or activity.

If you register your interest to be involved in Stage 2 of this study by providing your contact details, your e-mail address will be linked to your survey data so that we can contact you to discuss your participation. In this situation, your survey data is no longer anonymous. Your data will be confidential and stored securely, with only researchers accessing this information. Any identifying information will be removed, and researchers will give your data a code so that no one will know that any data can be associated with you.

Are there any risks or discomforts if I am involved?
Whilst it is anticipated that there are low risks for participants being involved in this study, there is a potential risk that you may experience low levels of emotional discomfort due to the nature of the information found within the online card sorting activity. You will be sorting/grouping information about palliative care which explores concepts around providing care and support to someone dying from an illness that cannot be cured. If in the unlikely event that you experience discomfort while completing the survey or have concerns regarding your health, you should close the browser window and speak with telephone counselling services such as Beyond Blue (1300 22 46 36), Lifeline (13 11 14) or contact a health professional or GP. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?
Participation is voluntary.
For the online survey, by clicking on the "I agree to participate" button at the start of the survey, you have indicated your willingness to be involved. You must be 18 years of age or older to participate and have a good understanding of English. You may refuse to answer any questions and can exit the survey at any time.

Recognition of Contribution / Time / Travel costs
If you would like to participate, in recognition of your contribution and participation time, you will be invited to go into the draw for one of three $50 gift vouchers by providing your contact details at the end of the online survey. This is not compulsory and will not be linked to your survey data.

How will I receive feedback?
Although direct feedback will not be provided to you at the completion of this study, findings from your participation could influence improvements to the CareSearch website. The CareSearch website is freely available to all participants. On project completion, outcomes of the project will be published in a research thesis, in peer-reviewed scientific journals and at scientific conferences. A summary of the findings from this research will also be available from the Research Centre for Palliative Care, Death and Dying website [https://www.flinders.edu.au/research-centre-palliative-care-death-dying].

Thank you for taking the time to read this information sheet, and we hope you will accept our invitation to be involved.

The Flinders University Social and Behavioural Research Ethics Committee has approved this research project in South Australia (Project number 8627). For queries regarding the ethics approval of this project, please contact the Executive Officer of the Committee via telephone at +61 8 8201 3116 or email human.researchethics@flinders.edu.au

If you would like a copy of these documents to save or print, you can download copies of this study information by clicking on the links below (these documents will open in a new window (tab) in your Internet browser).

Letter of Introduction (247kb PDF)

Stage 1 Participant Information (298kb PDF)

CONSENT
Thank you for reading this information - Would you like to participate?

By clicking the 'I agree to participate' button below, you have indicated that you are aged 18 or over and currently live in Australia. You also confirm that you understand English and are willing to participate in the research by completing the questionnaire.

By agreeing, you are aware that your participation is voluntary and that you may choose not to participate or to withdraw at any time. All electronic data collected will be anonymous; we do not ask you for any identifying information. This data will be stored securely and will be used for academic purposes only.

○ I agree to participate - continue to the online questionnaire (4)

○ I do not want to participate (5)

Skip To: End of Survey If Thank you for reading this information - Would you like to participate? By clicking the, 'I agree... = I do not want to participate

End of Block: Welcome and Study Information

Start of Block: START

We appreciate your help with our research.

In Part 1, the survey will ask some questions about you. How you use the Internet to look for health information and what types of problems you usually experience when trying to find and understand this information.
There are 24 questions in this survey, and it should take you approximately 15 minutes to complete.
Part 2 will then ask you to complete an online card sorting activity which will allow us to compare how individuals with different characteristics sort a variety of ideas into categories and if or how it is done differently.
The cards are a set of ideas that describe some of the different types of information that people may need when someone they know needs palliative care. Palliative care is a medical approach to care for a person who has a serious illness that cannot be cured.
Card sorting is an activity that developers of online resources use to help them to design websites.
This activity should take you approximately 15 minutes to complete.

You should need no more than 30 minutes to complete both the survey and card sorting activity.
You will also be provided with some information about how to be involved in the next stage of this research.

After you have finished the survey and card sorting activity, we would like to offer you an opportunity to go into the draw for one of three $50 gift vouchers in appreciation for your time.

Let's get started...

Part 1. Survey Questions

Please use the arrows to move through the survey.

This first section of the survey will ask you for some information about you, where you live and how you use the Internet in your everyday life.

Firstly, we would like to know a little information about you:
What is the postcode of where you live?

____

Q2 What is your gender?

○ Male (1)

○ Female (2)

○ Other (3)

○ Prefer not to say (4)

Q3 Please tell us your age (years)

____

Q4 Do you identify with being

○ Aboriginal (1)

○ Torres Strait Islander (2)

○ Both Aboriginal and Torres Strait Islander (3)

○ Neither Aboriginal nor Torres Strait Islander (4)

Q5 Can you tell us what language you usually use at home

○ English (1)

○ A language other than English (2)

Display This Question:

If Can you tell us what language you usually use at home = A language other than English

Q5A Please provide the language that is used at home if not English

____

Q6 What is the highest level of education that you have completed?

○ Tertiary degree or diploma (1)

○ Secondary school (Year 12 or equivalent) (2)

○ I did not complete secondary school (3)

Q7 Which of the following best describes your current employment status

○ I have full-time or part-time employment (1)

○ I am currently seeking employment (2)

○ I am not currently employed or seeking a job (3)

Display This Question:

If Which of the following best describes your current employment status = I am not currently employed or seeking a job

Q7A Are you:

○ A student (studying at any level or school / university / VET provider) (1)

○ Retired / Semi Retired (Volunteer) (2)

○ Responsible for home duties (including caring for children at home) (3)

○ A carer for someone who is ill, frail or living with a disability (4)

○ Other: Please describe (5) ____

Q8 Do you currently receive:

○ A Centrelink Disability Support Pension (DSP) (1)

○ A Disability Pension (VDP) from the Department of Veterans' Affairs (2)

○ No, I do not receive either of these (3)

Q9 What is your approximate household income for the year?

By asking you about your income, this information will help us to know how affordable Broadband / Internet access is for you.

○ Under $35,000 (1)

○ $35,000 to $59,999 (2)

○ $60,000 to $99,999 (3)

○ $100,000 to $149,000 (4)

○ $150,000 or more (5)

○ Prefer not to say (6)

End of Block: START

Start of Block: Internet Behaviour

Q10 We would now like to ask you some questions about whether you use the Internet, how you access online information, and your attitudes toward technology.

In the last 6 months, have you used the Internet?
This can be for any reason other than work: including banking, social media, finding and reading online information,

streaming movies, making an appointment or networking with friends, colleagues or groups as part of your work or social life.

○ Yes, I have (1)

○ No, I have not in the last 6 months, but I have used the Internet before (2)

○ I do not use the Internet myself; I have asked someone to do it for me (3)

Display This Question:

If We would now like to ask you some questions about if you use the Internet, how you access online... = I do not use the Internet myself, I have asked someone to do it for me

Or We would now like to ask you some questions about if you use the Internet, how you access online... = No I have not in the last 6 months, but I have used the Internet before

Q10A What was the reason that you have stopped using or do not use the Internet?

Please choose one or more answers that best suit your situation.

- I found it to be not helpful (1)
- I don't need the Internet (2)
- I no longer have a computer at home, or I am now unable to access a computer to use (3)
- I am now unable to afford the Internet at home or on my phone (4)
- I am now unable to use a computer because of pain or other health condition(s) (5)
- Other, please explain (6) ____

Q11 How often would you use the Internet?

○ At least once a day (1)

○ Once every few days (2)

○ Once a week (3)

○ Not very often - maybe once a month (4)

○ Only when the need arises, and it is urgent or important (5)

Q12 Where would you most commonly connect to the Internet to do what you need to do?

Please tick all boxes that apply.

- At work using my work computer or my work mobile device (7)
- At home using my computer (1)
- At home, using my mobile device (tablet or mobile phone) (2)
- At a friend's or relative's house using their computer, device or Internet (3)
- Using a computer in a public location (such as a library or cafe) (4)
- Using my mobile device in a public location (5)
- Other – please specify (6) ____

End of Block: Internet Behaviour

Start of Block: Difficulties using Technology

Q13 This next set of questions will ask if you experience difficulties using computers or devices and have problems viewing information on the screen.

How often do you need help with online tasks?

This can include help with banking, social media, finding and reading online information, streaming movies, making an appointment or networking with friends, colleagues or groups as part of your work or social life.

○ Yes, I need help all of the time (1)

○ Sometimes, depending on a specific task (2)

○ No, I can usually complete these by myself (3)

Display This Question:

If This next set of questions will ask if you experience difficulties using computers or devices and... = Yes, I need help all of the time

Or This next set of questions will ask if you experience difficulties using computers or devices and... = Sometimes, depending on a specific task

Q13A If you do need help doing online tasks, who do you usually ask for help?

○ Your partner or spouse (1)

○ Your son or daughter (2)

○ Your sibling (sister or brother) (3)

○ A neighbour or family friend (4)

○ A friend or acquaintance outside of the family (5)

○ A professional relating to the activity or task (such as a health professional, customer service officer, bank officer or librarian) (6)

○ Other - Please specify (7) ____

Q14 Do you live with a condition that makes it harder for you to access the Internet, use a computer or mobile device?

○ Yes, I do live with a condition that makes it hard for me to use technology or the Internet (1)

○ No, I do not have a condition (2)

Display This Question:

If Do you live with a condition that makes it harder for you to access the Internet, use a computer... = Yes, I do live with a condition that makes it hard for me to use technology or the Internet

Q14A Which of the following would you consider makes using technology or the Internet most difficult for you?

○ Difficulty sitting for long periods (1)

○ Eyes that tire easily (2)

○ Unsteady hands or fingers that have pain (3)

○ Difficulty concentrating for long periods (4)

○ Pain in the limbs (5)

○ Other – Please Specify (6) ____

Q15 Do you currently use additional devices, technology or features to make it easier for you to use the Internet every day?

○ I use adaptive or assistive technology (such as screen readers, modifications to the interface including pointers or speech recognition) to assist me (1)

○ I change the way the information shows on the screen using monitor or program settings (such as changing the text size or using zoom function) to make it easier for me (2)

○ I do not change any of the settings on my device because I do not know how to - but I think this would make my device easier for me to use if I could find out how (3)

○ I don't need to make any modifications to my device or the information on the screen (4)

End of Block: Difficulties using Technology

Start of Block: OHI

Q16
Please indicate how strongly you agree or disagree with the following statement
"I find it difficult to know whether the health information I find online is trustworthy."

○ Strongly disagree (1)

○ Disagree (2)

○ Neither disagree or agree (3)

○ Agree (4)

○ Strongly agree (5)

Q17 How confident are you at using computers, smartphones, tablets or other electronic devices to access the Internet to do what you need online?

○ Extremely confident - I consider myself an expert (1)

○ Somewhat confident - I can usually do what I need to do (2)

○ Only a little confident - I can do most things but need help regularly (3)

○ Not at all confident - I can do things with help always but rather get someone else to do them altogether (4)

○ I avoid using computers at all costs - I dislike technology and the Internet (5)

End of Block: OHI

Start of Block: e-HEALS

Q18
This series of questions will ask you about your use of the Internet to search, find, access and understand online health information to support your decisions about your own health.

Please indicate how strongly you agree or disagree with the following statements; understand online health information to support your decisions about your health. Please indicate how strongly you agree or disagree with the following statements

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
I know what health resources are available on the Internet (1)	○	○	○	○	○
I know *where* to find helpful health resources on the Internet (2)	○	○	○	○	○
I know *how* to find helpful health resources on the Internet (3)	○	○	○	○	○
I know how to use the Internet to answer my questions about health (4)	○	○	○	○	○
I know how to use the health information I find on the Internet to help me (5)	○	○	○	○	○
I have the skills I need to evaluate the health resources I find on the Internet (6)	○	○	○	○	○
I can tell high-quality health resources from low-quality health resources on the Internet (7)	○	○	○	○	○
I feel confident in using information from the Internet to make health decisions (8)	○	○	○	○	○

Q18A How *useful* do you feel the Internet is in helping you in making decisions about your health?

○ Not at all useful (1)

○ Not useful (2)

○ Unsure if it is useful (3)

○ Useful (4)

○ Very useful (5)

Q18B How *important* is it for you to be able to access health resources on the Internet?

○ Not at all important (1)

○ Not important (2)

○ Unsure if it is important (3)

○ Important (4)

○ Very important (5)

End of Block: e-HEALS

Start of Block: DHLI

Q19 We would also like to know how easy or difficult it is to find online health information using your computer to access the Internet and interact with different websites, forums or social media platforms. Firstly, please tell us how easy or difficult is it for you to ...

	Very difficult (1)	Rather difficult (2)	Rather easy (3)	Very easy (4)
Use the keyboard of a computer (e.g., to type words)? (1)	○	○	○	○
Use the mouse (e.g., to put the cursor in the right field or to click)? (2)	○	○	○	○
Use the buttons or links and hyperlinks on websites? (3)	○	○	○	○

Q19A When you search the Internet for health information, how easy or difficult is it for you to…

	Very difficult (1)	Rather difficult (2)	Rather easy (3)	Very easy (4)
Make a choice from all the information you find? (1)	○	○	○	○
Use the proper words or search query to find the information you are looking for? (2)	○	○	○	○
Find the exact information you are looking for? (3)	○	○	○	○
Decide whether the information is reliable or not? (4)	○	○	○	○
Decide whether the information is written with commercial interests (e.g., by people trying to sell a product)? (5)	○	○	○	○
Check different websites to see whether they provide the same information? (6)	○	○	○	○
To decide if the information you found is applicable to you? (7)	○	○	○	○
To apply the information you found in your daily life? (9)	○	○	○	○
To use the information you found to make decisions about your health (e.g., on nutrition, medication, or to decide whether to ask a doctor's opinion)? (10)	○	○	○	○

Q19B When you search the Internet for health information, how often does it happen that …

	Mostly (1)	Often (2)	Sometimes (3)	Never (4)
You lose track of where you are on a website or the Internet? (1)	○	○	○	○
You do not know how to return to a previous page? (2)	○	○	○	○
You click on something and get to see something different than you expected? (3)	○	○	○	○

Q19C
When typing a message (e.g., to your doctor, on a forum, or on social media such as Facebook or Twitter), how easy or difficult is it for you to …

	Very difficult (1)	Rather difficult (2)	Rather easy (3)	Very easy (4)
Clearly formulate your question or health-related worry? (1)	○	○	○	○
Express your opinion, thoughts, or feelings in writing? (2)	○	○	○	○
Write your message for people to understand exactly what you mean? (3)	○	○	○	○

Q19D This question is for people who have posted a message on social media such as Facebook or Twitter, a forum, or a (health care) rating site.

When you post a message on a public forum or social media, how often ...

	Mostly (1)	Often (2)	Sometimes (3)	Never (4)
Do you find it difficult to judge who can read along? (1)	○	○	○	○
Do you (intentionally or unintentionally) share your own private information (e.g., name or address)? (2)	○	○	○	○
Do you (intentionally or unintentionally) share some else's private information? (3)	○	○	○	○

End of Block: DHLI

Start of Block: Attitudes and Anxiety to Technology

Q20 Finally, we would like to know how comfortable you are using computers and the Internet.

This question will ask you to think about how uneasy you feel using computers or technology.
Please indicate how strongly you agree or disagree with the following statements

	Strongly disagree (1)	Disagree (2)	Somewhat disagree (3)	Somewhat agree (4)	Agree (5)	Strongly agree (6)
I feel confident and relaxed while working on a computer (1)	○	○	○	○	○	○
The harder I work at learning computers, the more confused I get (2)	○	○	○	○	○	○
I have sometimes thought that I am too old to learn about computers (3)	○	○	○	○	○	○
I have sometimes thought, "Computers don't like me" (4)	○	○	○	○	○	○
I always have problems working on computers (5)	○	○	○	○	○	○
I can usually manage to solve computer problems by myself (6)	○	○	○	○	○	○

End of Block: Attitudes and Anxiety to Technology

Start of Block: Registering for Stage 2

Stage 2 Study

Can you help us with the second stage of this study?
We would like to invite you to participate in the second stage of this study which will focus on how different individuals interact with a palliative care website focusing on how you use different areas of the website.

For this study, we will be using the Patients and Carers section of the CareSearch website.
CareSearch is a freely available, Australian-based online information resource for patients, carers, families, and healthcare professionals looking for palliative care information.

We will be testing the website and not your skills; we would like to invite everyone who has completed the survey - especially those who may find using the Internet, devices or websites difficult.

During this session, you will be asked to provide your feedback on features of the website relating to navigation, content, menus and how information is presented within pages.
We would also like to ask your thoughts about what parts of the website you like or dislike.

This session will require approximately 1 hour of your time, and at the end of the session, you will be provided with a digital $25 gift voucher in appreciation of your involvement.

Due to COVID-19 social distancing requirements, these sessions will be undertaken online using Zoom meeting software, which means you will need to be able to use and access a laptop or desktop computer and have the Internet to participate.

Would you like to read more information about participating in this study?

○ Yes, I am interested in reading more information about participating in Stage 2 of this study (4)

○ No, I am not interested in participating in this study (5)

Display This Question:

If Can you help us with the second stage of this study? We would like to invite you to participate... = Yes, I am interested in reading more information about participating in Stage 2 of this study

Please read the Stage 2 Participant Information provided below explaining the second study, how the sessions will be organised and what you will be asked to do.

JS

Stage 2 Info

INFORMATION SHEET
Stage 2 – Evaluating the CareSearch website interface

Title: Investigating the impact of digital readiness on usability evaluation outcomes within the online interface of a palliative care information resource

Researcher:
Ms Amanda Adams
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Supervisor(s):
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Description of the study

This study is part of a PhD project titled 'Evaluating the access and value of online health information resources' exploring the processes development teams use to build online health information resources (websites) and to find out if these influence how people who use these resources (known as 'end-users') perceive their value, relevance or usefulness.

This study will explore how end-user characteristics influence digital readiness levels by looking into the relationship between technological experience, digital skills, and digital health literacy levels within a sample of the Australian population. This research will also try to understand if digital health literacy levels impact how end-users can successfully use, access, and understand online health information resources.

End-user characteristics influence two important aspects of digital readiness - levels of digital health literacy (the ability to successfully find, understand and apply online health information to help with decisions about one's health); and the skills or abilities to successfully use and interact with the technology or devices including those that help with everyday tasks such as reading, writing and comprehension.

This study will be completed in two stages.

- Stage 1 will investigate how different end-user characteristics influence digital health literacy levels and explore the relationship between these characteristics and the different ways that people categorise health information into groups.
- Stage 2 will explore how individuals with specific levels of digital health literacy use a health website and find out what features help end-users find and understand information. This includes content, navigation, the flow of information, images or visual aspects, and the website's structure. This study will be open to eligible participants who complete Stage 1 of this study and evaluate the CareSearch palliative care website.

This study will explore palliative care themes and use the Patients and Carers section of the CareSearch website to explore these ideas. CareSearch is a freely available, Australian-based online information resource for patients, carers, families, and healthcare professionals looking for palliative care information. Palliative care is a medical approach to care for a person who has a serious illness that cannot be cured.

This information within this 'Information Sheet' only describes what is involved in Stage 2 of this study.

This project is supported by the College of Nursing and Health Sciences and has the Flinders University Social and Behavioural Research Ethics Committee (Project Number 8627).

Purpose of the study

This project aims to find out the levels of digital health literacy in a group of people from the general population. This sample will represent people across the community who access the Internet to find and use online health information. We will also explore if specific characteristics of these people influence how easy or how difficult it is to use health information websites. These characteristics could be where someone lives, their gender, if they can afford mobile phones, computers or the Internet, age, education and whether they like to use technology or the Internet. We are also trying to find out if there are features of website design that could help improve how people experience online information, every one by observing people using a website to find specific pieces of information.

We will be using the Patients and Carers section of the CareSearch website to explore these ideas. CareSearch is a freely available Australian-based online information resource for patients, carers, families, and healthcare professionals looking for palliative care information.

Eligibility to participate in Stage 2

You have already completed Stage 1 of this study by completing an online survey asking for some general information about you, such as your age, gender, postcode and living circumstances; about your online behaviour generally, attitudes towards technology, and how you look for online health information.
As part of this survey, you indicated a further interest in participating in the second stage of this study.

Once you have submitted your survey, researchers will analyse your survey data to determine if you are eligible to be involved in the second stage of the study. You will then be contacted by the researcher using the contact e-mail that you provided within the survey. The researcher will let you know if you are eligible to participate or not. If you are eligible, you can choose to participate in this second stage of the study – your involvement is voluntary.

What will I be asked to do?

The researcher will invite you to participate in a remote, online evaluation session using conferencing software (Skype or Zoom). This session can be undertaken at a time that is convenient to you and the researcher.
Being an online session, you will need access to a desktop or laptop computer with a camera and access to the Internet. It is also important that you understand the English language, as you will need to read and answer questions and follow instructions remotely. Some experience using a computer is recommended as the researcher will only provide limited assistance due to being online with you.
You will be able to undertake this session at a location of your choice, such as at home or a library, providing that you can find a quiet, private space to speak to the researcher.

During this session, you will be asked to view the Patients and Carers section of the CareSearch palliative care website. This website has been developed for all Australians and has information for people in the general public (health consumers) and health professionals. This session will use the website section written for the general public.
The evaluation session will include:

- An online card sorting activity will ask you to group words by 'dragging and dropping' word boxes into provided categories.
- A series of short activities that will explore how you use the website to find information and to complete a questionnaire that will ask you about your level of satisfaction using the website
- You provide feedback describing your views on the content, how the website works, and any problems or issues that you may find as you look for specific pieces of information within the section. You will also be asked to provide your opinion on what parts of the website you like or dislike.

This session will be audio and video recorded for retrospective data analysis. All of these files will have identifying information removed, and researchers will give your data a code so that no one will know that any data can be associated with you. All of your data will remain confidential and will be stored securely. Only researchers associated with this study will have access to this data.

This activity will take approximately 60 minutes to complete.
At the end of the session, you will be provided with a $25 digital gift voucher in appreciation of your time.

What benefit will I gain from being involved in this study?
Sharing your information on how you experience online health information in websites will provide us with valuable data and feedback on how we can better design, build, and test our online health resources. We can improve how people with different personal circumstances or backgrounds use and access important health information by designing with people in mind. By providing information about you and your Internet behaviour and observing how you use health, websites will help improve the CareSearch website and provide guidance for other websites to improve how people from the general population experience their resources.

Will I be identifiable by being involved in this study?
Your evaluation session data will not be anonymous; your identity will be known to the researcher. All of your data and files will be confidential. Once your session has been completed, your data will have all identifying information removed so that there is no possible way for any person to know that this information came from you. All information and results obtained in this study will be stored in a secure way, with only researchers involved in this study able to access this study data.
Outcomes of this study will be published in a research thesis, in peer-reviewed scientific journals and at scientific conferences. All data included in these reports will be de-identified so that no one will know that information came from you.

Are there any risks or discomforts if I am involved?
Whilst it is anticipated that there are low risks for participants being involved in this study, there is a potential that you may experience low levels of emotional discomfort due to the nature of the content of the website that you will be using. CareSearch provides palliative care information for the Australian population. The website section used for this study stage contains palliative care information for patients, carers, and families. You will be viewing content that explores concepts around providing care and support to someone dying from an illness that cannot be cured. If in the unlikely event that you experience discomfort while undertaking the evaluation session or have concerns regarding your health, you should speak with telephone counselling services such as Beyond Blue (1300 22 46 36), Lifeline (13 11 14) or contact a health professional or GP. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?
Participation is voluntary.
After reading both the information sheet and consent form provided by the researcher, you can sign the consent form and return it to the researcher via e-mail. Alternatively, at the beginning of the online evaluation session, the information found within the Consent form will be repeated to you in brief. The researcher will ask if you have any questions about the study and what you ask. If you are happy to continue, you will be asked to consent to take part verbally. This will be recorded and retained for our study records.

You may refuse to answer any questions at any time. You are free to withdraw from the evaluation session at any time without effect or consequences. You must be 18 years of age or older to participate and understand English in both written and spoken forms.

Recognition of Contribution / Time / Travel costs
You will receive a digital $25 shopping gift voucher after the evaluation session in appreciation of your time.

How will I receive feedback?
Although direct feedback will not be provided to you at the completion of this study, findings from your participation could influence improvements to the CareSearch website. The CareSearch website is freely available to all participants. On project completion, outcomes will be published in a research thesis, in peer-reviewed scientific journals and at scientific conferences. A summary of the findings from this research will also be available from the Research Centre for Palliative Care, Death and Dying website[https://www.flinders.edu.au/research-centre-palliative-care-death-dying].

Thank you for taking the time to read this information sheet, and we hope you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee *in South Australia (Project number 8627). For queries regarding the ethics approval of this project, please contact the Executive Officer of the Committee via telephone at +61 8 8201 3116 or email* human.researchethics@flinders.edu.au

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Register Stage 2
You can also download and save a copy of this information by clicking on the link below (this PDF will open in a new window (tab) in your Internet browser).
Stage 2 Participant Information (372kbPDF)

After reading the Stage 2 Participant Information, please select an option below:

○ I would like to register my interest to be involved in Stage 2 of this study (4)

○ I am not interested in participating in Stage 2 of this study (5)

Display This Question:

If You can also download and save a copy of this information by clicking on the link below (this PDF... = I would like to register my interest to be involved in Stage 2 of this study

Register E-mail

I acknowledge that by registering my interest to participate in Stage 2:

Researchers will analyse my survey data to work out if I am eligible to be involved in the second stage of this research study.
My survey data will be linked to my e-mail address (or phone number) so that researchers can contact me to discuss my eligibility.
I understand that my survey data will no longer be anonymous but will be kept confidential and de-identified at the end of the study. It will not be possible to associate any of the data collected with me.
I am aware that the researcher will contact me by using the contact details I provide below to discuss my eligibility to participate in the second study.

To register your interest, please provide a contact e-mail address or a phone number if you do not have an e-mail address

____

End of Block: Registering for Stage 2

Start of Block: Thank You - Gift Card Draw

Draw

Thank you for completing parts of this research study; your feedback is very valuable.

In appreciation for your time, we invite you to go into the draw for one of three $50 gift cards as a thank you for your participation.

This draw will be separate from registering your interest in Stage 2 of this study.

If you would like to enter the draw, you will need to provide a contact e-mail address (or phone number for those without an e-mail address) below.

If you have registered your interest in participating in Stage 2, you will need to provide your contact details again to be in the draw.

Your contact information will not be associated with your survey data.

○ Yes, I would like to go into the draw for one of three gift vouchers (1)

○ No, I do not want to enter (2)

Display This Question:

If Thank you for completing parts of this research study; your feedback is very valuable. In appre... = Yes, I would like to go into the draw for one of three gift vouchers

Draw E-mail Please provide your contact e-mail address (or phone number)

____

End of Block: Thank You - Gift Card Draw

Appendix 7.6 Electronic Health Literacy Scale questionnaire [493] and scale descriptors

Survey question	eHEALS question	Descriptor	Scale descriptors
EQ18_1	1. I know what health resources are available on the Internet	Likert Scale	1. Strongly Disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree
EQ18_2	2. I know where to find helpful health resources on the Internet	Likert Scale	1. Strongly Disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree
EQ18_3	3. I know how to find helpful health resources on the Internet	Likert Scale	1. Strongly Disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree
EQ18_4	4. I know how to use the Internet to answer my questions about health	Likert Scale	1. Strongly Disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree
EQ18_5	5. I know how to use the health information I find on the Internet to help me	Likert Scale	1. Strongly Disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree
EQ18_6	6. I have the skills I need to evaluate the health resources I find on the Internet	Likert Scale	1. Strongly Disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree
EQ18_7	7. I can tell high-quality health resources from low-quality health resources on the Internet	Likert Scale	1. Strongly Disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree
EQ18_8	8. I feel confident in using information from the Internet to make health decisions	Likert Scale	1. Strongly Disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree
EQ18A	eHSUPP1. How useful do you feel the Internet is in helping you in making decisions about your health	Likert Scale	1. Not useful at all 2. Not useful 3. Unsure 4. Useful 5. Very Useful

EQ18B	eHSUPP2. How important is it for you to be able to access health resources on the Internet?	Likert Scale	1. Not important at all 2. Not important 3. Unsure 4. Important 5. Very important

Appendix 7.7 Digital Health Literacy Instrument [516] and scale descriptors

DHLI Subscale	DHLI Question	Descriptor	Scale Descriptors
1) Operational	*How easy or difficult is it for you to:*		
DHQ19_1A	Use the keyboard of a computer (e.g., to type words)?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19_1B	Use the mouse (e.g., to put the cursor in the right field or to click)?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19_1C	Use the buttons or links and hyperlinks on websites?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
3) Information Searching	*When you search the Internet for information on health, how easy or difficult is it for you to:*		
DHQ19A_3A	Make a choice from all the information you find?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19A_3B	Use the proper words or search query to find the information you are looking for?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19A_3C	Find the exact information you are looking for?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
4) Evaluating Reliability	*When you search the Internet for information on health, how easy or difficult is it for you to:*		
DHQ19A_4A	Decide whether the information is reliable or not?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19A_4B	Decide whether the information is written with commercial interests (e.g., by people trying to sell a product)?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19A_4C	Check different websites to see whether they provide the same information?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
5) Determining Relevance	*When you search the Internet for information on health, how easy or difficult is it for you to:*		

DHQ19A_5A	Decide if the information you found is applicable to you?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19A_5B	Apply the information you found in your daily life?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19A_5C	Use the information you found to make decisions about your health (e.g., on nutrition, medication or to decide whether to ask a doctor's opinion)?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
2) Navigating	*When you search the Internet for health information, how often does it happen that:*		
DHQ19B_2A	You lose track of where you are on a website or the Internet?	Likert Scale (R1-4)	1. Mostly 2. Often 3. Sometimes 4. Never
DHQ19B_2B	You do not know how to return to a previous page?	Likert Scale (R1-4)	1. Mostly 2. Often 3. Sometimes 4. Never
DHQ19B_2C	You click on something and get to see something different than you expected?	Likert Scale (R1-4)	1. Mostly 2. Often 3. Sometimes 4. Never
6) Adding Content	*When typing a message (e.g., to your doctor, on a forum, or on social media such as Facebook or Twitter), how easy or difficult is it for you to:*		
DHQ19C_6A	Clearly formulate your question or health-related worry?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19C_6B	Express your opinion, thoughts, or feelings in writing?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
DHQ19C_6C	Write your message as such for people to understand exactly what you mean?	Likert Scale (R1-4)	1. Very difficult 2. Rather difficult 3. Rather easy 4. Very easy
7) Protecting Privacy	*When you post a message on a public forum or social media, how often :*		
DHQ19D_7A*	Do you find it difficult to judge who can read along	Likert Scale (R1-4)	1. Mostly 2. Often 3. Sometimes 4. Never
DHQ19D_7B*	Do you (intentionally or unintentionally) share your own private information (e.g., name or address)?	Likert Scale (R1-4)	1. Mostly 2. Often 3. Sometimes 4. Never
DHQ19D_7C*	Do you (intentionally or unintentionally) share some else's private information?	Likert Scale (R1-4)	1. Mostly 2. Often 3. Sometimes 4. Never

*Protecting Privacy – Q19D (A,B,C) optional

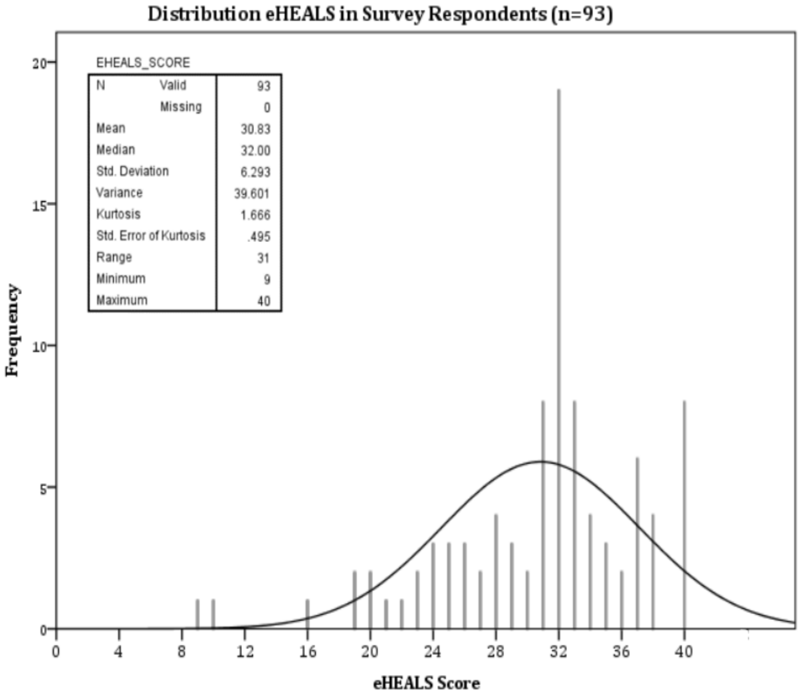
Appendix 7.8 Short Computer Anxiety Scale questionnaire [531] and scale descriptors

Survey Question	SCAS Question	Descriptor	Scale Descriptors
SCASQ20_1	1. I feel confident and relaxed while working on a computer	Likert Scale (R1-6)	1. Strongly agree 2. Agree 3. Somewhat agree 4. Somewhat disagree 5. Disagree 6. Strongly disagree
SCASQ20_2	2. The harder I work at learning computers, the more confused I get	Likert Scale (F1-6)	1. Strongly disagree 2. Disagree 3. Somewhat disagree 4. Somewhat agree 5. Agree 6. Strongly agree
SCASQ20_3	3. I have sometimes thought that I am too old to learn about computers.	Likert Scale (F1-6)	1. Strongly disagree 2. Disagree 3. Somewhat disagree 4. Somewhat agree 5. Agree 6. Strongly agree
SCASQ20_4	4. I have sometimes thought, "Computers don't like me."	Likert Scale (F1-6)	1. Strongly disagree 2. Disagree 3. Somewhat disagree 4. Somewhat agree 5. Agree 6. Strongly agree
SCASQ20_5	5. I always have problems working on computers.	Likert Scale (F1-6)	1. Strongly disagree 2. Disagree 3. Somewhat disagree 4. Somewhat agree 5. Agree 6. Strongly agree
SCASQ20_6	6. I feel confident and relaxed while working on a computer	Likert Scale (R1-6)	1. Strongly Agree 2. Agree 3. Somewhat agree 4. Somewhat disagree 5. Disagree 6. Strongly disagree

F=Forward, R=Reverse

Appendix 7.9 Survey sample frequency graphs and distribution analysis of questionnaire data within the survey

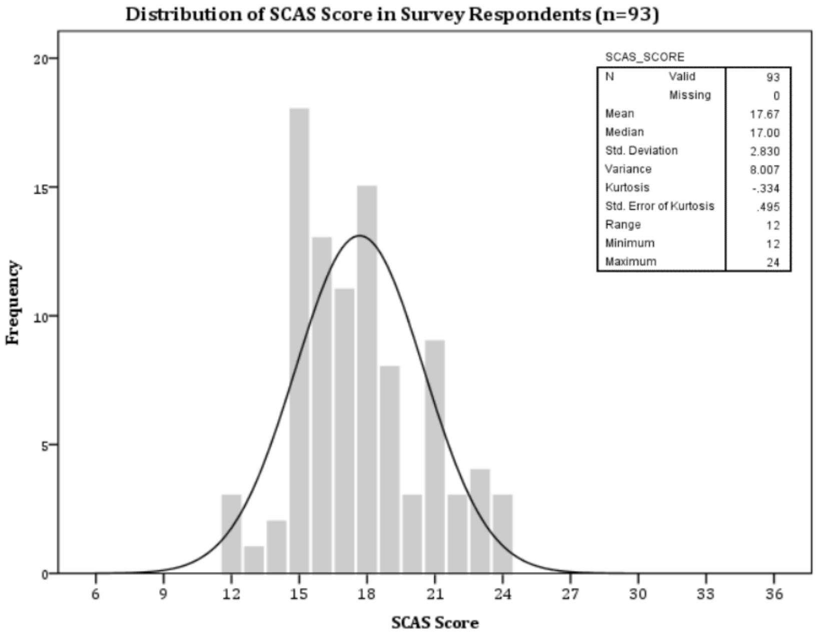
Graph A7.9A. eHEALS questionnaire



EHEALS_SCORE

N	Valid	93
	Missing	0
Mean		30.83
Median		32.00
Std. Deviation		6.293
Variance		39.601
Kurtosis		1.666
Std. Error of Kurtosis		.495
Range		31
Minimum		9
Maximum		40

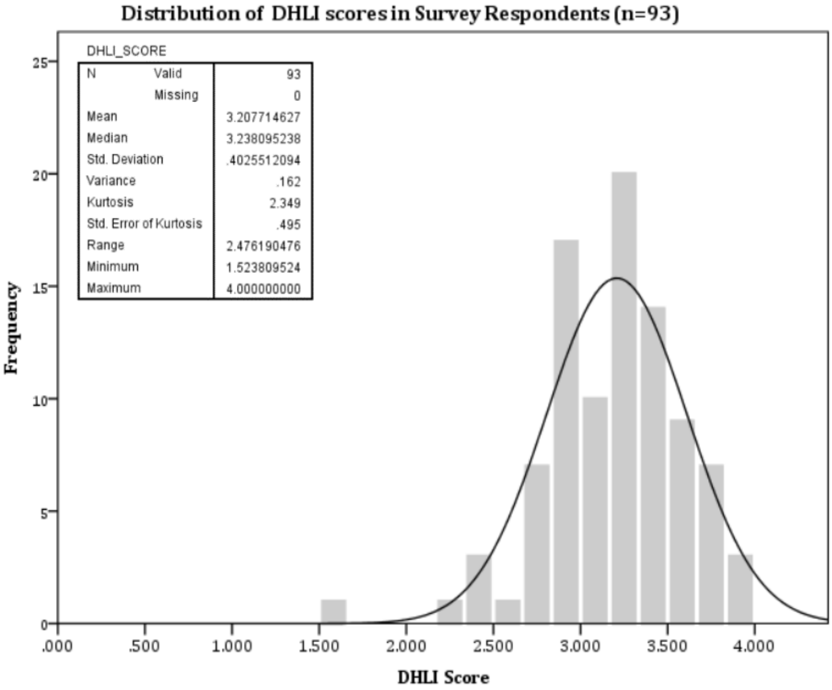
Graph A7.9B. SCAS questionnaire



SCAS_SCORE

N	Valid	93
	Missing	0
Mean		17.67
Median		17.00
Std. Deviation		2.830
Variance		8.007
Kurtosis		-.334
Std. Error of Kurtosis		.495
Range		12
Minimum		12
Maximum		24

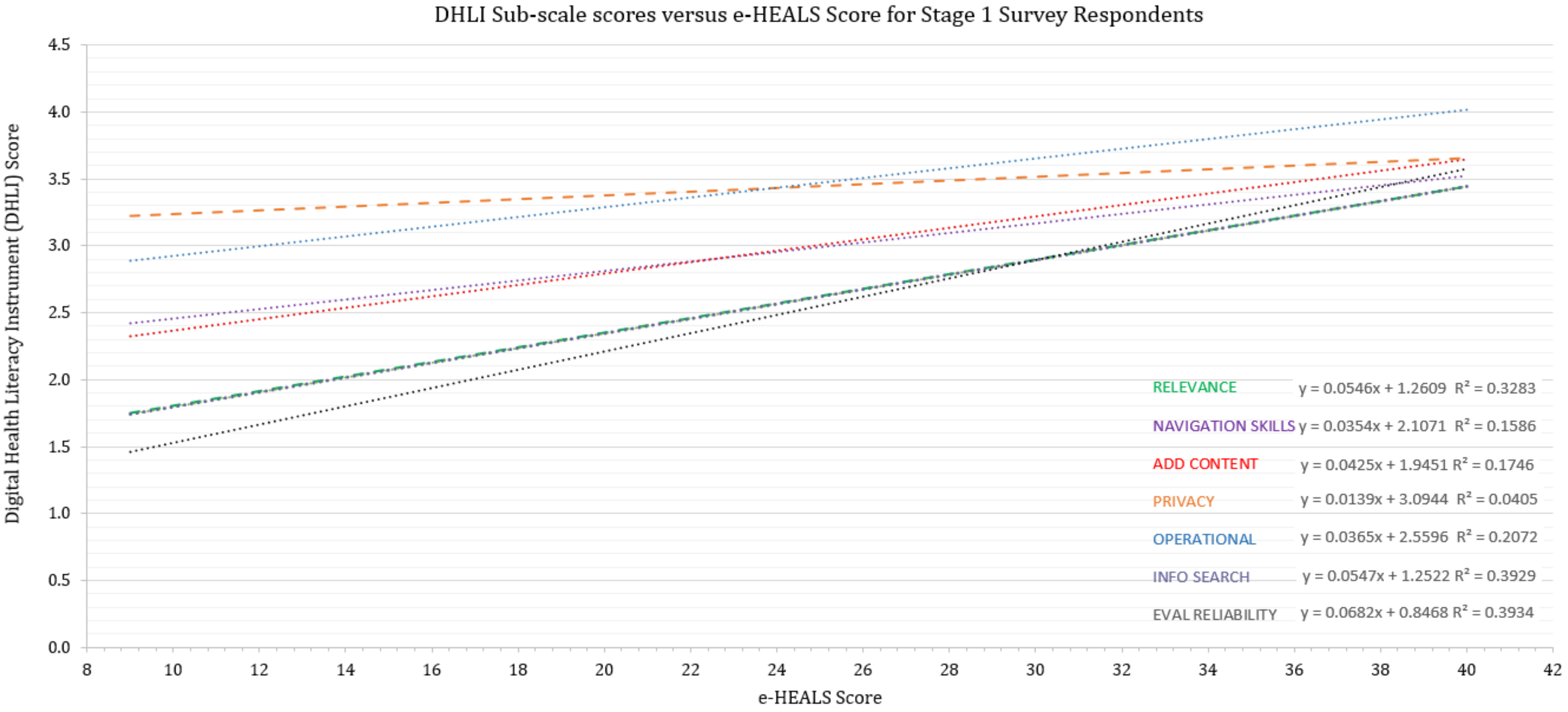
Graph A7.9C. *DHLI* Total score from DHLI questionnaire



DHLI_SCORE

N	Valid	93
	Missing	0
Mean		3.207714627
Median		3.238095238
Std. Deviation		.4025512094
Variance		.162
Kurtosis		2.349
Std. Error of Kurtosis		.495
Range		2.476190476
Minimum		1.523809524
Maximum		4.000000000

Appendix 7.10 Analysis of relationship between *DHLI* subscale and eHEALS questionnaire data within survey population



Appendix 7.11 Demographics of respondents with eligible or ineligible *DHLI* scores from surveys

	Eligible *DHLI* (*n*=93)	Non-eligible *DHLI* (*n*=8)
Age (yr) Mean± *SD* [Min-Max, Median]	54.29±17.31 [19-91, 55]	59.88±21.61 [18-81, 67.0]
Gender		
Male	23 (24.73)	3
Female	70 (75.27)	5
IRSAD percentile Mean ± *SD* [Min-Max, Median]	58.17±28.57 [2-98, 65]	61.13±25.26 [23-99, 66.5]
IRSAD quintile (%Total)		
Q1 (1-20)	15	0
Q2 (21-40)	9	2
Q3 (41-60)	20	1
Q4 (61-80)	26	4
Q5 (81-100)	23	1
Language (%Total)		
English at home	89	7
English as second language	4	1
Employment status (%Total)		
Employed full/part-time	55	2
Seeking employment	3	1
Not seeking employment	34	5
If not employed or seeking employment (%Total)		
Student	2	1
Retired/Semi-retired	29	4
Home duties	0	
Carer	2	

Other	1	
Education level (%Total)		
Tertiary	77	6
Secondary	10	1
Did not complete secondary	6	1
C-wealth support status (%Total)		
Centrelink Disability Support	3	0
Disability Pension	0	0
Neither	90	8
Income $ household/year (%Total)		
<$35,000	17	1
$36,000-$59,000	21	2
$60,000-$99,000	26	1
$100,000-$149,000	12	0
>$150,000	14	1
I prefer not to say	3	3

APPENDIX 8. ADDITIONAL INFORMATION RELATING TO THE DHL AND OUTCOMES FROM UEM ACTIVITIES CHAPTER

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Appendix 8.1 CareSearch's Patient and Carers section content site map

Section Name	First Level Page names	Second Level Page Names	Third Level Page Names
Introduction for Patients	Introduction for Patients		
Introduction for Carers	Introduction for Carers		
Introduction for Families	Introduction for Families		
How to Care	How to Care		
	Looking After Someone	Family Carer Role	
		Family conflict in caring	
		If you cannot continue in the Caring role	
		Looking after yourself	
		Managing daily life	
		Paid Careworkers in the home	
		Respite	
		Social Support	
		Tips for carers about visitors	

Practical Caring Resources	Who is a Carer	
	Getting Practical Help	
	Managing Medicines	Costs of Medicines
		Medicines Explained
		Practical Ways to Manage Medicines
		Tips for Managing Medicines
	Supporting Carers	Coming Home When Someone is Ill
		Coping with Long Distance Caring
		Family Carer Coordinating Role
		Practical Assistance
		Responding to Their Feelings
		Saying Goodbye
		Tips for Visitors
		What to Say
	Young People provide care too	
	Carers Needs Tool	Carer Resources (CareSearch)

Living with Illness	Living with Illness	Changes Over Time	
			Course Of Illness
			Quality Of Life
		Complementary Therapies	
			Some of the More Common
			Therapies
		Continuing To Work	
		Emotional Challenges	Anxiety and Depression
			Making Decisions
			The Hard Thing About Being Cared
			For
			When Someone You Care About is
			Seriously Ill
			When You Are Seriously Ill
			Would it Help to Talk to Someone?

		Financial Matters	
			Costs of Care
			Financial Help and Advice
			Financial Resources
			Superannuation and Insurances
		Planning for the Future	Advance Care Planning
			Funerals
			Wills
		Spirituality	
		Support Groups	
		Symptoms	Pain
		Why is Communication Important?	Communicating with Health
			Professionals
			Difficult Conversations
			Family Communication
			Talking with Children

Specific Groups	Specific Groups	Aboriginal and Torres Strait Islander	
		People	
		Lesbian, Gay, Bisexual, Transgender	
		and Intersex (LGBTI)	
		Homelessness	
		Intellectual Disability	
		Living Alone	
		Mental Illness	
		Multicultural	Other Languages
		Older People	
		Children and Adolescents	
		Prisoners and Their Families	
		Refugees and Asylum Seekers	
		Rural and Remote	
		Young Carers	
Bereavement, Grief and Loss	Bereavement, Grief and Loss	Children and Grief and Loss	

		Grief and Sadness
		Loss of a Child
		Remembering
		Grief and Loss Resources
At the End	At the End	Caring at the End
		Changes at the Time of Death
		Dying at Home
		Family Issues at the End
		Immediately After a Death
		Place of Care, Place of Death
		Preparing for the End
Using Online Information	Using Online Information	How Research Contributes
		Is it Trustworthy?
		Sources of Information
		Using Information
About Palliative Care	About Palliative Care	It's Not Just Cancer

		Referring to Palliative Care	
		What is Palliative Care?	
		Who Provides Palliative Care	Coordinating Palliative Care
			The Role of Health Professionals
			The Role of Specialist Palliative Care
		Why Information Matters	Patient's Need for Information
			Family Carer's Need for Information
Finding Services	Finding Services	Palliative Care Services	
		National Resources	
		Disease-Specific Resources	
		State Resources	Australian Capital Territory
			New South Wales
			Northern Territory
			Queensland
			South Australia
			Tasmania

Victoria	
Western Australia	

Appendix 8.2 System Usability Scale (SUS)[597] questionnaire and data variables

Question	SUS Question	Descriptor	Scale descriptors
SUS_Q1	I think I would like to use this palliative care website	Likert Scale	7. Strongly disagree 8. 9. 10. 11. Strongly agree
SUS_Q2	I found the palliative care website unnecessarily complex	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree
SUS_Q3	I thought the palliative care website was easy to use	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree
SUS_Q4	I think I would need the support of a technical person to be able to use this palliative care website	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree
SUS_Q5	It was easy to learn to use the palliative care website to be well integrated	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree
SUS_Q6	I thought there was too much inconsistency in this palliative care website	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree
SUS_Q7	I would imagine that most people would learn to use this palliative care website very quickly	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree
SUS_Q8	I found the palliative care website very awkward to use	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree
SUS_Q9	I felt very confident using the palliative care website	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree

SUS_Q10	I needed to learn a lot of things before I could get going with this palliative care website	Likert Scale	1. Strongly disagree 2. 3. 4. 5. Strongly agree

Appendix 8.3A Participant demographics of individuals undertaking usability evaluation sessions

	Stage 2 Usability evaluation groups		***p* Value**
	Low *DHLI* (*n*=3)	**High *DHLI* (*n*=3)**	**Low vs High DHLI**
Age (yr) Mean± *SD* [Min-Max, Median]	51.67±21.73 [27-68, 60]	53.33±12.70 [46-68, 46]	.914 ^{I}
Gender (%Total)			.400 ^{C}
Male	1 (33.33)	3 (100.0)	
Female	2 (66.67)	0	
IRSAD Percentile Mean ± *SD* [Min-Max, Median]	59.0±23.64 [42-86, 49]	58.0±15.13 [46-75, 53]	.954 ^{I}
IRSAD Quintile (%Total)			.796 ^{M}
Q1 (1-20)	0	0	
Q2 (21-40)	0	0	
Q3 (41-60)	2 (66.67)	2 (66.67)	
Q4 (61-80)	0	1 (33.33)	
Q5 (81-100)	1 (33.33)	0	
Language (%Total)			1.000 ^{C}
English at home	2 (66.67)	3 (100.0)	
English as a second language	1 (33.33)	0	
Employment status (%Total)			.739 ^{M}
Employed Full / part-time	1 (33.33)	1 (33.33)	
Seeking employment	0	0	
Not seeking employment	2 (66.67)	2 (66.67)	
If not employed or seeking employment (%Total)			
Student	1	1	
Retired/semi-retired	1	1	
Home duties	0	0	

Carer	0	0	
Other	0	0	
Education level (%Total)			.317 [M]
Tertiary	2 (66.67)	3 (100.0)	
Secondary	0	0	
Did not complete secondary	1 (33.33)	0	
Commonwealth support status (%Total)			
Centrelink Disability Support	0	0	
Disability Pension	0	0	
Neither	3 (100.0)	3 (100.0)	
Income $ household/year (%Total)			.184 [M]
<$35,000	1 (33.33)	0	
$36,000-$59,000	1 (33.33)	1 (33.33)	
$60,000-$99,000	1 (33.33)	0	
$100,000-$149,000	0	1 (33.33)	
>$150,000	0	1 (33.33)	
I prefer not to say	0	0	

[I]=Two-tailed Independent T-test using Levene's test for equality of variance to compare means where statistical significance is determined when *p*<0.05.

[C]=2x2 Crosstabs using two-tailed Pearson's Chi-squared analysis using Phi and Cramer's V nominal association, for those producing > 20% of cells with an expected count of less than 5, results from the two-tailed Fisher's Exact Test [a] are reported, statistical significance is determined where *p*<0.05.

[M]=Two-tailed nonparametric analysis using Mann-Whitney U test for ordinal variables comparing either ranked means or medians depending on distribution similarity. Asymptotic significance is determined when *p*<0.05. *1 participant in each group did not undertake the open card sort activity in Stage 1, therefore *n*=2 for these questions

Appendix 8.3B Participant demographics of individuals undertaking usability evaluation sessions

	Stage 2 Usability evaluation groups		***p* Value**
	Low *DHLI* (*n*=3)	**High *DHLI* (*n*=3)**	**Low vs High DHLI**
Use of Internet in last 6 months (%Total)	3 (100.0)	3 (100.0)	
Frequency of use in the last 6 months (%Total)			.317 ^{M}
Once a day	2 (66.67)	3 (100.0)	
Few days	0	0	
Once a week	0	0	
Once a month	0	0	
As the need arises	1 (33.33)	0	
Where do you primarily access the Internet			
Work	1	2	
Home - Computer	0	1	
Public - Computer	1	1	
Other	1	1	
Device Choice			
Desktop / Laptop computer	2 (66.67)	3 (100.0)	
Tablet (iPad)	1 (33.33)	0	
Help with online tasks (%Total)			.114 ^{M}
Help all of the time	0	0	
Sometimes depending on the task	2 (66.67)	0	
No help	1 (33.33)	3 (100.0)	
If help is required, who do you ask (%Total)			
Partner	0		
Son / daughter	0		
Sibling	0		

Neighbour or friend	0		
Friend/acquaintance outside the family	2		
Specific professional	0		
Live with a condition impacts technology and Internet use (%Total)			
Yes	0	0	
No	3 (100.0)	3 (100.0)	
Use of devices, technology or features to help with access or usability of information (%Total)			.361 [M]
Adaptive or assistive tech	0	0	
Change information on the screen	0	2 (66.67)	
I don't but would like too	2 (66.67)	0	
I don't need to	1 (33.33)	1 (33.33)	
"I find it difficult to know whether the health information I find online is trustworthy." (%Total)			*.034* [M]
Strongly disagree	0	2 (66.67)	
Disagree	0	1 (33.33)	
Neither disagree nor agree	3 (100.0)	0	
Agree	0	0	
Strongly agree	0	0	
Confidence level using technology to access the Internet to find health information (%Total)			.072 [M]
Extremely confident	0	2 (66.67)	
Somewhat confident	1 (33.33)	1 (33.33)	
Only a little confident	1 (33.33)	0	
Not at all confident	1 (33.33)	0	
Avoid tech-Internet	0	0	

[I]=Two-tailed Independent T-test using Levene's test for equality of variance to compare means where statistical significance is determined when $p<0.05$.

[C]=2x2 Crosstabs using two-tailed Pearson's Chi-squared analysis using Phi and Cramer's V nominal association, for those producing > 20% of cells with an expected count of less than 5, results from the two-tailed Fisher's Exact Test [a] are reported, statistical significance is determined where $p<0.05$.

[M]=Two-tailed nonparametric analysis using Mann-Whitney U test for ordinal variables comparing either ranked means or medians depending on distribution similarity. Asymptotic significance is determined when $p<0.05$. *1 participant in each group did not undertake the open card sort activity in Stage 1, therefore $n=2$ for these questions

Appendix 8.3C Participant demographics of individuals undertaking usability evaluation sessions

	Stage 2 Usability evaluation groups		*p* Value
	Low *DHLI* (*n*=3)	High *DHLI* (*n*=3)	Low vs High DHLI
e-HEALS Score Mean ± *SD* [Min-Max, Median]	21.0±2.646 [19-24, 20]	27.33±15.04 [10-37, 35]	.543 [I]
e-Heals SQ1. How useful do you feel the Internet is in helping you in making decisions about your health? (%Total)			*.034* [M]
Not useful at all	0	0	
Not useful	0	0	
Unsure if it useful	3 (100.0)	0	
Useful	0	1 (33.33)	
Very useful	0	2 (66.67)	
e-HEALS SQ2. How important is it for you to be able to access health resources on the Internet? (%Total)			.178 [M]
Not at all important	0	0	
Not important	1 (33.33)	0	
Unsure if important	1 (33.33)	1 (33.33)	
Important	1 (33.33)	0	
Very important	0	2 (66.67)	
***DHLI* Score Mean ± *SD* [Min-Max, Median]**	2.659±0.243 [2.381-2.833, 2.762]	3.730±0.099 [3.619-3.810, 3.762]	*.002* [I]
DHLI Operational skills Mean ± *SD* [Subscale 1a, 1b, 1c]	2.889±0.192	4.0±0.0	*.010* [I]
DHLI Information searching Mean ± *SD* [Subscale 2a, 2b, 2c]	2.667±0.333	3.333±0.333	.070 [I]
DHLI Evaluating reliability Mean ± *SD* [Subscale 2d, 2e, 2f]	2.556±0.509	3.889±0.192	*.013* [I]

DHLI Determining relevance Mean ± *SD* [Subscale 2g, 2h, 2i]	2.778±0.192	3.667±0.0	*.015*[I]
DHLI Navigation skills Mean ± *SD* [Subscale 3a, 3b, 3c]	2.667±0.0	3.889±0.192	*.008*[I]
DHLI Adding content Mean ± *SD* [Subscale 4a, 4b, 4c]	2.444±0.694	3.667±0.577	.079[I]
DHLI Protecting privacy Mean ± *SD* [Subscale 5a, 5b, 5c]	2.50±0.236	3.667±0.333	*.025*[I]
SCAS Mean ± *SD* [Min-Max, Median]	18.33±3.06 [15-21, 19]	14.333±2.081 [12-16, 15]	.134[I]
Survey Duration (secs) Mean± *SD* [Min-Max, Median]	3169.5±3202.49 [905-5434, 3169.5]	8159.0±12367.92 [800-22438, 1239]	.631[I]
CS Duration (secs)* Mean ± *SD* [Min-Max, Median]	827.50±702.16 [331-1324]	1091±596.80 [669-1513]	.725[I]
Created Categories* Mean±*SD* [Min-Max, Median]	2.50±0.71 [2-3]	7.0±0 [7-7]	*.012*[I]
Card sort activity completed (%Total)	2 (66.67)	2 (66.67)	
Card sort activity not attempted (%Total)	1 (33.33)	1 (33.33)	

[I]=Two-tailed Independent T-test using Levene's test for equality of variance to compare means where statistical significance is determined when $p<0.05$.

[C]=2x2 Crosstabs using two-tailed Pearson's Chi-squared analysis using Phi and Cramer's V nominal association, for those producing > 20% of cells with an expected count of less than 5, results from the two-tailed Fisher's Exact Test [a] are reported, statistical significance is determined where $p<0.05$.

[M]=Two-tailed nonparametric analysis using Mann-Whitney U test for ordinal variables comparing either ranked means or medians depending on distribution similarity. Asymptotic significance is determined when $p<0.05$. *1 participant in each group did not undertake the open card sort activity in Stage 1, therefore $n=2$ for these questions

Appendix 8.4A Observations and data captured from L-*DHLI* group narratives during semi-structured interviews

Low *DHLI*			
Mean Age (±*SD*) Range, Median	51.67±21.73 [27-68, 60]		
Gender M:F	1:2		
General Characteristics	• 2 English as the primary language, 1 English is second language (Thai primary) • 1 Employed full time, 1 Student, 1 Retired • 2 Tertiary educated, 1 Did not complete Secondary • Salary per year between $33,000 - $99,000 • 2 require some help depending on the task, 1 needs no help • 1 'Somewhat confident', 1 'Only a little confident' and 1 'Not confident at all' self-rated online ability		
Mean *DHLI* Score	2.659±0.243 [2.381-2.833, 2.762]		
Mean *DHLI* Operational skills	2.889±0.192	**Mean *DHLI* Navigation skills**	2.667±0.0
Mean *DHLI* Information searching	2.667±0.333	**Mean *DHLI* Adding content**	2.444±0.694
Mean *DHLI* Evaluating reliability	2.556±0.509	**Mean *DHLI* Protecting privacy**	2.50±0.236
Mean *DHLI* Determining relevance	2.778±0.192		
Mean SCAS±*SD* [Min-Max, Median]	18.33±3.06 [15-21, 19]		
Personal preference for technology when viewing or searching for online information:			
Device preference and purpose	Two different sets of end-users: Technological proficient and two less confident • Technological proficiency – Low *DHLI* due to language status: - Smartphone and desktop/laptop		

	• Technologically limited: - Uses the phone as a phone, and has a computer, preferences the tablet - Tablet – limited access to the Internet (affordability) at home, uses work Internet mainly - Don’t have a printer, so can not print pages out - Learning to listen to podcasts and streaming online videos - Download and print for reading later (sometimes) – especially more critical, more extended, or more in-depth information
Information interactions	• Technological proficiency – Low *DHLI* due to language status: - Competent at scrolling and reading the information, has proficient English that does not need to translate but does “Google” terms if unsure - No problems with navigation and can move more seamlessly between pages of the section • Technologically limited: - Annoyed at logins and passwords, prefers the least number of clicks if possible - Alternates back and forward until finds what is needed, not systematic and does not try a new path “*I like to have paper things to read as well”, for example, “if I were in this situation with somebody, I would try and get the booklet probably. I mean, you can read it on there, but I like to sit down and read it not on a computer*” [P6]
Interaction behaviours observed	• Technological proficiency – Low *DHLI* due to language status: - Confident user and no real issues with navigation or site structure - Easily navigated and had no issues with either menu or moved through the site efficiency - Reads each page thoroughly before moving on to the next page - Automatically scrolls to the bottom of the page • Technologically limited: - Navigation descriptors are not a problem; although drop-down menus are used, however buttons increase ease - LH Menu –not aware of location or function - Limited navigational ability, no scroll or pause to look around the webpage - Even though complete instruction is provided, but hesitates to ‘press’ on anything that has not been attempted previously – gets lost very easily “*I am pretty terrible at working a computer*” [P3] “*I am terrible at following instructions” ... reading these on the screen*” [P3] “*At least this one kinda opened and showed you a thing* [video on a webpage], *otherwise when you have got to do too many things, then I find it traumatic*” [P3]

	“*I would find it more traumatic trying to find or open something about the ‘thing’, than dealing with trauma with the thing*” itself [P3] “*I guess if it is not right for you, you would kinda go back and press the next one until you found something*” [P3]
Thoughts on Patients and Carers section	• Technological proficiency – Low *DHLI* due to language status: - For people with English as a second language, medical and technical terms are translated ‘easily’ using an online translator More likely, the amount of text is an issue, and they would use Google Translate “*For people who are not bilingual, it is difficult for them for them to use this site*” [P2] “*It is difficult for someone who is using another language and will be an obstacle for them*” [P2] • Technologically limited: - The menu structure was confusing – only noticed LH menu categories after looking for a while “*It is a bit tricky, this one* [website structure]” [P6]
Summary	• Language and comprehension of English was an issue and was compounded by palliative care language and length/amount of information presented • Experienced issues with the vertical drop-down (flip) menu – more functional than anything else • Two participants had not used Zoom previously • Need to structure information to make it easy to find • Frustrated easily, annoyed for not being able to navigate and find the information • Finds simple structure sites easy to use and are more likely to persist – motivation to learn new skills “*I am not mad about all of this stuff, but I do what I have to do*” [P6] • Skim navigation method – along the surface of the site without thinking or knowing how to get deeper into the site to find information

Appendix 8.4B Observations and data captured from H-*DHLI* group narratives during semi-structured interviews

High *DHLI*			
Mean Age (±*SD*) Range, Median	53.33±12.70 [46-68, 46]		
Gender M:F	3:0		
General Characteristics	• English as the primary language • 1 Employed full time, 1 Student, 1 Retired • 3 Tertiary educated • Salary per year between $36,000 - >$150,000 • No help required with Internet tasks • 2 'Extremely confident', 1 'Somewhat confident' self-rated online ability		
Mean *DHLI* Score	3.730±0.099 [3.619-3.810, 3.762]		
Mean *DHLI* Operational skills	4.0±0.0	**Mean *DHLI* Navigation skills**	3.889±0.192
Mean *DHLI* Information searching	3.333±0.333	**Mean *DHLI* Adding content**	3.667±0.577
Mean *DHLI* Evaluating reliability	3.889±0.192	**Mean *DHLI* Protecting privacy**	3.667±0.333
Mean *DHLI* Determining relevance	3.667±0.0		
Mean SCAS±*SD* [Min-Max, Median]	14.333±2.081 [12-16, 15]		
Personal preference for technology when viewing or searching for online information			
Device preference and purpose	• Preference for desktop/laptop or mobile phone • Smartphone for everything but prefer desktop for academic or professional activities • Smartphone as a phone will use this for short quick searches (such as meanings for words) but will send links to the desktop or laptop to read		

	• Smartphone searching but would use the desktop as a method of reading more in-depth information – will not read hard to access or read the information on • No or limited tablet use, table considered useless with not large enough screen “*I don’t like things hidden behind menus*” [P5] and is a function of age and previous experience with books and paper.
Information interactions	• If time allows, participants will download information to read later • Preference for written information over videos or images as easy to quickly move though
Interaction behaviours observed	• Easily navigated and had no issues with either menu or moved through the site efficiency • Read each page thoroughly before moving on to the next page • Automatically scrolls to the bottom of the page • Google search to get to the site that is required, targeted search • Most likely to navigate via a search engine and then systematically look for information
Thoughts on Patients and Carers section	• Direct links are required, and there needs to be some thought about what is most important, and this information must be up front and easy to find for people who can’t navigate • COVID specific information indicates that this site is only servicing Victoria “*Too much information for new visitors especially for those who are coming for the first time – would feel overwhelmed and perhaps feel pressure to read everything when perhaps they need a little information to start with and then give them an option to read more later when they need it*” [P1] • Colour and images were recognised as being a helpful mechanism to differentiate features
Summary	• Very confident user of websites and did not have any problems with the website section • Uses methodical approach to interacting with the section, was not flustered with the amount of information presented • Main issues with information structure, site structure and information architecture and identification of the audience for the site – recognises the need to restructure by ‘type of visitor’ • Identified the issue with vertical menu flip over • Confident searcher but did not like NOT being able to find information • Frustrated by levels in the site and was confused by the amount of information in the section • Caught up on pages or landmarks that did not provide the information that was being looked for

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Dear Professor Shanks,
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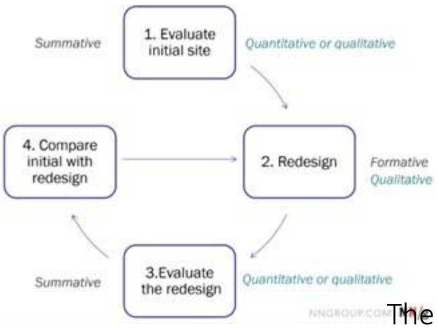

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