

Digital Health in Lymphoedema Care

By

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ABSTRACT

Background

Lymphoedema is a chronic inflammatory condition affecting millions of people globally. The condition is characterised by the accumulation of fluid, fibrosis, and adipose tissue in areas of compromised lymphatic drainage. The condition results in swollen limbs, causing discomfort and distress, thereby significantly diminishing patients' quality of life. If left untreated, lymphoedema can lead to severe physical sequelae, including limb disfigurement and skin infections known as cellulitis. Traditional care is limited by its dependence on in-person visits which can hinder timely intervention and adequate treatment.

Given the profound impact of lymphoedema on patients' quality of life and the severe complications which can arise when left untreated, forms of innovative care which can enhance the care of this chronic condition are warranted. Digital health, which encompasses information and communication technologies delivered through electronic health (eHealth) modalities such as computer-based interventions, mobile health (mHealth), ubiquitous health (uHealth) and telehealth, provides an innovative approach to the care of this chronic condition.

The adoption of innovative telehealth solutions surged during the COVID-19 pandemic, enabling lymphoedema patients to continue receiving care despite enforced lockdowns. Prior to this period, telehealth and other eHealth modalities had been scarcely researched in the context of lymphoedema care.

Globally, there is a rapid and widespread adoption of eHealth modalities, extending beyond telehealth to include technologies such as robotics, wearable devices, health information systems, and applications of artificial intelligence. Additionally, uHealth technologies are emerging, with research increasingly focused on the continuous and personalised monitoring of individuals in their everyday lives. Despite these advancements in other health domains, the utilisation of digital health in lymphoedema care may be limited and may not have reached its full potential.

Method and results

Research from 2021 to 2024 was conducted to address the question, "How is digital health being utilised in the prevention, diagnosis, assessment, and treatment of lymphoedema?" It was not known how many types of eHealth modalities were being used in lymphoedema care. It was also unclear whether contemporary challenges in digital health, such as issues of accessibility, appropriateness, and applicability, were affecting the adoption and use of digital health technologies in lymphoedema care.

A literature review was first conducted to explore the concepts of "digital health" and "eHealth." The review revealed a lack of consensus in terminology, with both terms being used interchangeably by researchers. To address this issue, a distinction between the terms was proposed, culminating in a publication designed to assist researchers in navigating the complexities of terminology within this field. "Digital health" was identified as the umbrella term, encompassing "eHealth" as a subset focused on the application of electronic health modalities, including emerging fields such as advanced computing sciences, big data, genomics, and artificial intelligence.

Subsequently, classification systems for digital health were reviewed in the literature, and two were applied to the context of lymphoedema care: the Population, Intervention, Comparator, Outcome, Timing, Setting, Communication, Technology, and Context (PICOTS-ComTeC) Framework and the World Health Organization's classification of digital health interventions. This analysis offered a foundational understanding of the broad scope of eHealth implementation in lymphoedema care across both published and unpublished literature.

A narrative review was then conducted revealing examples of how eHealth was being used across the spectrum of prevention, diagnosis, assessment, and treatment of lymphoedema. Fourteen use cases were found across all phases of the spectrum of care. Examples included robotic-assisted surgery to reduce the likelihood of lymphoedema after lymphadenectomy, machine learning to predict patients at risk of filarial-related lymphoedema, and a novel wearable device prototype designed to provide manual lymphatic drainage.

A mixed methods study on a sample of Australian Lymphoedema Practitioners was then conducted to understand if, and how, lymphoedema practitioners were using digital health. Fifteen different types of eHealth were reported including eHealth records, ePrescribing, eReferrals, eResults, health apps, telehealth, applications of artificial intelligence, mHealth, health knowledge management, clinical decision support systems, healthcare information systems, digital games, wearable electronic devices, instructive online information and infoveillance.

Practitioners commonly utilised eRecords, mHealth, healthcare information systems, and instructive online information. However, more advanced eHealth technologies, such as robotics, were not reported as being in use. Although telehealth is not a new concept, its application in lymphoedema care was limited by challenges in conducting specific assessments remotely. Additional barriers to the adoption of digital health were identified through the themes of data security concerns, the time required for training, a lack of available digital solutions and immaturity of this field, insufficient skills or awareness and patient acceptance.

Focussing on treatment alone, a systematic review was conducted to understand the impact of digital health interventions on patients. Instructive online information, telehealth, and digital gaming were found to have been used to positively impact lymphoedema outcomes, self-care, psychosocial outcomes, and disease comprehension.

The research then aimed to understand contemporary digital health issues by investigating health system challenges and exploring whether and how digital health interventions were being used to address and overcome these obstacles. Based on the World Health Organization's description of health system challenges, Lymphoedema Practitioners reported issues related to information, availability, quality, acceptability, utilisation, efficiency, cost, and accountability. Digital health was reportedly used in a number of ways to impact patients, providers, health system managers and data services.

The contemporary concepts of accessibility, appropriateness, and applicability were then explored through case studies and perspective pieces. Accessibility was examined by investigating the impact of disabilities, such as blindness, on lymphoedema training and clinical practice. It was found that a lack of digital accessibility could stop digital content and medical technology being accessed and significantly impact the ability of health professionals with disabilities to train and work in lymphoedema care.

Appropriateness was evaluated by testing the ability of generative artificial intelligence driven chatbots to produce clinically appropriate information. It was determined that the chatbots mostly provided appropriate clinical information comparable to that which would be provided online through reputable industry websites. The information derived was not superior to that of an experienced lymphoedema practitioner in aspects of differential diagnosis. In addition to this, some of the information provided by the chatbot was incorrect.

Applicability was examined by investigating the practical integration of digital tools into various lymphoedema care real-world settings. Digital health was effectively utilised in various ways: social media was leveraged for patient advocacy, a digital community of practice supported continuing professional development, telehealth facilitated virtual wound and lymphoedema services, and instructive online information provided digital training for staff, patients, and practitioners.

The applicability of eHealth was further evaluated by developing digital research prototypes including a chatbot, educational app, online course, serious game, and digital assessment tool. These prototypes aimed to translate insights from earlier thesis activities into impactful research products which could inspire future research. Five research products were successfully developed, with many valuable lessons learned during the prototype development process.

Research contribution

The works contained within this thesis are original and innovative. The unique contribution to research is a comprehensive description of how digital health interventions are being used in the prevention, diagnosis, assessment, and treatment of lymphoedema. Through sixteen publications and the development of five digital research prototypes this thesis represents a significant contribution to the understanding and application of digital health in lymphoedema care, addressing a critical gap in the existing literature.

The findings from the various works contained within this thesis were disseminated through presentations at Lymphology and Phlebology conferences, with the aim of assisting Lymphoedema Practitioners and Phlebologists in understanding how to best leverage digital health.

It is hoped however that the impact of this thesis extends beyond lymphoedema care. The framework for understanding digital health is applicable to all healthcare stakeholders. Additionally, the insights gained from developing digital prototypes, like the chatbot, may have benefits beyond the healthcare sector. For example, the lessons learned from building the chatbot prototype could benefit anyone looking at developing a website which incorporates chatbot technology.

Conclusion

Digital health was utilised in various aspects across the prevention, diagnosis, assessment, and treatment of lymphoedema, with eighteen eHealth modalities identified. Advanced eHealth modalities like robotics and applications of artificial intelligence were reported in research environments but were not yet fully integrated into clinical practice. Telehealth, despite its established presence, still faced adoption barriers. Issues related to accessibility, appropriateness, and applicability of digital health in lymphoedema care presented both challenges and opportunities. Digital health has yet to achieve its full potential in this field, underscoring the need for further research to fully harness its capabilities in lymphoedema care.

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. and 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 A Mangion

Date 13th November 2024

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In my first year of candidature, during a trip to the rural South Australian town of Whyalla, I experienced the next level of Professor Piller's unwavering dedication to lymphology. Together with his devoted wife, we drove for over six hours to volunteer our time, offering screening services and imparting knowledge about lymphoedema to both patients and practitioners. Our small clinical team efficiently attended to helping more than seventy patients in a single day. After one of the busiest clinical days of my Physiotherapy career, I observed that Professor Piller still had the same inspiring energy that I had admired when he was on stage. His enjoyment in genuinely helping people was evident.

The experience in Whyalla highlighted that when you do what you love, and are surrounded by the right people, you will have the energy and enthusiasm to excel in your work whilst positively impacting the lives of everyone around you.

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PUBLICATIONS

Below is a list of 16 publications, arranged in the order of appearance within this thesis, developed during the candidature from 2021-2024 at Flinders University.

Published

- Mangion A, Piller N. The Use of eHealth and Digital Health Technology for Lymphoedema Care. *Journal of Lymphoedema*. 2023;18(1):22-27
- Mangion A, Ivasic B, Piller N. The Utilization of e-Health in Lymphoedema Care: A Narrative Review. *Telemedicine and eHealth*. 2024;30(2):331-340
- Mangion A, Ivasic B, Piller N. A Systematic Review of eHealth and mHealth Interventions for Lymphoedema Patients. *Clinical eHealth*. 2024;7:120-132
- Mangion A, Murdoch K, Piller N. Accessibility in Lymphoedema Practice: Digital and Practical Therapy Considerations. *Journal of Lymphoedema*. 2024;19(1):30-33
- Mangion A, Piller N. Generative Artificial Intelligence in Lymphoedema Care. *Journal of Lymphoedema*. 2024;19(1):57-59
- Mangion A, Piller N. Generative Artificial Intelligence and ChatGPT as a Chatbot for Chronic Oedema Information. *Wounds International*. 2024;15(2):14-17
- Mangion A, Piller N. Generative Artificial intelligence via ChatGPT for the Early Intervention of Breast Cancer-Related Lymphoedema. *Wounds International*. 2024;15(3):10-13
- Mangion A, Piller N. Generative Artificial Intelligence for Differential Diagnosis of Lymphoedema and Lipoedema. *Wounds International*. 2024;15(3):21-26
- Mangion A, Freeland R, Piller N, Hayes S, Treadgold C, Koelmeyer L, Reul-Hirche H. Encouraging exercise: The Role of the ENCORE Program in Supporting Breast Cancer Care. *Journal of Lymphoedema*. 2024;19(1):52-56
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- Mangion A, Piller N. What is Digital Health, eHealth, uHealth and Healthcare 4.0? Submitted to Informatics and Health. July 2024
- Mangion A, Bareham M, Piller N. Social Media and Patient Advocacy in Lymphoedema Care; A Perspective Piece with Australian of the Year, South Australian Local Hero 2022. Submitted to Informatics and Health. July 2024
- Mangion A, Svensson-Florida B, Piller N. Digital Community of Practice in Lymphoedema Care. Submitted to Informatics and Health. July 2024
- Mangion A, Leahy C, McCormack B, and Piller N. Virtual Wound and Lymphoedema Services – An Exploration of Qualitative Perspectives from Virtual Practitioners. Submitted to Informatics and Health. August 2024

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The Australian Institute of Lymphoedema, which was under sole directorship during the completion of this candidature, provided funding of conference flights and accommodation as well as software licencing fees.

FREQUENTLY USED TERMS

Acronyms have been intentionally minimised in this thesis to reduce reading complexity and to enhance accessibility for a diverse audience. Further definitions of terms can be found in Chapters Three, Four and Seven.

Applications of Artificial Intelligence: The use of artificial intelligence (AI) technologies in healthcare.

Breast Cancer-Related Lymphoedema (BCRL): A type of lymphoedema arising after breast cancer treatment.

Bioimpedance Spectroscopy (BIS): A medical device which measures fluid in bodily tissues.

Chatbot: Digital software that can establish a sequential conversation with humans.

Clinical Decision Support System: Digital tools designed to assist healthcare providers in making clinical decisions.

Digital Games: An interactive software-based entertainment activity played on electronic devices.

Digital Health Interventions (DHIs): Digital functionality delivered through eHealth modalities for health purposes such as improving diagnosis, treatment, and patient management.

Electronic Health (eHealth): Healthcare delivered electronically in various modalities.

eHealth Modality: A specific type of digital tool used to deliver healthcare services, information, or interventions.

eHealth Records: Digital versions of a patient's paper chart, known as Electronic Health Records (EHRs) or Electronic Medical Records (eMRs).

eLearning: A form of Instructive Online Information where education content is delivered online.

eLibrary: Electronic storage of information. A form of knowledge management.

ePrescribing: The process of electronically generating and transmitting some form of a prescription.

eReferrals: An electronic process where a healthcare provider sends a referral to another provider.

eResults: The electronic delivery of health results.

Health Apps: Mobile or computer-based applications designed to promote health and wellness, track health metrics, and / or provide healthcare-related information.

Health Knowledge Management: The systematic management of health-related knowledge.

Healthcare Information Systems: Integrated digital systems used to collect, store, manage, and transmit healthcare information.

Information and Communication Technology (ICT): Infrastructure and components which can store, process, and transmit information.

Instructive Online Information: Educational content delivered online.

Infoveillance: The systematic collection, analysis, and interpretation of data obtained from online sources.

Lymphoedema: A chronic medical condition involving swelling in bodily tissues due to lymphatic system malfunction or overwhelm.

Manual Lymphatic Drainage (MLD): A special form of massage designed to drain excess fluid from bodily tissues into the lymphatic system.

Mobile Health (mHealth): Health delivered through a portable mobile device such as a mobile phone.

Robotics: Machines that perform tasks and rely on computer systems for control, programming, and data processing.

Serious Games: Games that deliver educational content whilst still being fun.

Telehealth: The use of video or other digital technology to remotely deliver care.

Ubiquitous Health (uHealth): The integration of healthcare services and monitoring into everyday environments.

Wearable Electronic Devices: Portable electronic devices worn on the body.

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CHAPTER ONE: INTRODUCTION AND THESIS OBJECTIVES

Chapter overview

This chapter outlines the thesis structure and aims.

Highlights

The highlights of this chapter include:

- Presenting the structure, objectives and research activities planned for inclusion in this thesis
- Demonstration of the research outcomes hierarchy and research logic model
- The provision of definitions of contemporary issues impacting digital health including accessibility, appropriateness and applicability
- The inclusion of a list of research activities performed in addition to research presented within this thesis such as lymphoedema-related volunteer outreach and conference presentations.

Thesis overview

Widespread adoption of digital health without research

The COVID-19 pandemic significantly accelerated the adoption of digital health, leading to the replacement of routine face-to-face lymphoedema care with telehealth as an innovative means of connecting with patients remotely.⁽¹⁾ Despite the widespread integration of digital health, there has been a notable absence of research on digital health implementation in lymphoedema care and a lack of guidance on how to best leverage digital technology for this condition. This gap in research underscores the urgent need for a thorough evaluation of digital health in lymphoedema care to ensure the effective and optimised use of technology in improving patient outcomes. Investigating digital health and electronic health (eHealth) methods is crucial for avoiding suboptimal implementation and establishing general guidelines to further develop digital health interventions (DHIs).⁽²⁾

Thesis structure

This thesis contains twenty-two chapters. This chapter provides the thesis aims and describes how the research will achieve the desired objectives. **Chapters Two to Four** describe what lymphoedema and digital health are. **Chapters Five to Six** explore the classification of digital health and then how to apply these classification systems to lymphoedema care. **Chapters Seven to Nine** describe where digital health is being used in the prevention, diagnosis, assessment and treatment of lymphoedema. **Chapter Ten** explores health system challenges. **Chapter Eleven** explores digital accessibility within lymphoedema training and clinical practice. **Chapter Twelve** explores appropriateness of generative artificial intelligence. **Chapters Thirteen to Twenty-One** explores applicability through case studies and research prototypes. **Chapter Twenty-Two** concludes this thesis and outlines the total number of eHealth modalities discovered within this research.

Aims

Overarching aim

This thesis aims to comprehensively describe how digital health is being used in the prevention, diagnosis, assessment, and treatment of lymphoedema.

Primary objective

The primary objective of this thesis is to quantify the types of eHealth modalities being used at different stages of lymphoedema care, namely prevention, diagnosis, assessment, and treatment.

Secondary objective

The secondary objective is to explore contemporary issues including accessibility, appropriateness and applicability.

Research roadmap and hypotheses

The research roadmap is illustrated in Figure 1. The roadmap starts with a statement of the problem, then the proposal and the research which needs to be conducted in order to answer the problem. This roadmap ultimately leads to achievement of the thesis' overarching aim.

The research hypotheses were, firstly, that the number of eHealth modalities used in lymphoedema care is limited, and secondly, that digital health may not have reached its full potential. The determination of whether the use is "limited" will be based on the reported number of eHealth modalities currently in use.

Research contribution

This research will make a conceptual and practical contribution to the field of lymphoedema care by:

- I. Understanding the various definitions of digital health and eHealth
- II. Exploring the various classification systems of eHealth and relating this to lymphoedema care
- III. Investigating what, why, when, where, and how eHealth technologies are being used in lymphoedema care in published literature and in current clinical practice
- IV. Describing contemporary issues in the field of digital health
- V. Exploring case studies of successful implementation in lymphoedema care.

Outcomes hierarchy and research logic model

Outcomes hierarchy

An outcomes hierarchy illustrating the assumed cause-and-effect relationships between research outcomes was developed (Figure 2).^(3, 4) The outcomes hierarchy started with an understanding of lymphoedema and digital health and continued through to ultimately providing direction for future research. The long-term vision, beyond the scope of this thesis and illustrated with the dotted line, would be to enable Lymphoedema Practitioners and researchers to optimally leverage digital health for improved lymphoedema care.

Research logic model

Logic models are used to simplify complex concepts and relationships during research planning and implementation.⁽⁵⁾ A research logic model (Figure 3) was developed to describe the desired outcomes and clarify how the research would achieve outcomes by linking inputs, activities, outputs, and short-term, intermediate, and long-term outcomes.⁽⁶⁾

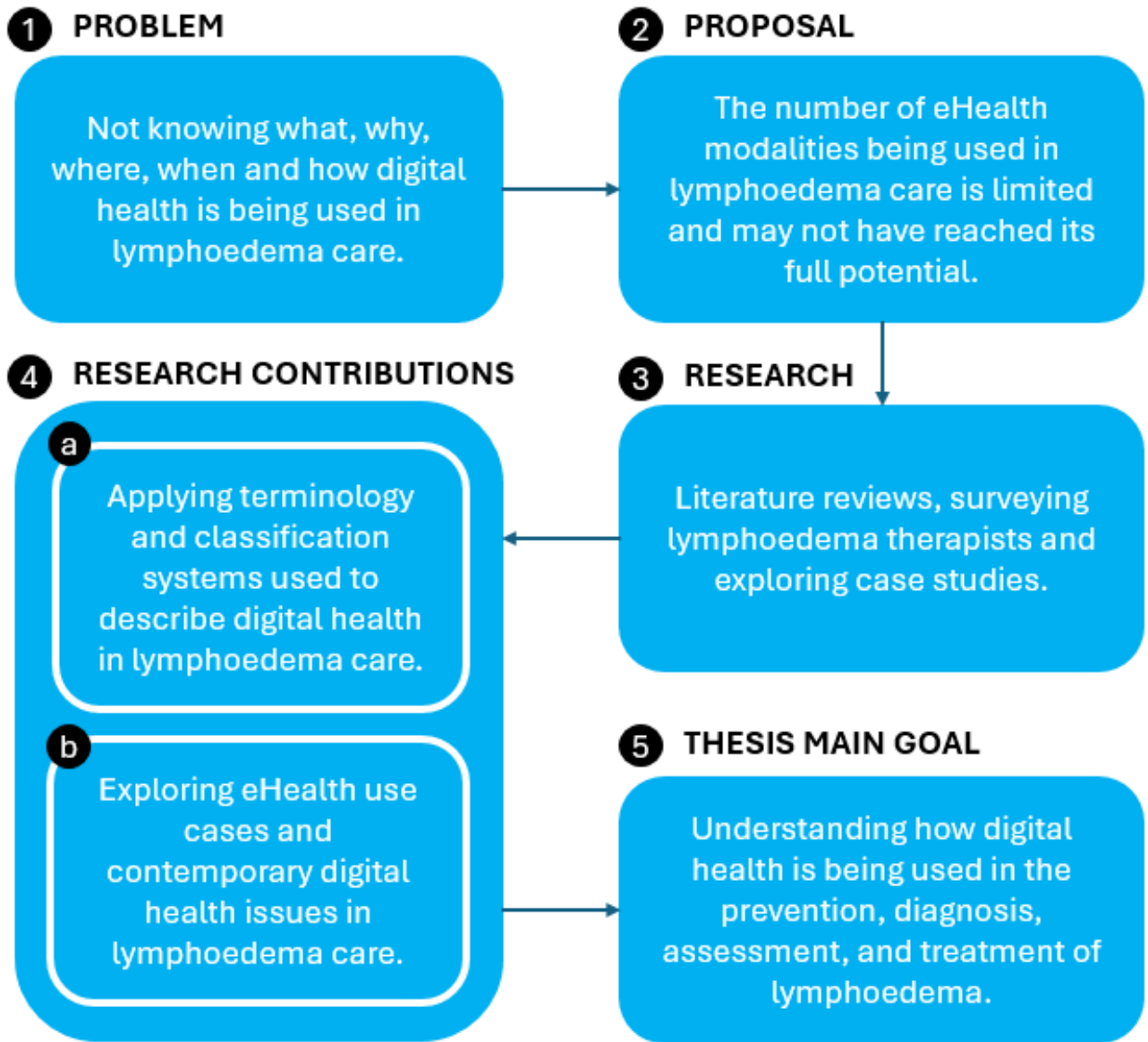


Figure 1 - Research roadmap

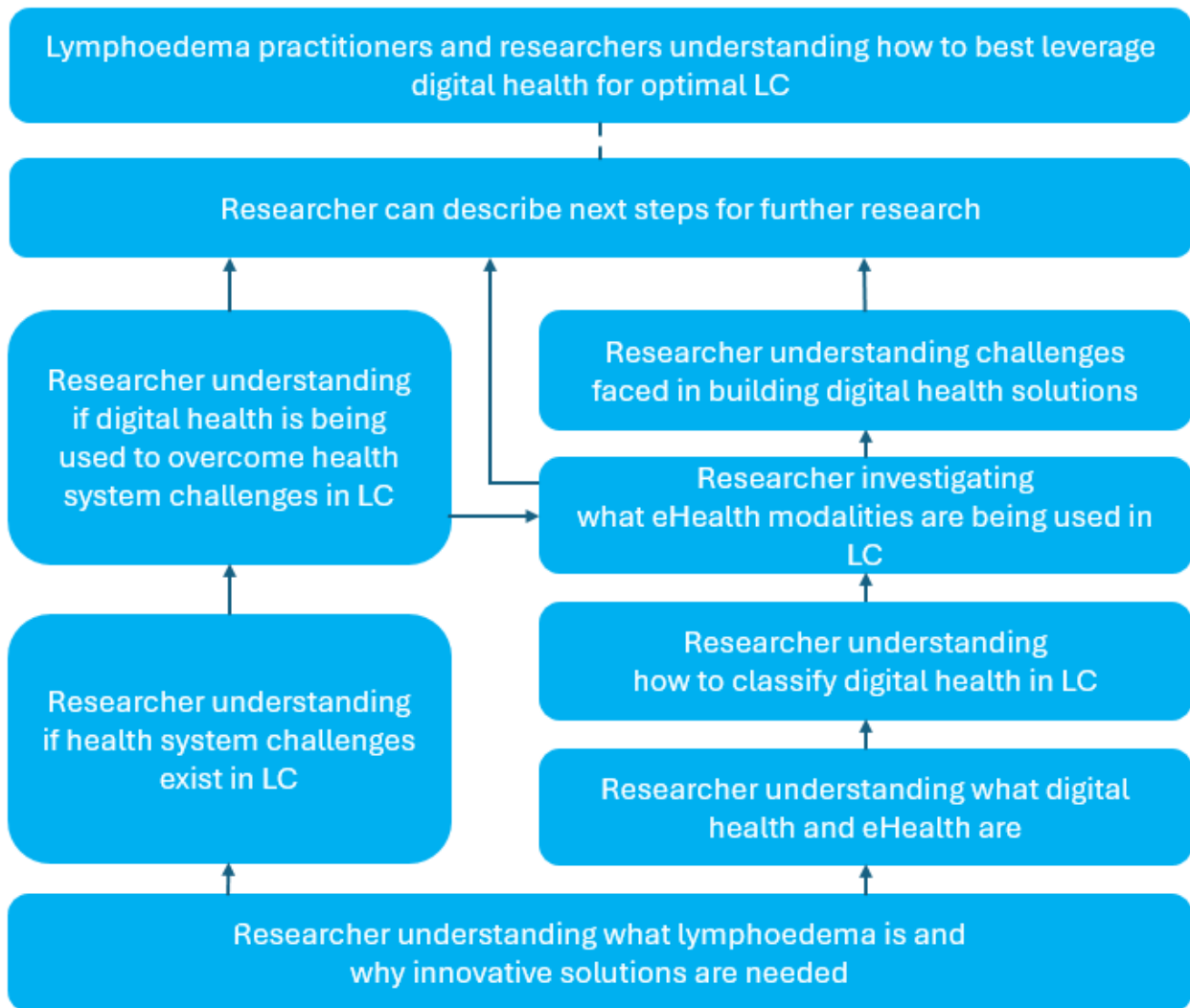


Figure 2 - Outcomes hierarchy

LC = lymphoedema care

Thesis aim:

Understand how digital health is being utilised for the prevention, diagnosis, assessment, and treatment of lymphoedema

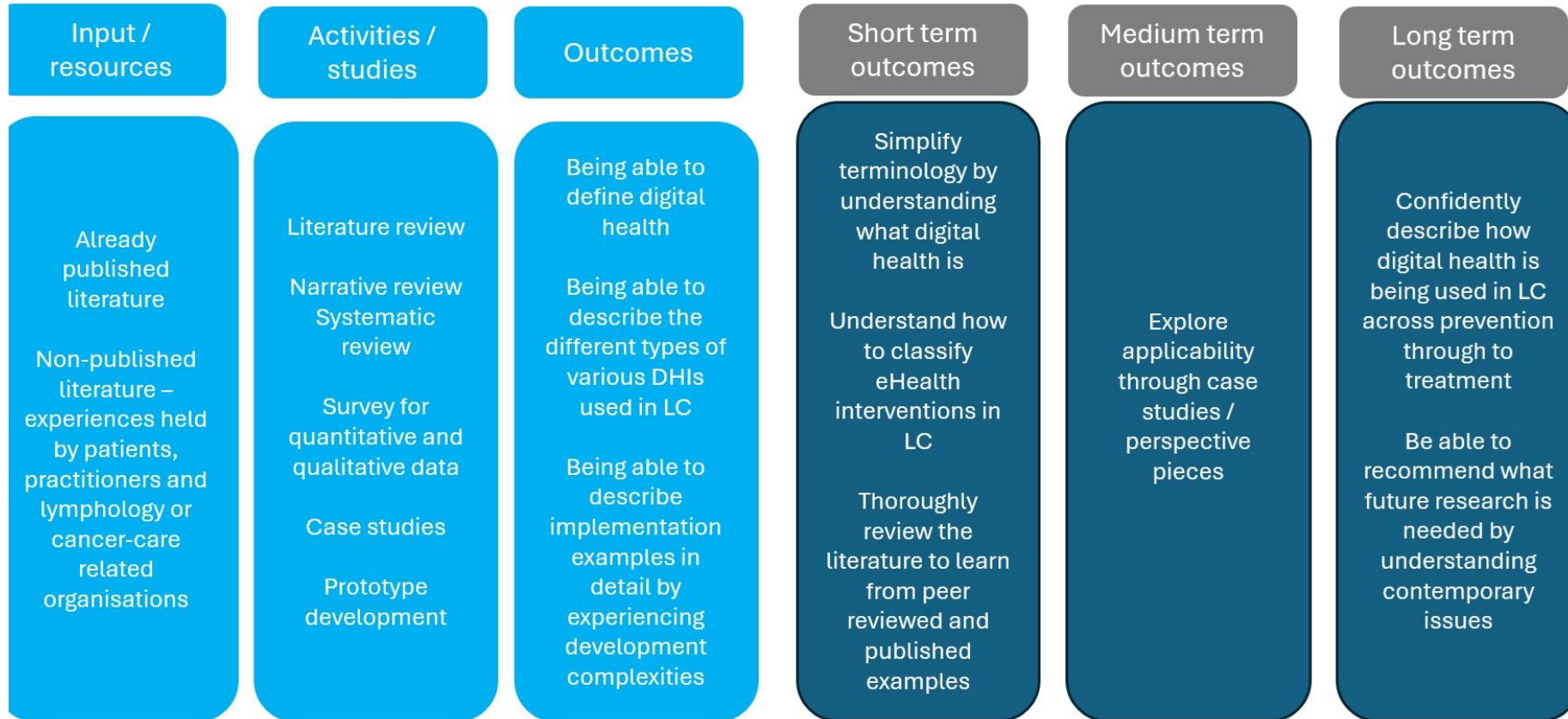


Figure 3 - Research logic model

LC = lymphoedema care

Planning publications and research activities

Planning publications to support achieving the overarching aim

Planning the research involved initially asking several questions:

- What is digital health?
- Where and why is digital health being utilised in lymphoedema care?
- How could digital health be effectively implemented in lymphoedema care?

Planning occurred for how each of the questions could be answered through research projects (Figure 4).

Accessibility, appropriateness and applicability

The question of “How could digital health be effectively implemented in lymphoedema care?”, encompassed a broad and complex scope. Consequently, it was decided that this thesis would focus on three aspects of digital health: accessibility, appropriateness, and applicability. These aspects were selected as a foundational step towards addressing the overarching question.

Instead of evaluating the accessibility, appropriateness, or applicability of eHealth modalities, research aimed to explore contemporary issues related to these concepts. One such example of a contemporary issue was the use of generative artificial intelligence as a clinical decision support system, examining its potential role and appropriateness in the context of lymphoedema care. (Figure 5). It was hypothesised that reaching a definitive conclusion on the accessibility, appropriateness, and applicability of eHealth modalities would not be feasible, as this thesis represents only a small contribution to the larger body of work needed to make such a determination.

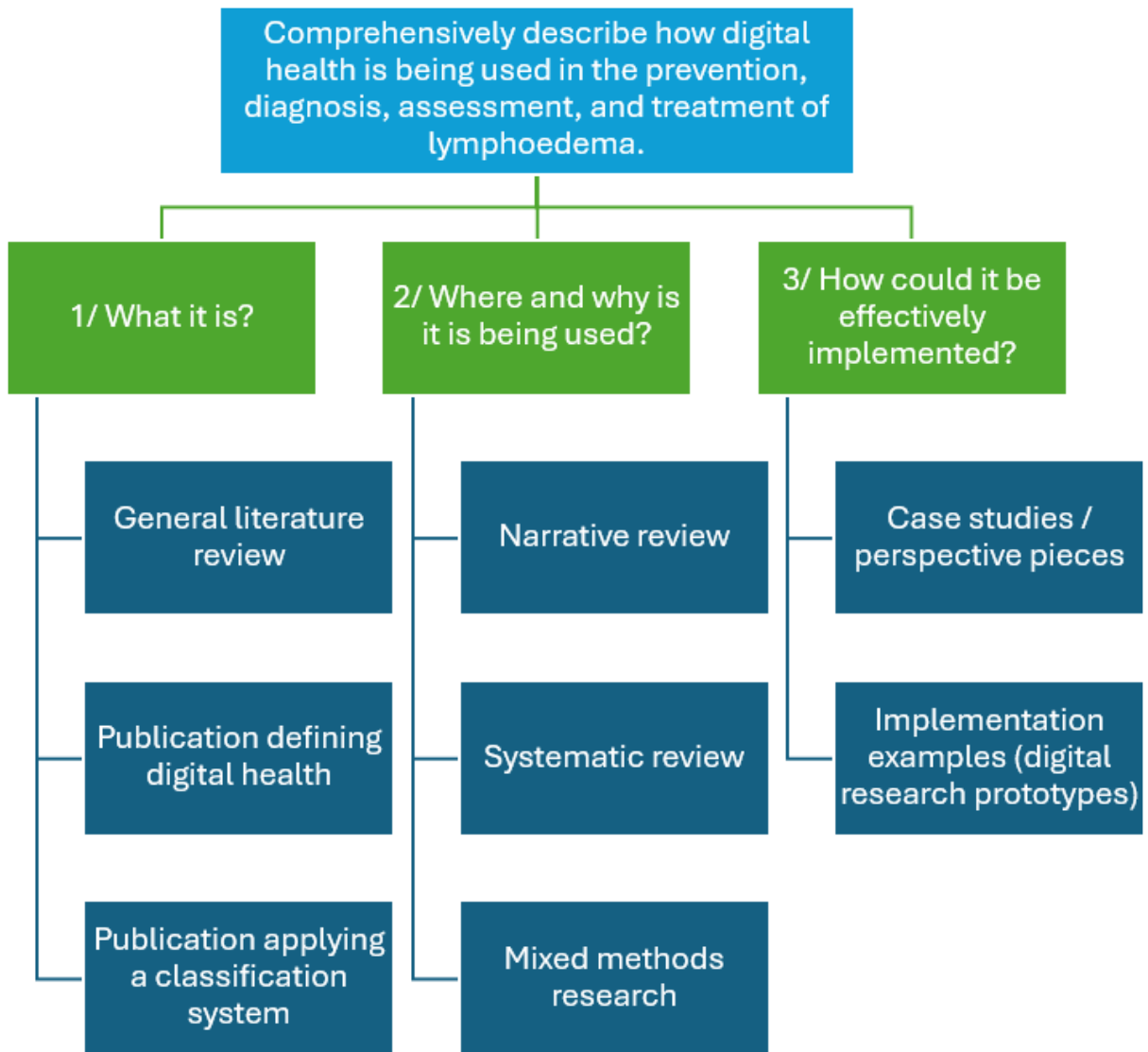


Figure 4 - Planning publications and research activities to answer the research question

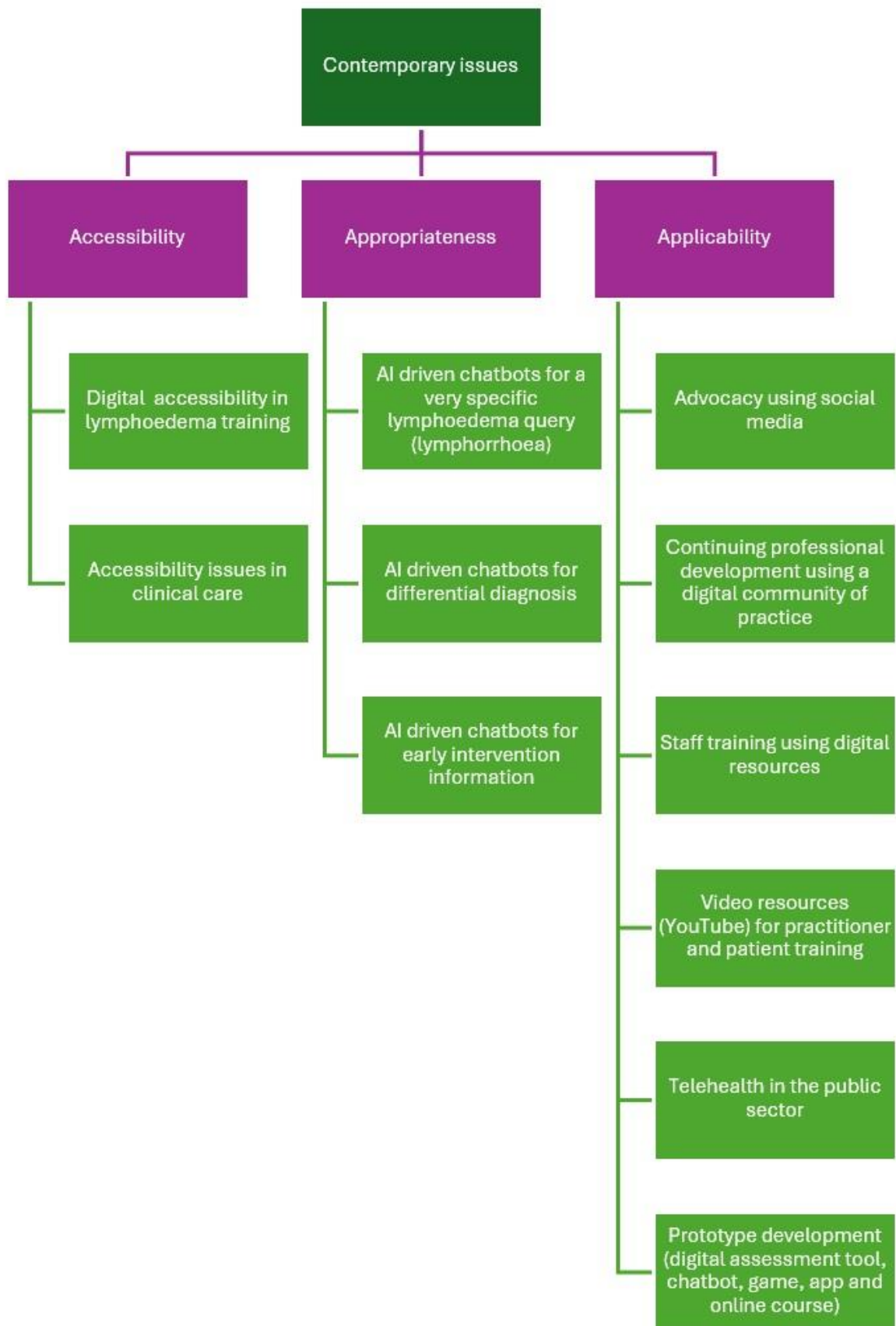


Figure 5 - Planning case studies for accessibility, appropriateness and applicability

[AI = artificial intelligence]

Accessibility

Health equity is the principle that drives a commitment to reducing—and ultimately eliminating—disparities in health.⁽⁷⁾ Individuals with disabilities, such as those with mobility impairments, deafness and blindness, or intellectual disabilities, encounter numerous challenges in attaining optimal health and accessing high-quality healthcare.⁽⁸⁾ Data indicates that, compared to individuals without disabilities, those with disabilities have reduced access to healthcare, higher rates of depression and anxiety, and seek medical care more often.^(9, 10) Consequently, it is illogical to design health systems without considering the needs of those who will depend on them the most, highlighting the critical importance of accessibility.

Accessibility is a broad reaching concept involving five dimensions including affordability, acceptability, availability, geographic accessibility and the appropriateness and suitability of health services.⁽¹¹⁾ Given the scope is so broad, it was decided that certain aspects of accessibility would be focussed on within this thesis, namely digital accessibility in both lymphoedema training and clinical practice.

Digital accessibility is defined as “...designing digital systems and services to enable access for individuals, including those with disabilities, including visual, auditory, motor, or cognitive impairments.”⁽¹²⁾

Research aimed to answer the question, “What digital accessibility factors could stop digital health being used?” This was best explored by understanding the perspectives of individuals who face significant barriers when digital content is not accessible. To investigate this, this thesis aimed to document the experiences of a blind health professional navigating both lymphoedema training and clinical practice. Gaining insight directly from someone personally affected by accessibility issues allowed for a unique research opportunity. Similar to patient-centred research, this approach provided a direct perspective on the challenges faced, enriched by lived experience.

Appropriateness

As a highly contemporary issue, the use of artificial intelligence (AI) driven chatbots have recently emerged. “The OpenAI's chatbot allegedly gained more than 1 million users in the first few days after its launch and 100 million in the first 2 months, positioning itself as the fastest-growing consumer application in history.”⁽¹³⁾ In aspects of AI supporting healthcare, appropriateness is essential given “...the goal of artificial intelligence is to enable machines to mimic human thoughts and behaviours, including learning, reasoning, predicting, and so on.”⁽¹⁴⁾

Appropriateness means the degree to which a particular intervention, method, or outcome is suitable for the intended purpose or context. Weiner et al (2017) define appropriateness as "...the perceived fit, relevance, or compatibility of the innovation or evidence-based practice for a given practice setting, provider, or consumer; and/or perceived fit of the innovation to address a particular issue or problem."⁽¹⁵⁾

In this thesis, appropriateness was considered to mean the degree to which AI was able to produce suitable responses for the intended purpose, such as patient education or differential diagnosis. This thesis aimed to answer the question, "Can AI driven chatbots deliver suitable responses contextualised to lymphoedema care?" To investigate this a series of investigations were designed to test emerging AI driven chatbot technology.

Applicability

Atkins et al (2010) defined applicability "...as the extent to which the effects observed in published studies are likely to reflect the expected results when a specific intervention is applied to the population of interest under "real-world" conditions." Research should address how specific aspects of the design of the study affected the final population or the quality of the intervention, and how greatly (and in which direction) these may differ from more representative populations in practice.⁽¹⁶⁾ In later research, applicability was defined by Sekhon et al (2017) as "A multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention."⁽¹⁷⁾

For digital health technologies to be effective, they must be applicable to various healthcare scenarios and seamlessly integrate into existing healthcare systems. This involves ensuring that digital tools are user-friendly for both patients and healthcare providers and that they address specific health needs. Design and usability, stakeholder engagement and uptake, project management and resourcing, process and implementation, and evaluation are all important considerations.⁽¹⁸⁾

In this thesis, applicability was considered to mean the relevance or suitability of research findings or interventions to lymphoedema care. The two questions that aimed to be answered were, "What digital health interventions have, and are, being applied in lymphoedema care?" and "How can this research be translated into lymphoedema-related digital research products?"

This thesis aimed to explore applicability in lymphoedema care in several ways:

- Through the narrative and systematic review revealing various use cases.
- Through detailed case studies/perspective pieces demonstrating successful implementation in the “real-world”.
- Finally, through translational research by applying the knowledge gained from within this thesis to digital prototypes. It was hypothesised that rigorous engagement in the development of digital health products would yield valuable insights more reflective of “real-world” conditions, as the process involved practical application rather than purely theoretical exploration.

With all of this in mind, the complete research plan is pictured below (Figure 6). At each stage of planning, a question was asked which aimed to be answered through research:

- What is digital health? Answered through a publication defining digital health.
- Where and how is digital health being utilised in lymphoedema care? Answered through a narrative and systematic review, application of classification systems and mixed methods research.
- What are accessibility issues? Answered through accessibility case studies.
- Is current emerging technology appropriate? Answered through publications on generative artificial intelligence.
- What are real world examples of implementation? Answered through case studies exploring applicability in real-world settings.
- How can this research be translated into digital research products? Answered through research prototype development.

Thesis plan

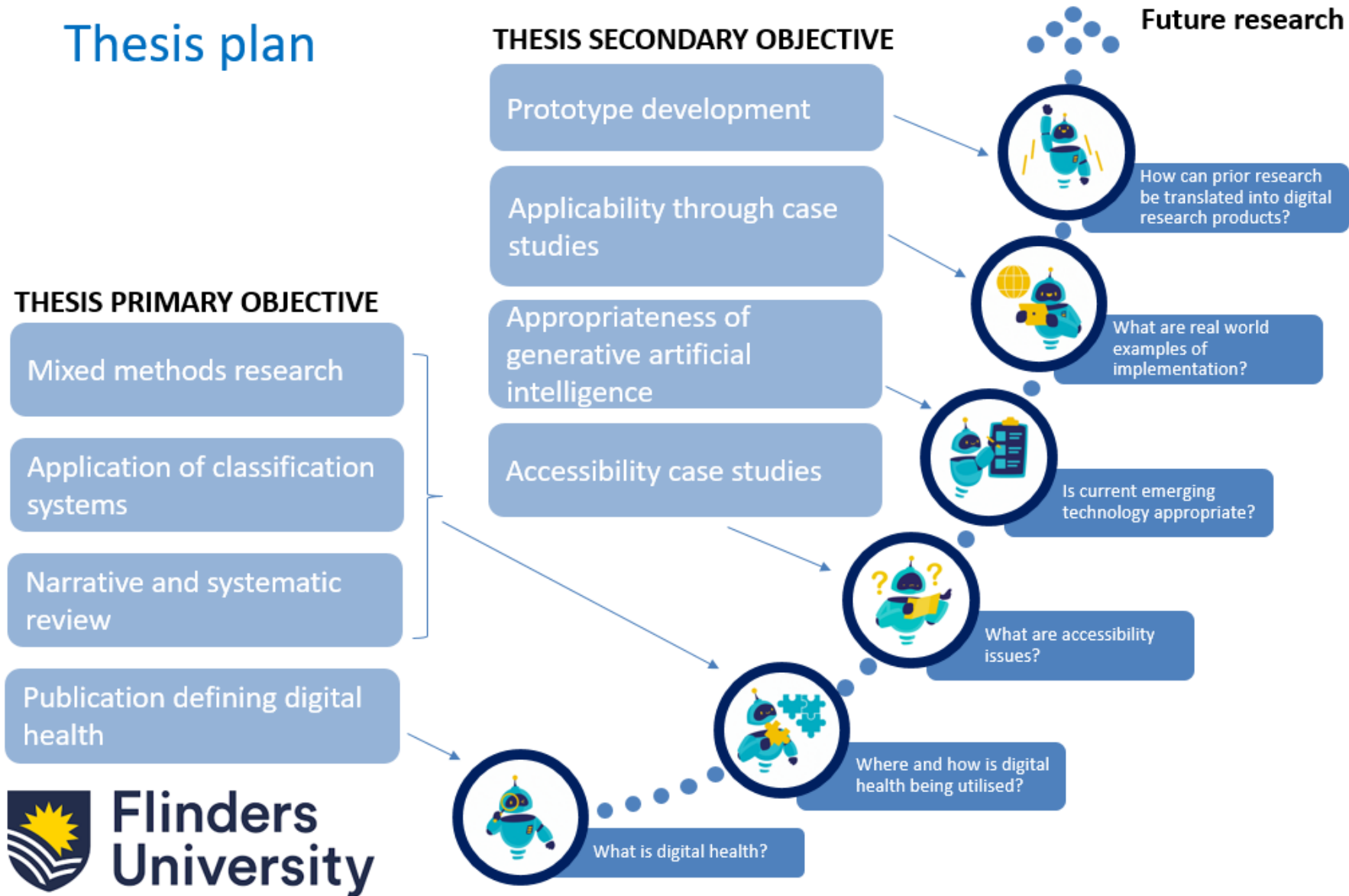


Figure 6 - Thesis plan with consideration of primary and secondary thesis objectives

Research activities

The creation of the outcomes hierarchy and logic model influenced not only the research plan but also associated research activities. Activities which were performed to support this thesis included:

- Literature reviews including a narrative and systematic review
- Mixed methods research on Australian lymphoedema practitioners, perspective pieces / case studies and prototype development
- Co-authoring as first author a chapter on artificial intelligence in a renowned textbook called Lymphoedema - Complete Medical and Surgical Management (2nd Edition, Elsevier). This publication was excluded from this thesis.
- Co-authoring a publication, as second author, on education in lymphology. Piller N, Mangion A. The importance and relevance of patient education about lymphology and lymphoedemas. Journal of Lymphoedema. 2024;19(1):5-6. This publication was excluded from this thesis.
- Presenting at Flinders University to raise other researchers' awareness through the candidature presentations
- Presenting at Lymphology and Phlebology conferences to raise Lymphoedema Practitioners and Phlebologists awareness of the research findings:
 - o Australasian College of Phlebology 2023, team presentation [Adelaide]
 - o Australasian Lymphology Conference 2024 [Adelaide]
 - o Australasian College of Phlebology 2024 [Fiji]
- Volunteering to contribute to the wider lymphoedema community:
 - o Volunteering on the Encouragement, Normalcy, Counselling, Opportunity, Reaching Out, Energies Revived (ENCORE) board (a well-respected breast cancer rehabilitation program)
 - o Volunteering to offer early intervention services and to present the research findings in a rural town of Whyalla, South Australia, 2023 [Adelaide] (Figure 7)
 - o Establishing the framework for Monique Bareham's advocacy website (www.lymphadvocate.com)
 - o Answering queries for the Australian Lymphoedema Professional Google Group community of practice.
- Contributing to advancing lymphoedema practice in Australia as an Australasian Lymphology Association (ALA) and Casley-Smith International recognised lymphoedema trainer.
 - o Assisted a fellow PhD candidate in becoming a qualified lymphoedema practitioner through self-funding her professional lymphoedema training through the Australian Institute of Lymphoedema (Yani Dick).



Figure 7 - Presenters being awarded their certificate of attendance in Whyalla

[From left to right pictured are Kellie Thomas, Professor Neil Piller, Rae Williams, Monique Bareham, Andrea Mangion, Toni Piller and Dr. Vani Prasad].

CHAPTER TWO: LYMPHOEDEMA

Chapter overview

This chapter defines lymphoedema, outlines the four phases of care—prevention, diagnosis, assessment, and treatment—and emphasises the critical importance of research in this area.

Highlights

The key highlights of this chapter include:

- The demonstration of the author's comprehensive understanding of lymphoedema through presenting an awareness of relevant evidence-based literature
- Articulation of the research imperative by noting that, despite the rapid adoption of digital health technologies since the COVID-19 pandemic, there remains a lack of research on how digital health is being implemented in lymphoedema care.

Defining lymphoedema

Chronic oedema and the lymphatic system

Chronic oedema refers to the persistent accumulation of fluid in the tissues, leading to swelling. It can occur due to various underlying causes, such as lymphatic dysfunction, venous insufficiency, or other systemic conditions such as heart or kidney failure. In recent years, advances in understanding of tissue fluid formation and lymphatic drainage have reinforced the idea that the lymphatic system plays a role in all forms of chronic oedema.⁽¹⁹⁾

Lymphoedema and chronic tissue changes

Lymphoedema is a chronic inflammatory condition whereby chronic oedema is the predominate symptom.⁽²⁰⁾ Swelling occurs in areas of compromised lymphatic drainage due to a failure in the lymphatic system, which is responsible for draining excess fluid and waste products from tissues and returning them to the bloodstream. Lymphoedema is associated with three consequences at the tissue level:

- Fluid (oedema) accumulation in the interstitial spaces
- Fibrotic tissue induration (extracellular matrix remodelling)
- Fatty tissue (adipose tissue deposition).⁽²¹⁾

The progression of lymphoedema is described in stages from 0 to 3 by the International Society of Lymphology (ISL).⁽²²⁾ A publication which described the ISL stages and changes occurring in both the lymphatic vessels as well as the tissues was provided by Mihara et al (2012) (Figure 8).⁽²³⁾ Microscopic evaluation of lymphatic vessels was conducted to elucidate the changes in lymphatic vessels in patients with different stages of lymphoedema. In pre-clinical lymphoedema (Stage 0), microvascular networks were observed to nourish the well-developed walls of the collecting lymphatic vessels. These microvascular networks were found to gradually diminish as the disease advances through its stages. Additionally, the lumen of the lymphatic vessels was found to dilate in Stage 1, subsequently contract in Stage 2, and ultimately become sclerosed by Stage 3. These changes reflect the involvement of fluid, fibrosis and fatty tissue deposition.

In plain language, lymphoedema causes swollen limbs that gradually enlarge, filled not only with fluid but also with hardened and fatty tissue. Over time, the lymphatic vessels also become damaged. Like a plumbing system that becomes clogged, these vessels can no longer effectively move lymph fluid as the condition worsens.

Types of lymphoedema

Lymphoedema is classified into two main types: primary and secondary. Primary lymphoedema is the less common form, which arises due to intrinsic abnormalities of the lymphatic system such as reduced lymphatic growth, increased lymphatic size, increased number of vessels, growth in the incorrect location, valvular dysfunction, and/or functionally inadequate drainage with impaired contractility.⁽²⁴⁾

On the other hand, secondary lymphoedema is more prevalent and occurs due to damage to the lymphatic system. This damage can be caused by a variety of factors including surgical procedures (such as the removal of lymph nodes during cancer treatment), radiation therapy, infection, filariasis, trauma and obesity.^(25, 26) Damage to the lymphatic system can also result from other conditions, such as venous insufficiency, where the lymphatic system becomes chronically overwhelmed.⁽²⁷⁾

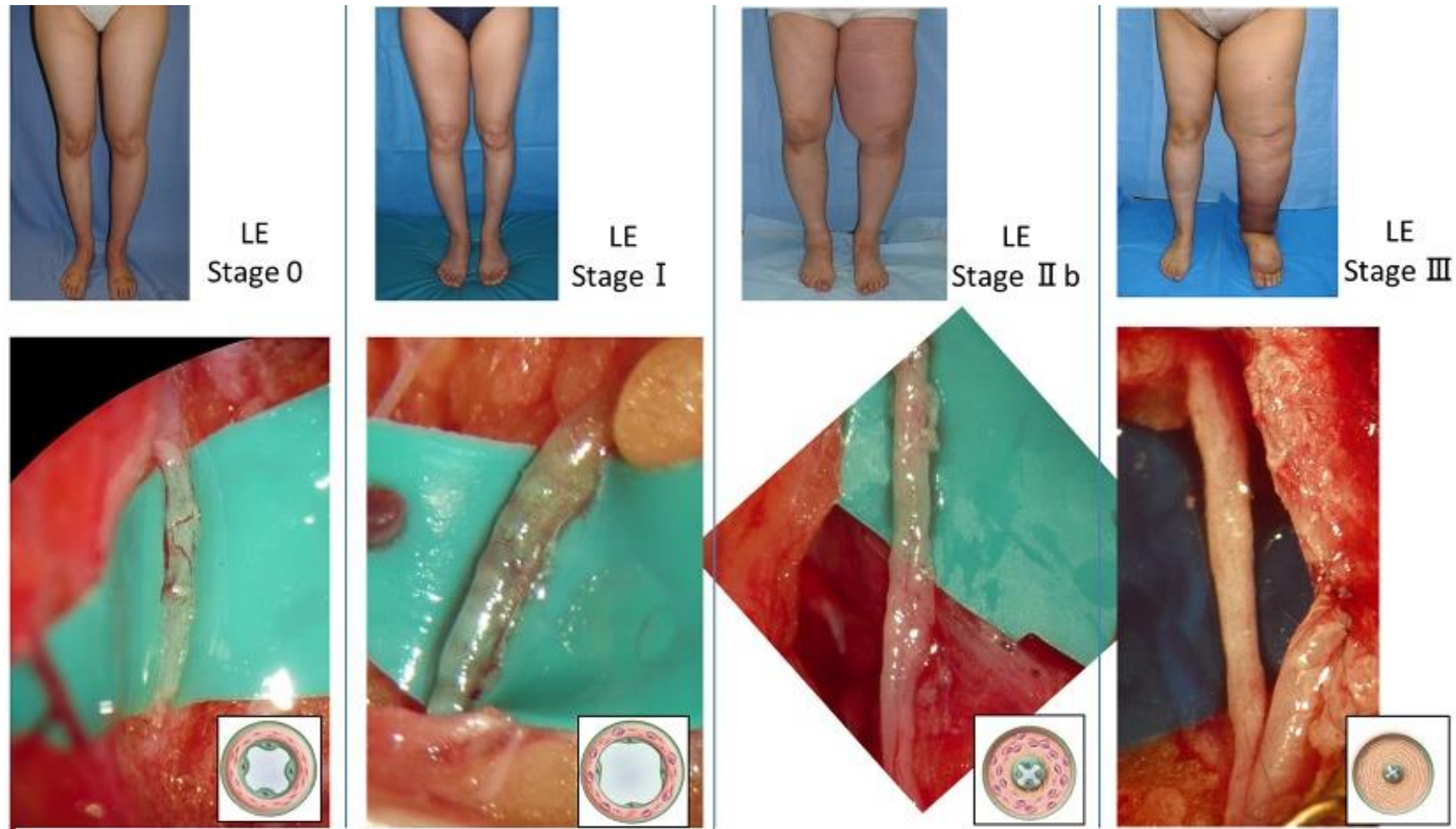


Figure 8 - The stages of lymphoedema and associated changes within lymphatic vessels

[Pictured are different presentations of patients with lymphoedema across the stages 0 to 3. Below the patient presentation is a picture of the same patient's lymphatic vessel under a microscope in the region of swelling. From Mihara et al (2012) distributed under a Creative Commons Attribution License <https://creativecommons.org/licenses/by/4.0/>. No changes made]⁽²³⁾

There are several types of secondary lymphoedema with four examples including:

- **Cancer-related lymphoedema:** This type occurs when lymph nodes are dissected (known as lymphadenectomy), and lymphatics are damaged from radiation for the treatment of cancer. When lymphoedema develops as a consequence of cancer treatment, the preceding term indicates the specific type of cancer treatment that caused the lymphoedema. For example, if the lymphoedema resulted after breast cancer treatment, it is known as breast cancer-related lymphoedema (BCRL).⁽²⁸⁾
- **Filarial-related lymphoedema:** This type occurs when microscopic worms damage the lymphatic system. The disease is found in sub-Saharan Africa, India, Southeast Asia, parts of South America, the Caribbean and the South Pacific.⁽²⁹⁾
- **Phlebolympheoedema:** This type occurs when there is both chronic venous insufficiency (CVI) and lymphatic insufficiency.⁽³⁰⁾
- **Obesity-related lymphoedema:** This type occurs when obesity leads to lymphoedema. Obesity and lymphatic dysfunction have a reciprocal relationship, where obesity can impair lymphatic function, and impaired lymphatic function can subsequently promote further adipose tissue accumulation.⁽³¹⁾

Despite their different origins, all types of lymphoedema lead to the chronic tissue changes described above.

Physical and psychological consequences

Lymphoedema has numerous physical and psychological consequences. One of the most serious physical complications is cellulitis, a bacterial skin infection.⁽³²⁾ Cellulitis can cause redness, pain, and warmth in the affected area, and if left untreated, it can lead to severe systemic infections, requiring hospitalisation. Patients with advanced lymphoedema are at particular risk of developing cellulitis with risk being associated with duration of swelling and having poorly controlled lymphoedema.⁽³³⁾ Recurrent episodes of cellulitis are common, with the incidence rate ranging from 16% to 53% within three years, which is why treatment is required.⁽³⁴⁾

In the United States of America cellulitis "...accounts for approximately 3.7 billion dollars in ambulatory care costs and 650000 hospitalizations annually."⁽³⁵⁾ In Australia the cost of cellulitis is hundreds of millions.⁽³⁶⁾

According to the Agency for Clinical Innovation, during the 2015-16 period, the cost of admission to a New South Wales (NSW) public hospital for patients with cellulitis as the primary diagnosis and lymphoedema as a secondary diagnosis was \$6,193 per admission, with an average length of stay of 5.53 days. The average cost of two sets of custom-made compression garments for a typical lower limb lymphoedema patient was therefore approximately 14 percent of the total cost of a hospital admission.⁽³⁷⁾ Consequently, in Australia, most jurisdictions offer garment subsidy programs, as it is more cost-effective to invest millions of dollars into funding lymphoedema garments than to cover the costs associated with cellulitis-related hospital admissions.

Elephantiasis is another severe form, and consequence, of chronic lymphoedema. It is characterised by extreme swelling and thickening of the skin and underlying tissues and often leads to significant disfigurement (Figure 9). The term usually refers to lymphoedema caused by filarial parasites, but can also be from other causes such as exposure of bare feet to irritant alkaline clay soils or from severe stages of other forms of lymphoedema, such as in severe cases of genital lymphoedema, when the swollen area is significantly disfigured.⁽³⁸⁻⁴⁰⁾



Figure 9 - Elephantiasis of leg due to filariasis

[Image from the Centers for Disease Control and Prevention's Public Health Image Library (PHIL). Public domain. Created 1962. Captured in Luzon, Philippines. No changes made.]⁽⁴¹⁾

Lymphorrhoea, the leakage of lymph fluid through the skin, is another complication in advanced lymphoedema.⁽⁴²⁾ In the legs it usually appears as weeping of clear, straw-coloured fluid through the pores of the skin. Lymphorrhoea can unexpectedly develop in patients with any form of chronic oedema, and it may also result from factors such as cellulitis, open wounds, obesity, and immobility.⁽⁴³⁾

Psychologically, the consequences of lymphoedema can be profound. The chronic and visible nature of the condition can lead to feelings of embarrassment, social isolation, and low self-esteem.⁽⁴⁴⁾ Patients may experience anxiety and depression due to the ongoing need for treatment, the fear of complications, and the impact on their daily lives. The constant management required for lymphoedema, including wearing compression garments and performing daily skin care routines, can be burdensome, contributing to psychological stress.⁽⁴⁵⁾

Four phases of care

The four phases of lymphoedema care are:

- prevention
- diagnosis
- assessment
- treatment

Prevention

The prevention of lymphoedema is usually referred to in the literature in regard to measures patients can take, once already having lymphoedema, to maintain their lymphatic health and avoid risk factors. Strategies include maintaining good skin care and hygiene to prevent infections, protecting the affected limb from trauma and infection, and engaging in regular, moderate exercise to promote lymphatic flow.^(46, 47) Maintaining a healthy weight is also crucial as obesity is a known risk factor.⁽⁴⁸⁾

An approach for the prevention of lymphoedema before it occurs is known as the “Prospective Surveillance Model”, initially published by Stout et al (2012).⁽⁴⁹⁾ This approach is recommended for patients after cancer treatment, whereby the risk of lymphoedema is known. This approach involves patients and practitioners working together to monitor for early signs of lymphoedema through regular screening (every 3 to 6 months for the first 2 to 5 years) to detect lymphoedema at a subclinical stage. By detecting signs of lymphoedema at a very early stage, interventions can occur sooner to prevent lymphoedema from progressing to clinical stages.⁽⁵⁰⁾ This method relies on bioimpedance spectroscopy (BIS), a technology which measures fluid levels in the body.⁽⁵¹⁾

The other side to lymphoedema prevention involves avoiding factors known to cause the condition in the first place, such as avoiding lymph node removal if undergoing cancer treatment. While this is challenging given that lymphadenectomy is standard practice for cancer treatment, advancements in cancer surgical techniques have been made to minimise lymphatic damage, thereby reducing the risk of developing lymphoedema. For instance, sentinel lymph node biopsies are now often performed instead of full axillary lymph node dissections in breast cancer surgery.⁽⁵²⁾ This approach reduces the risk of developing lymphoedema whilst still providing essential cancer treatment.

There are also innovative surgical techniques that aim to minimise and/or prophylactically correct lymphatic disruption, such as axillary reverse mapping (ARM) and lymphatic-venous anastomoses (LVAs) after cancer surgery.⁽⁵³⁾ ARM is a technique used during cancer surgery to identify and preserve lymphatic pathways that drain the arm, aiming to reduce the risk of post-surgical lymphoedema.⁽⁵⁴⁾ LVAs involve microsurgery to create connections between lymphatic vessels and veins with the aim of improving lymphatic drainage.⁽⁵⁵⁾

Diagnosis

The diagnosis of lymphoedema is usually made through a combination of clinical evaluation and diagnostic imaging.⁽⁵⁶⁾ Practitioners begin with a detailed medical history and physical examination, looking for characteristic signs such as persistent swelling, skin changes, and limb heaviness. Further testing is then performed to confirm the findings of the medical history and physical examination. Diagnostic imaging techniques, such as lymphoscintigraphy and indocyanine green lymphography (ICG), are used to visualise the lymphatic system and assess its function.^(57, 58)

Lymphoscintigraphy works by injecting a small amount of radioactive tracer into the body, which travels through the lymphatic system, allowing for imaging that highlights lymphatic drainage patterns and identifies blockages or abnormalities. An example of the resulting image is presented below.

In the image below a patient has lymphoedema of their right arm (Figure 10). The swollen limb is bigger by 0.5, 0.5, 1.0, and 0 cm in the upper arm, elbow, forearm, and wrist (a), respectively, compared to the healthy side (left, b). On lymphoscintigraphy, a normal lymph vessel distribution was found in both upper limbs (c) suggesting normal lymphatic drainage in this patient's deep lymphatic system.⁽⁵⁹⁾

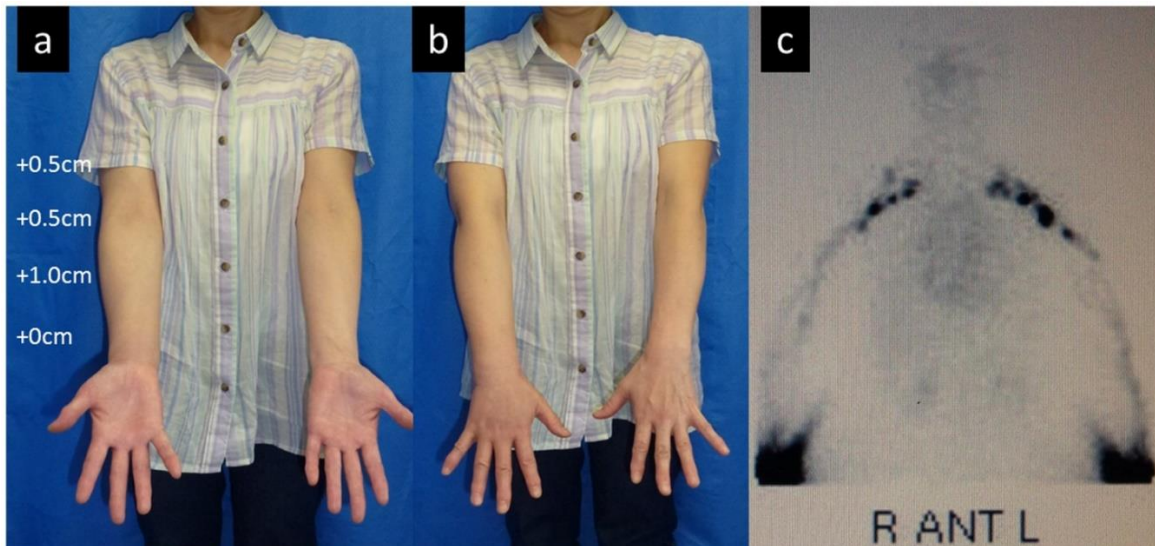


Figure 10 - A patient with secondary lymphoedema and their lymphoscintigraphy results

[Image from Mihara et al (2012). Distributed under a Creative Commons Attribution License. <https://creativecommons.org/licenses/by/4.0/deed.en>. No changes made.](⁵⁹)

Given that the patient is showing signs of lymphoedema, it would be expected that imaging would reveal abnormalities in lymph flow. This is where ICG may be appropriate for determining problems in the superficial lymphatic system. ICG involves injecting a fluorescent dye into the skin, which then travels through the lymphatic vessels. Near-infrared imaging is used to visualise and assess lymphatic function in real-time. In the same patient's case, the ICG image was abnormal, revealing the dye accumulating in the tissues instead of being collected by the lymphatic system and transported to the axillary lymph nodes, as would occur with normal lymphatic activity (Figure 11).⁽⁵⁹⁾

Terms such as splash, stardust or diffuse patterns describe what the ICG images look like when there is abnormal lymphatic drainage. In this patient's case, a splash pattern (SP) was present in the lateral forearm over the upper arm, axilla, and precordia. In the medial upper arm, diffuse (DP) and splash patterns were mixed in some regions.

Linear patterns (LP) demonstrate that lymphatic fluid is draining through lymphatic vessels. In this patient's case, a LP was noted in the shoulder whereby lymph drainage was occurring to nearby lymph nodes.

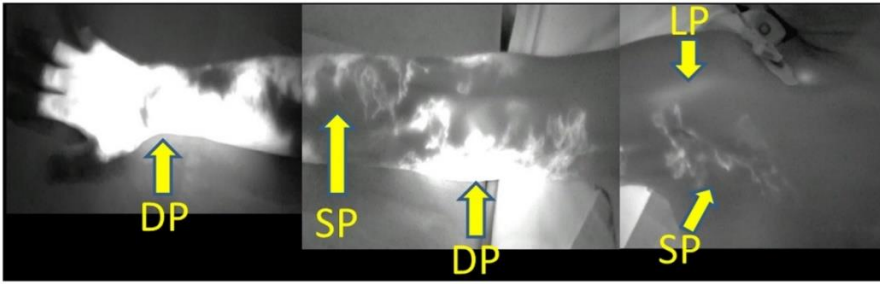


Figure 11 - A patient with secondary lymphoedema and their indocyanine green lymphography results

[Image from Mihara et al (2012). Distributed under a Creative Commons Attribution License. <https://creativecommons.org/licenses/by/4.0/deed.en>. No changes made.](⁵⁹)

Assessment

The assessment of lymphoedema, in conjunction with a medical examination and history taking for differential diagnosis, usually involves the use of specialised medical equipment to accurately quantify the extent of swelling and detect early fluid accumulation.⁽⁵⁶⁾ Measurements of limb circumference or volume are used to track the extent of swelling over time. These measurements are performed with a tape measure, through water displacement volumetry or through perometry.⁽²²⁾ Perometry uses infrared light to scan a limb, allowing for precise measurement of its volume without physical contact.⁽⁶⁰⁾

BIS, which measures the resistance of body tissues to electrical currents, allows for the detection of fluid accumulation in the early stages of the condition.⁽⁶¹⁾ BIS, when compared to measuring limb circumference, has been shown to provide more precise identification of patients likely to benefit from early intervention.⁽⁵¹⁾ Unlike tape measurements, which rely on external circumferential changes, BIS provides a precise, objective assessment by measuring changes in tissue fluid composition and impedance. This allows for the detection of subtle fluid imbalances that may occur before visible or palpable changes in limb circumference, making BIS a more sensitive tool for identifying lymphoedema at its earliest stages.

Treatment

Conservative lymphoedema care usually involves skin care, compression therapy, decongestive exercises and lymphatic drainage massage. The Casley-Smith method, developed in Australia by Drs John and Judith Casley-Smith, incorporates four key components in a method known as Complex Physical Therapy.^(56, 62) The method includes the following:

- Skin care via caring for wounds, using creams, covering cuts and scratches and treating scars. Medical devices, such as low-level lasers, can also assist with wound healing and pain.^(63, 64)

- Compression therapy via the use of compression garments, such as sleeves, stockings, bandages, wraps, and pneumatic compression pumps to apply pressure to the affected area.
- Decongestive exercises via gentle movements accompanied with deep breaths to stimulate the lymphatic system. Deep breathing is an evidence-based modality for lymphoedema care through encouraging changes in abdominal pressure and therefore facilitating deep lymphatic drainage.⁽⁶⁵⁾
- Graduated cardiovascular and resistance training via a prescribed exercise program.^(66, 67)
- Lymphatic drainage massage or manual lymphatic drainage (MLD) via gentle, rhythmic massage techniques which stimulate the lymphatic system.
- Education and self-management via lessons and information about the condition. Patients are taught how to perform MLD, apply compression garments, engage in appropriate exercises, and maintain good skin care.
- The Casley-Smith method also promotes a holistic, multidisciplinary approach to lymphoedema care. This involves collaboration between various healthcare professionals, including doctors, nurses, physiotherapists, occupational therapists, dieticians and exercise physiologists to provide comprehensive care tailored to the patient's needs.

Complex Physical Therapy, while involving relatively simple treatments, is evidence-based and achieves remarkable results. The results of a patient with breast cancer-related lymphoedema having treatment before (Figure 12) and after (Figure 13) are shown in the images below.⁽⁶⁸⁾



Figure 12 - Before Complex Physical Therapy

[Image from Casley-Smith et al (1998)]⁽⁶⁸⁾



Figure 13 - After Complex Physical Therapy

[Image from Casley-Smith et al (1998)]⁽⁶⁸⁾

The Casley-Smith method continues to evolve with new research through the work of Casley-Smith International.⁽⁶⁹⁾ An example of this is the enhanced understanding of the mechanisms and rationale behind the delivery of MLD, which has been improved through research on ICG leading to a better comprehension of lymphatic drainage pathways.⁽⁷⁰⁾ To illustrate this a patient example is presented below.

In the image below a patient is receiving MLD to their arm. In the upper limb the axillary lymph nodes usually drain the arm.⁽⁵⁸⁾ ICG has been injected and the lymphatic pathways are shown at the forearm and distal arm. The green line and arrow indicate the direction of the lymph fluid towards the axillary lymph nodes. In MLD the lymphoedema practitioner uses their hands to move the fluid towards the patient's axilla (Figure 14).⁽⁷⁰⁾ ICG is therefore used to assist in confirming pathways of lymphatic drainage for MLD.



Figure 14 - Indocyanine green lymphography being used to assist in confirming pathways of drainage for manual lymphatic drainage

[From Ciudad et al (2021). Distributed under a Creative Commons Attribution Non-Commercial License <http://creativecommons.org/licenses/by-nc/4.0/>. No changes made.](⁷⁰)

Surgical lymphoedema care typically encompasses three main types of procedures: liposuction, LVA and lymph node transfer (LNT). Liposuction is used to remove excess fatty tissue, particularly when conservative treatments have been ineffective. LVA involves microsurgery connecting lymphatic vessels to nearby veins, allowing lymph fluid to bypass damaged areas and drain more effectively. LNT involves transplanting lymph nodes from one well-functioning part of the body to the affected area by lymphoedema, which can help restore lymphatic function.

None of these surgical approaches are described as a cure for lymphoedema but they are evidence-based treatment modalities which can improve lymphoedema symptoms.⁽⁷¹⁾

Innovative solutions

Despite being a prevalent and debilitating condition, the fundamental approach of conservatively managing lymphoedema has seen little change over the past two decades. While the Casley-Smith method is effective, the methods are labour-intensive, require significant patient compliance, and provide symptomatic relief without addressing the underlying cause. Innovative solutions to assist in any aspect of prevention, diagnosis, assessment and treatment are warranted.

Digital health presents a multitude of possibilities from instructive online information on lymphoedema to advanced applications involving wearables, applications of artificial intelligence (AI) and robotics.

The research imperative

Why must research be conducted in this area?

The diagnosis of lymphoedema is often delayed. A study from 2013 revealed that patients with both primary and secondary lymphoedema experienced significant delays in diagnosis, with primary lymphoedema patients being particularly affected. “On average, it took 13.5 years from first symptoms to lymph drainage therapy in these patients and 13.7 years until compression therapy.”⁽⁷²⁾

While these delays might seem extreme for any health condition, delays in diagnosis and assessment remains a significant issue. A 2023 Australian government paper by the Australian Institute of Health and Welfare, aimed at determining the prevalence of the condition, was unable to clearly state the prevalence.⁽⁷³⁾ The paper emphasised that a critical issue in not being able to clearly define the prevalence was the misdiagnosis or missed diagnosis of lymphoedema, resulting from a lack of understanding and awareness of its presentation among medical practitioners. The Australian Institute of Health and Welfare stated, “Appropriate training and the provision of resources will help to facilitate early detection of the condition and improve outcomes for people living with lymphoedema.”

Digital health provides a means to deliver appropriate training and resources. We are living in an age where patients increasingly turn to online sources before consulting their own doctors.^(74, 75) Hennessey et al (2020) describe how “...patients can find healthcare professionals actively posting on Twitter, Facebook, Instagram, TikTok, and other social media platforms, offering their expertise, debating policies and practices, promoting patient care and education, and raising awareness of new health-related developments.”⁽⁷⁵⁾ This highlights the positive impact of practitioners using social media to engage with the public and share their knowledge. However, the authors also emphasised the associated risks, such as fines for healthcare practitioners who fail to comply with privacy and security requirements. The article by Hennessey et al includes instances of health practitioners being terminated for inappropriate use of social media. There is therefore the need for healthcare professionals to understand how to best leverage these technologies safely and effectively, balancing the benefits of increased accessibility and engagement with the necessity of adhering to professional and legal standards.

Chapter One highlighted that, despite the extensive integration of digital health across various healthcare fields following the COVID-19 pandemic, there remains a significant gap in research specifically addressing the implementation of digital health within lymphoedema care. Furthermore, there is a lack of clear guidance on how to optimally leverage digital technologies for managing this condition. It is, therefore, imperative that research be conducted which examines what digital health entails within the context of lymphoedema care, investigates where and how these technologies are currently being utilised, and explores the contemporary challenges influencing their adoption, appropriateness and applicability.

Far beyond the necessity of understanding the effective use of these technologies lies a more profound existential inquiry. With the advent and rise of AI, the author's supervisor posed a critical question: "Are we, as healthcare professionals, on the verge of becoming merely gatekeepers and operators of technology, or will we retain a role comparable to our current one in the future?"⁽⁷⁶⁾ This question compels a deeper reflection on the evolving function of healthcare professionals within an increasingly digital and automated healthcare landscape. With this question in mind, it is imperative that we remain at the forefront of health research by rigorously investigating digital health. This area of research is not only essential but also holds significant promise for the future of healthcare, making it an exciting and critical field of study.

Two pivotal quotes underscore the pressing need for research in digital health. The first quote emphasises the profound transformation that digital health may bring stating, "The "e-health" era is nothing less than the digital transformation of the practice of medicine, as well as the business side of the health industry.... The Internet is the next frontier of health care. Health care consumers are flooding into cyberspace, and an Internet-based industry of health information providers is springing up to serve them. Internet technology may rank with antibiotics, genetics, and computers as among the most important changes for medical care delivery."⁽⁷⁷⁾ This underscores the radical shifts expected in both medical practice and healthcare business models due to digital technologies.

The second quote further elaborates on the promise of emerging technologies to enhance healthcare, noting that these innovations hold the potential to improve both the quality of and access to healthcare services: "...technologies with practical applications that have the potential to improve both quality of and access to healthcare....telemedicine, health information systems, databases, genomics, biotechnology, eLearning, continuing professional development, nanotechnology, drug treatment technologies, decision making tools, diagnostic aids, eLibraries, laboratory tools, and robotics are all innovative or 'disruptive' technologies that promise a better health for our children."⁽⁷⁸⁾

CHAPTER THREE: DIGITAL HEALTH

Chapter overview

In Chapter Four a publication is presented which aims to answer the question, “What does the term digital health mean?” This chapter details the underlying concepts which informed the development of this publication.

Highlights

The key highlights of this chapter include:

- The demonstration of the author’s comprehensive understanding of digital health literature
- Uncovering six key concepts in understanding digital health including: 1) the term encompasses eHealth; 2) digital health is accomplished through digital technologies; 3) the concept is more complex than simply using digital technologies; 4) the term includes health informatics; 5) the term also includes the subsets of digital medicine and digital therapeutics and; 6) digital health involves technology being used to improve patient care and healthcare outcomes.

Defining digital health

What does the term digital health mean?

“Digital health refers to the use of information and communications technologies in medicine and other health professions to manage illnesses and health risks and to promote wellness.”⁽⁷⁹⁾ Digital health encompasses a wide range of applications and tools designed to improve the efficiency, accessibility, and quality of healthcare. “Digital health is about the proper use of technology for improving the health and wellbeing of people at individual and population levels, as well as enhancing the care of patients through intelligent processing of clinical and genetic data.”⁽⁸⁰⁾

Broadly digital technologies are being described as revolutionising the global health sector with authors referring to a “... tidal wave of technological innovations, which has become a veritable tsunami during the past few years.”⁽⁸¹⁾ Despite the rapid growth of this field, several aspects, particularly terminology, remain inadequately understood. The terms “digital health” and “eHealth” are used interchangeably with a mixture of concepts including health informatics and Healthcare 4.0 being thrown into the mix.

Several authors have highlighted the problem pertaining to definitions of digital health and eHealth. Some examples are:

- Oh et al (2005) in a systematic review of the term eHealth found 51 unique published definitions. The authors avoided attempting to create another definition and stated, “The widespread use of the term suggests that eHealth is an important concept, and the term is a useful “tool” to express that concept. It is generally understood despite the lack of a precise definition.”⁽⁸²⁾
- Boogerd (2015) stated “In addition to the wish for a uniform definition of eHealth, the availability of related terms such as Medicine 2.0, Web 2.0, Health 2.0, mHealth, Telecare and Telehealth may be confusing. Although not identical, there seems to be a lot of overlap, and different terms are used interchangeably throughout literature.”⁽⁸³⁾
- Al-Rimaw et al (2016) stated “At other times, telehealth and telemedicine are referred to as applications of e-health; in some instances, e-health is subsumed under the umbrella of health informatics. Such confusion and uncertainty undermine the conceptual development of eHealth and give rise to the question of what does really eHealth represents.”⁽⁸⁴⁾
- Fatehi et al (2020) stated, “Ambiguity in the definition of digital health is a hurdle for research, policy, and practice in this field.”⁽⁸⁰⁾
- Osama et al (2023) state, “Nowadays, many people are talking about e-health, yet few of them have come up with a definition that explains this relatively new term.”⁽⁸⁵⁾
- Zrubka et al (2024) refer to a “bewildering array of terms in use” for describing digital health and eHealth. “Abundant, yet vaguely defined definitions in digital health represent a challenge for clinicians, decision makers, developers, and researchers.”⁽⁸⁶⁾

Method

A literature review was undertaken of definitions of the terms “digital health” and “eHealth” by reviewing:

- Existing systematic reviews or comprehensive literature reviews namely the work of
 - o Fatehi (2020) who reported finding 95 unique definitions of digital health ⁽⁸⁰⁾
 - o Pagliari et al (2005), who provided 36 definitions of eHealth ⁽⁸⁷⁾
 - o Oh et al (2005) who found 51 definitions of eHealth ⁽⁸²⁾
 - o Zrubka et al (2024) who provided 1 definition of eHealth behaviour, defined digital health and defined other related terms ⁽⁸⁶⁾
- Other papers in the field by searching for publications with the term “digital health.” Articles that provided their own definition of digital health, without solely relying on another source, and included a dedicated section—or were entirely focused on explaining digital health—were selected.

- Definitions from leading Australian or global digital or health agencies such as the Australian Institute of Health and Welfare, the Australian Digital Health Agency who produce the Australia's National Digital Health Strategy and the NSW Government department of eHealth ⁽⁸⁸⁻⁹⁰⁾
- Private organisations publications including Rowlands paper and Arthur D Little's. ^(91, 92)

Results

Helpful definitions were found in several publications with a sample of definitions being presented in Table 1. ^(80, 86, 89-91, 93-104) Digital health was found to be an umbrella term (Figure 16) encompassing many sub-components such as eHealth, health informatics and the concept of Healthcare 4.0.

The definition provided by the Australian Government's Digital Health Agency states that digital health is more than using technology and involves several other considerations. "Digital health is not simply about the latest technology. It is about supporting a modern, high-quality health system, improving the quality of life of individuals, families and communities, and equipping people to confidently manage their health and wellbeing journey. It's also about enabling healthcare providers to maximise their skills and contributions by increasing effectiveness and efficiency. Digital health is the foundation for all modern health service delivery and should improve safety, quality, productivity and efficiency."⁽⁹⁰⁾ This definition alone represents several themes of what digital health should accomplish (quality of life, confidence for patients and practitioners, connection and the quality of care) and how it should be measured (with care being safe, effective and productively delivered) (Figure 15).

Key concepts

Six key concepts emerged integral to understanding the umbrella term digital health.

- The term encompasses eHealth which is orientated towards what types of digital tools are used through computers, mobile phones or at a distance through telehealth ⁽¹⁰⁵⁾
- Digital health is accomplished through digital technologies ⁽⁸⁶⁾
- The concept is more complex than simply using digital technologies and includes notions such as data harvesting and decentralisation of data ⁽⁹¹⁾
- The term includes health informatics and consideration of the interaction between humans and information. This includes emerging areas such as the use of advanced computing sciences in 'big data', genomics and artificial intelligence. ⁽¹⁰⁵⁾

- v) The term includes the subsets of digital medicine and digital therapeutics which is concerned with the positioning of solutions as health (wellbeing), medicine or therapeutic solutions. Within this concept lies other concepts including Healthcare 4.0, the Internet of Medical Things and WBANs. ⁽¹⁰⁶⁻¹⁰⁸⁾
- vi) Digital health involves technology being used to improve patient care and healthcare outcomes. ⁽⁹⁰⁾

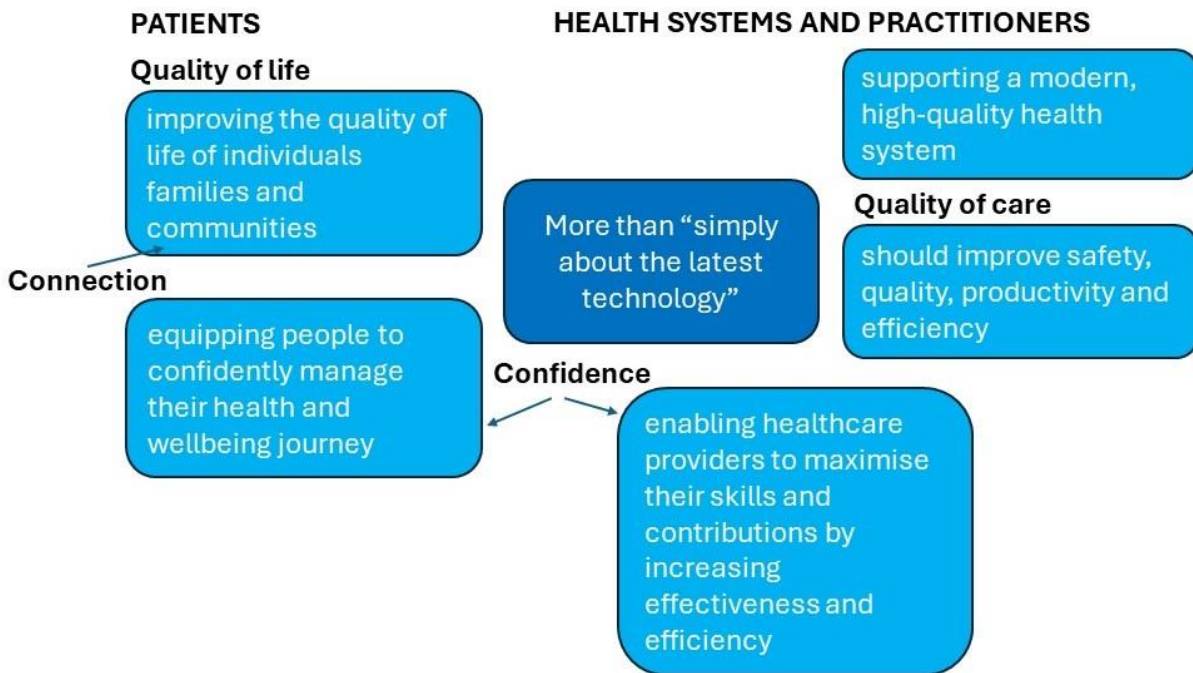


Figure 15 - Australian Digital Health Agency definition of digital health grouped into themes

Examples of definitions which illustrate the scope of eHealth, data (informatics) and digital therapeutics are presented below (Figure 17). Examples of definitions illustrating technology, platforms and systems as well as the many outcomes digital health is meant to improve are also presented below (Figure 18).

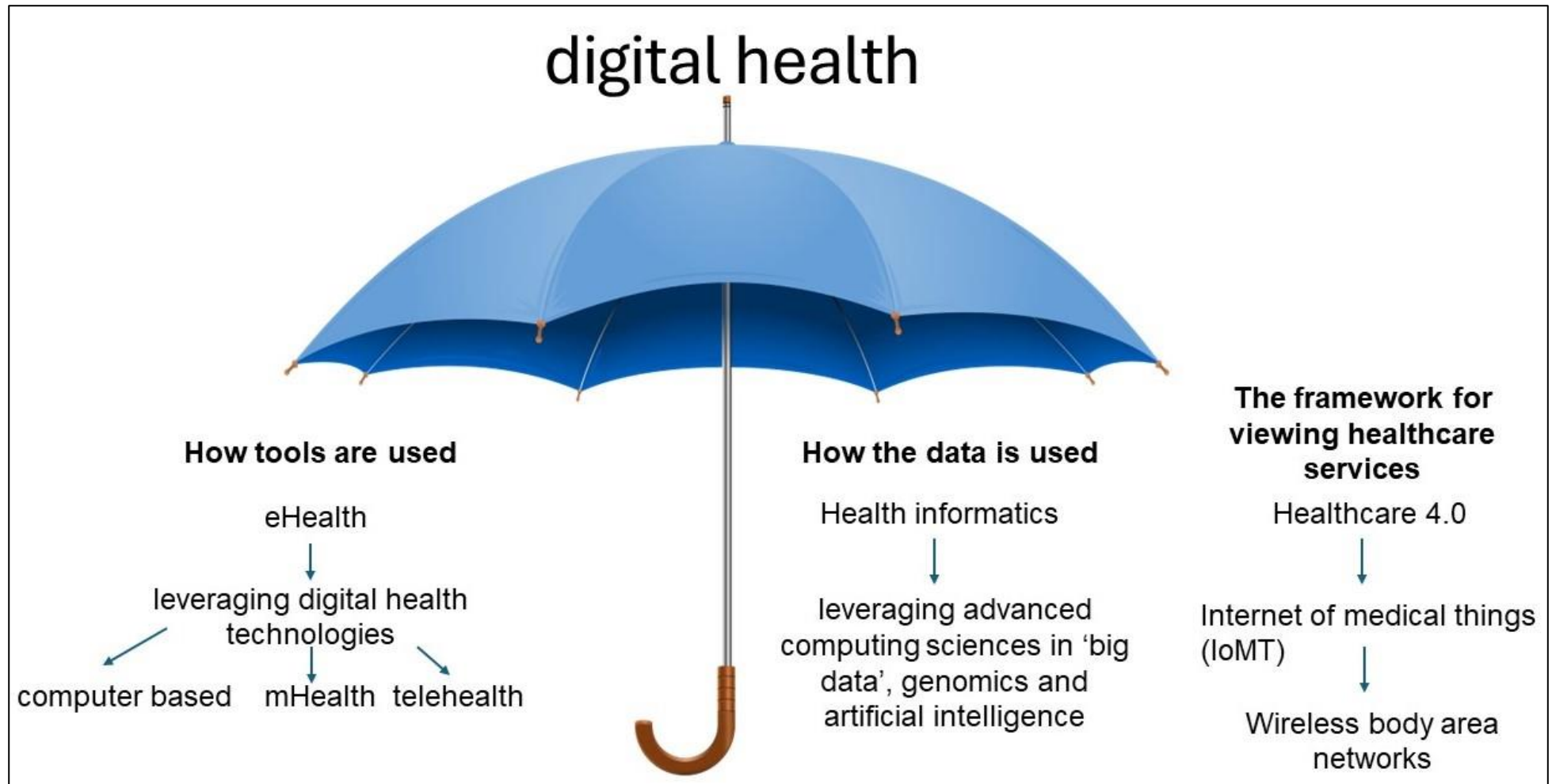


Figure 16 - Digital health as an umbrella term

Involves data

Rowlands (2019) Digital health is “Health and healthcare in the context of digital societies. Digital health:

1. Harvests data, information and knowledge in real time from all societal activities, not just interactions with the health system and/or data traditionally regarded as “health” data;
2. Uses sophisticated analytics to distil knowledge from these data;
3. Intervenes in the widest possible range of societal and economic activities and technologies to encourage and generate better health and better value for health investments;
4. Is citizen (not provider/customer/patient) centric, decentralised and requires health service providers to participate, not control.”

World Health Organisation (2023) “Digital health is the systematic application of information and communications technologies, computer science, and data to support informed decision-making by individuals, the health workforce, and health systems, to strengthen resilience to disease and improve health and wellness.”

Caballero-Urbe and Khan (2019) “Digital health is an emerging field combining informatics to organize and improve health services through the Internet and related computer technologies, with emphasis on global, regional, and local healthcare perspectives. In other words, it is simply medical treatment utilizing cyberspace and applying Internet and global communication networks to healthcare.”

Includes eHealth

Herold et al (2015) “Digital Health is an umbrella term that covers the application of digital technologies in the context of health and, is a subordinate construct that comprises both Electronic Health and Mobile Health.”

Joshua et al (2022) “The term “digital health” is a catch-all phrase that refers to eHealth, mHealth, and other emerging fields of research and practice.”

Kim et al (2023) “Digital health includes telemedicine, mobile health, telehealth, health information technology, and the use of wearable devices.”

Involves digital therapeutics

Zrubka et al (2024) “Digital health involves technologies including artificial intelligence (AI), virtual reality, digital therapeutics, wearables, remote monitoring, and software.”

Siddarth et al (2024) “Digital health encompasses digital medicine, which includes digital therapeutics (DTx).”

Figure 17 - Themes of involving data, therapeutics and eHealth from definitions of digital health

Technologies, platforms and systems

Siddarth et al (2024) "Digital health is a broad category comprising technologies, platforms, and systems that engage consumers for lifestyle, wellness, and health-related purposes; capture, store, or transmit health data; and/or support clinical operations."

Digital health refers to systems, tools and services based on information and communications technology that can be used to treat patients and collect and share a patient's health information. Digital health in Australia has a broad scope, and includes (but is not limited to):

- mobile health and applications (such as SMS reminders via mobile messaging, wellness apps, My Health app and Medicare Online)
- digital medicines including electronic prescribing and electronic medication charts
- healthcare identifiers
- electronic health records (including My Health Record)
- telehealth and telemedicine
- wearable devices (such as fitness trackers and monitors)
- robotics and artificial intelligence
- electronic referrals
- access to trusted data.

Digital health can increase the quality and efficiency of information sharing between healthcare consumers and providers across the health system.

Improves several outcomes

Kim et al (2023) "Digital health is described as the use of information and communication technologies in healthcare and medicine. It leverages technology and data to (1) improve healthcare service delivery and patient outcomes, (2) engage patients and support positive health behaviors, and (3) develop health data repositories to expand population-based research."

Australian Digital Health Agency (2023) "Digital health is not simply about the latest technology. It is about supporting a modern, high-quality health system, improving the quality of life of individuals, families and communities, and equipping people to confidently manage their health and wellbeing journey. It's also about enabling healthcare providers to maximise their skills and contributions by increasing effectiveness and efficiency. Digital health is the foundation for all modern health service delivery and should improve safety, quality, productivity and efficiency."

Figure 18 - Themes of involving technologies, platforms and systems and many outcomes from definitions of digital health

Key concept (i): Digital health involves health informatics

What is health informatics?

“Informatics involves the practice of information processing and the engineering of information systems. The field considers the interaction between humans and information.”⁽¹⁰⁹⁾

Health informatics (also called health care informatics, healthcare informatics, medical informatics, nursing informatics, clinical informatics, or biomedical informatics) is informatics in health care.

It appears that definitions of health informatics continue being revised.⁽¹¹⁰⁾ Examining definitions of healthcare informatics and healthcare data analytics by Wan and Gurupur (2020) assisted in understanding the focus on “data” being integral to definitions of health informatics (Figure 19).⁽¹¹¹⁾ Two examples of definitions are below:

“...the definition for healthcare informatics needs the following key ingredients: a) convergence of disciplines that are associated with data flow and processing, b) systems thinking, c) purpose of the tasks performed in this discipline, and d) a required critical outcome. With these ingredients in mind we can define healthcare informatics as, “...a transdisciplinary study of the data flow and processing into more abstract forms such as information, knowledge, and wisdom along with the associated systems needed to synthesize or develop decision support systems for the purpose of helping the healthcare management processes achieve better outcomes in healthcare delivery.”

“Healthcare data analytics is more strongly associated with the science of data analysis in terms of data manipulation, data semantics, data mining, and statistics. Therefore, we can define healthcare data analytics as “a study of methods and techniques to analyse data, discover new information and knowledge, link data in terms of its semantics, and describe data to other informaticians, managers, and other stakeholders.”

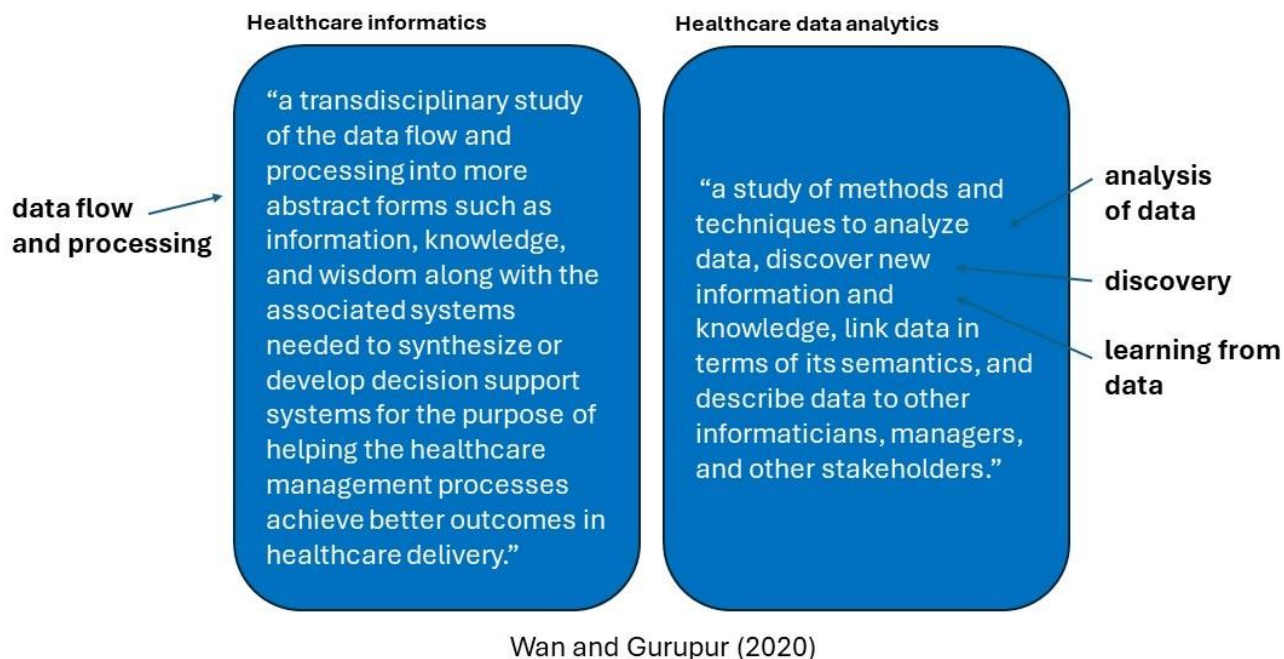


Figure 19 - Definitions of healthcare informatics vs healthcare data analytics

What is advanced computing sciences in ‘big data’, genomics and artificial intelligence?

Big data, genomics, and AI are revolutionising the healthcare landscape. “Big data in health” encompasses high volume, high diversity biological, clinical, environmental, and lifestyle information collected from single individuals to large cohorts, in relation to their health and wellness status, at one or several time points.”⁽¹¹²⁾

Genomics, the study of an organism's complete set of deoxyribonucleic acid (DNA), provides critical information about genetic predispositions and disease mechanisms, paving the way for tailored treatments.⁽¹¹³⁾

Advanced computing sciences is involved in AI whereby technologies leverage advanced algorithms and machine learning to process and interpret large volumes of data, identify patterns, and make predictive analyses.⁽¹¹⁴⁾ Together, these technologies are enhancing diagnostic accuracy, advancing personalised medicine, and driving innovative research in healthcare.

A diagram (Figure 20) illustrates how big data encompasses the collection, analysis, and utilisation of vast and complex datasets, followed by machine learning and data analysis. This then leads to more precise and personalised medical care.⁽¹¹⁵⁾

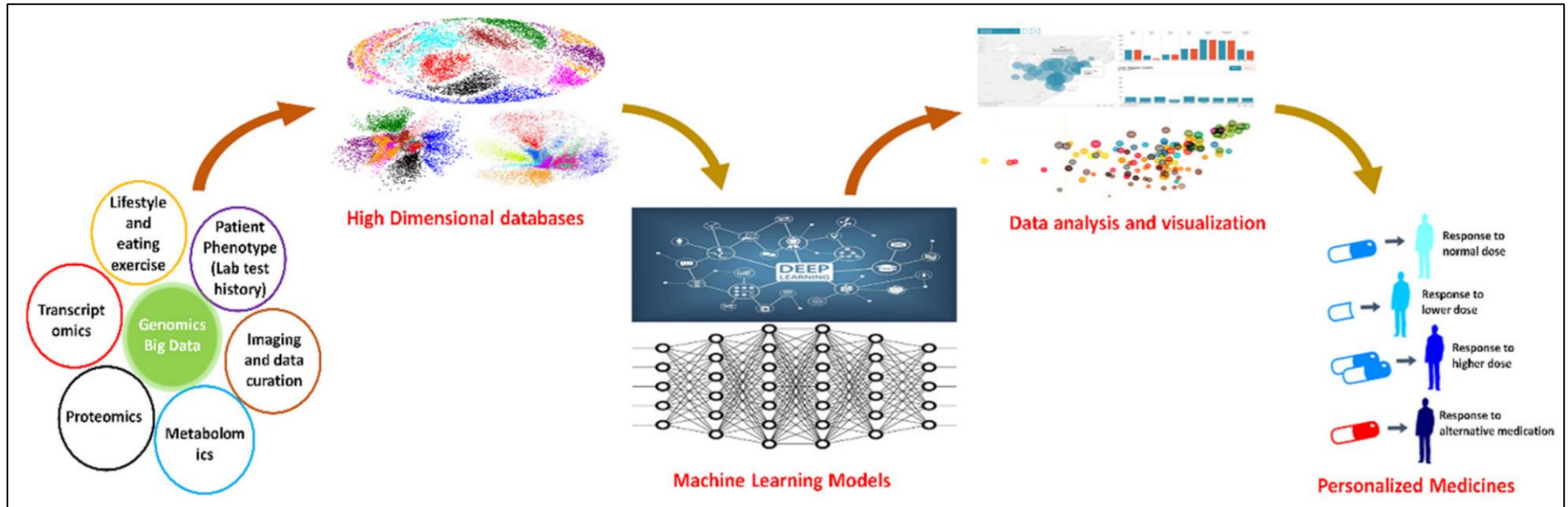


Figure 20 - The overall computational approach for personalised medicine

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Key concept (ii): Digital health is an umbrella term encompassing eHealth

What is eHealth?

Many different definitions of eHealth have been published.^(82, 84, 87) An example of a heavily cited (over 4250 times as of July 2024) definition is eHealth can be defined as "... an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology."⁽¹¹⁶⁾ This definition by Eysenbach (2001) acknowledges that eHealth is broad reaching and refers to using information and communication technology (ICT) in a purposeful manner to achieve better health outcomes.

Eysenbach's definition was revised by Pagliari et al (2005) to, "eHealth is an emerging field of medical informatics, referring to the organization and delivery of health services and information using the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a new way of working, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology."⁽⁸⁷⁾ In this definition, eHealth is said to belong to medical informatics, however informatics is its own umbrella term.⁽¹¹⁷⁾

Al-Rimaw et al (2016) after analysing multiple definitions of eHealth provided 6 themes (Figure 21) involving what eHealth means.⁽⁸⁴⁾ They describe what eHealth:

- Means - health is referred to in reference to health services as opposed to health outcomes with wellbeing and wellness being uses as a synonymous term
- Uses - information and communication technology
- Involves - various stakeholders including professionals, patients or clients, business sector, health care organisations, government and communities
- Creates - improving health care, encouraging health care organizations to be innovative in health care delivery approaches, making the-health information accessible, effective and efficient and cost effective and helping health care professionals and managers in decision making
- Effects - can be applied and attain its effects; locally, nationally, and internationally
- impacts - can be applied in clinical practice areas, education, research, administration, health surveillance, health literature, and business

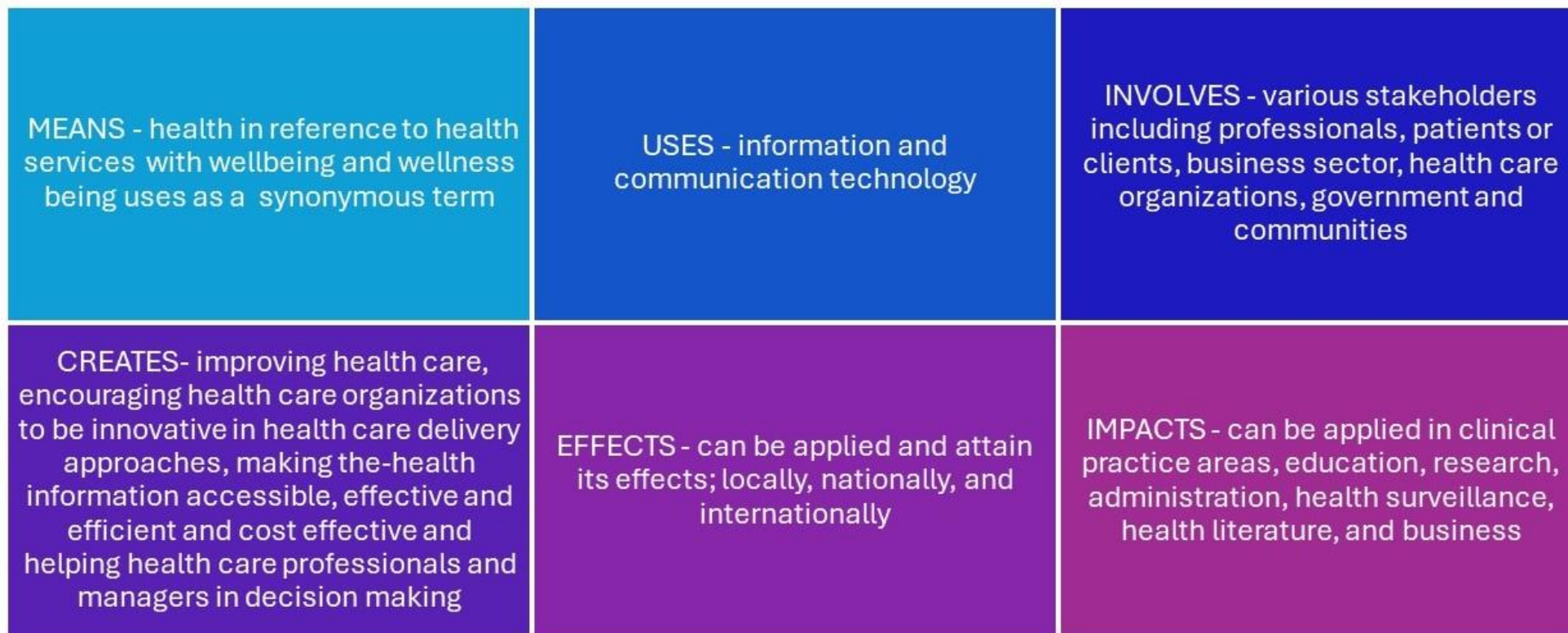


Figure 21 - Themes of what eHealth is

[Diagram created by the author based on themes in Al-Rimaw et al 2016.]⁸⁴

What does the “e” mean?

The “e” stands for electronic.⁽¹¹⁶⁾ In Eysenbach’s definition, 13 other e’s were provided:

- Efficiency
- Enhancing quality of care
- Evidence based
- Empowerment of consumers and patients by making the knowledge bases of medicine and personal electronic records accessible to consumers over the Internet
- Encouragement of a new relationship between the patient and health professional
- Education of physicians through online sources
- Extending the scope of health care beyond its conventional boundaries.
- Ethics
- Equity
- Easy-to-use
- Entertaining (no-one will use something that is boring!) and
- Exciting.

However, even with these additional "e" terms, eHealth's true meaning remained elusive. This is where examining the use of “e’s” outside of healthcare, such as by contrasting it with concepts like eBusiness and eCommerce, helped with understanding what eHealth means:

- “eCommerce, short for “electronic commerce,” refers to business transactions that take place entirely online.” Also “Carrying out commercial transactions online.”
- “eBusiness, also known as “electronic business,” is a more comprehensive term for doing business online.” Also ” Carrying out all kinds of business and services activities online.”⁽¹¹⁸⁾

In this context, eHealth can be understood simply as carrying out health activities online (Figure 22).

eBusiness = Carrying out all kinds of business and services activities online

eCommerce = Carrying out commercial transactions online

eHealth = Carrying out health activities online

Figure 22 - eBusiness, eCommerce and eHealth

How is eHealth different to digital health?

The terms digital health and eHealth have been used interchangeably. Some authors define eHealth as the same as digital health. A current example from 2024 is Zrubka et al who defined digital health and eHealth as synonymous but distinguished telehealth from mHealth (Figure 23).

(86)

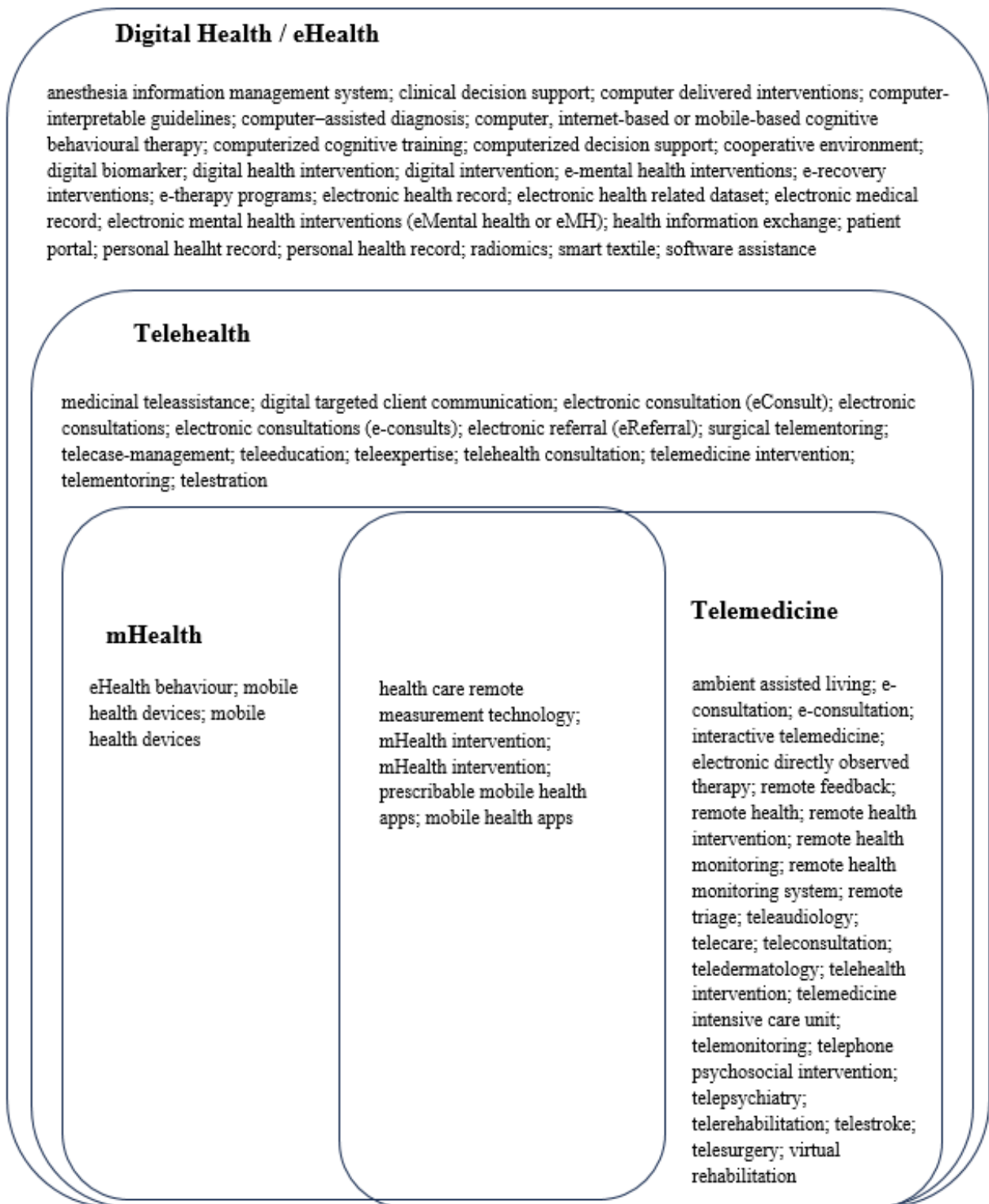


Figure 23 - Definition of digital health and eHealth

[From Zrubka et al (2024) Appendix 5. Published under a Creative Commons Attribution 4.0 International License <http://creativecommons.org/licenses/by/4.0/>. No changes made.](⁸⁶)

Some authors on the other hand, consider digital health to be an umbrella term which includes the concept of eHealth^(92, 97, 103). A helpful illustration explaining the intersection of digital health, eHealth, mHealth and tele terms was provided by Herold et al (2022) (Figure 24).⁽¹⁰³⁾ From their viewpoint, digital health is an umbrella term which includes both eHealth and mHealth.

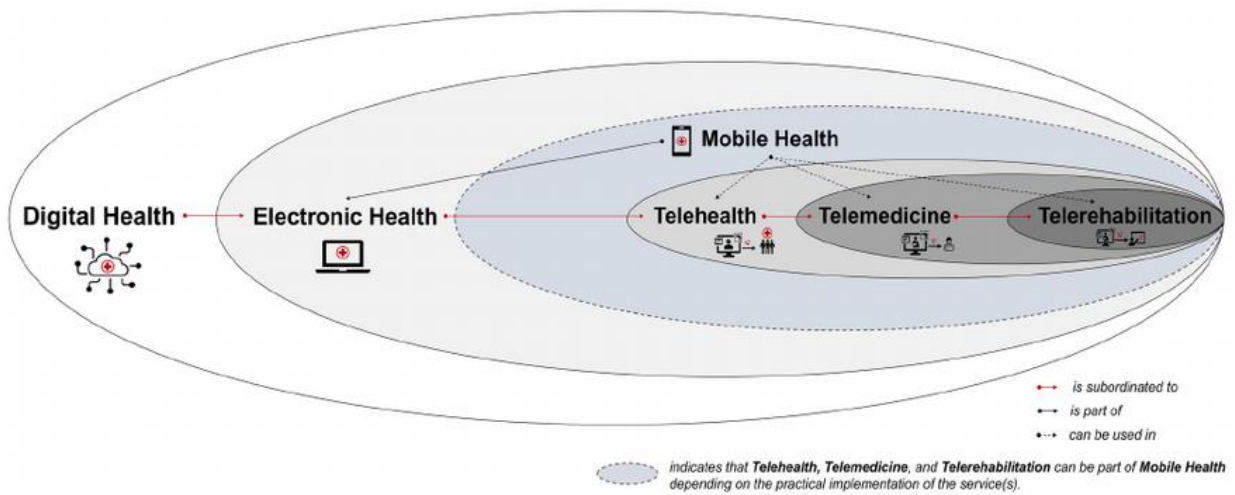


Figure 24 - Illustration of the relationship between digital health, eHealth, mHealth, telehealth, telemedicine and telerehabilitation

[From Herold et al (2022) published under a Creative Commons Attribution 4.0 International License. <http://creativecommons.org/licenses/by/4.0/> No changes made.](¹⁰³)

What does mHealth and telehealth mean?

The difference in terminology between digital and electronic (“e”), mobile (“m”) and tele was attempted by Burrell and colleagues.⁽¹¹⁹⁾ “For technology, the broadest terms are digital and “e” (electronic) referring to the use of all digital, electronic, and computer technologies, followed by “tele” meaning “at a distance” referring to telecommunication technology, and then “m” (mobile) referring specifically to mobile telecommunication technology.” This statement allows for the helpful distinction that mHealth refers to mobile or on the go technology and tele involves any services delivered at a distance (Figure 25).

Term	Meaning
digital and “e” (electronic)	referring to the use of all digital, electronic, and computer technologies
“m” (mobile)	referring specifically to mobile telecommunication technology
“tele”	meaning “at a distance”

Figure 25 - Terminology related to e, m and tele

What is eHealth as a Service (eHaaS)?

There is a drive towards patient centric health systems which is focussed on putting the needs, preferences, and values of patients at the centre of healthcare decisions and services.⁽⁹⁰⁾ Black et al (2014) in their paper on eHealth-as-a-Service (eHaaS) mentioned \$466.7 million dollars of funding by the Australian Federal Government in 2010 for the implementation of personally controlled electronic health records (PCEHR).⁽¹²⁰⁾ Black and Sahama (2014) write “eHealth-as-a-Service (eHaaS) offers an alternative stakeholder-centric construct that establishes the PCEHR as the keystone of a holistic eHealth ‘as a service’ framework unifying longitudinal patient data from disparate sources. The building blocks of an eHealth system, personal health records (PHR), electronic medical records (EMR) and Electronic Health Records (EHR) are encapsulated in the eHaaS framework with the interconnections comprising human behaviour and information flow a principle design consideration.”⁽¹²¹⁾ From this definition we can understand that within the eHaaS framework, key components are:

- Electronic Health Records (EHR): Comprehensive records that integrate data from multiple sources.
- Electronic Medical Records (EMR): Managed by healthcare providers, these records contain detailed medical histories and treatment information.
- Personal Health Records (PHR): Managed by patients, these records contain health information entered by the individual.

An illustration of how to understand these concepts is provided (Figure 26) and was adapted from an illustration from Black and Sahama.⁽¹²¹⁾ A crucial aspect of the eHaaS design is the consideration of how people interact with these records and how information flows between different systems and stakeholders. An illustration (Figure 27) is provided of this adopted from Black et al (2014).⁽¹²⁰⁾

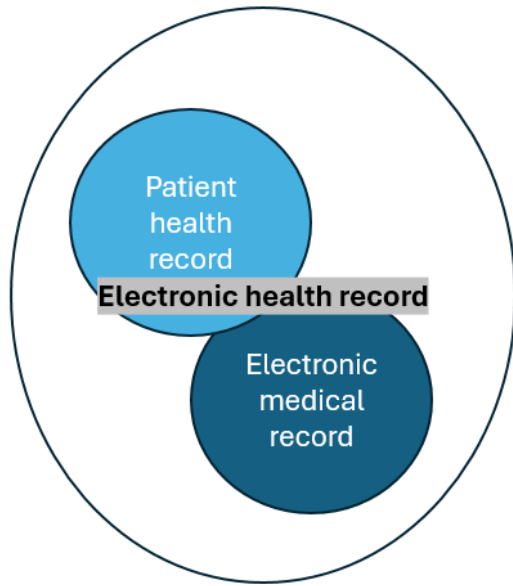


Figure 26 - Electronic health record vs medical and patient

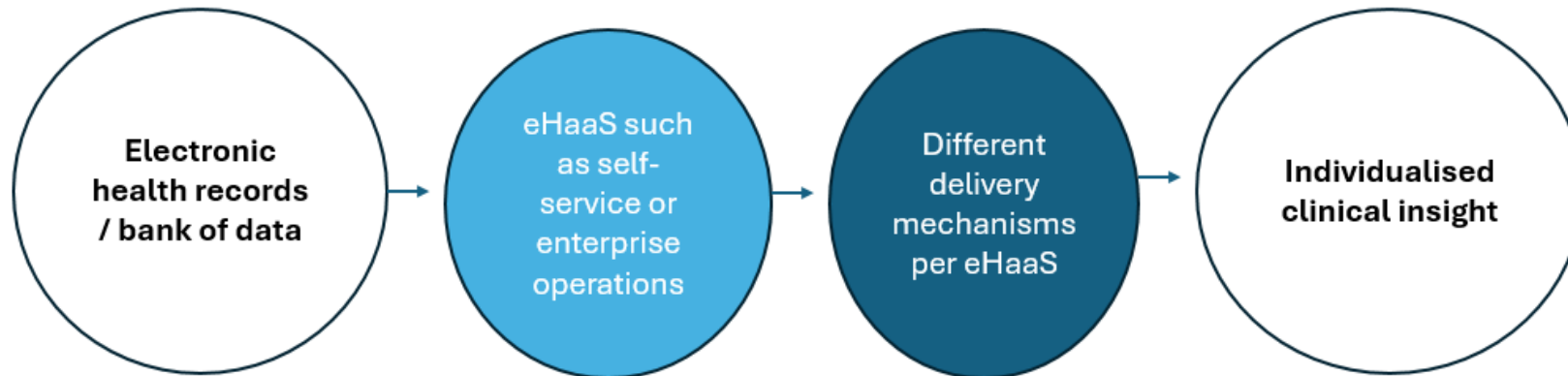


Figure 27 – eHaaS unifies patient data from disparate sources

The concept of eHaas helps to highlight that eHealth focuses on the delivery mechanism of different digital solutions e.g. portable or mobile applications, web-based software or cloud-based file servers. With this in mind, eHealth can be viewed in terms of how healthcare services are delivered electronically (Figure 28).

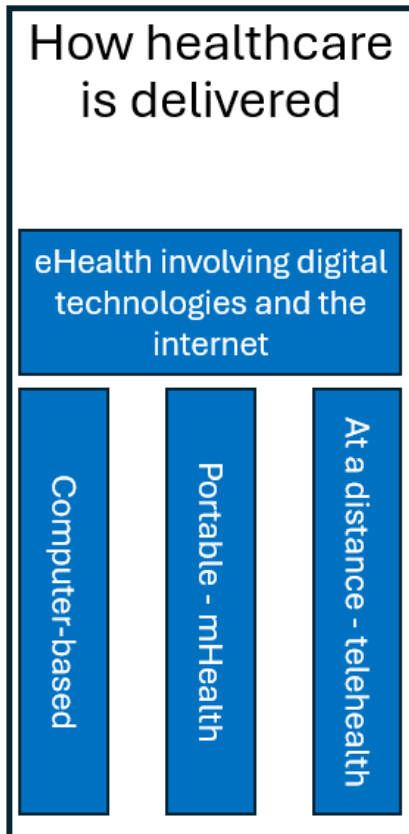


Figure 28 - How healthcare services are delivered through eHealth

What are eHealth modalities?

“Typically, an eHealth modality is considered to be some specific form of technology that is applied in the context of health care.”⁽¹²²⁾

There are various types of eHealth modalities. Some include:

- **Telehealth** involves healthcare at a distance or remotely through telecommunications technology. Telehealth includes the subsets of telemedicine and telerehabilitation.⁽¹⁰³⁾
- **Computer-based or web-based interventions** are healthcare interventions delivered online, usually through a desktop computer.⁽¹²³⁾
- **Mobile Health (mHealth)** refers to healthcare services and information provided via mobile devices such as smartphones and tablets.⁽¹²⁴⁾

- **Robotics** whereby “A robot is a reprogrammable, multifunctional manipulator designed to move material, parts, tools, or specialized devices, through variable programmed motions for the performance of a variety of tasks.”⁽¹²⁵⁾
- **Electronic Health Records (EHR) or eRecords** are digital versions of patients' paper charts. EHRs include data such as medical history, treatment plans, test results, and immunisation records. As mentioned in the previous section, the concept of eHealth as a service (EaaS) relies on the use of EHRs.⁽¹²⁰⁾
- **Electronic results or eResults** refers to the digital or electronic delivery of outcomes, such as test results, reports, or data, typically accessed through online platforms or systems.
- **Health Information Systems (HIS)** involves management of healthcare data, including patient records, hospital administration, and public health information. Health information systems support decision-making, resource allocation, and policy development in healthcare.⁽¹²⁶⁾ EHRs are enabled through HIS.
- **Wearable medical devices** are gadgets like fitness trackers, smartwatches, and medical devices that monitor health metrics such as heart rate, physical activity, sleep patterns, and blood glucose levels. Wearable devices provide continuous health monitoring and can alert users and healthcare providers to potential health issues.⁽¹²⁷⁾
- **Software leveraging Artificial Intelligence (AI)** involves various ways in which AI can be used such as through processing large amounts of healthcare data to identify patterns, predict outcomes, and personalise treatment plans. AI can assist in diagnostics, predictive modelling, and automating patient care.⁽¹¹⁴⁾
- **Electronic mail or Email** is communicating digitally. Email consultations, for example, are a way to deliver healthcare online.⁽¹²⁸⁾
- **Online information** includes any form of digital information. Anyone can post online information, leading to one librarian inventing the CRAAP test to evaluate online information (Currency, Relevance, Authority, Accuracy, and Purpose).⁽¹²⁹⁾ Instructive online information is health information designed to provide education or specific health instructions.⁽¹³⁰⁾ Electronic learning or eLearning, is a form of instructive online information.
- **Electronic Transfer of Prescriptions (ETP) or ePrescriptions** typically refers to the prescription of medication digitally.⁽¹³¹⁾
- **Health knowledge management** involves “...three conceptual domains: personal learning (knowledge creation); communities of practise (knowledge normalisation); and the exercise of technical expertise and technology (knowledge application).”⁽¹³²⁾
- **Clinical decision support systems** assist health professionals in making more informed decisions when providing care.⁽¹³³⁾
- **Social media** refers to digital platforms for information exchange and discussions.⁽¹³⁴⁾

- **Digital games** are interactive software-based entertainment experiences played on electronic devices such as computers, consoles, or mobile devices. Serious games are digital games designed with the primary purpose of educating, training, or solving real-world problems, rather than solely for entertainment.⁽¹³⁵⁾
- **Digital communities of practice** are online networks where professionals or learners with shared interests collaborate, share knowledge, and develop skills in a specific field or domain.⁽¹³⁶⁾
- **Infoveillance** is the use of digital tools and technologies to monitor and analyse information, particularly online data, for public health surveillance and other purposes.⁽¹³⁷⁾

Key concept (iii): Digital health is accomplished through digital technologies

“Digital health is a field that aims to improve patient care through the use of technology, such as telemedicine, mobile health, electronic health records, and artificial intelligence.”⁽¹³⁸⁾ Digital health would not be achieved without the use of digital technologies.

What is a digital health intervention?

The term used for digital tools and technologies is "digital health intervention" (DHI). Zrubka et al (2024) refer to DHIs through technologies which allow for digital health. “Digital health involves technologies including artificial intelligence (AI), virtual reality, digital therapeutics, wearables, remote monitoring, and software.”⁽⁸⁶⁾

Various definitions of DHIs are provided (Table 1). A representation of extracted common themes encompassing the defining components of “what” and “why” from the definitions of DHIs is below (Figure 29).

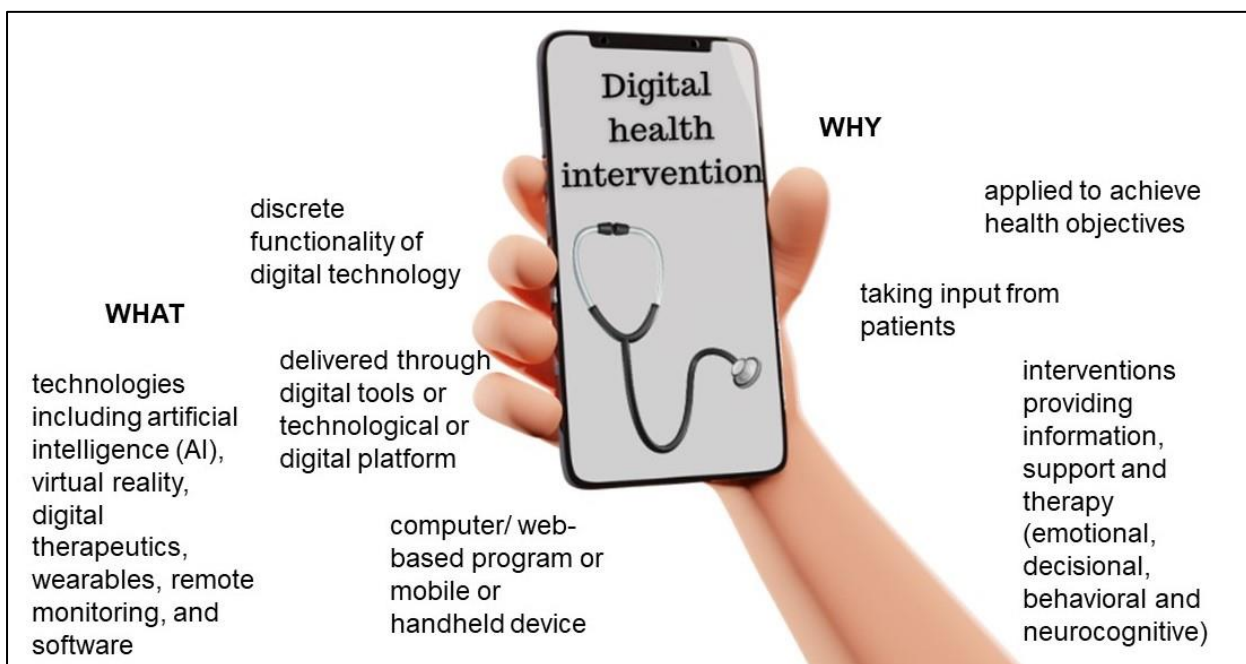


Figure 29 - Themes from definitions of digital health interventions encompassing “what” and “why” components of various definitions

What are types of digital health interventions (DHIs)?

The World Health Organization (WHO) state, “A digital health intervention is defined here as a discrete functionality of digital technology that is applied to achieve health objectives.”⁽¹³⁹⁾ DHIs are defined according to the WHO in Table 2.⁽¹⁰⁴⁾

What are digital health services?

The WHO describe how digital services deliver or execute the digital health intervention(s). Under their classification system there are 5 types of services (Figure 30).⁽¹⁰⁴⁾



Figure 30 - World Health Organization classification of services and application types

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Key concept (iv): Digital health is more complex than simply using digital technologies and includes concepts such as data harvesting and decentralisation of data

Is digital health simply using digital technologies?

In Rowlands (2020) white paper on digital health he highlights that traditional definitions of digital health “miss the mark.”⁽⁹¹⁾ The point is made that simply using digital technologies does not comprise digital health. He comments that “...information and communication technologies (ICT) have been used in healthcare for the last 70+ years. The technologies have matured, and their sophistication and ubiquity are accelerating exponentially, but ICT is still ICT.”

Rowlands defines digital health as “...health and healthcare in the context of digital societies” including the following four components:

- Harvesting of data, information and knowledge in real time from all societal activities, not just interactions with the health system and/or data traditionally regarded as “health” data
- Using sophisticated analytics to distil knowledge from these data
- Intervening in the widest possible range of societal and economic activities and technologies which encourage and generate better health and better value for health investments
- Being citizen (not provider/customer/patient) centric, decentralised and requiring health service providers to participate, not control usage.

What is uHealth?

The concept of data harvesting from all societal activities led to research into a concept known as Ubiquitous Health (uHealth), which refers to the integration of healthcare services into everyday environments through the pervasive use of digital technologies. uHealth aims to make healthcare continuously accessible to individuals, regardless of their location, by leveraging the omnipresence of technology in daily life.⁽¹⁴⁰⁾ Saleemi et al (2023) stated, “This next wave in technology is changing the way users interact with context-aware and adaptable smart devices that integrate into the environment to allow users to stay connected from anywhere.”⁽¹⁴¹⁾

In other areas of health, such as mental health research, there is over a decade of research into uHealth.⁽¹⁴²⁾ It is unknown whether research on uHealth is being conducted in lymphoedema care.

Key concept (v): Digital health encompasses the terms digital medicine and digital therapeutics

What is digital medicine and digital therapeutics?

The digital health umbrella (Figure 16) encompasses the terms digital medicine and digital therapeutics (Figure 31). Digital health encourages clients to maintain healthy lifestyles (e.g., mobile apps and social media platforms), digital medicine involves more complex medical solutions such as ingestible sensors and digital pills or software as a medical device (SaMD) whereas digital therapeutics involves even more complex medical digital interventions.⁽¹⁰⁶⁾

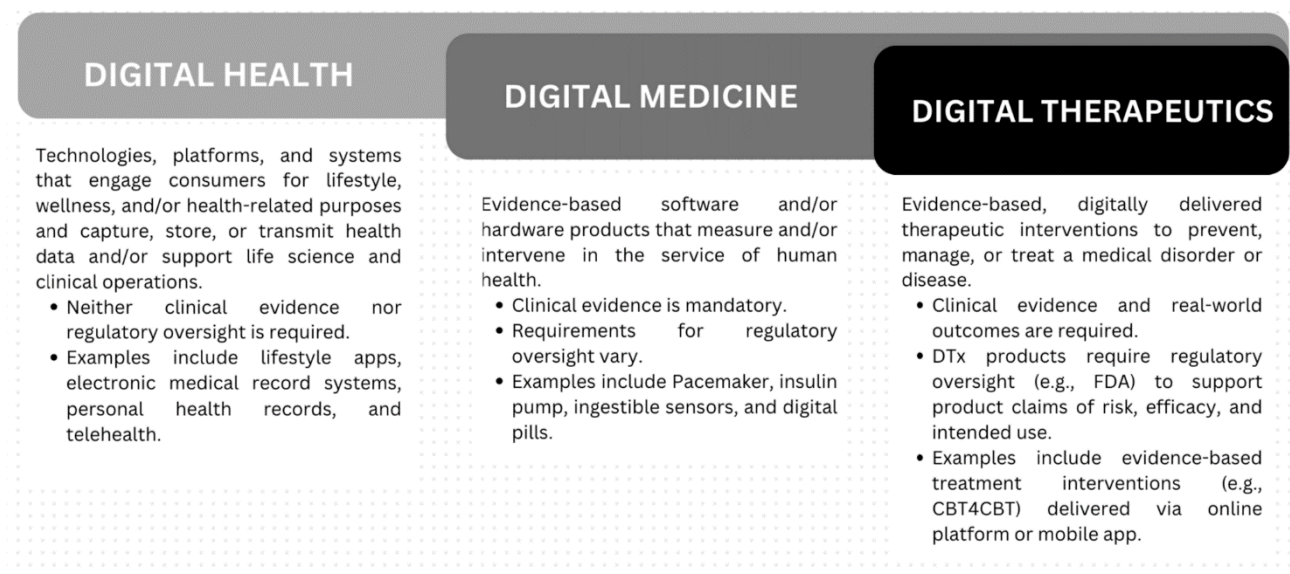


Figure 31 - Digital health vs digital medicine and digital therapeutics

[From Sawyer-Morris et al (2024). Published under a Creative Commons Attribution 4.0 International License <http://creativecommons.org/licenses/by/4.0/>. No changes made]⁽¹⁰⁶⁾

The distinction between digital health, digital medicine, and digital therapeutics is crucial because each category has different implications for regulation, safety, and efficacy standards.⁽¹⁴³⁾

Understanding these distinctions ensures that products are appropriately classified and reviewed by regulatory bodies like the Therapeutic Goods Administration (TGA), which impacts their approval, use, and market access.

Key concept (vi): Digital health involves digital technologies being used to improve patient care and healthcare outcomes

How can patient care and healthcare outcomes be improved?

The Australian Government's Digital Health Agency (2024) states "Digital health is not simply about the latest technology. It is about supporting a modern, high-quality health system, improving the quality of life of individuals, families and communities, and equipping people to confidently manage their health and wellbeing journey. It's also about enabling healthcare providers to maximise their skills and contributions by increasing effectiveness and efficiency."⁽⁹⁰⁾ With this definition in mind, from the perspective of policy makers and regulators, four overall outcomes for the Australian health system aim to be achieved (Figure 32):

- **Digitally enabled:** Health and wellbeing services are connected, safe, secure and sustainable. Digital enablement means collecting data, information, and knowledge in real-time from all areas of society, not just from health system interactions or traditional health data, and using advanced analytics to extract meaningful insights from this data.⁽⁹¹⁾
- **Person-centred:** Australians are empowered to look after their health and wellbeing, equipped with the right information and tools. What person centred means is captured in the following statement, "Digital health transforms how medicine is delivered and managed: instead of relying on the acute, episodic collection of health information at doctor visits, digital health technologies offer a more comprehensive portrait of an individual patient's health by offering new access to care and greatly enhanced monitoring outside the clinic visit."⁽⁹⁵⁾
- **Inclusive:** Australians have equitable access to health services, when and where they need them. The concept of accessibility becomes an important consideration.
- **Data-driven:** Readily available data informs decision making at the individual, community and national level, contributing to a sustainable health system.





HEALTH SYSTEM OUTCOMES ENHANCED BY DIGITAL HEALTH	
 <p>1. Digitally enabled: Health and wellbeing services are connected, safe, secure and sustainable</p>	 <p>2. Person-centred: Australians are empowered to look after their health and wellbeing, equipped with the right information and tools</p>
 <p>3. Inclusive: Australians have equitable access to health services when and where they need them</p>	 <p>4. Data-driven: Readily available data informs decision making at the individual, community and national levels, contributing to a sustainable health system</p>

Figure 32 - Australian Government's Digital Health Strategy health system outcomes

[From the National Digital Health Strategy 2023-2028. © Australian Digital Health Agency, 2023 licensed under CC BY-NC 4.0 <https://creativecommons.org/licenses/by-nc/4.0/deed.en>. No changes made.]⁹⁰⁾

What is Healthcare 4.0?

By digital health being digitally enabled, person centred, inclusive and data driven, the umbrella term digital health also encompasses the concept of Healthcare 4.0 (or Health 4.0) (Figure 16).

In the book "Healthcare 4.0" by Chanchaichujit et al (2019), the authors explain that the period between 1970 and 1990 witnessed the rise of modular or silo information and communication (ICT) systems in the healthcare sector, which were referred to as Healthcare 1.0.⁽¹⁴⁴⁾ Over the next fifteen years, the majority of ICT systems began networking and using EHRs for Healthcare 2.0.

Starting in the year 2000, there was a significant advancement in genomic information, as well as the introduction of wearable and implantable technologies. Healthcare 3.0 then emerged.

The current trend in healthcare is the development of Healthcare 4.0, which involves the integration of technologies such as the Internet of Things (IoT) for data collection, the increased utilisation of AI for analysis, and the implementation of blockchain for storing patient medical records. The emphasis on collaboration, coherence, and convergence is expected to enhance the predictive and personalised nature of healthcare.

The transition from Healthcare 1.0 to 4.0 is depicted in Figure 33.

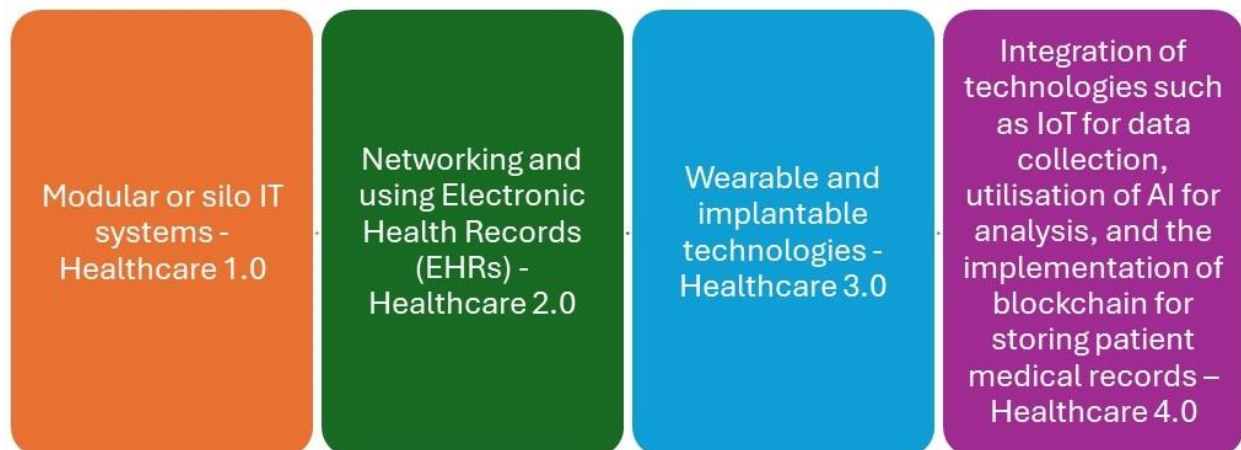
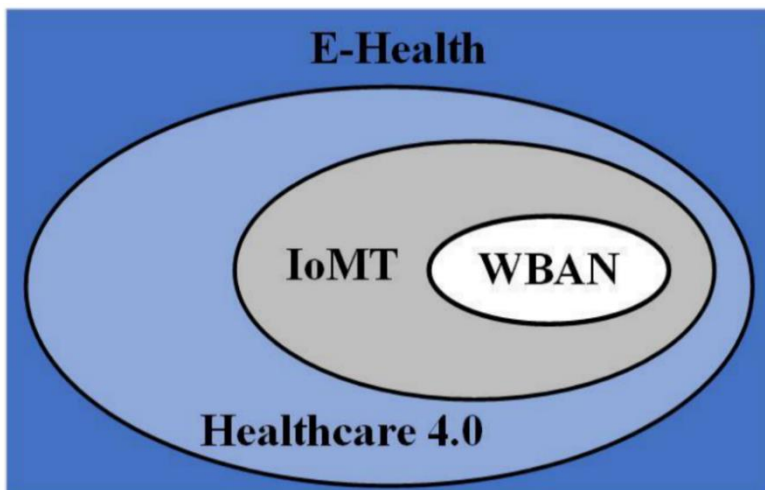


Figure 33 - From Healthcare 1.0 to 4.0

“Healthcare 4.0 is interpreted as the enhanced interconnection between cyber and physical aspects, and interconnection solutions provided by innovative information and communication technologies such as Big Data, the IoT, and cloud computing.”⁽¹⁰⁸⁾ Healthcare 4.0 can therefore be understood as:

- referring to the fourth industrial revolution in healthcare involving the integration of advanced digital and networking technologies, such as AI and the IoT to improve healthcare delivery systems.⁽¹⁴⁴⁾
- housing the concepts of the IoT and Wireless Body Area Networks (WBANs) (Figure 34) ⁽⁸⁵⁾



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Figure 34 - eHealth includes Healthcare 4.0 and IoMT

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What is the Internet of Medical Things (IoMT)?

The Internet of Things (IoT) refers to the network of physical objects—such as devices, vehicles, appliances, and other items—that are embedded with sensors, software, and other technologies to connect and exchange data with other devices and systems over the internet. These interconnected devices can collect and share data, automate processes, and provide real-time insights, enabling smarter decision-making and more efficient operations.⁽¹⁴⁵⁾

The Internet of Medical Things (IoMT) refers to applying the Internet of Things (IoT) into the medical field.⁽¹⁴⁶⁾ A helpful illustration is provided by Kumar et al (2023) on how the IoMT works (Figure 35).⁽¹⁴⁷⁾

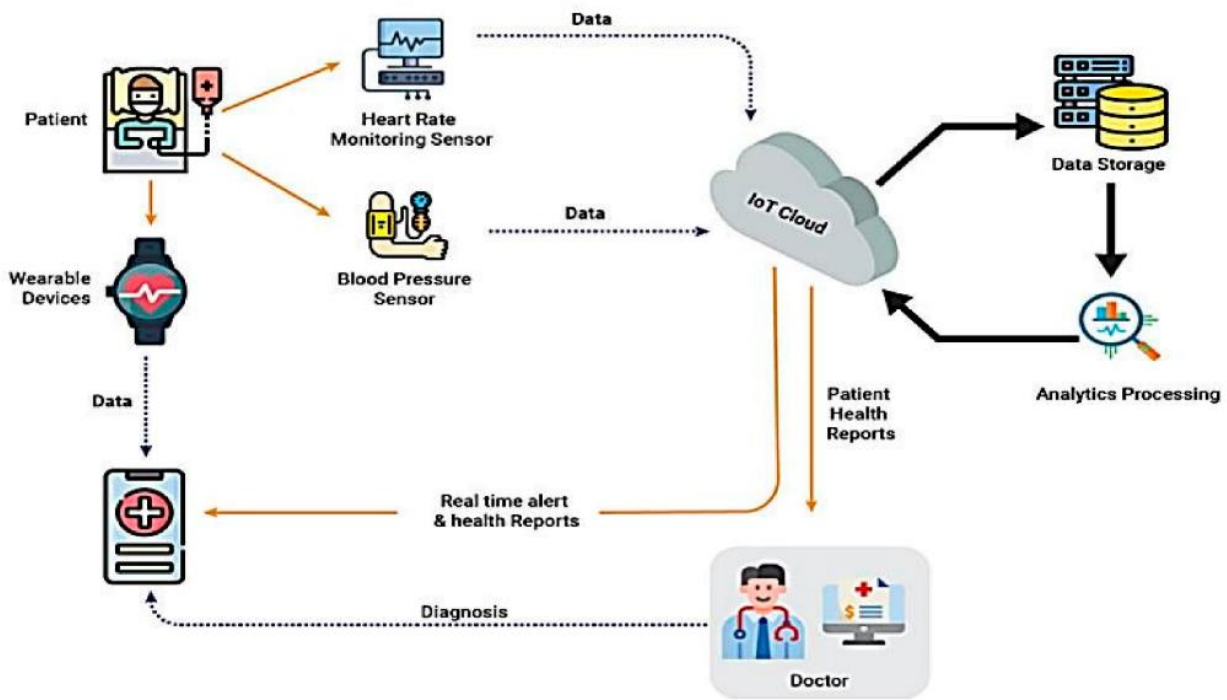


Figure 35 - IoT in healthcare

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The IoMT has four layers of structure (Figure 36).

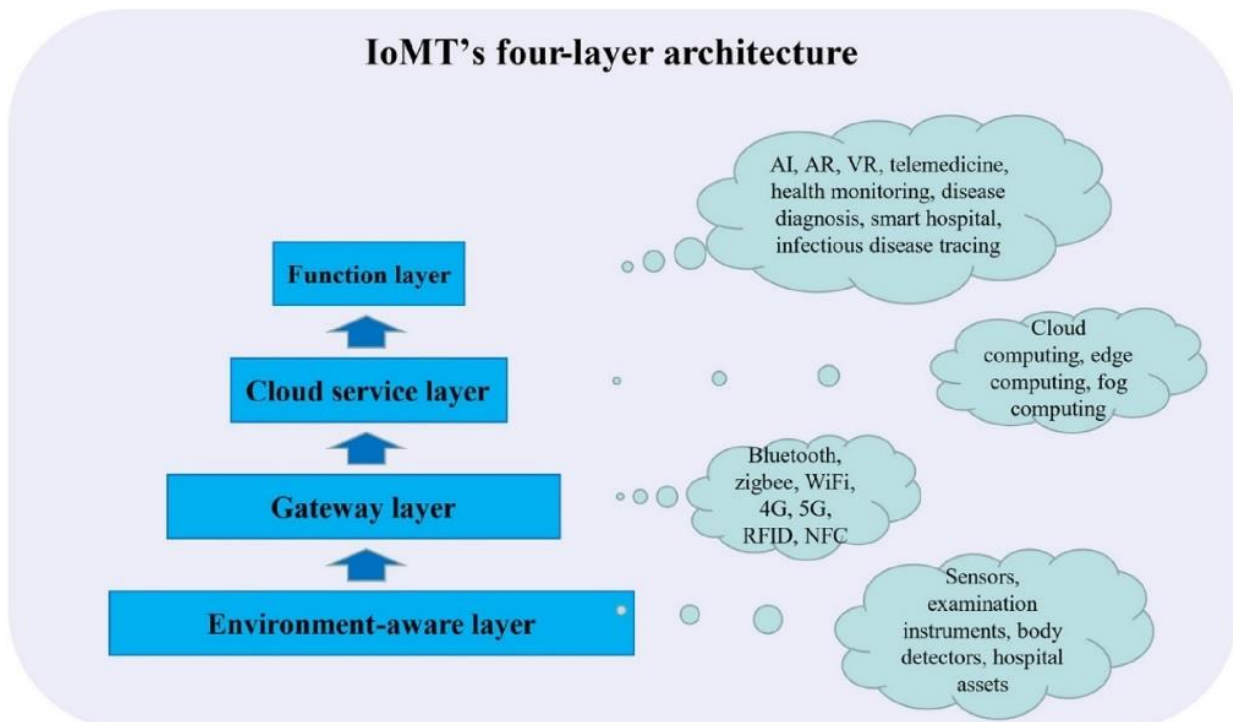


Figure 36 - IoMT four-layer architecture

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What are Wireless Body Area Networks?

Wireless Body Area Networks (WBANs) are specialised networks composed of miniaturised sensors and devices that are either implanted in or worn on the human body.⁽¹⁴⁸⁾ These devices are wirelessly connected and designed to monitor and collect physiological data, which can then be transmitted to external systems for analysis. WBANs are primarily used in healthcare and medical applications to provide continuous, real-time monitoring of a person's health status without any constraints on patients' normal daily life activities.

Definitions of digital health interventions

Table 1 - Definitions of digital health and digital health interventions

Publication / source	Context	Definition
Zrubka (2024) ⁽⁸⁶⁾	What digital health is	Digital health involves technologies including artificial intelligence (AI), virtual reality, digital therapeutics, wearables, remote monitoring, and software.
World Health Organization 2018 ^(104, 105, 139)	What a digital health intervention is	A digital health intervention is defined here as a discrete functionality of digital technology that is applied to achieve health objectives
Escriva, 2018 ⁽¹⁴⁹⁾	How digital health can be delivered	They can be delivered through digital tools (D-tools) including computers, websites, mobile phones, smartphone applications (apps), and wearable devices.
Hollis, 2017 ⁽¹⁵⁰⁾	What digital health interventions are	Interventions that provide information, support and therapy (emotional, decisional, behavioural and neurocognitive) for physical and/or mental health problems via a technological or digital platform (e.g. website, computer, mobile phone application (app), SMS, email, videoconferencing, wearable device)
Nicholl, 2017 ⁽¹⁵¹⁾		Interventions accessed via computer, mobile phone, or other handheld devices, including web-based, desktop computer programs, or apps

Table 2 - Types of digital health interventions according to the World Health Organization

Category		Digital Health Interventions
1.1	Targeted communication to Persons	1.1.1 Transmit health event alerts to specific population group(s)
		1.1.2 Transmit targeted health information to person(s) based on health status or demographics
		1.1.3 Transmit targeted alerts and reminders to person(s)
		1.1.4 Transmit diagnostics result, or availability of result, to person(s)
1.2	Untargeted communication to Persons	1.2.1 Transmit untargeted health information to an undefined population
		1.2.2 Transmit untargeted health event alerts to undefined group.
1.3	Person to Person communication	1.3.1 Peer group for individuals
1.4	Personal health tracking	1.4.1 Access by the individual to own medical or summary health records
		1.4.2 Self-monitoring of health or diagnostic data by the individual
		1.4.3 Active data capture/documentation by an individual
		1.4.4 Access by the individual to verifiable documentation of a health event or health status
1.5	Person based reporting	1.5.1 Reporting of health system feedback by persons
		1.5.2 Reporting of public health events by persons
1.6	On demand communication with persons	1.6.1 Look-up of information on health and health services by individuals
		1.6.2 Simulated human-like conversations with individual(s)
1.7	Person-centred financial transactions	1.7.1 Transmit or manage out-of-pocket payments by individuals
		1.7.2 Transmit or manage vouchers to individuals for health services
		1.7.3 Transmit or manage incentives to individuals for health services
1.8	Person-centred consent management	1.8.1 Manage provision and withdrawal of consent by individual(s)
2.1	Identification and registration of persons	2.1.1 Verify a person's unique identity
		2.1.2 Enrol person(s) for health services/clinical care plan
2.2	Person-centred health records	2.2.1 Longitudinal tracking of person's health status and services
		2.2.2 Manage person-centred structured clinical records
		2.2.3 Manage person-centred unstructured clinical records (e.g. notes, images, documents)
		2.2.4 Routine health indicator data collection and management
2.3	Healthcare provider decision support	2.3.1 Provide prompts and alerts based according to protocol

Category		Digital Health Interventions
		2.3.2 Provide checklist according to protocol
		2.3.3 Screen persons by risk or other health status
2.4	Telemedicine	2.4.1 Consultations between remote person and healthcare provider
		2.4.2 Remote monitoring of person's health or diagnostic data by provider
		2.4.3 Transmission of medical data (e.g. images, notes, and videos) to healthcare provider
		2.4.4 Consultations for case management between healthcare providers
2.5	Healthcare provider communication	2.5.1 Communication from healthcare provider to supervisor(s)
		2.5.2 Communication and performance feedback to healthcare provider(s)
		2.5.3 Transmit routine news and workflow notifications to healthcare provider(s)
		2.5.4 Transmit non-routine health event alerts to healthcare provider(s)
		2.5.5 Peer group for healthcare providers
		2.5.6 Generative AI for tailored content creation
2.6	Referral coordination	2.6.1 Coordinate emergency response and transport
		2.6.2 Manage referrals between points of service within health sector
		2.6.3 Manage referrals between health and other sectors (social services, police, justice, economic support schemes)
2.7	Scheduling and activity planning for healthcare providers	2.7.1 Identify persons in need of services
		2.7.2 Schedule healthcare provider's activities
2.8	Healthcare provider training	2.8.1 Provide training content to healthcare provider(s)
		2.8.2 Assess capacity of healthcare provider(s)
2.9	Prescription and medication management	2.9.1 Transmit or track prescription orders
		2.9.2 Track individual's medication consumption
		2.9.3 Report adverse drug effects
2.10	Laboratory and diagnostics imaging management	2.10.1 Transmit person's diagnostic result to healthcare provider
		2.10.2 Transmit and track diagnostic orders
		2.10.3 Capture diagnostic results from digital devices
		2.10.4 Track biological specimens
2.11	Healthcare provider financial transactions	2.11.1 Verify individual's health coverage and financing scheme membership
		2.11.2 Receive payments from individuals

Category		Digital Health Interventions
3.1	Human resource management	3.1.1 List health workforce cadres and related identification information
		3.1.2 Monitor performance of healthcare provider(s)
		3.1.3 Manage registration/certification of healthcare provider(s)
		3.1.4 Record training credentials of healthcare provider(s)
		3.1.5 Manage health workforce activities
3.2	Supply chain management	3.2.1 Manage inventory and distribution of health commodities
		3.2.2 Notify stock levels of health commodities
		3.2.3 Monitor cold-chain sensitive commodities
		3.2.4 Register licensed drugs and health commodities
		3.2.5 Manage procurement of commodities
		3.2.6 Report counterfeit or substandard drugs by persons
3.3	Public health event notification	3.3.1 Notification of public health events from point of diagnosis
3.4	Civil Registration and Vital Statistics (CRVS)	3.4.1 Notify, register and certify birth event
		3.4.2 Notify, register and certify death event
3.5	Health system financial management	3.5.1 Register and verify health coverage scheme membership of persons
		3.5.2 Track and manage insurance billing and claims processes
		3.5.3 Transmit and manage payments to health facilities
		3.5.4 Transmit and manage routine payroll payment to healthcare provider(s)
		3.5.5 Transmit or manage financial incentives to healthcare provider(s)
		3.5.6 Manage and plan budget allocations, revenue and expenditures
		3.5.7 Determine level of subsidies for health coverage schemes
		3.5.8 Collect health insurance contributions
3.6	Equipment and asset management	3.6.1 Monitor status and maintenance of health equipment
		3.6.2 Track regulation and licensing of medical equipment
3.7	Facility management	3.7.1 List health facilities and related information
		3.7.2 Assess health facilities
3.8	Person-centred health certificate management	3.8.1 Register and store current health certificate information
		3.8.2 Retrieve and validate current health certificate information

Category		Digital Health Interventions
		3.8.3 Revoke and update health certificate
4.1	Data Management	4.1.1 Form creation for data acquisition
		4.1.2 Data storage and aggregation
		4.1.3 Data synthesis and visualizations
		4.1.4 Automated analysis of data to generate new information or predictions on future events
4.2	Data coding	4.2.1 Parse unstructured data into structured data
		4.2.2 Merge, de-duplicate and curate coded datasets or terminologies
		4.2.3 Classify disease codes or cause of mortality
4.3	Geo spatial information management	4.3.1 Map location of health facilities/structures and households
		4.3.2 Map location of health event
		4.3.3 Map location of persons and settlements
		4.3.4 Map location of healthcare provider(s)
		4.3.5 Map health and health indicator data to geographic data
4.4	Data exchange and Interoperability	4.4.1 Point-to-point data integration
		4.4.2 Standards-compliant interoperability
		4.4.3 Message routing
4.5	Data governance compliance	4.5.1 Authentication and authorisation
		4.5.2 Data privacy protection
		4.5.3 Data consent and provenance
		4.5.4 Trust architecture

CHAPTER FOUR: CONTRIBUTING TO THE FIELD OF DIGITAL HEALTH BY DEFINING THE TERM

Chapter overview

Eysenbach's 2001 publication, "What is eHealth?" has garnered thousands of citations.⁽¹¹⁶⁾ It offers a helpful working definition of what eHealth is. At the start of Chapter Three it was outlined that, since the release of Eysenbach's definition, authors continue to refer to struggling with a persistent lack of consensus on terminology.^(80, 82, 85, 86)

After spending extensive time grappling with the ostensibly simple question, "What is digital health?", the objective of this research was to demystify the concept and provide clarity, ultimately enriching the discourse and understanding within this rapidly evolving domain. This chapter presents the author's publication which defines what digital health is. In this perspective piece, a new definition of digital health is presented by delving into four key subdomains and introducing emerging themes such as Healthcare 4.0 and ubiquitous health (uHealth).

Highlights

The key highlights of this research include:

- A demonstration of the author's comprehensive understanding of what the term "digital health" means
- The provision of a conceptual framework for understanding digital health encompassing four subdomains including: 1) how healthcare is delivered including the concepts of eHealth, mHealth, telehealth and uHealth; 2) how digital products are positioned and regulated including the concepts of digital health, wellness and therapeutic solutions; 3) how society, industry, and patient care are impacted including the concept of Healthcare 4.0; and 4) how health data is used and interpreted including the field of health informatics.
- Clarity on what the term eHealth means. eHealth was found to be an umbrella term which includes computer-based solutions, portable solutions through mHealth, remote solutions through telehealth, and home-based solutions through uHealth.

Publication title - What is Digital Health, eHealth, uHealth and Healthcare 4.0?

Reference

Mangion A, Piller N. What is digital health, eHealth, uHealth and Healthcare 4.0? Submitted to Informatics and Health. July 2024.

Credit

Conceptualisation, methodology, writing – original draft, review, and editing by A.M. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 100% of the data collection and analysis and 95% of the writing and editing.

Publication

Abstract

Despite the rapid expansion of digital health, a lack of consensus on terminology remains. In this perspective piece a revised definition of digital health is provided with consideration of the complexity and wide-reaching scope of this field. Digital health encompasses four subdomains including: 1) how healthcare is delivered including the concepts of eHealth, mHealth, telehealth and uHealth; 2) how digital products are positioned and regulated including the concepts of digital health, wellness and therapeutic solutions; 3) how society, industry, and patient care are impacted including the concept of Healthcare 4.0; and 4) how health data is used and interpreted including the field of health informatics.

Background

Eysenbach's 2001 publication, "What is eHealth?" has profoundly shaped the field of digital health, becoming a seminal reference frequently cited.⁽¹¹⁶⁾ Despite the rapid expansion of the field, a consensus on terminology remains elusive. The terms digital health and electronic health (eHealth) are often used interchangeably or said to belong to related fields such as medical informatics.⁽⁸⁷⁾ Researchers, such as Zrubka et al (2024), have noted the "bewildering array of terms in use".⁽⁸⁶⁾

An understanding of terminology has been assisted by Herold et al. (2022) who explained that digital health is an umbrella term encompassing eHealth, mobile health (mHealth), and telehealth.⁽¹⁰³⁾ In their helpful publication the authors explained that mHealth refers to the use of mobile wireless technologies whilst telehealth refers to the utilisation of electronic communications and information technologies to remotely provide health care services

In the authors' opinion, an emerging concept which should also be considered under the eHealth umbrella is ubiquitous health (uHealth) which is sometimes referred to as pervasive health.^(152, 153) uHealth focuses on integrating healthcare into people's everyday lives through digital systems comprising one or more information systems, their stakeholders, and environments.⁽¹⁵⁴⁾ With this in mind, digital health can be understood to be achieved through eHealth, using digital technologies to deliver healthcare via computers, mobile devices, and telehealth, reaching anyone, anytime, and anywhere through uHealth.

Fatehi et al (2020) emphasised that digital health prioritises the provision of healthcare over the mere use of technology.⁽⁸⁰⁾ The field of digital health therefore must extend beyond the delivery of healthcare through digital technologies to include three other subdomains (Figure 37). Such subdomains include how digital products are positioned and regulated; how society, industry, and patient care are impacted; and how health data is used and interpreted. The subdomains are not mutually exclusive and often interact with and influence each other.

How digital solutions are packaged and marketed includes the concepts of digital medicine and digital therapeutics.^(86, 99, 107) Digital health encompasses a broad range of technologies aimed at improving health, fitness, and wellness with minimal regulatory oversight. In contrast, digital medicine and therapeutics require stringent regulatory control as they focus on diagnosing, treating, and managing medical conditions with evidence-based interventions.⁽¹⁰⁷⁾ Software as medical devices (SaMD), like all medical devices, are evaluated for their perceived potential risk to patients through relevant regulatory bodies.⁽¹⁵⁵⁾

Consider the scenario of a patient using a mobile app for treating a medical condition which leverages nano sensors. The app connects to web-based software, allowing doctors to monitor progress through the electronic medical health record (eMHR) on their desktop computer or mobile phone. The app reflects software services being positioned as a digital therapeutic solution whilst computer-based and mHealth systems are also involved in the scenario as forms of eHealth which deliver healthcare.

Digital health also includes the societal and ethical implications of eHealth, introducing Healthcare 4.0, which focuses on creating smarter, safer, and more interconnected health systems through digital technologies.⁽¹⁰⁸⁾ This paradigm shift leverages advanced technologies, impacts multiple stakeholders across various sectors, and includes concepts such as the Internet of Things (MIoT), blockchain for health, domotics for health through home automation and medical cyber-physical systems (CPS).^(145, 156-158)

To illustrate this concept, imagine a scenario of a patient's home which connects all smart devices using different but compatible communication networks and gathers detailed data on human activity, health and infrastructure through various smart sensors. The data is then analysed and intelligent execution of necessary healthcare comes from all kinds of actuators, such as home automation devices, medical equipment, and home nursing robots.⁽¹⁵⁹⁾ In this scenario, digital technologies have enabled a smart healthcare system per the premise of Healthcare 4.0. The concept of uHealth is also involved in this scenario through monitoring the patient in their home environment in real time.

The field of digital health also includes medical informatics and consideration of how health data will be used. The effective use of digital health allows for harvesting of data, information and knowledge in real time from all societal activities, not just interactions with the health system.⁽⁹¹⁾ Computational approaches for personalized medicine involve using genomic data or other forms of data and artificial intelligence (AI) to tailor medical treatments to individual patients enabling more precise diagnosis, targeted therapies, and predictive modelling of disease progression and treatment responses.⁽¹¹⁵⁾ For example, a nutrition wearable that painlessly measures key dietary biomarkers and sends the information to an app empowers individuals to precisely track how their bodies respond to different foods, representing personalized healthcare.⁽¹²⁷⁾

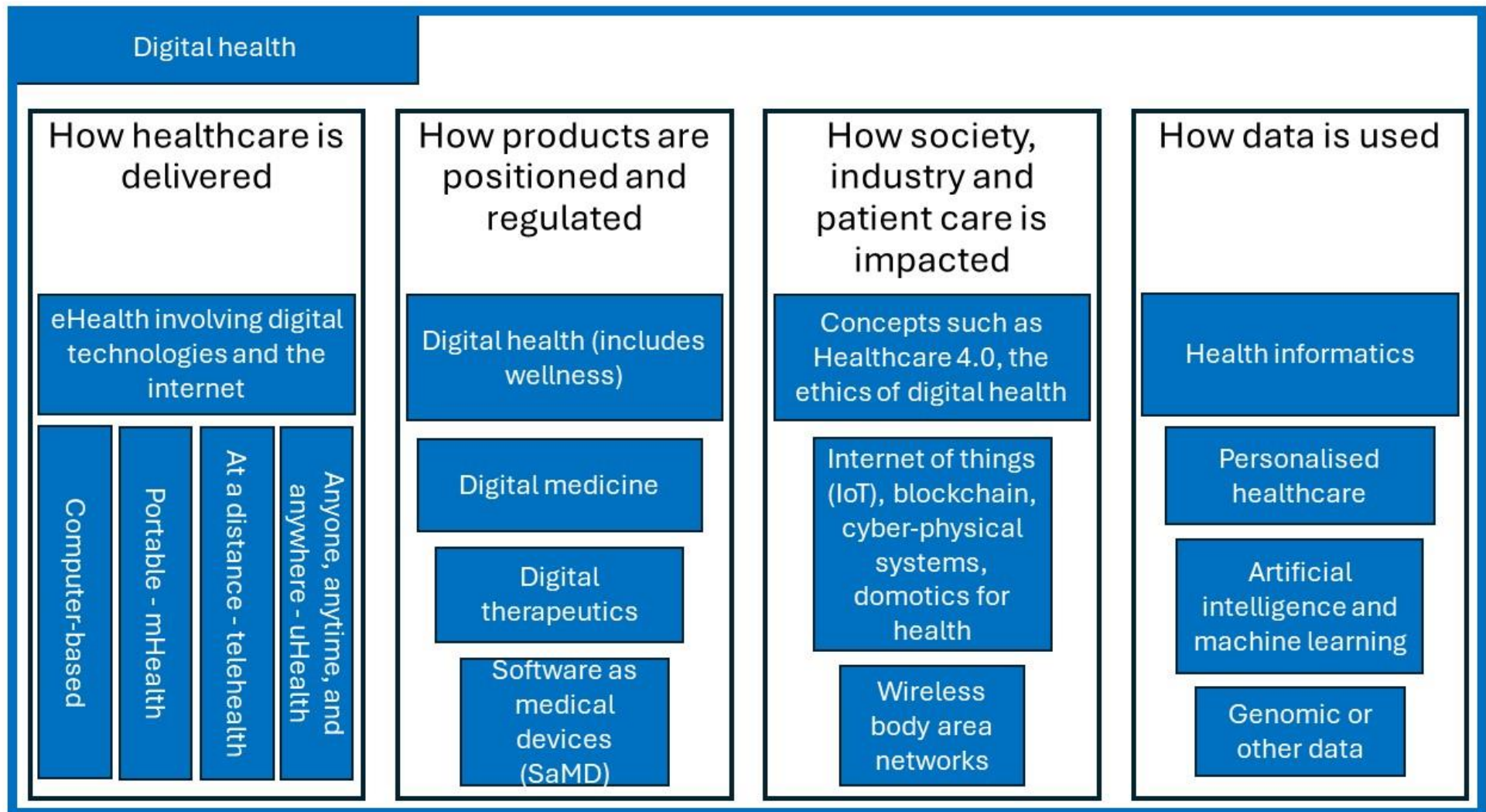


Figure 37 - Digital health with examples of included concepts under each subdomain

Revised definition

With all this in mind, we cautiously attempt another definition of digital health, acknowledging Oh et al (2005), who mentioned not having the "...chutzpah to attempt another 'better' definition of eHealth".⁽⁸²⁾ Humbly, we define digital health as follows:

"Digital health broadly refers to using information and communication technologies to improve healthcare outcomes for patients, practitioners, communities, and healthcare systems. It encompasses eHealth, which includes computer-based, mobile (mHealth), remote (telehealth) and ubiquitous (uHealth) healthcare solutions. Digital health relies on health data and includes health informatics, which examines the interaction between humans and health information. Such data can be used for a variety of purposes such as personalized medicine.

Effective digital health delivery involves many stakeholders across sectors, considering ethical, health system, delivery, and societal impacts. The application of digital health spans clinical practice, education, research, administration, health surveillance, health literature, policy, and business. Services can be packaged as digital health and wellness solutions, digital medicine, or digital therapeutics."

Conclusion

Digital health encompasses four subdomains of how healthcare is delivered including the concepts of eHealth, mHealth, telehealth and uHealth; how digital products are positioned and regulated including the concepts of digital health, wellness and therapeutic solutions; how society, industry, and patient care are impacted including the concept of Healthcare 4.0; and how health data is used and interpreted including the field of health informatics. As digital health continues to evolve, definitions must be revised to reflect the field's complexity and wide-reaching scope.

CHAPTER FIVE: CLASSIFICATION OF DIGITAL HEALTH

Chapter overview

Classification frameworks are helpful in digital health as they provide a structured approach to categorising and evaluating the diverse range of digital health interventions (DHIs).⁽¹⁶⁰⁾

Frameworks facilitate the comparison of different tools and approaches through enabling the use of common terminology.⁽⁸⁶⁾

A significant challenge in conducting the narrative and systematic reviews, presented in Chapters Seven and Nine, was deciding which eHealth modalities to include, largely due to the absence of clear definitions for these interventions. To address this, this chapter focuses on exploring classification frameworks of digital health to help clarify these definitions.

This chapter presents six classification frameworks for digital health including: 1) the National Institute for Health and Care Excellence (NICE) framework for digital health technologies; 2) the Digital Public Health Intervention Classification Framework; 3) the Shannon-Weaver Model of Communication; 4) the Institute of Medicine's quality measures; 5) the World Health Organization (WHO) Classification of Digital Health Interventions and; 6) the Population, Intervention, Comparator, Outcome, Timing, Setting, Communication, Technology, and Context (PICOTS-ComTeC) framework.

The frameworks are used throughout this thesis. At the end of this chapter, the PICOTS-ComTeC framework is applied to lymphoedema. In Chapter Six, the World Health Organization's (WHO) classification framework (V1.0) is applied to lymphoedema. In Chapter Eight the same framework is used for describing eHealth interventions and in Chapter Ten, this framework is revisited to examine health system challenges. In Chapter Twenty-Two the WHO classification framework (V2.0) is used to describe the total number of DHIs reported in this thesis.

Highlights

The key highlights of this chapter include:

- An awareness of the World Health Organization's (WHO) classification framework which is used throughout this thesis to classify DHIs
- Application of the PICOTS-ComTeC framework
- An appreciation of when it would be appropriate for researchers and practitioners to use various frameworks. The PICOTS-ComTeC framework is particularly useful for researchers when describing DHIs. Whereas the WHO classification model is particularly useful for health practitioners who seek to understand the impact of the DHIs on particular segments of the healthcare system and is also useful for describing health system challenges.

Established classification systems for digital health

How is digital health classified?

Several digital health checklists and classification frameworks exist.^(86, 160) Six frameworks are described briefly below:

- National Institute for Health and Care Excellence (NICE) framework for digital health technologies
- Digital Public Health Intervention Classification Framework
- Shannon-Weaver Model of Communication
- Institute of Medicine's Quality Measures
- World Health Organization (WHO) Classification of Digital Health Interventions
- PICOTS-ComTeC framework.

National Institute for Health and Care Excellence (NICE) framework

The United Kingdom (UK) National Institute for Health and Care Excellence (NICE) framework aims to establish standardised criteria that can assess DHIs by providing classification into evidence tiers based on the impact they have on patient outcomes.⁽¹⁶¹⁾ In this framework, digital health technologies (DHTs) are categorised into one of 3 tier levels (with Tier 3 split into Tier 3a and 3b) according to their intended function.⁽¹⁶²⁾ Tier 1 involves DHTs with potential system benefits but no direct user benefits. Tier 2 involves DHTs which help users to understand healthy living and illnesses but are unlikely to have measurable user outcomes. Tier 3a involves DHTs for preventing and managing diseases. They may be used alongside treatment and will likely have measurable user benefits and lastly Tier 3b which involves DHTs with measurable user benefits, including tools used for treatment and diagnosis, as well as those influencing clinical management.

Digital Public Health Intervention Classification Framework

The Digital Public Health Intervention Classification Framework was designed for the reporting of digital public health intervention functions and effectiveness. It includes an assessment of the public health area (Governance, Financing, Human Resources, Health Information, Systems, Research, Social Participation & Health, Communication, Health Protection, Health Promotion, Disease Prevention, Health Care Preparedness for Public Health Emergencies and Other Areas) as well as the Digital Function (System Service, Information, Simple Monitoring, Communication, Preventive Behaviour Change, Treatment, Active Monitoring, Calculation and Diagnostic).⁽¹⁶⁰⁾

Shannon-Weaver Model of Communication

The Shannon-Weaver Model of Communication involves information on the Sender, Message, Encoder, Channel/medium, Decoder, Receiver, and Information exchange/transmission pattern.⁽¹⁶³⁾ This provides a description of the information and communication technology (ICT) application for the purpose of communication exchange.

Institute of Medicine's Quality Measures

The Institute of Medicine's quality measures involves a broad set of benefits DHIs may deliver (Safe, Effective, Patient-centred, Timely, Efficient, and Equitable) as well as the geographic scope (Geography) and technological features (Technology) of DHIs.^(164, 165)

World Health Organization (WHO) Classification of Digital Health Interventions

The World Health Organization (WHO) Classification of Digital Health Interventions v1.0 (2018) provides a comprehensive framework for understanding of how digital technologies can be utilised in healthcare.⁽¹³⁹⁾ It delineates specific use cases of DHIs across four primary categories: clients (Figure 38), healthcare providers (Figure 39), health system or resource managers (Figure 40), and data services (Figure 41).

The WHO Classification also includes descriptions of eight health system challenges (Figure 42). The challenges are information, availability, quality, acceptability, utilisation, efficiency, cost and accountability. By leveraging DHIs, health systems have the potential to mitigate barriers associated with health system challenges, such as improving the availability of services. For example telehealth can expand access to care, particularly for underserved populations, by overcoming geographic limitations and reducing distance as a barrier to healthcare access.

A second edition of the classification of digital interventions, services, and applications in health was released by the WHO in 2023.⁽¹⁰⁴⁾ This revision aimed to enhance clarity and consistency in digital health terminology, supporting global efforts to effectively implement and evaluate digital health solutions.



1.0 CLIENTS

1.1	TARGETED CLIENT COMMUNICATION	1.3	CLIENT TO CLIENT COMMUNICATION	1.6	ON-DEMAND INFORMATION SERVICES TO CLIENTS
1.1.1	Transmit health event alerts to specific population group(s)	1.3.1	Peer group for clients	1.6.1	Client look-up of health information
1.1.2	Transmit targeted health information to client(s) based on health status or demographics	1.4	PERSONAL HEALTH TRACKING	1.7	CLIENT FINANCIAL TRANSACTIONS
1.1.3	Transmit targeted alerts and reminders to client(s)	1.4.1	Access by client to own medical records	1.7.1	Transmit or manage out of pocket payments by client(s)
1.1.4	Transmit diagnostics result, or availability of result, to client(s)	1.4.2	Self monitoring of health or diagnostic data by client	1.7.2	Transmit or manage vouchers to client(s) for health services
1.2	UNTARGETED CLIENT COMMUNICATION	1.4.3	Active data capture/ documentation by client	1.7.3	Transmit or manage incentives to client(s) for health services
1.2.1	Transmit untargeted health information to an undefined population	1.5	CITIZEN BASED REPORTING		
1.2.2	Transmit untargeted health event alerts to undefined group	1.5.1	Reporting of health system feedback by clients		
		1.5.2	Reporting of public health events by clients		

Figure 38 - The ways digital health interventions can impact clients

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2.0

HEALTHCARE PROVIDERS

2.1	CLIENT IDENTIFICATION AND REGISTRATION	2.5	HEALTHCARE PROVIDER COMMUNICATION	2.8	HEALTHCARE PROVIDER TRAINING
2.1.1	Verify client unique identity	2.5.1	Communication from healthcare provider(s) to supervisor	2.8.1	Provide training content to healthcare provider(s)
2.1.2	Enrol client for health services/clinical care plan	2.5.2	Communication and performance feedback to healthcare provider(s)	2.8.2	Assess capacity of healthcare provider(s)
2.2	CLIENT HEALTH RECORDS	2.5.3	Transmit routine news and workflow notifications to healthcare provider(s)	2.9	PRESCRIPTION AND MEDICATION MANAGEMENT
2.2.1	Longitudinal tracking of clients' health status and services	2.5.4	Transmit non-routine health event alerts to healthcare provider(s)	2.9.1	Transmit or track prescription orders
2.2.2	Manage client's structured clinical records	2.5.5	Peer group for healthcare providers	2.9.2	Track client's medication consumption
2.2.3	Manage client's unstructured clinical records	2.6	REFERRAL COORDINATION	2.9.3	Report adverse drug events
2.2.4	Routine health indicator data collection and management	2.6.1	Coordinate emergency response and transport	2.10	LABORATORY AND DIAGNOSTICS IMAGING MANAGEMENT
2.3	HEALTHCARE PROVIDER DECISION SUPPORT	2.6.2	Manage referrals between points of service within health sector	2.10.1	Transmit diagnostic result to healthcare provider
2.3.1	Provide prompts and alerts based according to protocol	2.6.3	Manage referrals between health and other sectors	2.10.2	Transmit and track diagnostic orders
2.3.2	Provide checklist according to protocol	2.7	HEALTH WORKER ACTIVITY PLANNING AND SCHEDULING	2.10.3	Capture diagnostic results from digital devices
2.3.3	Screen clients by risk or other health status	2.7.1	Identify client(s) in need of services	2.10.4	Track biological specimens
2.4	TELEMEDICINE	2.7.2	Schedule healthcare provider's activities		
2.4.1	Consultations between remote client and healthcare provider				
2.4.2	Remote monitoring of client health or diagnostic data by healthcare provider				
2.4.3	Transmission of medical data to healthcare provider				
2.4.4	Consultations for case management between healthcare provider(s)				

Figure 39 - The ways digital health interventions can impact healthcare providers

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3.0 HEALTH SYSTEM MANAGERS

3.1 HUMAN RESOURCE MANAGEMENT		3.3 PUBLIC HEALTH EVENT NOTIFICATION		3.6 EQUIPMENT AND ASSET MANAGEMENT	
3.1.1	List health workforce cadres and related identification information	3.3.1	Notification of public health events from point of diagnosis	3.6.1	Monitor status of health equipment
3.1.2	Monitor performance of healthcare provider(s)	3.4 CIVIL REGISTRATION AND VITAL STATISTIC		3.6.2	Track regulation and licensing of medical equipment
3.1.3	Manage certification/ registration of healthcare provider(s)	3.4.1	Notify birth event	3.7 FACILITY MANAGEMENT	
3.1.4	Record training credentials of healthcare provider(s)	3.4.2	Register birth event	3.7.1	List health facilities and related information
3.2 SUPPLY CHAIN MANAGEMENT		3.4.3	Certify birth event	3.7.2	Assess health facilities
3.2.1	Manage inventory and distribution of health commodities	3.4.4	Notify death event		
3.2.2	Notify stock levels of health commodities	3.4.5	Register death event		
3.2.3	Monitor cold-chain sensitive commodities	3.4.6	Certify death event		
3.2.4	Register licensed drugs and health commodities	3.5 HEALTH FINANCING			
3.2.5	Manage procurement of commodities	3.5.1	Register and verify client insurance membership		
3.2.6	Report counterfeit or substandard drugs by clients	3.5.2	Track insurance billing and claims submission		
		3.5.3	Track and manage insurance reimbursement		
		3.5.4	Transmit routine payroll payment to healthcare provider(s)		
		3.5.5	Transmit or manage incentives to healthcare provider(s)		
		3.5.6	Manage budget and expenditures		

Figure 40 - The ways digital health interventions can impact health system managers

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4.0 DATA SERVICES

4.1	DATA COLLECTION, MANAGEMENT, AND USE	4.2	DATA CODING	4.3	LOCATION MAPPING
4.1.1	Non-routine data collection and management	4.2.1	Parse unstructured data into structured data	4.3.1	Map location of health facilities/structures
4.1.2	Data storage and aggregation	4.2.2	Merge, de-duplicate, and curate coded datasets or terminologies	4.3.2	Map location of health events
4.1.3	Data synthesis and visualization	4.2.3	Classify disease codes or cause of mortality	4.3.3	Map location of clients and households
4.1.4	Automated analysis of data to generate new information or predictions on future events			4.3.4	Map location of healthcare providers
				4.4	DATA EXCHANGE AND INTEROPERABILITY
				4.4.1	Data exchange across systems

Figure 41 - The ways in which digital health interventions can impact data services

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HEALTH SYSTEM CHALLENGES

1	INFORMATION	3	QUALITY	6	EFFICIENCY
1.1	Lack of population denominator	3.1	Poor patient experience	6.1	Inadequate workflow management
1.2	Delayed reporting of events	3.2	Insufficient health worker competence	6.2	Lack of or inappropriate referrals
1.3	Lack of quality/reliable data	3.3	Low quality health commodities	6.3	Poor planning and coordination
1.4	Communication roadblocks	3.4	Low health worker motivation	6.4	Delayed provision of care
1.5	Lack of access to information or data	3.5	Insufficient continuity of care	6.5	Inadequate access to transportation
1.6	Insufficient utilization of data and information	3.6	Inadequate supportive supervision		
1.7	Lack of unique identifier	3.7	Poor adherence to guidelines		
2	AVAILABILITY	4	ACCEPTABILITY	7	COST
2.1	Insufficient supply of commodities	4.1	Lack of alignment with local norms	7.1	High cost of manual processes
2.2	Insufficient supply of services	4.2	Programs which do not address individual beliefs and practices	7.2	Lack of effective resource allocation
2.3	Insufficient supply of equipment			7.3	Client-side expenses
2.4	Insufficient supply of qualified health workers			7.4	Lack of coordinated payer mechanism
5	UTILIZATION	8	ACCOUNTABILITY		
5.1	Low demand for services	8.1	Insufficient patient engagement		
5.2	Geographic inaccessibility	8.2	Unaware of service entitlement		
5.3	Low adherence to treatments	8.3	Absence of community feedback mechanisms		
5.4	Loss to follow up	8.4	Lack of transparency in commodity transactions		
		8.5	Poor accountability between the levels of the health sector		
		8.6	Inadequate understanding of beneficiary populations		

Figure 42 - Health system challenges

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PICOTS-ComTeC framework

The PICOTS-ComTeC framework stands for Population, Intervention, Comparator, Outcome, Timing, Setting, Communication, Technology, and Context.⁽⁸⁶⁾ This framework facilitates clear identification and descriptions of what DHIs are being used in research.

Application of this framework to lymphoedema care is provided in Table 2. An example scenario is applied for research on a mobile phone app for breast cancer-related lymphoedema.

PICOTS-ComTeC framework and application to lymphoedema

[From Zrubka et al (2024) Appendix 6. Published under a Creative Commons Attribution 4.0 International License. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>. No changes made.]⁽⁸⁶⁾

Table 3 - PICOTS-ComTeC framework and application to lymphoedema

Item	Explanation	Example of application to lymphoedema care
Population Domain	Characterization of patients/ population(s)	P – Patients living with breast cancer-related lymphoedema from 18 to 80 years of age. Patients must have access to a mobile phone (Android or iPhone) and be able to access the phones apps.
• Target Population/ Diagnosis	Diagnosis/ condition/ population (may be more than one)	
• Demographic Characteristics	Socio-demographics of population (e.g., age, gender, education)	
• Special User Characteristics	DHI relevant user characteristics (e.g., digital literacy, PC access)	
Intervention Domain	Description of DHI Intervention including key components and interactions	I – Mobile phone app (Android and iPhone accessible) which allows patients to track their progress and report measures to the lymphoedema practitioner. Daily updates should be entered of their symptoms as well as reports of their self-management.
• Key Function/ Intended Use	Intended function (e.g., online screening to identify high-risk patients)	
• Modality	Design elements to achieve key function (e.g., behavioral, communication)	
• Limits of intervention	To specify those situations or thresholds where the DHI can be used, and beyond which the DHI should be replaced by face-to-face care	
Comparator Domain	Non-DHI(s) or alternative DHI(s) with same function	C – Lymphoedema physiotherapist seeing the patient at face-to-face appointments and asking them how they are progressing
• Model of Care	Current model of care and/or clinical pathway, may be redesigned by DHI	
• Alternative Digital Health Interventions	DHI(s) with the same purpose (e.g., smart phone vs PC retinal screening)	
• Usual Care Alternatives	Usual treatment or care (e.g., compare with paper-based surveillance)	
Outcomes Domain	Outcomes relevant to patients and other stakeholders	O – Self report measures of symptom severity including signs of swelling and fibrosis
• Health Benefits	Clinical and patient reported outcomes	
• Improved Care Structure or Process	Health care system improvements (e.g., access to care, adherence to guidelines, patient health literacy, self-management)	

Item	Explanation	Example of application to lymphoedema care
<ul style="list-style-type: none"> • Social/ Societal Benefits 	Humanistic, social, or societal effects (e.g., DHI could improve social support, or reduce stigma of a condition)	
<ul style="list-style-type: none"> • Safety 	May reduce health related risks or improve patient safety	
<ul style="list-style-type: none"> • Non-health Related Risks 	Non-health related risks including data privacy (e.g., unauthorized access and use of personal data)	
<ul style="list-style-type: none"> • Efficacy, Convenience, and Economic Benefits 	DHIs could deliver the same outcome with greater efficiency, or less effort	
Timing Domain	Timing and duration of treatment and follow-up	T – 6-week intervention period. Daily check-ins on the app vs weekly therapy sessions for the control
<ul style="list-style-type: none"> • Timeliness 	Timely delivery of services could improve outcomes (e.g., telestroke DHI to shorten time to thrombolysis could improve survival)	
<ul style="list-style-type: none"> • Frequency and Duration of Intervention 	Increased DHI use may improve outcomes (e.g., increased use in cardiac rehabilitation associated with greater weight-loss)	
Setting Domain	DHIs may increase access to or improve quality of health care. Potential benefits may vary by setting.	S – Home and community for the mHealth intervention and hospital inpatient environment for the control
<ul style="list-style-type: none"> • Care Setting 	Settings where DHI may be useful include pre- and post-hospitalization, emergency care, primary and community care.	
<ul style="list-style-type: none"> • Patient Location 	DHIs can bring care to the patient’s location (e.g., in-home hospital care during COVID-19, public kiosks providing access to nurses).	
<ul style="list-style-type: none"> • Geographic Scope 	DHIs can improve access to health care (e.g., rural Alaska). Culture may limit use (e.g., telehealth differences in Brazil vs Canada).	
Communication Domain	DHIs may have different users with different roles. Function impacts frequency of interaction (e.g., post-surgical vs routine monitoring).	Com – The app provides alerts to remind patients to check-in daily. The app has an in-app messaging functioning allowing the patient to practitioner communication.
<ul style="list-style-type: none"> • User 	DHI users may vary (e.g., activity monitoring for patient lifestyle modification involving healthcare providers, or support groups).	
<ul style="list-style-type: none"> • Message 	Unit of information collected and communicated by DHI (e.g., text, diagnostic image, or machine-readable data) impacts function.	
<ul style="list-style-type: none"> • Interaction Pattern 	Differences in interactions (e.g., synchronous (real-time) or asynchronous) could impact outcomes in critical situations.	
<ul style="list-style-type: none"> • User Experience 	Improving user experience may improve outcomes (e.g., when human factors were considered in digital interface design).	
Technology Domain	Use of different technologies (i.e., communication channel, device, software, or system) may impact DHI performance.	Te – mHealth through a mobile phone app
<ul style="list-style-type: none"> • Channel/ Medium 	Channel selection may impact patient access and DHI effectiveness (e.g., DHIs that exclude patients without telephone access).	

Item	Explanation	Example of application to lymphoedema care
• Device	DHIs involve devices or user interfaces that may vary in cost and accessibility (e.g., patient access to mobile phone vs PC)	
• Software	Algorithms (e.g., for machine learning) and software components (e.g., for security) used by DHIs may affect performance.	
• System	Compatibility with data standards (e.g., FHIR) and interoperability with larger healthcare systems may affect DHI potential.	
• Data Management	Considerations include data quality, timeliness, interoperability (e.g., with EHR), security, patient privacy, and legal requirements.	
Context domain	Capture additional information that may influence the usability, access, or overall value of DHIs.	C – The app has been TGA and FDA registered as a medical therapeutic device. The app will be made free of charge to patients for the research study but could be commercialised.
• Regulatory status	The relevant regulatory category and authorization status for the DHI to identify appropriate comparators. (E.g., FDA approved or investigational)	
• Medical / legal liability	Specify if certain legal provisions influence the availability or effect of the DHI. (e.g., can a medical expert give advice or only tests results can be communicated)	
• Financing	Specify if certain reimbursement or financing rules or pricing schemes influence the availability of functionality of the DHI. (e.g., in-app purchases, free from health service provider, subscription fee etc.)	

CHAPTER SIX: APPLICATION OF A DIGITAL HEALTH CLASSIFICATION SYSTEM TO LYMPHOEDEMA CARE

Chapter overview

This chapter presents a publication whereby the World Health Organization's (WHO) classification framework (V1.0) was applied to lymphoedema to understand where eHealth was being used across four categories: clients, healthcare providers, health system or resource managers, and data services.

Highlights

The key highlights of this research include:

- A significant contribution towards the primary aim of this thesis
- This was the first publication, to the author's knowledge, to acknowledge the wide reach of eHealth implementation in both published and unpublished lymphoedema literature, utilising a globally adopted classification system
- Building appreciation of the WHO classification system which was found to be straightforward to apply.

Publication title - The Use of eHealth and Digital Health Technology for Lymphoedema Care

Reference

Mangion A, Piller N. The Use of eHealth and Digital Health Technology for Lymphoedema Care. *Journal of Lymphoedema*. 2023;18(1):22-27

Credit

Conceptualisation, methodology, writing—original draft, review, and editing by A.M. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 100% of the data collection and analysis and 95% of the writing and editing.

Publication

Abstract

While electronic health (eHealth) has been gaining in popularity in recent years, its adoption was accelerated by the COVID-19 pandemic, when restrictions on in-person consultations compelled healthcare practitioners to turn to modalities such as telehealth for patient management.

There are numerous potential benefits of using eHealth in lymphoedema management, including improved access to care, better tracking of symptoms and enhanced options for patient engagement and empowerment. As healthcare practitioners continue to prioritise patient-centred care, with an emphasis on putting the patient's needs first and making treatment as accessible as possible, eHealth offers a promising opportunity to improve lymphoedema care. This article provides an overview of eHealth, explores a classification system for the various forms of eHealth, discusses the rationale for using eHealth, and proposes future research directions in lymphoedema care.

Background

The World Health Organization defines eHealth as: "The cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research".⁽¹⁶⁶⁾ eHealth encompasses a wide range of modalities that utilise digital technology, including robotics, artificial intelligence, wearable devices connected to smart phones, electronic health records and databases, telehealth and virtual consultations via video, mobile health (mHealth) including apps, and online information systems such as websites and online courses.^(82, 167, 168)

A patient-centred health system is one that prioritises the needs of patients.⁽¹⁶⁹⁾ Virtual consultations via telehealth, for example, are one way of creating a more patient-centred health system by making care more convenient to patients.^(170, 171) With the increasing adoption of eHealth technologies, patients may benefit from a more personalised and integrated approach to lymphoedema care.

Exploring a classification system for the different types of eHealth

A model for understanding how to classify eHealth modalities has been developed by the WHO.⁽¹³⁹⁾ The WHO classified digital health interventions by the ways digital and mobile technologies are being used to support health system needs. In this model, digital health interventions are organised into four groupings based on the targeted primary user (Table 4).

Table 4 - Four categories of digital health interventions

Interventions for clients

- 7 sub-categories
- Examples include targeted client communication and personal health tracking

Interventions for healthcare providers

- 10 sub-categories
- Examples include telemedicine and healthcare provider training

Interventions for health system or resource managers

- 7 sub-categories
- Examples include human resource management and equipment management

Interventions for data services

- 4 sub-categories
- Examples include data collection management and location mapping

[The four categories of overarching groupings of digital health interventions adapted from the World Health Organization's Classification of Digital Health Interventions.]

Under each category are subcategories of interventions and examples of various types of technology that can be used to achieve the overarching group function.

One example of interventions for clients (Figure 43) is “targeted client communication”. Hawkins et al (2008) state that this allows for separate audience segments (often demographic categories) to benefit from a shared message.⁽¹⁷²⁾ Targeted client communication can be achieved in several ways, including sending health event alerts to specific population groups, health information based on health status or demographics, targeted alerts and reminders, and diagnostic results. Health promotion through mHealth and mobile phone SMS alerts is one way in which targeted health communication can be delivered.

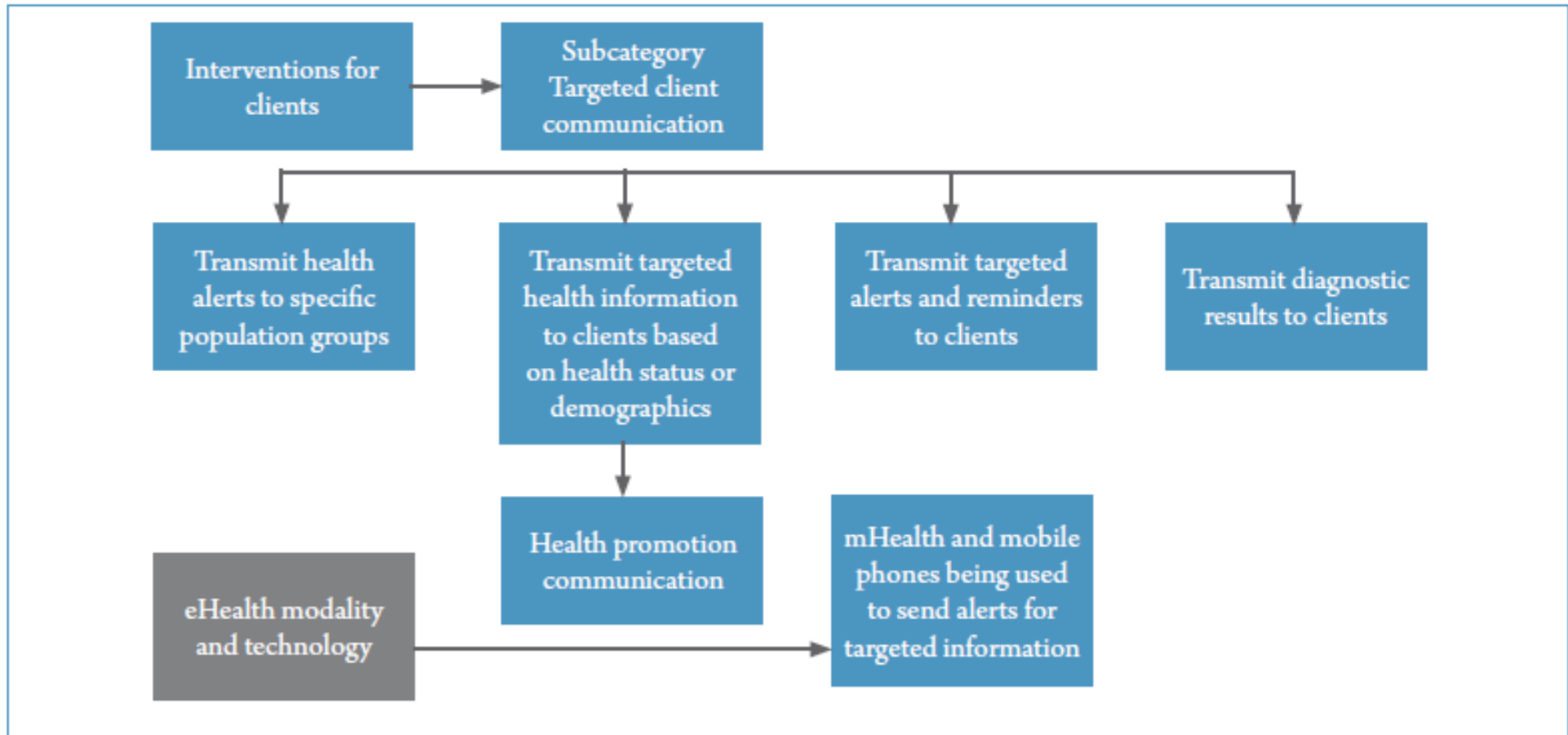


Figure 43 - Interventions for clients with the subcategory of targeted client communication

[A description of how digital and mobile technologies are being utilised to support health system needs. One example is provided of an eHealth modality and technology adopted from the World Health Organization’s Classification of Digital Health Interventions.]

Despite the fact that research in eHealth for lymphoedema care is in its infancy, Mangion et al. (2023) have demonstrated the existence of a wide variety of use cases.⁽¹³⁰⁾ The WHO model is applicable to lymphoedema as demonstrated with intervention examples (Table 5). In the table the following Digital Health Interventions (DHIs) are applied:

- **Targeted client communication.** Fu et al (2022) implemented a web and mobile based intervention which was used to deliver specific information.⁽¹⁷³⁾ Another example could simply be the use of email to communicate specific health messages to patients.
- **Personal health tracking.** An example by Singh et al (2022) is provided of wearable fitness trackers.⁽¹⁷⁴⁾
- **Telehealth.** An example of a publication is provided by Noble-Jones et al (2021).⁽¹⁾
- **Healthcare provider training.** An example of a publication is by Kucukakkas and Ince (2022) whereby YouTube was assessed as an educational medium.⁽¹⁷⁵⁾
- **Human resource management.** An example is the Australasian Lymphology Association which has a register of lymphoedema practitioners.⁽¹⁷⁶⁾
- **Equipment and asset management** such as Impedimed's register of where bioimpedance spectroscopy devices are located.⁽¹⁷⁷⁾
- **Data collection, management and use.** An example is provided by Mwingria et al (2017) where a mobile survey evaluated lymphatic filariasis in Tanzania.⁽¹⁷⁸⁾
- **Location mapping** such as where Kondeti et al (2019) used machine learning to predict filariasis in India.⁽¹⁷⁹⁾

Table 5 - Application of the World Health Organization’s Classification of Digital Health Interventions to lymphoedema care

Table 2. Application of the World Health Organization’s Classification of Digital Health Interventions to lymphoedema care.					
Overarching grouping	Subcategory examples	Example of intervention	eHealth modality / technology examples	Description of eHealth	Publication author
Interventions for clients	Targeted client communication	Transmission of targeted health information to clients based on health status or demographics	Online education and videos, mHealth and the use of SMS information services	Web and mobile-based intervention for women treated for breast cancer to remotely manage chronic pain and symptoms related to lymphoedema	Fu et al, 2022
	Personal health tracking	Self-monitoring of health or diagnostic data by client	Wearables and fitness trackers	Post-cancer treatment physical activity interventions being monitored by pedometers for activity tracking	Singh et al, 2022
Interventions for healthcare providers	Telemedicine/ telehealth	Consultations between remote client and healthcare provider	Health hotlines, teleconsultations	Telehealth for remote consultations.	Noble-Jones et al, 2021
	Healthcare provider training	Providing training content and reference material to healthcare providers	eLearning via an app or desktop computer, virtual learning, educational videos, multimedia learning	Youtube, a free social media platform, which health practitioners may use as a source of lymphoedema education	Küçükakkaş and İnce, 2022
Interventions for health system or resource managers	Human resource management	Managing registration/ certification of healthcare providers	Online databases of practitioners’ certifications	A website providing a directory of appropriately trained lymphoedema specialists	Australasian Lymphology Association, 2023
	Equipment and asset management	Monitoring status and maintenance of health equipment	List of available equipment and physical assets, such as hospital beds, for tracking and maintenance of equipment	A website with a directory of locations where bioimpedance spectroscopy devices are available	Impedimed, 2023
Interventions for data services	Data collection management and use	Automating analysis of data to generate new information or predictions on future events	Online surveys, predictive analytics, machine learning and artificial intelligence	Utilisation of a mobile survey instrument incorporating machine learning to evaluate lymphatic filariasis morbidity in Mtwara Municipal Council, Tanzania	Mwingira et al, 2017
	Location mapping	Mapping location of clients and households	Machine learning and artificial intelligence	Application of machine learning to predict filariasis using socio-economic factors in India	Kondeti et al, 2019

[The four categories of overarching groupings of digital health interventions applied to publications or real world examples in lymphoedema care.]

The rationale for using eHealth

Healthcare may become more accessible, efficient and effective by leveraging digital technologies to improve accuracy of care, access to care, and decrease treatment costs. It may also facilitate communication, patient engagement and information sharing for enhanced condition monitoring and symptom management.

i) Enhancing accuracy of care

eHealth has the potential to improve the accuracy of lymphoedema care in several ways. For example, robotic-assisted surgery is being used to reduce surgeon error and improve outcomes in lymphadenectomies and lymphaticovenous anastomosis procedures.⁽¹⁸⁰⁻¹⁸³⁾

The potential benefits of robotic-assisted surgery include improved precision, increased dexterity during surgery, better lymph node retrieval timing and decreased incision size.⁽¹⁸⁴⁻¹⁸⁶⁾ In the case of lymphadenectomies, robotic-assisted surgery may have the potential to reduce the risk of complications such as postoperative lymphoedema.

In a systematic review by Gkegkes et al (2019), only 4 out of 51 patients (7.8% over a variable follow-up period from 2 to 67 months) reported lymphoedema following robotic-assisted lymphadenectomy.⁽¹⁸¹⁾ Within the group the number of dissected lymph nodes ranged between 5 and 34. This rate of post-operative lymphoedema is lower than has been reported for traditional surgery types.⁽¹⁸⁷⁾ This is particularly important, given that morbidity is higher for inguinal lymphadenectomy compared to cervical or axillary lymphadenectomy, as found in a review by Sarnaik et al (2009).⁽¹⁸⁸⁾

Additionally, patient satisfaction rates have been reported to be higher in robot-assisted surgery procedures compared to conventional surgery.⁽¹⁸⁹⁾ One reason for improved satisfaction, as described by the authors, could be that the robot technology can assist with aesthetically pleasing incisions, which the authors describe being: "Typically due to less traumatization and lack of hematoma-related complications."

eHealth technologies are being used to diagnose lymphoedema remotely and improve the accuracy of monitoring and treatment. For example, remote surveys and telemedicine consultations have been shown to help healthcare practitioners identify lymphoedema symptoms earlier and make more informed decisions about treatment.^(1, 190, 191)

Furthermore, 3D scanning and imaging devices are being developed to accurately measure limb volume and track changes in the affected limb over time, which may be especially useful in monitoring the progression of lymphoedema.⁽¹⁹²⁻¹⁹⁴⁾

ii) **Improving access to care and reducing treatment costs**

Technologies such as telehealth and remote monitoring allow lymphoedema patients to receive care from their own homes, which is important for patients who live in remote or rural areas.⁽¹⁹⁵⁾ This can improve access to care and reduce the need for patients to travel long distances to see their healthcare practitioners.

This may also lead to reduced costs. Naumann et al (2023) compared 55 individuals who received telehealth and in-person care following breast cancer surgery.⁽¹⁹⁶⁾ They found that the median attendance costs per participant was AU\$39.68 (range \$28.52–\$68.64) for telehealth and \$154.26 (range \$81.89–\$251.48) for the in-person cohort, an average cost saving of \$114.58 per session.

iii) **Improving communication and enhancing patient engagement**

Using eHealth tools may help lymphoedema patients learn remotely and be empowered in their self-care. Complex concepts, such as how the lymphatic system works and how to perform exercises, can be explained through video technology and online avatars, which improves communication and, therefore, patients' ability to engage with lymphoedema concepts.

Further research is required in this area, but an example of research investigating eHealth was a study by Fu et al (2022).⁽¹⁷³⁾ They reported on a randomised controlled trial of a web and mobile app with a programme of exercises designed for breast cancer patients to manage chronic pain and lymphoedema symptoms, providing them with more information about their condition and empowering them to make informed decisions about their care. At the 12-week endpoint, the authors found that the patients using the app had significant improvements in chronic pain, arm and hand swelling and heaviness. Usability and feasibility testing demonstrated that "Patients love the web-based program, especially the videos using the avatar technology to demonstrate the complicated lymphatic system and illustrate the physiological functions of each exercise and detailed step-by-step instructions for each exercise."

iv) **Enhancing information sharing for improved condition tracking and symptom management**

eHealth solutions may help healthcare practitioners monitor lymphoedema patients more closely and adjust treatment plans as needed. For example, Kalinga et al (2022) reported on mobile phone-based text messages being used to assist community health workers with reporting of cases of lymphatic filariasis morbidity in Tanzania.⁽¹⁹⁷⁾ Not only did the eHealth technology help to improve patient reporting, but it also assisted with simplifying the exchange of information between lower and higher levels of management within the health programme.

v) Improving outcomes of complex lymphatic therapy

Complex physical therapy (CPT) is a comprehensive treatment approach used to manage lymphoedema, which can involve a combination of lymphatic drainage, compression therapy, exercise, and skin care.⁽⁶²⁾ eHealth technologies have the potential to improve outcomes of CPT. For example, Pawar et al (2022) reported on a prototype robot that has been developed to improve lymphatic drainage.⁽¹⁹⁸⁾ The prototype lymphatic drainage robot is programmed to stimulate the lymphatic system. The robot climbs up the limb, applying radial pressure on the skin to remove the excess fluid into the lymph vessels towards the upper side of the limb.

Further research and industry opportunities

There are many research and industry opportunities related to eHealth and lymphoedema care that involve examining the efficacy and feasibility of interventions as well as governance, legal and ethical concerns.

i) Efficacy and feasibility

There is the need for rigorous research to evaluate the effectiveness of eHealth technologies in lymphoedema care. eHealth resources need to be designed appropriately with consideration of factors such as efficacy and impact on patients' lives, as well as feasibility, accuracy and factors such as complexity which impact usability.

For example, one study looking at online resources for lymphoedema found that resources were above the recommended levels for readability and complexity, which has consequences for people living with lymphoedema.⁽¹⁹⁹⁾ The authors stated: "The suitability level is barely adequate for the intended audience." Therefore, eHealth resources need to be designed keeping the end user in mind.

Another consideration is the assessment of the quality of eHealth resources placed for free for public access on the internet, such as via the social media platform YouTube. A study of 90 free educational videos about lymphoedema rehabilitation on YouTube found many were of poor quality, with the authors concluding: "The biggest obstacle for YouTube to be an excellent source of information is that it hosts large volumes of uncontrolled and low-quality data".⁽¹⁷⁵⁾ The authors also state: "Videos uploaded under the headings of like sexuality, violence, racism, and copyrights are subject to a specific checking process. However, this type of control is not in question especially in medical videos." It is, therefore, important that health practitioners assess the quality of free online content before encouraging patients to search online for information.

ii) Governance, legal and ethical concerns

eHealth poses important ethical, legal, and regulatory challenges related to data privacy, security, and equity, which need to be addressed to fully realise its potential benefits. For example, informed consent on an app requires a balance between convenience and appropriate disclosure. Zegers et al (2021) discuss the fact that consent on commercial mobile apps typically consists of checking a box and that users rarely read the terms and conditions.⁽²⁰⁰⁾

If eHealth is to revolutionise healthcare systems, there must be governance systems in place to help healthcare systems adapt. The National eHealth Strategy Toolkit is designed to guide policy-makers and was developed by the WHO and International Telecommunication Union (2012).⁽²⁰¹⁾ It is a resource for establishing national eHealth/digital health strategies, which are necessary for national governance and a supportive ecosystem for digital health.

Conclusion

eHealth represents a rapidly growing field that is transforming the way healthcare is delivered and experienced. Ongoing research on eHealth in lymphoedema, industry support, and policy leadership are required.

CHAPTER SEVEN: A NARRATIVE REVIEW OF WHERE EHEALTH IS BEING USED IN LYMPHOEDEMA CARE

Chapter overview

This chapter presents a narrative review on the utilisation of eHealth in lymphoedema care. This narrative review was designed to provide a broad reaching view of implementation examples of digital health in lymphoedema care from published research. The planned systematic review, in Chapter Nine, would have excluded many of the research papers discussed herein due to its rigorous methodology and stringent inclusion and exclusion criteria.

Highlights

The key highlights of this research include:

- The provision of definitions of what digital health interventions are including what robotics is as well as instructive online information
- To the author's knowledge, this was the first publication to document use cases of eHealth in lymphoedema care
- This research alone fulfilled much of primary thesis objective with the finding that there were many more use cases than anticipated including broad reach spanning all four phases of care (preventative, diagnostic, assessment, and treatment phases).

Publication title - The Utilization of e-Health in Lymphoedema Care: A Narrative Review

Reference

Mangion A, Ivasic B, Piller N. The Utilization of e-Health in Lymphoedema Care: A Narrative Review. *Telemedicine and eHealth*. 2024;30(2):331-340.

Credit

Conceptualisation, methodology, validation, investigation, and writing—original draft, review, and editing by A.M. Methodology, validation, investigation, and writing—review and editing by B.I. Conceptualisation and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 70% of the data collection and analysis and 95% of the writing and editing.

Publication

Abstract

Background: Electronic health (eHealth) refers to technologies that can be utilised to enhance patient care as well as collect and share health information. e-Health comprises several umbrella terms, including telehealth, mobile health, eHealth, wearables, and artificial intelligence. The types of eHealth technologies being utilised in lymphoedema (LE) care are unknown.

Method: In this narrative review, a search of published research on the utilisation of eHealth technologies in LE-related care was conducted.

Results: Five different types of e-Health modalities were found (robotics, artificial intelligence, electronic medical records, smart wearable devices, and instructive online information) spanning 14 use cases and 4 phases of care (preventative, diagnostic, assessment, and treatment phases). Broad e-Health utilization examples were found including robotic-assisted surgery to reduce the likelihood of LE after lymphadenectomy, machine learning to predict patients at risk of filarial-related LE, and a novel wearable device prototype designed to provide lymphatic drainage.

Conclusions: eHealth has reported merit in the prevention, diagnoses, assessment, and treatment of LE with utilization demonstrating cutting edge applicability of eHealth for achieving optimal patient care and outcomes. As technology continues to advance, additional research into the utilisation of eHealth in LE care is warranted.

Introduction

Lymphoedema (LE) is a progressive and chronic health disorder caused by impaired lymphatic system function and subsequent inflammatory processes.⁽²⁰²⁾ The condition is characterized by prolonged swelling, skin and tissue changes such as fibrotic tissue deposition, and subsequent skin infections known as cellulitis. The two types of LE are primary, which is related to lymphatic system malformation, and secondary, which arises due to lymphatic system impairment brought on by system injury or obstruction. In developing nations, secondary LE is commonly related to filariasis whereby parasitic worms damage the lymphatic system, whereas in developed nations, secondary LE frequently develops after cancer treatments and lymphadenectomy causing reduction of the lymphatic system's transport capacity.^(29, 203, 204)

Lifelong care is necessary for LE, whether primary or secondary, as it is a chronic disease with no known cure. Traditional care, such as through the Casley-Smith method of Complex Physical Therapy (CPT), has a large focus on in-person treatment as well as self-administered care through techniques, including self-lymphatic drainage and exercise.^(56, 68)

Although in-person care has been shown to effectively reduce lymphoedematous limbs, there is the need for researchers to examine ways of improving the delivery of patient-centred care, which takes into account the patient's desire for information as well as patient and practitioner shared decision-making with a mutually agreed upon management plan.^(205, 206) Electronic health (eHealth), also referred to as digital health, may be one such medium that assists with improving LE patient-centred care.

eHealth can be thought of as an umbrella term, which encompasses a range of technologies that can be used to treat patients as well as collect and share a person's health information.⁽²⁰⁷⁾ eHealth encompasses multiple modalities such as telehealth, telemedicine, mobile health (mHealth), electronic medical or health records (EMR/EHR), wearables, robotics, and artificial intelligence. mHealth incorporates wireless devices such as tablets, computers, smartphones, and mobiles with health-based applications that can support patient education, care, and research.^(167, 168) eHealth can be used to support health care services, health surveillance, health literature, and health education, knowledge, and research.⁽²⁰⁸⁾

eHealth has been found to be effective in increasing self-care for chronic health conditions such as type-2 diabetes mellitus, cardiovascular disease, and chronic obstructive pulmonary disease when compared with traditional care.⁽²⁰⁹⁾ Penedo et al (2020) in their narrative review on e-Health state that, "The increasing use of e-Health has ushered in a new era of patient-centred cancer care that moves beyond the traditional in-person care model to real-time, dynamic, and technology-assisted assessments and interventions".⁽²¹⁰⁾ Given the promising results of e-Health technology for chronic health care an investigation into the utilization of e-Health for LE is warranted as the use cases are currently unknown.

Methods

A literature search was undertaken to identify published research on the types of e-Health modalities being used for LE. Peer-reviewed research was searched on MEDLINE and Institute of Electrical and Electronics Engineers (IEEE Xplore®) databases (up to December 24, 2022) using search terms related to LE, digital health, m-Health, and e-Health, including telehealth, electronic learning (eLearning), and robotics. Reference lists were also reviewed from retrieved articles. The intention was to produce a review, neither scoping nor meta-analytic, but rather narrative, and complementary to a planned systematic review on the impact of e-Health on LE patients, an earlier systematic review of artificial intelligence for LE and systematic reviews on e-Health in cancer care.⁽²¹¹⁻²¹⁹⁾

Titles and abstracts were screened by two researchers (A.M. and B.I.) with full article screening and thematic analysis by one author (A.M.) with coding using Microsoft Excel.^(220, 221) Meta-synthesis, through an interpretative approach, was used to identify grand narratives and mutually exclusive macro-categories (e-Health modalities).⁽²²²⁾ Based on purpose and findings, micro-categories (use cases and phases of care) were inductively identified. Direct relationships between themes were illustrated by a thematic map.⁽²²³⁾ Samples of contemporary literature were captured without risk of bias assessment. At least one example of peer-reviewed research utilising an eHealth modality was required to consider a use case, representing applied application of a modality for a practical purpose.

Results

Five different types of eHealth modalities were found (robotics, artificial intelligence, electronic medical records, smart wearable devices, and instructive online information) spanning 14 use cases and 4 phases of care (preventative, diagnostic, assessment, and treatment phases). A thematic map (Figure 44) was developed to illustrate the relationships between the different types of modalities, use cases, and phases of care.

Robotics

Robotics can be defined as “the scientific and engineering discipline concerned with the creation, composition, structure, evaluation and properties of embodied artificial capabilities.”⁽²²⁴⁾ Robotics in e-Health integrates multiple disciplines, such as machinery, information, materials, intelligent control, and biomedicine.⁽²²⁵⁾ Robotics was found to have three use cases as outlined hereunder.

Use case 1: improving traditional surgery that may cause LE using robotics

A use case was identified involving robotics being used to improve traditional surgery (lymphadenectomy) known to cause LE. Robotics was reportedly used to assist with (1) imaging the lymph nodes that needed removal and (2) the lymph node surgery itself.

Robotic-assisted lymphadenectomy was found to be associated with decreased postoperative complications, such as LE, when compared with traditional surgery.^(182, 226, 227) Explanations for this included surgeon tremor filtration, improved ergonomics, and geometric accuracy resulting in less surgical trauma.⁽¹⁸¹⁾

The Da Vinci Robotic system (Intuitive Surgical, Inc., TM Sunnyvale, CA) is an example of a robotic brand used in research. The robotic-assisted technique was described as the surgeon directing the robotic arms of the system through a console, by means of hand controls and pedals, using a stereoscopic viewing system.⁽¹⁸⁰⁾ In a randomized controlled trial by Chen et al (2021) modified radical mastectomy for breast cancer was performed on 60 patients.⁽¹⁸²⁾ Thirty of which had axillary lymph node dissection performed using the robotic system and 30 of which were in the control group and received lymphadenectomy by conventional means. LE was experienced by significantly more patients in the control group (2/30, 6.67%) than in the robotics group (8/30, 26.67%, $p < 0.05$). The robotic intervention was, therefore, able to assist with the prevention of LE.

Use case 2: improving traditional LE surgical outcomes using robotics

Traditional LE microsurgery involves techniques such as lymph node transplantation and lymphovenous anastomoses (LVA) microsurgery.⁽⁷¹⁾ LVA surgery involves a vein being connected to a lymphatic vessel by a surgeon who uses a microscope to see tiny blood vessels and lymphatic vessels ranging approximately between 0.3 and 0.8 mm in diameter. An example of eHealth utilisation is by van Mulken et al (2020) who claim to have performed the first instance of human LE robotic super-microsurgery utilizing a specialized microsurgical robotic platform called MUSA (MicroSure, Eindhoven, The Netherlands).⁽²²⁸⁾ One year after the study, follow-up data confirmed the feasibility of the robotic-assisted LVA surgery. Clinical outcomes were comparable between the robotic and manual LVA procedures.⁽²²⁹⁾

Another example in LVA surgery was the reporting of the Symani robotic surgical system (Medical Microinstruments [MMI], Calci, Italy).⁽¹⁸³⁾ In comparison with the MUSA robot, which uses fixed joysticks connected to a scaffold, Lindenblatt et al (2022) describe using the Symani robot consisting of flexible robotic arms. In 5 patients, 10 robotic-assisted anastomoses were performed, with the research demonstrating feasibility in this small cohort. Further research is warranted to assess the impact of robotic surgery on larger cohorts of patients.

eHealth modalities, phases of care and use cases

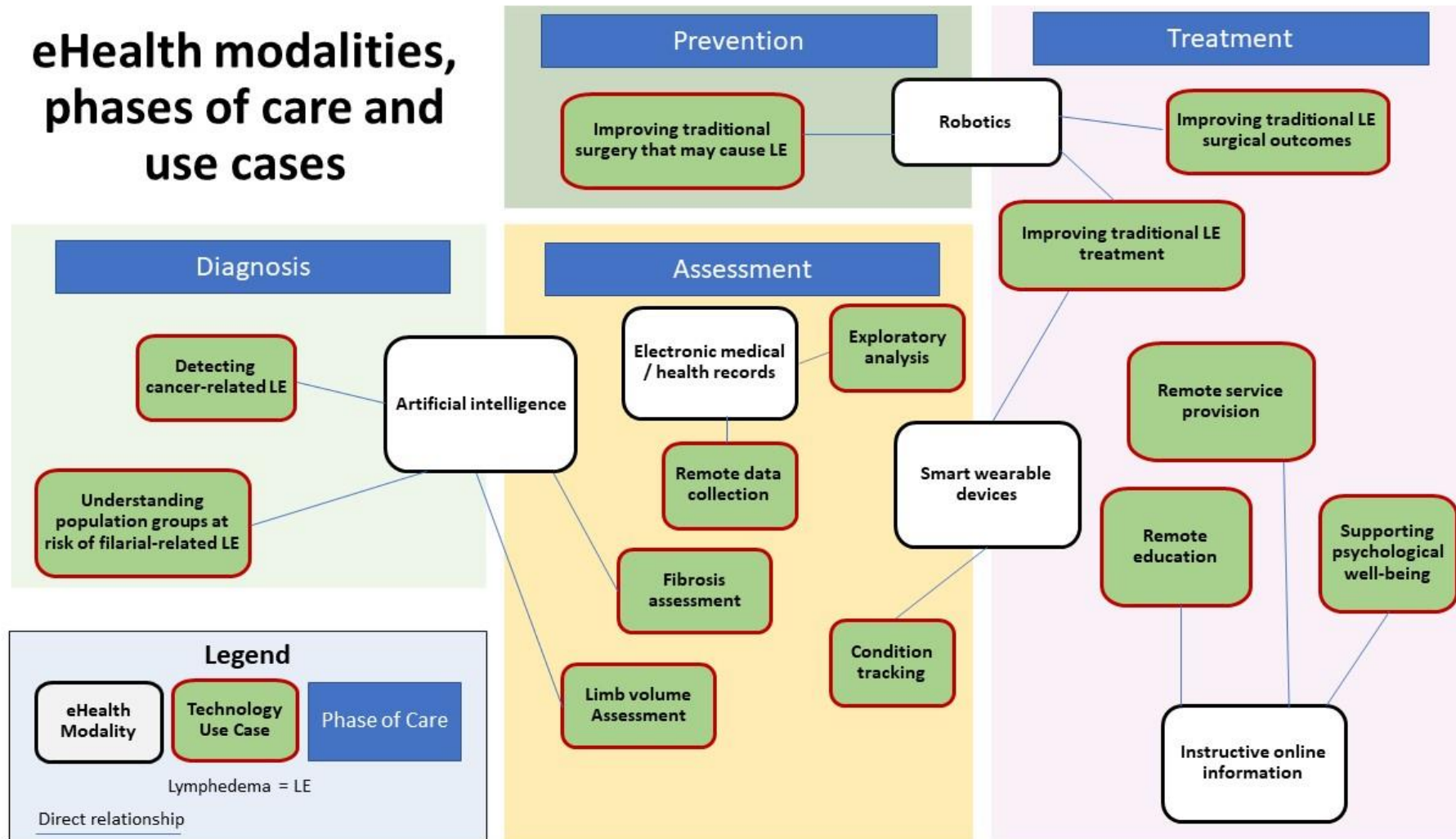


Figure 44 - Thematic map showing the different types of e-Health modalities and use cases as they relate to lymphoedema diagnosis, prevention, assessment, and treatment phases of care

Direct relationships between e-Health modalities and use cases are illustrated by the solid line.

Use case 3: improving traditional LE treatment using robotics

Lymphatic massage is one of the primary components of CPT.⁽⁶²⁾ An e-Health example of advancements in this area includes a prototype of an autonomous portable and mobile robotic device that offers lymphatic drainage. The prototype includes a combination of soft and hard robotic hardware designed to stimulate the lymphatic system. The robot “climbs” up the human limb while applying radial pressure on the skin.⁽¹⁹⁸⁾

The climbing action is performed using servo motors mounted on a robotic mechanism. The squeezing action for lymphatic drainage is accomplished by soft pneumatic actuators operated by an air pump. The device's actuators and sensory system connect to a control module through hoses and wires. The complex system includes numerous subcomponents, including a control module housing a microcontroller, mini air pump, solenoid exhaust valve, hose connections, a motor driver, liquid crystal display, and other miscellaneous electronic components. Further research is warranted to progress this type of technology.

Artificial intelligence

Artificial intelligence is the capability of a computer system to mimic human cognitive functions such as learning and problem-solving. Mathematics and logic are applied by computer systems to simulate reasoning that people use to learn from new information to make decisions.

Machine learning is an application of artificial intelligence. It involves computer systems using mathematical models of data to help a computer learn without direct instruction. The system is able to automatically improve itself through experience.^(230, 231) There are many algorithms that are utilized in machine learning, one example being the artificial neural network (ANN). ANNs are used to describe computing systems inspired by the biological neural networks of human brains.⁽²³²⁾ Artificial intelligence was found to have four use cases as outlined hereunder.

Use case 4: understanding population groups at risk of filarial-related LE using artificial intelligence

An implementation example of machine learning in LE is the use case of understanding population groups at risk of filarial-related LE. Tracking of filarial-related LE in developing nations is needed whereby accurate prediction of prevalence is essential for mass treatment campaigns. In the utilization examples as follows, machine learning and mapping of the disease distribution allowed for directing LE preventive measures to the population at risk.

In Nigeria, machine learning (Random Forest algorithm among others) was used to create a map to estimate the number of people living in areas of risk of lymphatic filariasis.⁽²³³⁾ The study was able to demonstrate that ~110,000,000 individuals lived in areas at risk of lymphatic filariasis transmission.

Similarly, in Samoa identification of locations with high infection prevalence were estimated by using a combination machine learning (Random Forest algorithm) and geostatistics. The study found that the majority (52%) of infections could be identified by sampling of 17.7% households.⁽²³⁴⁾ The impact of this research being that a targeted sampling strategy was more efficient than random sampling for locating residual filarial-related infections at the household level. Targeted care could then be directed at those in need.

Use case 5: detection of cancer-related LE using artificial intelligence

Early diagnosis of LE is essential, with medical devices such as bioimpedance spectroscopy being well researched as an applicable medical device for measuring LE.⁽²³⁵⁾ Given the importance of early detection, machine learning was investigated by Fu et al (2018) to determine if cancer-related LE could be detected based on real-time symptom reporting. In their web-based study real-time reporting of symptoms was captured using a m-Health system. Data regarding demographic and clinical information, LE status, and symptom features were collected. Five renowned classification algorithms of machine learning were compared, including the ANN. The ANN achieved the best performance for detecting LE (accuracy of 93.75%, sensitivity of 95.65%, and specificity of 91.03%). The authors stated that “Such detection accuracy is significantly higher than that achievable by current and often used clinical methods such as bio-impedance analysis”.⁽¹⁹⁰⁾

Use case 6: assessment of fibrosis using artificial intelligence

Imaging through photography is an established method for recording the severity of LE.⁽²³⁶⁾ An advanced application of imaging in eHealth utilized machine learning to assist with the diagnosis and staging of LE by estimating tissue status. Collagen disorganization, as a representation of fibrosis level, was demonstrated using machine learning (Support Vector Machine algorithm) and multiphoton laser microscopy (MPM). MPM was used to provide instantaneous in vivo tissue imaging at the cellular and subcellular levels.⁽²³⁷⁾ Further research in this area may assist with quantification of the severity of fibrosis.

Use case 7: assessment of limb volume using artificial intelligence

Conventionally, water volume displacement, perometry, and tape measurements are used to assess changes in limb volume caused by LE.⁽²³⁸⁾ An example of e-Health in this field is a double-image camera-based tool and machine learning (multiple algorithms), which were used to calculate limb volume. In the study by Notash et al (2022) two cameras captured two pictures of an arm, and along with machine learning, a measure of limb volume was established. This method was shown to be a reliable and valid technique for the measurement of arm volume.⁽¹⁹⁴⁾

Another example of e-Health was a video and artificial intelligence-based solution used to measure anatomical parameters, including volume and foot length, to detect LE. The Heartfelt device (Heartfelt device HF-1; Heartfelt Technologies Ltd.) was used to acquire a 3D image of the foot. Mathematical computation and logic were applied to a programmatically adjustable anatomical model of a human to estimate limb volume. The authors found that the Heartfelt device measured foot volume and length more precisely than either water displacement or manual foot length measurements.⁽²³⁹⁾

Electronic medical and health records

Two use cases were identified relating to LE involving EHRs and EMRs. EHRs are a digital version of clinical notes that were historically kept in paper form.⁽²⁴⁰⁾ EHRs contain a wealth of data that may be used to identify potentially eligible patients for clinical trial enrolment.⁽²⁴¹⁾

Use case 8: exploratory analysis using electronic medical and health records

In a study by Tidhar et al (2023) descriptive analysis of an EHR database was performed on 6,013 patients with LE in Israel. The exploratory analysis was used to identify variant characteristics of LE that were present in a record keeping database. The data extracted included comorbidities, chronic medication use, stage of LE, frequency, body area impacted, and types of interventions. This study provided a comprehensive description of patient characteristics receiving CPT.⁽²⁴²⁾

Use case 9: remote data collection using electronic medical and health records

Mobile phone-based text messages were reported to have been used for the purpose of remote data collection. In a study in Tanzania, Community Health Workers used text messages to report lymphatic filariasis-related LE in real time. As a novel approach to medical record acquisition, the study reported that the tool was relevant and feasible.⁽¹⁹⁷⁾ This study identified that real-time reporting allowed data collection and availability of the information to be immediate and more accurate compared with written reports, which were reportedly based on memory and could often miss many of the salient points captured by immediacy.

Instructive online information

Instructive online information is already widespread across many mediums (such as websites, social media, and mobile apps) and is delivered through several forms of e-Health, including telehealth, eLearning courses, and across social media platforms. Instructive online information is being used to educate both patients and practitioners.^(175, 243-245) Three use cases utilizing instructive online education were found and are explored as follows.

Use case 10: remote education using instructive online information

Previous research has shown that health care practitioners have unmet educational needs in relation to LE.⁽²⁴⁶⁾ Archibald et al. reported on the development of an eLearning module in a subacute hospital setting for the purposes of continuing professional development for medical staff. The module on common infections was tested on 15 residents and 3 staff physicians. The module included questions such as “Which of the following are risk factors for cellulitis?” with answer options making mention of LE. The participants reportedly felt the content was generally appropriate, the module well designed, and significant improvements in knowledge were gained.⁽²⁴⁷⁾

Use case 11: remote service provision using instructive online information

Remote service provision can be delivered through m-Health and web-based education as well as telehealth. These modalities can either be patient or practitioner directed and are explored hereunder.

Patient-directed care facilitated by m-Health and web-based education

e-Health aims to empower patients with their self-care. The-Optimal-Lymph-Flow (TOLF) is an example of e-Health in which a patient-centred mobile and web-based behavioural and educational program focused on self-care strategies. This program was found to help breast cancer survivors manage chronic pain and swelling associated with breast cancer-related LE.^(173, 248, 249)

Practitioner-directed care facilitated by telehealth

Numerous examples of telehealth implementations have been reported as a result of the COVID-19 pandemic as it necessitated a shift in reliance from in-person care to e-Health.⁽²⁵⁰⁾ One example was from experiences of a range of service providers in Wales (United Kingdom) who indicated, through a cross-sectional online survey, their readiness to offer virtual services during the COVID-19 pandemic. Benefits of telehealth were reported as minimizing the danger of COVID-19 transmission, encouraging value-based health care, and facilitating rapid care were cited as important advantages of telehealth.

Difficulties of telehealth were reported including the restriction of palpation possibly impacting the quality of the assessment. Gabe-Walters and Noble-Jones reported that “Lymphoedema can lead to complicated problems and deterioration, requiring dexterity and sensory skills to assess limbs and skin condition, which may render virtual care unsuitable for some.”⁽¹⁹¹⁾

A second example of eHealth during the COVID-19 pandemic was from a provider of primary and tertiary health care in Qatar, which implemented a blended in-person and telehealth system. The service quickly developed online educational treatment resources and implemented telerehabilitation for patients. Challenges in virtual consultations were described as technical difficulties, internet connectivity problems, and low camera clarity as well as older patients needing help in operating the application.

Patient privacy was also raised as a concern as “...some patients were uncomfortable exposing their affected area through a videoconference despite the pre-obtained consent and the high security requirements of the application”.⁽²⁵¹⁾ Similar to the publication by Gabe-Walters and Noble-Jones, an inability to touch the patient was raised as a challenge. As was the importance of e-Health decreasing the risk of transmission of disease from in-person care. The authors conclude by stating, “our experience suggests that a hybrid system of face-to-face and televirtual consultations may provide an opportunity to improve accessibility to lymphoedema care and reduce waiting time and may thereby become a sustainable model of care even after the pandemic.”

A third example of e-Health implementation is from Chile, where a public referral hospital was able to provide telehealth services and adapt to virtual models of care throughout the pandemic.⁽²⁵²⁾ Similar barriers to the previous examples were experienced.

Use case 12: supporting psychological well-being using instructive online information

The psychosocial impact of LE has been well documented.⁽⁴⁴⁾ An example of e-Health being used to support psychological care is demonstrated in a study that used a social network system, the Telegram™ messenger service, to educate and motivate patients and compared this with group-based education.⁽²⁵³⁾ The authors stated that “although the social network-based education method was effective, the group-based education method was more beneficial.”

A study by Nelson et al., assessing education about LE prevention, found that patients relied on peer groups for their information. “Patients cited other breast cancer survivors as information sources at the same frequency as the surgical team and at a greater frequency than radiation oncologists. Books were as equally important as survivor groups”.⁽²⁵⁴⁾ This suggests that further research is required on how social media networks can enable LE patients to support one another, as well as how e-Health can effectively mimic group-based education.

Smart wearable devices

Smart devices include features such as connectivity, user interaction, autonomy, and context awareness. Silverio-Fernández et al. define smart devices as "...a context-aware electronic device capable of performing autonomous computing and connecting to other devices wire or wirelessly for data exchange".⁽²⁵⁵⁾ Two use cases are explored hereunder using smart wearable devices.

Use case 13: improving traditional LE treatment using smart wearable devices

Before exploring the utilization example of improving traditional LE treatment using smart wearable devices, defining what makes a standard medical device become a smart wearable device is necessary.⁽²⁵⁶⁾ Pneumatic compression devices, as medical devices, will be used for this purpose.

Traditional pneumatic compression devices that inflate and deflate air pockets have been utilized for decades in patient care.^(257, 258) The programming of such traditional pneumatic compression devices may rely on digital technology; however, they are not considered eHealth but rather medical devices. What seems to distinguish eHealth from medical devices is the use of more advanced technology such as electronics, microprocessors, information communication technology, artificial intelligence, or machine learning capability that contribute to the devices being "smart" in nature. The following use case demonstrates the evolution of a traditional pneumatic compression device from a medical device to a wearable device, and then into a smart device.

A prototype of a wearable garment by Yoo et al. consisted of origami-inspired soft fabric pneumatic actuators, which created normal and shear forces for application of Manual Lymphatic Drainage (MLD). Shear forces were created by the unfolding of the garment's Z-shaped fold lines as the actuators were inflated.⁽²⁵⁹⁾ Such technology was considered in the making of an e-Health device, whereby the use of electronics in a portable pneumatic compression sleeve enabled graduated compression.⁽²⁶⁰⁾ The device by Gao et al. consisted of a specialized garment, microfluidic valves and an Arduino Nano Every microcontroller (Arduino, Italy) that applied gradient pressure along the limb, mimicking the squeezing and dragging motion administered during MLD.

Although not technically a smart device at this stage, devices with capability to report total treatment time to an app for self-care tracking would take new prototypes to the next level. Such technological advancement occurred in 2022 with research by Rockson et al on the "Dayspring wearable advanced compression device" consisting of a programmable segmental controller and a sleeve garment. The application of graduated pressure to the limb in the sleeve was connected to a mobile phone application that tracked individual pressures and device usage.⁽²⁶¹⁾ In the future, such devices may offer an alternative to traditional pneumatic compression devices.

Use case 14: condition tracking using smart wearable devices

Another example of the use of e-Health is in the advancement of pedometers and activity monitors, which assist with condition tracking.⁽²⁶²⁾ Lucas et al. investigated an e-Health system called Capturing and Analyzing Sensor and Self-Report Data for Clinicians and Researchers (COMPASS) on three cancer patients. The study utilized smart devices and e-Health records to remotely monitor multiple domains of patient-related outcomes. The COMPASS system included three components: (1) a device worn by patients to passively monitor physiological function; (2) an interface to sync with patients' smartphone; and (3) a web-based clinician interface to deliver customizable reports.⁽²⁶³⁾ Further research is required into systems that can allow patients to connect remotely to their LE practitioner for improved condition tracking and symptom monitoring.

Future possibilities

Owing to the rapid development of technology, the utilisation of eHealth in LE care will likely become a prominent topic of future research. Improving web-based instructional content appears to be a priority as existing LE educational information, on popular social media platforms such as YouTube and Instagram, were reported to be low quality.^(175, 244) Although the quality of educational content on social media and website platforms needs improvement, considering their popularity they are positioned as critical tools to aid information dissemination.⁽²⁶⁴⁾

It may also be a priority for health systems to look at standards of data privacy as eMRs are more well utilized. In a study looking at how secure information was in the United States, Na et al (2018) were able to reidentify nearly all (94.9%) individual adults from the National Health and Nutrition Examination Survey using machine learning techniques.⁽²⁶⁵⁾ e-Health development, therefore, needs to consider robust means of protecting patient privacy.

As technology continues to evolve, there would be advantages in clinical practice if 3D scanning technology with artificial intelligence, applied to the calculation of limb volume, continued to improve.⁽²³⁹⁾ As reported in Use Case 7, assessment of limb volume using artificial intelligence may allow for the replacement of time-consuming circumferential measures and cumbersome water volume displacement while improving accuracy.

It may be worthwhile exploring the use of digital survey tools for LE early intervention services, as comparable accuracy has been found with that of bioimpedance spectroscopy, for cost-effective detection through real-time symptom evaluation of those at risk.⁽¹⁹⁰⁾

Telehealth is likely to remain an important e-Health modality that should be considered outside of necessary utilisation, well after the COVID-19 pandemic, as the concept of lowering the danger of disease transmission through virtual care will still be relevant. Research has shown that hospital visits were associated with more than a threefold increased risk of acute infection.⁽²⁶⁶⁾ Considering that cellulitis in LE is a global problem that results in hospitalisation, any means by which LE patients can be encouraged to stay out of hospital warrants further investigation.⁽³²⁾ Apart from decreasing the risk of infection, telehealth may also serve to reduce financial expenditure on health systems. An in-person model caring for patients with chronic leg ulcers found that costs were 30% higher when compared with a telehealth model.⁽²⁶⁷⁾

As technological innovation continues, e-Health will continue to adopt and incorporate new LE devices and technologies. For instance, robotics is an intriguing subject in which significant changes are likely to occur, which may drastically alter the administration of traditional CPT. As “service robots” with human behavioural sensing for in-home massage gather a considerable amount of academic interest, robots may be utilised more frequently to replace practitioner-administered manual lymphatic drainage.⁽²²⁵⁾ The challenge will be moving ahead with new technologies and understanding one's strategic position in the use of these technologies as a tool that is exercised through professional judgment to avoid practitioners feeling “...nothing more than gatekeeper and button pusher...”.⁽⁷⁶⁾

Current use of robotics for lymphadenectomy and LVA procedures, for example, involve robotic-assisted procedures whereby the robotic systems enhance the capability of the surgeon. Individual surgeon clinical reasoning remains of utmost importance. Where clinical reasoning may not be as essential, autonomous robots may become more widely utilised. Autonomous robotic products have the potential to improve patient outcomes and represent medical, engineering, and science communities coming together to improve the delivery of health.⁽²⁶⁸⁾

Conclusion

This review demonstrates the diverse use of e-Health modalities spanning the prevention, diagnosis, assessment, and treatment phases of care for LE. Cutting edge applications for achieving optimal patient care and outcomes are demonstrated. Further research is required to fully understand the breadth of utilisation in LE, benefits to patients and practitioners, and how to best use e-Health to advance traditional care. Areas for future development include improvement in the quality of educational content on social media and website platforms, improvement in standards of data privacy of EMRs and EHRs, and the evolution of e-Health to further advance in-person and other traditional forms of care.

CHAPTER EIGHT: A MIXED METHODS ANALYSIS OF WHERE IN AUSTRALIA EHEALTH IS BEING USED IN LYMPHOEDEMA CARE

Chapter overview

This chapter presents research on a small sample of Australian lymphoedema practitioners. Building on the knowledge obtained in Chapter Seven, an investigation was conducted into where lymphoedema practitioners were utilising eHealth for the prevention, diagnosis, assessment, and treatment of lymphoedema. This research leveraged the World Health Organization's (WHO) classification model for describing eHealth interventions as described in Chapter Five.⁽¹³⁹⁾

Highlights

The key highlights of this research include:

- A significant contribution to the primary thesis objective
- The confirmation of findings from the narrative review
- The finding that a small sample of Australian lymphoedema practitioners were using many different types of eHealth spanning prevention, assessment, diagnosis and treatment
- The finding of the use of eRecords, healthcare information systems, mHealth and instructive online information being common amongst lymphoedema practitioners. More sophisticated forms of eHealth, such as robotics, were not reported.
- The finding of telehealth, whilst not new, was hindered by difficulties in performing specific lymphoedema assessments remotely.

Research

Aim

To understand how Australian lymphoedema practitioners were using eHealth across the spectrum of prevention, diagnosis, assessment, and treatment of lymphoedema.

Method

Mixed-methods research was designed to capture both qualitative and quantitative data through an electronic survey. A survey was designed and hosted within Qualtrics.⁽²⁶⁹⁾ The survey included some pre-qualification questions and then questions pertaining to health system challenges faced by practitioners, challenges perceived to be faced by patients, and questions about the application of eHealth to overcome challenges. Descriptive statistics would be used to describe quantitative data. Qualitative data would be analysed by thematic analysis.⁽²⁷⁰⁾

The project was approved by Flinders University's Human Research Ethics Committee (HREC project number 7454). The survey was sent to members of the Australian Lymphoedema Professionals Google Group (researched in Chapter Fourteen). There are approximately four-hundred and fifty (450) members across Australia, New Zealand (NZ) and the United Kingdom (UK). All members of the Australian Lymphoedema Professionals Google Group are health practitioners, and the survey asked a pre-qualification question which excluded practitioners who worked outside of Australia. Data was collected from the 18th of May 2024 to the 31st of July 2024.

Results

A total of 24 respondents participated, of which 15 respondents (60%) completed 95% or more of the survey. Duration taken to provide responses was on average 50 minutes (SD=145).

Respondents (n=24) reported spending most of their working hours in sectors of private practice (n=14 / 58.3%), public hospitals (n=7 / 29.2%), private hospital (n=1 / 4.2%), education (n=1 / 4.2%), and other (n=1 / 4.2%) (Figure 45).

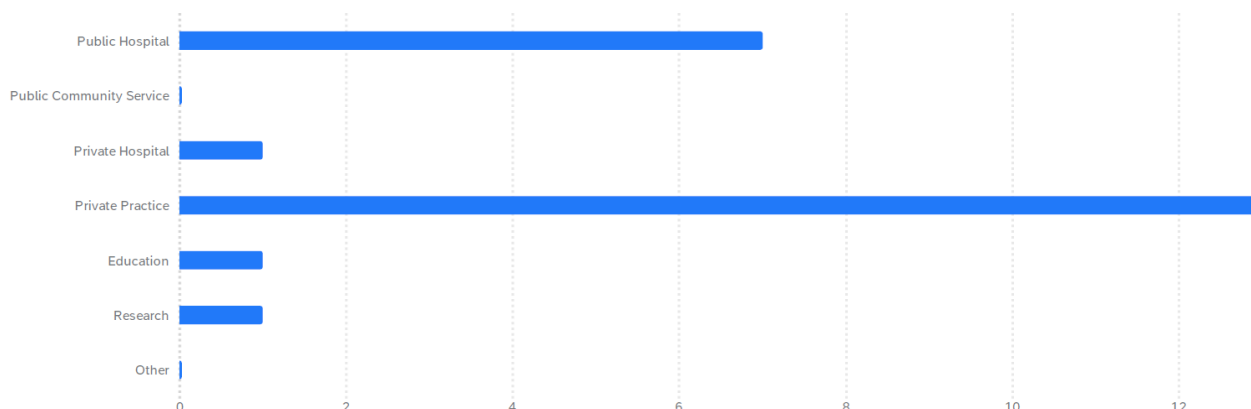


Figure 45 - Work sector of respondents

The types of eHealth modalities being used included:

- eRecords
- ePrescribing
- eReferrals
- eResults
- Health apps
- Telehealth
- Applications of AI
- Using mobile phones (mHealth)
- Health knowledge management
- Clinical decision support system
- Healthcare information systems
- Digital games
- Wearable electronic devices
- Instructive Online Information
- Infoveillance

Use of eHealth records was the highest response (n=13), followed by mHealth or mobile phones (n=13), eReferrals (n=10), healthcare information systems (n=10), instructive online information (n=8), health knowledge management (n=7), ePrescribing (n=6), telehealth (n=6), eResults (n=4), health apps (n=3), AI (n=2), wearables (n=2), infoveillance (n=2), clinical decision support system (n = 2) and digital games (n=1). Robotics and other modalities had no responses (Figure 46).

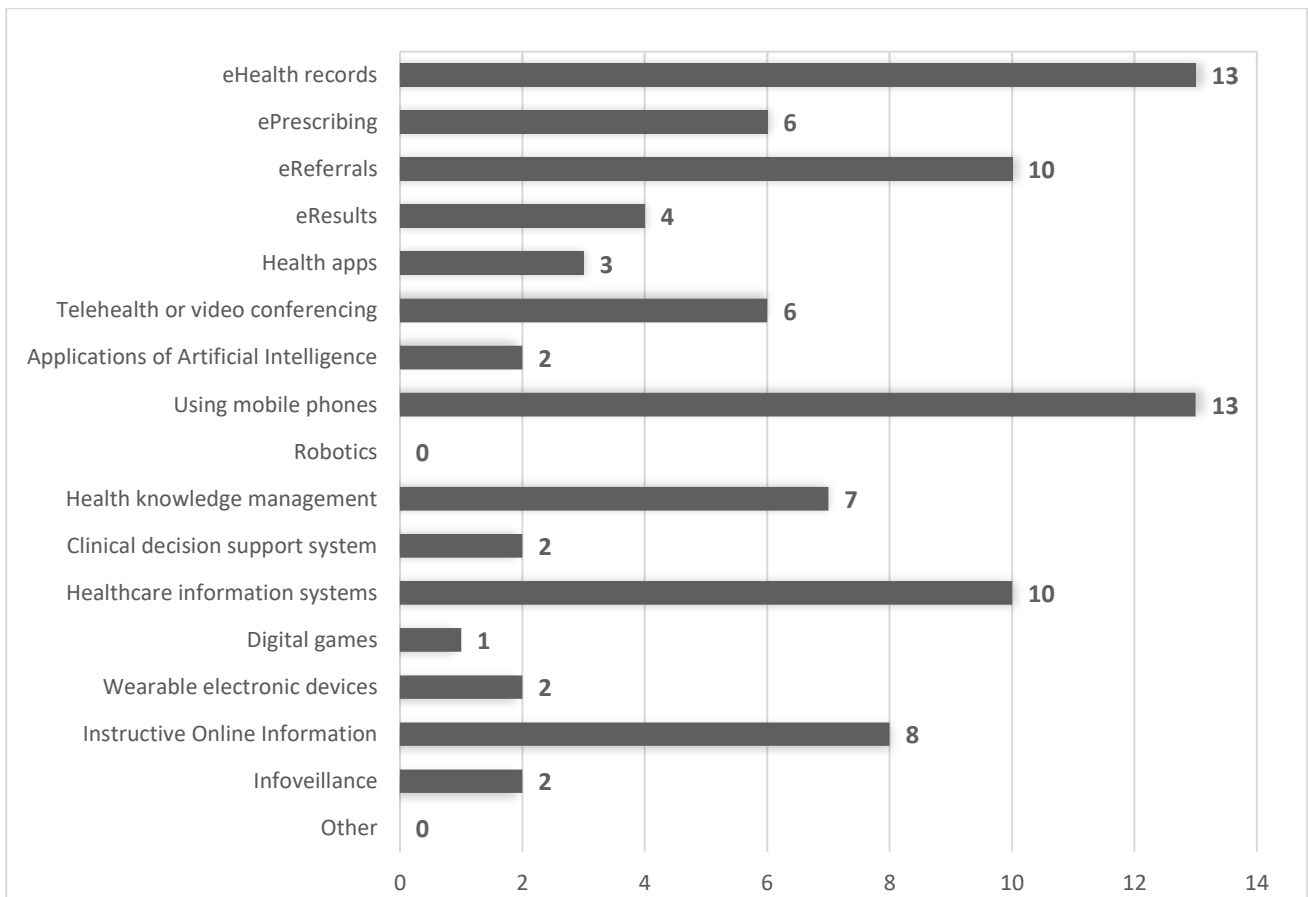


Figure 46 - Types of eHealth being used by lymphoedema practitioners

Prevention

Themes for respondents using eHealth for the prevention of lymphoedema included leveraging instructive online information within eHealth to inform patients of reputable websites, blogs, and information resources related to lymphoedema (n=6). Other themes included email (n=4), eHealth records (n=3), prescribing / ordering garments (n=2), online education through eLearning (n=1), and health knowledge management (n=1) (Table 6).

Table 6 - Theme summary for use cases for prevention

Theme	Count
Instructive information	6
Email	4
eHealth records	3
ePrescribing garments	2
eLearning	1
Health knowledge management	1

For health knowledge management, the specific software brand of Mailchimp was referred to in one response.⁽²⁷¹⁾

Diagnosis

Themes for respondents using eHealth for the diagnosis of lymphoedema included use of eHealth records (n=3), clinical decision support (n=2), followed by eLearning (n=1) and health knowledge management (n=1) (Table 7).

Table 7 - Theme summary of use cases for diagnosis

Theme	Count
eHealth records	3
Clinical decision support	2
eLearning	1
Health knowledge management	1

Several clinicians reported that diagnosis was not their role therefore they did not use eHealth for this purpose (n = 4).

Assessment

Themes for respondents using eHealth for the assessment of lymphoedema included use of eHealth records (n = 10), eResults (n = 2), telehealth (n = 1) and clinical decision support (n = 1) (Table 8). Of these responses, one respondent added that, "I also use tissue analytics for monitoring and reporting wounds."

Table 8 - Theme summary of use cases for assessment

Theme	Count
eHealth records	10
eResults	2
Telehealth or video conferencing	1
Clinical decision support	1

Treatment

Themes for respondents using eHealth for the treatment of lymphoedema included instructive online information (n = 7), telehealth (n = 4), ePrescribing (n = 3), eHealth records (n= 1), mobile phones (n = 1) and health apps (n=1) (Table 9).

Table 9 - Theme summary of use cases for treatment

Theme	Count
Instructive online information	7
Telehealth	4
ePrescribing garments	3
eHealth records	1
Using mobile phones	1
Health apps	1

Themes of innovative ways eHealth was being used included telehealth (n = 5), bioimpedance spectroscopy (n = 2) and clinical decision support systems (n = 2). One therapist stated, “Nothing noteworthy” and another “I don't believe I have.”

Bioimpedance data, acting as an eHealth modality rather than just a simple medical device, was illustrated through a practitioner stating, “Bioimpedance due to the data availability in real time to assist in clinical decision making.”

One practitioner highlighted that the use of telehealth is not new through the following comment, “Video conferencing, not so new but very effective as everyone has capacity on their phones.”

A few other practitioners commented on how they were using telehealth to make it innovative. Examples were:

- “Telehealth for prospective surveillance and lymphoedema follow up of rural patients.”
- “Telehealth as it empowers patients to have treatment anywhere.”
- “Telehealth - videocall, particularly for head and neck lymphoedema patient (with or at risk of).”

The most common theme of challenges in using eHealth for lymphoedema care were difficulties in providing specific lymphoedema assessments online (n = 7). Other themes are presented in Table 10.

Table 10 - Theme summary of reported challenges to using eHealth for lymphoedema care

Theme	Count
Difficult to provide specific assessment	7
Data security	2
Time needed to train	2
Lack of solutions	2
Lack of skill	1
Lack of awareness	1
Patient acceptance	1
Infancy / early stages of implementation	1

Some interesting quotes were:

- “As we can conduct Arterial Brach Pressure Index (ABPI) and vascular screening in clinic I am more apprehensive to use telehealth until this is done for people with lower limb lymphoedema. Some patients find it difficult to accept telehealth. However, I find many flourish. I find a hybrid model works best i.e. first appointment face to face (F2F) to practice skills so the person can feel how much pressure to apply for MLD, etc, and then videocall works well.”

- “I try to tailor my information to the individual client so as not to overwhelm them, I am in far north Queensland and secure connections are an issue. For people who are remote, eHealth is sometimes the only option, but I would be concerned re: correct technique, follow up etc.”
- “Would love to see more innovative solutions that improve patient's quality of life, and to improve practitioner's efficiency - e.g. methods to more easily measure and monitor patients' progress.”

Discussion

This research achieved its objective of understanding how Australian lymphoedema practitioners are using eHealth across the spectrum of prevention, diagnosis, assessment, and treatment of lymphoedema. eRecords, healthcare information systems, mHealth and instructive online information were common.

One practitioner referred to video conferencing being “not so new,” suggesting that the technology is now considered common place. The most common theme however of barriers to digital health being used was difficulty in providing specific lymphoedema assessments. Despite telehealth not being new, there are still difficulties associated with its delivery.

In other areas of medicine telehealth still presents challenges. Despite significant advances in audio/visual technology, telemedicine in surgery continues to limit a surgeon's ability to physically examine and assess a patient following surgery.⁽²⁷²⁾ In a pilot study by Noble et al (2019) involving responses from 53 women with breast cancer, only 15% said they would have accepted post-op video teleconsultation if this was offered.⁽²⁷³⁾ 25% of participants reported not having a suitable telehealth appropriate device, being defined as an internet connected device with a camera and speakers, reflecting that one quarter of the group had accessibility issues.

This then raises the need for further research to investigate if it is skills, knowledge, accessibility, technology or perception which are limiting effective specific lymphoedema assessments being performed remotely. If knowledge is a limiting factor, guidelines provided by Noble-Jones et al (2021) provide very helpful and practical tips as to how lymphoedema practitioners can overcome such challenges.⁽¹⁾ An example of helpful patient instructions from this publication is provided below (Figure 47).

Conclusion

A small sample of Australian lymphoedema practitioners reported using several different types of eHealth spanning prevention, assessment, diagnosis and treatment. The use of eRecords, healthcare information systems, mHealth and instructive online information was common amongst practitioners.

More sophisticated forms of eHealth, such as robotics and advanced applications of AI were not reported. Telehealth, whilst not new, was hindered by difficulties in performing specific lymphoedema assessments remotely.

Future research, involving a larger sample of practitioners, should continue to investigate the use of digital health in lymphoedema including why lymphoedema practitioners use digital health and how skills, knowledge, accessibility, technology or perception of the technologies can be improved, for the benefit of patient care.

Box 1. Information included in Lymphoedema Network Wales home measurement guidance sheets for patients

To measure the size of your leg, you will need a tape measure with centimetres and millimetres marked on it. The tape measure needs to be of the soft variety, for example a tailor's or dressmaker's tape measure.

If you do not have one of these, you can use a piece of string and a DIY tape measure to measure the string, but this is not as accurate.

DO NOT USE A METAL DIY TAPE MEASURE DIRECTLY ON YOUR SKIN AS IT CAN CAUSE CUTS

General technique

Make a note of what position you are in to do the measurements, for example, sitting in the chair with your legs down or with your legs up on the bed or settee, and if you are doing it yourself or someone else is doing it for you. Write which limb you are measuring and state if it is left or right.

Using the tape, keep the tension even:



Correct



Incorrect

Hand held tape measure: place the tape measure snugly around the limb without tightening the tape (hold the tape to prevent it slipping/falling down)

Make a note of the number on the tape in centimetres and millimetres, whether it is a left or right leg being measured.

Leg lower limb

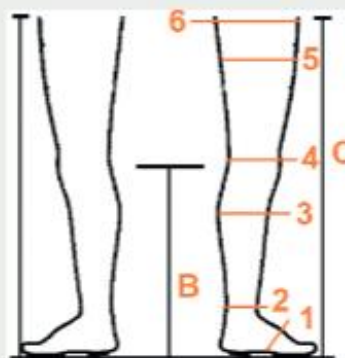
It is best to measure in sitting position or with legs up on the bed or settee (elevated), make a note of the position you are in to do the measurement.

Measure how long your leg is, there are 3 measurements, your shoe size, the length of your lower leg and the length of your whole leg. You can write all of the measurements in centimetres and millimetres on the table.

- A. Shoe size (UK or European)
- B. Heel to knee crease (line on back of knee)
- C. Heel to gluteal (bottom) crease

Then measure the circumference of your foot and leg:

- 1. Around foot
- 2. Ankle
- 3. Calf (widest part)
- 4. Knee (at level of crease behind knee)
- 5. Thigh (widest part)
- 6. Groin (as high as you can)



Recording your measurements

How tall are you?

What position were you in?

- Sitting on a chair
- Legs up (on settee or bed)

Who did the measurements?

- I did
- Someone else

Measurement	LEFT	RIGHT
Measurement A – shoe size (UK or European)		
Measurement B – heel to knee crease (line on back of knee)		
Measurement C – heel to gluteal (bottom) crease		
1. Around foot		
2. Ankle		
3. Calf (widest part)		
4. Knee (at level of crease behind knee)		
5. Thigh (widest part)		
6. Groin(as high as you can)		

Figure 47 - Example of home measurement guidance sheet for patients

[From Noble-Jones et al (2021). Published under a Creative Commons Attribution, Non-commercial License 4.0 <https://creativecommons.org/licenses/by-nc/4.0/deed.en>. No changes made.] ⁽¹⁾

CHAPTER NINE: A SYSTEMATIC REVIEW OF WHERE EHEALTH IS BEING USED IN LYMPHOEDEMA TREATMENT

Chapter overview

This chapter presents a systematic review on the application of eHealth and mHealth interventions in the treatment of lymphoedema.

Highlights

The key highlights of this research include:

- This research concluded the primary thesis objective of quantifying the types of digital health interventions reported in published literature
- This work represents the first systematic review on a wide range of eHealth modalities in lymphoedema treatment
- This review revealed the necessity for researchers to carefully consider their methodologies prior to undertaking randomised controlled trials (RCTs) in this field. It became evident which research teams demonstrated greater methodological rigor in testing their eHealth modalities before attempting RCTs. The key lesson acquired was the importance of thoroughly prototyping digital tools, before progressing to feasibility testing before proceeding with RCTs.
- An insight into the design factors which impact adherence to eHealth modalities. These findings were considered in the build of the digital prototypes in Chapters Eighteen to Twenty-One.

Publication title – A Systematic Review of eHealth and mHealth Interventions for Lymphoedema Patients

Reference

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Credit

Conceptualisation, methodology, validation, investigation, and writing original draft, review, and editing by A.M. Methodology, validation, investigation, and writing review and editing by B.I. Conceptualisation, methodology, investigation, writing - editing and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 70% of the data collection and analysis and 95% of the writing and editing.

Publication

Abstract

Lymphoedema is a chronic inflammatory disease that causes chronic swelling in the affected area, necessitating daily treatment. Millions of people worldwide are affected. The investigation of strategies to improve the overall health of patients, such as through the utilisation of electronic health (eHealth), is justified considering the ongoing burden of daily self-care. This research aimed to (a) identify current published research in eHealth and mobile health (mHealth) interventions for patients living with lymphoedema; (b) assess feasibility and efficacy of the interventions; and (c) understand whether intervention adherence was affected by using eHealth. A systematic review was undertaken. Seven databases including MEDLINE, Scopus, Web of Science, CINAHL, the Cochrane Library, PsycINFO and IEEE Xplore were searched. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses were used. 1857 studies were identified through the database search with 9 meeting the inclusion criteria for a total of 1031 participants. There were 3 types of eHealth, including instructive online content, telehealth, and digital gaming. The efficacy of various eHealth and mHealth modalities was demonstrated in areas such as lymphoedema outcomes, self-care, psychosocial outcomes, and disease comprehension. Reports of feasibility demonstrated that eHealth modalities were generally well accepted or preferred over conventional methods. 7 studies reported or discussed adherence and provided insight into the relationship between the design of the eHealth tool and the completion of the intervention. Several distinct categories of eHealth and mHealth interventions were shown to improve disease comprehension, psychosocial and lymphoedema outcomes. Findings from this systematic review may have an impact on the design of future studies in this domain, including consideration of early user acceptance testing when developing eHealth tools. With the ongoing progress in eHealth technology, further investigation into eHealth is warranted given the encouraging results observed in a limited number of studies.

Introduction

Lymphoedema (LE) is a chronic inflammatory disease caused by compromised lymphatic drainage. Persistent swelling is the main symptom, resulting from the accumulation of interstitial fluid in tissues, followed by the deposition of fibrotic and fatty tissue.^(202, 274) LE, like other chronic inflammatory diseases, progressively worsens through several stages. Both body tissue and the lymphatic vessels themselves become inundated with fibrotic and fatty tissue as the condition progresses.⁽²³⁾

LE affects millions of people worldwide. The condition can affect any body part such as the arms or legs, head, neck or oral cavity, trunk or genital area.⁽²⁷⁵⁾ There are two types of LE: primary and secondary.⁽²⁷⁶⁾ Primary LE results from a failure of the structure or function of the lymphatic system, usually associated with a malformation of the lymphatic system. Aplasia (lack of development), hypoplasia (too few or too small) or hyperplasia (too many or too large) of any of the lymph vessels or nodes results in primary LE. Secondary LE is acquired after injury, surgery, or radiotherapy which can overwhelm the lymphatic system. Cancer interventions, for example, are a common cause of secondary LE in developed countries where removal of lymph nodes and radiation damage lymphatic vessels and reduce the transport capacity of the lymphatic system, resulting in accumulation of interstitial fluid.⁽²⁰³⁾ In developing countries, secondary LE resulting from surgical procedures or other medical interventions, is linked to delayed cancer detection and late implementation of early-stage LE treatments.⁽²⁷⁷⁾ However, the prevailing factor leading to LE in developing countries is filariasis, a condition in which the lymphatic system is affected as a result of infestation by parasitic worms.⁽²⁷⁸⁾

The severity of LE is classified by the International Society of Lymphology (ISL) into stages 0 to 3.⁽²⁷⁹⁾ Subclinical LE is defined as stage 0 when an increase in interstitial fluid is detected, usually through bioimpedance spectroscopy, but the body region does not appear to be swollen to the naked eye. Clinical LE appears from stage 1 when mild signs of swelling in the body region can be detected, and the volume of the limb has increased. LE progresses to stage 2, associated with more swelling and tissue fibrosis, through stage 3 where body regions become overwhelmed with oedema, fibrotic and fatty tissue deposition.

As the stages of LE progress, patients may experience changes in the size of their limb, limb infections known as cellulitis, and in severe untreated cases lymphorrhoea where lymph and its contents leaks through the skin.^(32, 280) Furthermore, patients experience higher levels of functional impairment, anxiety and depression, and poorer psychological adjustment than the general population. Poor quality of life (QoL) is associated with the frequency of cellulitis, the presence of pain, poor skin quality, the presence of swelling in the dominant limb, and reduced limb mobility.⁽²⁸¹⁾

LE is a lifelong condition that is expensive to manage, and practitioner-led interventions are difficult to access. Research indicates that as the severity of LE worsens, out-of-pocket expenses related to care and the number of days off work also increase.^(282, 283) As reported by patients, access to treatment may be hindered if it is difficult to arrange an appointment and access a suitably certified LE therapist who possesses the necessary knowledge and skills to assist the patient.⁽²⁸⁴⁾

After gaining access to a certified LE therapist, patients must maintain lifelong self-care routines including lymphatic drainage and wearing compression garments. Consequently, adherence becomes critical to maintaining daily self-management. The complexity of treatment regimens, the burden of symptoms, the balance of treatment time and life demands, and the lack of education and support have been cited as impediments to treatment adherence.⁽²⁸⁵⁾

Patient knowledge has been suggested to be an important factor for optimal adherence to self-management regimens and risk reduction behaviours.^(286, 287) Research has shown that patients have expressed concern about the lack of LE education.^(285, 288, 289) Inaccurate information provided by healthcare professionals as well as information overwhelm can also be problematic.⁽²⁸⁹⁾ Therefore, more research is required on solutions that can improve the domains of access to care, adherence to treatment, and LE education. Electronic health (eHealth), which is also known as digital health, may be one solution that has the potential to address all of these domains.

eHealth, inclusive of mobile health (mHealth), can be defined as the broad use of health information and communication technologies and networks to enhance patient-centred care.^(168, 210) eHealth is a broad definition that includes health informatics, health monitoring, telehealth, mobile and mobile technology, social networks, and online learning.⁽²⁹⁰⁾ mHealth specifically refers to wireless applications used in the delivery of health services, including mobile computing, medical sensor, and communication technologies for healthcare.⁽²⁹¹⁾ Other definitions include mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices.⁽²⁹²⁾

A narrative review outlined how eHealth and mHealth technologies are being used for the prevention, detection, assessment and treatment of LE. Robotics, artificial intelligence, electronic medical records, smart wearable devices, and instructive online information were shown to be being used across a broad range of use cases, such as robotic-assisted surgery to decrease the risk of LE after lymphadenectomy.⁽¹³⁰⁾ A model for understanding how to classify eHealth modalities, developed by the World Health Organization (WHO), was then applied to LE. Under this model, eHealth interventions for patients, healthcare providers, health systems, and data services was demonstrated.⁽²⁹³⁾ A systematic review on artificial intelligence for LE found “AI offers a variety of solutions to the most challenging problems in lymphoedema practice”.⁽²¹²⁾

A comprehensive systematic review of all forms of eHealth and mHealth on patient outcomes had not been performed. It was unknown how many eHealth modalities were being used to treat patients living with LE, the feasibility and efficacy of such interventions, and whether such interventions could assist with adherence.

Methodology

A systematic review of eHealth and mHealth interventions was carried out according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) for new systematic reviews, including searches for databases and registers, summarized in Figure 48.⁽²⁹⁴⁾ The research protocol was prospectively registered within the database of the International Prospective Register of Systematic Reviews (PROSPERO: registration number CRD42022311638).

Eligibility criteria

Studies were included based on the Population, Intervention, Comparison, Outcome, and Study Design Framework (PICOS). Studies published in English or translated into English were accepted.

Population

The review population included any patient living with LE from stage 0 to 3 according to the ISL classification system or as reported by the study.⁽²⁷⁹⁾ Studies that focused on breast cancer interventions were included if the cohort included some patients with LE. Such papers were identified through LE diagnosis being described in the cohort or through descriptions of the resolution of LE symptoms resulting from the intervention.

Intervention

Several eHealth and mHealth interventions for LE treatment were included, such as electronic health records, information services provided by the Internet, digital gaming, eLearning, virtual reality devices, and robotics; or mHealth interventions including mobile and wireless applications, such as text messaging, applications, phone calls, wearable devices, remote sensing, online support groups via apps, and social media use. mHealth included all devices and software allowing patients to log, store and monitor their health (known as computerized condition tracking) and access electronic health records on their mobile devices.

The authors note that the definition of eHealth is controversial and there is difficulty in differentiating whether some medical devices are simply wellness equipment or health products as opposed to eHealth.⁽²⁵⁶⁾ Bioimpedance spectroscopy (BIS) devices will be used as an example of this reviews protocol's differentiation between health products and eHealth. BIS devices are used to measure stage 0 LE. They store data in the machine on a local computer or in the cloud.

They were to be excluded if the BIS device was used in conventional mode but to be included if remote condition tracking was investigated. Remote condition tracking, where a healthcare professional can assess, monitor and care for patients virtually is a form of eHealth.

Studies were included if eHealth was the focus or if an eHealth modality was incorporated into the interventions. Studies that used digital technology as part of the study (such as digital questionnaires, computer software, and nomograms) but did not investigate the results of the digital technology itself were excluded. Studies that examined the impact of eHealth and mHealth interventions only on practitioners were excluded. Robotics being used to improve surgeon precision was an example of such studies being omitted. If both patient and practitioner outcomes were reported, the study was included, but the practitioner data was omitted.

Comparison, outcomes, and review design

The primary outcomes of this review were to (a) identify current published research on eHealth and mHealth interventions in patients living with LE; (b) assess the feasibility and efficacy of the interventions; and c) understand if the adherence to the intervention was affected using eHealth. During the data extraction phase, the inclusion and exclusion criteria outlined in the PROSPERO-registered protocol were modified. The original protocol was based on the inclusion of several study types including research without comparison, including no therapy, and the inclusion of studies without specific treatment outcome measures that impact patients. Instead, investigations were only included if they focused on the impact of eHealth interventions by including a comparison intervention and reported outcome measurements impacting patients before and after an intervention. Protocol articles, pilot studies with 5 or fewer LE patients, case reports, before and after intervention, non-experimental observational studies or studies involving epidemiological data analysis were omitted. Studies using Portable Three-Dimensional Imaging Systems using photos, for example, were omitted as the focus was not on LE treatment but rather studies comparing traditional assessment methods to eHealth assessment innovations.^(295, 296) Studies using machine learning to detect LE, for example, where no comparator intervention was used, were also omitted. Reviews, meta-analyses, protocols and opinion pieces and studies without methods or results were omitted.

Search strategy

A comprehensive search of the literature was performed across seven electronic databases. MEDLINE, Scopus, Web of Science, CINAHL, the Cochrane Library, PsycINFO and IEEE Xplore up until the 8th of November 2022. During the data extraction phase, the PROSPERO-registered protocol was modified to exclude manual searches of the reference lists of the retrieved papers.

The search strategy was evaluated and approved by the Flinders University librarian (JM). Search terms were used in different combinations, including the following keywords: lymphoedema (also lymphoedema), oedema (also edema), lymphatic oedema, digital, electronic health, eHealth, mobile health, mHealth, mobile application, internet, apps, e-learning, telehealth, telemedicine, telerehabilitation, activity monitor, text message, robotic, social media, medical informatics, mobile phones, telephone, cell phone, smartphone, intranet, e-support, communication technology, information technology and health information technology.

The results of the searches were extracted and loaded into Covidence (Veritas Health Innovation, Australia). Covidence is a Web-based collaboration platform that facilitates the creation of systematic and other types of literature reviews while aiding in the PRISMA process.

Data selection and extraction

Two researchers (AM and BI) independently screened the abstracts and titles from the search results based on the inclusion and exclusion criteria. Differences were resolved by a third researcher (NP). Then the article was recovered for full text screening.

Data was then systematically extracted and summarized in a table in Microsoft Excel that includes the first author's name, country and publication year, eHealth role and modality, objective, primary intervention, duration of intervention, study design, participants, outcomes, feasibility / acceptability, and adherence.

Methodological quality assessment

The risk of bias and methodological quality was independently evaluated by a researcher (AM) and accuracy was reviewed by two researchers (BI and NP). Randomized controlled trials (RCT) were evaluated using the Cochrane Collaboration tool for risk of bias.⁽²⁹⁷⁾ The risk of bias was determined by assessing random sequence generation (selection bias), allocation concealment (selection bias), blinding of participants and personnel (performance bias and detection bias), blinding of outcome assessment (performance bias and detection bias), incomplete outcome data (attrition bias), selective outcome reporting (reporting bias), and other bias criteria.

Parameters of bias in each study were judged as "low", "some concerns", or "high". "Low" risk of bias will involve the study being judged to be at low risk of bias for all domains. "Some concerns" will involve the study being judged to raise some concerns in at least one domain, but not to be at high risk of bias for any domain. "High" risk of bias will involve the study being judged to be at high risk of bias in at least one domain or the study being judged to have some concerns for multiple domains in a way that substantially lowers confidence in the result.

Robviz, an online visualization tool, was used to generate figures demonstrating the risk of bias of the domain-level judgement per individual study (Figure 49), and a summary figure of weighted bar graphs of the distribution of risk of bias judgments within each bias domain (Figure 50).⁽²⁹⁸⁾

Data analysis

Meta-analysis was deemed unsuitable due to the heterogeneity of methodology and the reported outcomes, making a narrative overview of the findings, along with descriptive statistics and tabular summaries of the extracted data, the most appropriate approach.

Results

Review selection and participants

The literature search yielded 1857 articles for title and abstract screening (Figure 48). Following selection, 159 studies were included in the full text review. Many studies were excluded due to being proof-of-concept papers (n = 19) or having incorrect methods such as not having a comparison intervention (n = 109). After exclusion, 9 studies were included for analysis, which are presented in Table 11.^(173, 253, 299-305)

The included studies were published between 2010 and 2022, with more than 66% published in 2018 or later. The most common publication country was the United States (n = 3; 33%); The remaining studies were carried out in Australia (n = 2; 22%), Japan (n = 1, 11%), Egypt (n = 1, 11%), China (n = 1, 11%) and Iran (n = 1, 11%).

There were a total of 1032 participants in all studies at the beginning of the interventions. There was a total of 911 participants at the final analysis stage. Of this number, 825 (90%) had a form of LE. In most studies (n = 8, 89%) all participants had LE, while in the Sherman et al. (2018) study only 32% (n = 98) had LE. Most participants had breast cancer related LE (n = 795, 87%) and a small minority had gynaecological cancer related LE (n = 30, 3%).

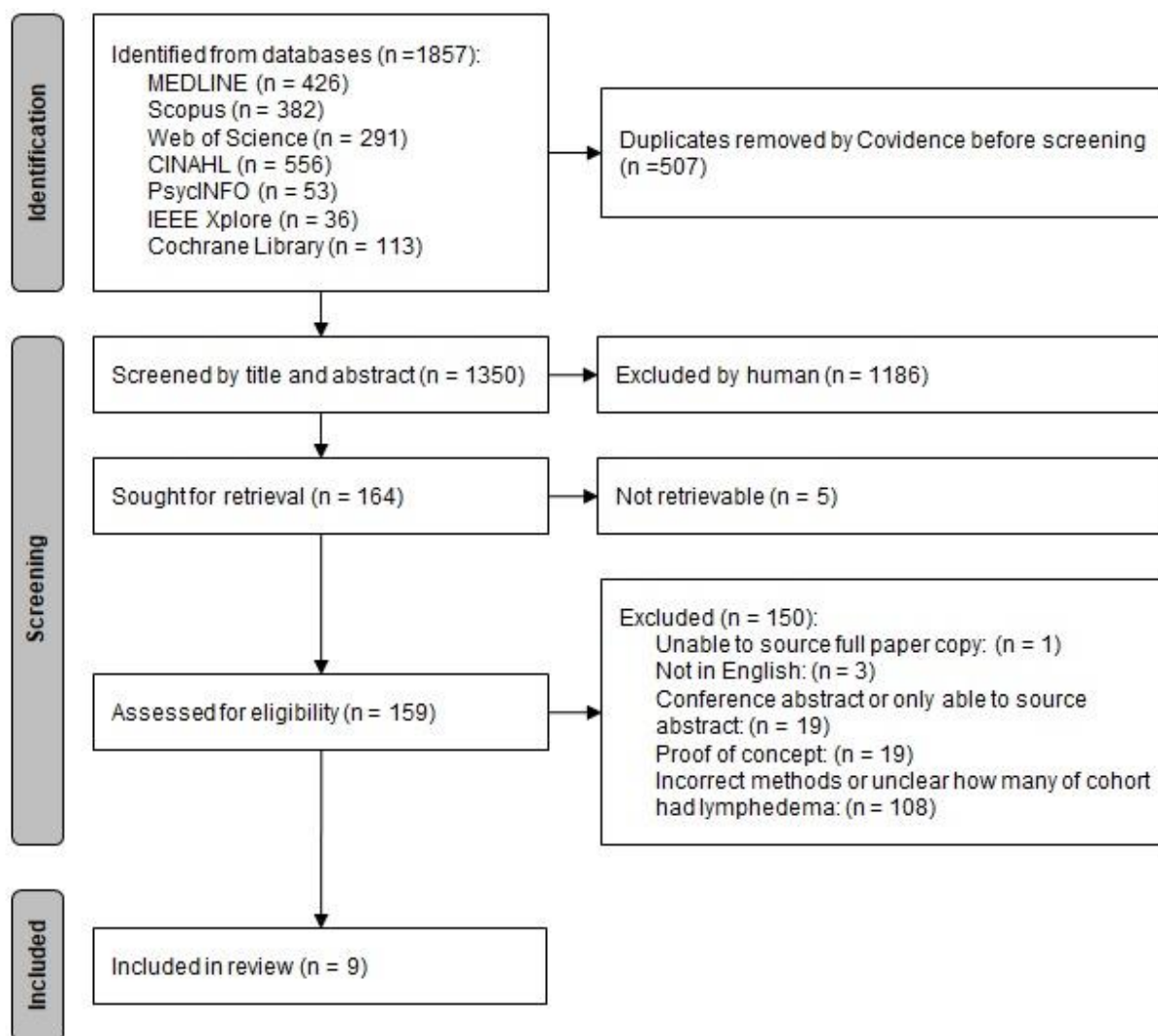


Figure 48 - Flow of studies through the different phases of the systematic review process

There was heterogeneity in the reporting of age statistics. 2 studies reported age ranges that ranged from 20 years to 69 years. For the remaining 7 studies, the weighted average age was 54.7 years. All participants were female, noting that the Li et al (2022) study did not explicitly state gender; however, all participants were treated for breast cancer.

Level of methodological quality

The results of the methodological evaluation are presented in Figure 49 and Figure 50. Of the 9 included studies, 8 (89%) were RCTs and 1 (11%) was quasi-randomized. For overall risk of bias, 4 (44%) studies had high risk, 1 (11%) some concerns and 4 (44%) had low risk of bias. 4 studies (44%) had some concerns or high risk in the randomization process, 2 studies (22%) had some concerns or high risk due to missing outcome data and 4 studies (44%) had some concerns of bias in the selection of the reported result.

		Risk of bias domains					
		D1	D2	D3	D4	D5	Overall
Study	Atef et al. 2020	⊗	+	-	+	-	⊗
	Fu et al. 2022	+	+	+	+	+	+
	Hayes et al. 2013	+	+	+	+	+	+
	Li et al. 2022	-	-	⊗	-	-	⊗
	McClure et al. 2010	+	+	+	+	+	+
	Okutsu et al. 2014	-	+	+	+	+	-
	Omidi et al. 2020	+	-	+	-	-	⊗
	Ridner et al. 2020	+	+	+	+	+	+
	Sherman et al. 2018	-	+	+	+	-	⊗

Domains:
D1: Bias arising from the randomization process.
D2: Bias due to deviations from intended intervention.
D3: Bias due to missing outcome data.
D4: Bias in measurement of the outcome.
D5: Bias in selection of the reported result.

Judgement
⊗ High
- Some concerns
+ Low

Figure 49 - Cochrane Risk of Bias summary per study

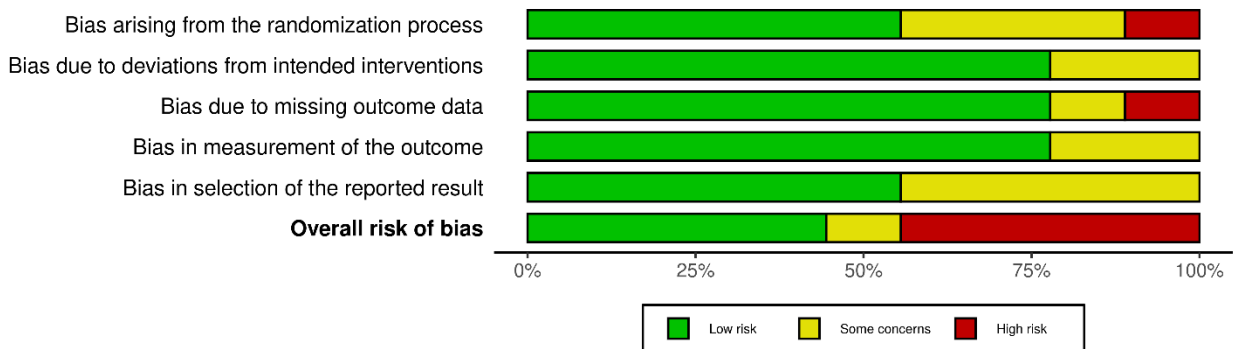


Figure 50 - Cochrane Risk of Bias summary across all studies

Interventions in patients living with lymphoedema

Most (n = 6, 67%) studies used eHealth interventions as the main focus of the research, while the remainder (n = 3, 33%) of the studies involved eHealth as part of the intervention. eHealth modalities included instructive online information (n = 6, 66%), telehealth (n = 2, 22%) and digital gaming (n = 1, 11%).

The breakdown of each eHealth modality and type of technology is presented in Table 12. The technologies used in the studies included web and mobile platforms with videos and text, traditional video resources, a digital writing program, social media-based education, video, text and voice functions used on a mobile phone, telephone-delivered exercise intervention, and a video game.

2 of the 9 (22%) studies focused on mHealth. Fu et al (2022) used instructive online materials through both the web and mobile-based platform.⁽¹⁷³⁾ Okutsu et al (2014) used video, text, and voice functions for telehealth to provide self-care consultations by mobile phone.⁽³⁰⁰⁾

A diagram of the different eHealth modalities, interventions, and outcomes is presented in Figure 51. Outcomes were reported in areas of health outcomes (such as decreased chronic pain), LE outcomes (such as reduction of oedema), psychosocial outcomes (such as improvement in QoL domains), and disease comprehension (such as improved disease knowledge).

Outcomes of Instructive Online Information

Ridner et al (2020) compared a Web-Based Multimedia Intervention (WBMI) with a hard copy of an educational pamphlet.⁽²⁹⁹⁾ The WBMI achieved statistically significant results for providing better information and improving mood. Fu et al (2022) also examined WBMI's by looking at two types of programs; The Optimal Lymph-Flow™ (TOLF) versus an Arm Precaution Group (inclusive of videos on therapeutic limb mobility exercises and risks for LE).⁽¹⁷³⁾ TOLF was described as a self-study program that empowers patients to learn about LE.⁽³⁰⁶⁾ The TOLF group had statistically significant results for chronic pain reduction, reduction of LE symptoms and improved musculoskeletal outcomes.

As another form of WBMI, Li et al (2022) and Omidy et al (2020) used social media platforms to provide education.^(253, 305) Li et al (2022) compared social media-based education to group-based education. The intervention achieved statistically significant differences in causing a change in knowledge of the disease and nursing satisfaction. There were also fewer cases of oedema in the intervention group (2 cases) compared to the control group (5 cases).

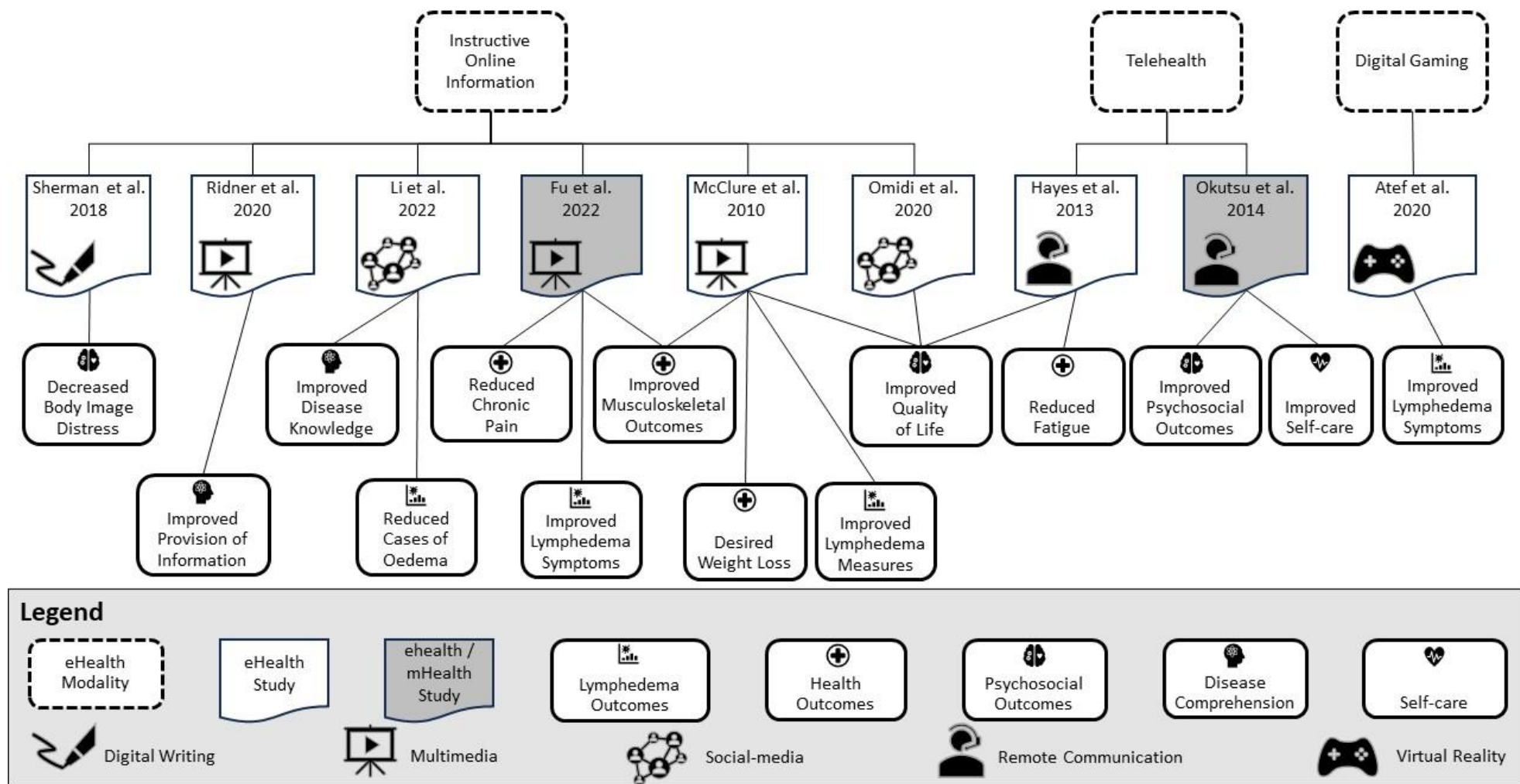


Figure 51 - Classification of studies to eHealth modalities, interventions and outcomes

Omidi et al (2020) compared social media-based education to group-based education. The interventions showed improvement in most of the QoL after three months of intervention. Although the social network-based education method was effective, the group-based education method was found to be more beneficial in these QoL domains. Sherman et al (2018) used a digital program and assessed the Web-based My Changed Body (MyCB) psychological intervention, a structured writing exercise designed to promote self-compassionate attitudes (such as self-kindness) to the control of expressive writing. This study found statistically significant results to reduce body image distress and improve body appreciation among breast cancer survivors.⁽³⁰²⁾

McClure et al (2010) compared a Breast Cancer Recovery Program (BCRP), using video as eHealth technology, with usual recommendations.⁽³⁰⁴⁾ The BCRP achieved statistically significant clinical results with improvements in LE measures, musculoskeletal outcomes, weight loss, and mood.

Outcomes of Digital Gaming

Atef et al (2020) compared virtual reality-based exercises and usual care with proprioceptive neuromuscular facilitation and usual care.⁽³⁰¹⁾ The digital gaming intervention achieved statistically significant clinical results for reducing LE symptoms.

Telehealth Outcomes for Remote Service Provision

Okutsu et al (2014) compared telephone-assisted support with routine self-care support.⁽³⁰⁰⁾ Hayes et al (2013) compared a face-to-face and telephone-delivered exercise intervention vs usual care.⁽³⁰³⁾ Both telehealth interventions achieved statistically significant clinical outcomes including improved self-care, fatigue prevention, psychosocial outcomes, and QOL.

Feasibility and acceptability

Reports of feasibility from within the studies demonstrated that eHealth modalities were generally well accepted or preferred over conventional methods. As an example, Atef et al (2020) who investigated usual care plus virtual reality through a digital game, via the Nintendo Wii® video game, compared to proprioceptive neuromuscular facilitation stretches. The authors stated "...that both virtual reality and proprioceptive neuromuscular facilitation have a beneficial therapeutic effect on edema in patients with unilateral postmastectomy lymphoedema; neither method was found to be superior, except virtual reality was found to be superior to proprioceptive neuromuscular facilitation in motivating patients and providing visual feedback."

Two studies had established the feasibility and user accessibility prior to RCT stage.^(173, 249, 302, 307-309) As an example of feasibility results, Fu et al (2022) referred to the intervention as safe, effective, and affordable "...as a replacement or complement therapy for chronic pain management for millions of breast cancer survivors." The authors described further benefits, including cost savings, by stating, "The low-cost, detailed description of interventions, and technologically driven delivery model of TOLF make it relatively easy to implement TOLF in clinical practice or at home".⁽¹⁷³⁾

Adherence

Eight (88%) studies reported completion rates, dropout numbers, or adherence. Omidi et al (2020) stated that "Due to the particular design of the present study, the adherence rate could not be appropriately investigated" but still provided completion rates for the intervention vs control groups.⁽³⁰²⁾ One study provided drop out numbers but did not provide explanations as to whether the eHealth intervention or study design led to this.⁽²⁵³⁾ One study provided no information on adherence.⁽³⁰⁵⁾

Design of the eHealth tool

One study by Ridner et al. (2020) reported that the design of their eHealth intervention negatively impacted completion rates.⁽²⁹⁹⁾ In the pamphlet group, 77.5% completed that program, compared with 58.8% in their eHealth intervention group. The authors stated: "In developing a program that tried to meet a wide range of educational needs, we developed a lengthy program that may be better absorbed in selective chunks based on individual preferences". Having found this, the authors also stated, "Feedback from participants was positive on actual content, and we suggest this program's usefulness as an online reference for BCRL patients deserves exploration".

Self-care outcomes

LE self-care outcomes were improved through a simple mHealth intervention in the study by Okutsu et al (2014).⁽³⁰⁰⁾ Once every 2 weeks, qualified lymphatic drainage personnel used video, text, and voice functions of mobile phones to respond to self-care consultations (mechanism of LE onset, complications, observation points, topics of note in daily living, skin care, drainage, compression, and exercise). This included aspects of support received by the intervention group in addition to routine self-care support.

Okutsu et al (2014), found the intervention group was significantly better for LE self-care in areas such as selecting shoes, self-drainage, wearing compression garments, and implementing bandaging ($P < 0.005$), moisturizing and observing oedema ($P < 0.01$). The authors stated that "The patients' recognition of the self-care effect was linked to their belief in the effect of self-care, which finally led to adherence to care". The authors also stated, "A mobile phone-based support system means support whenever and wherever it is needed, provided there is a signal. It is possible to address patients' needs without increasing their burden. Such a support system, whereby patients can receive support while at home, can be extremely worthwhile, particularly for those who are less mobile due to diseases similar to lower leg lymphoedema."

McClure et al (2010) also found that "Adherence was high for this safe and effective program, which improved lymphoedema physical and emotional symptoms" with excellent adherence to the exercise and relaxation regimen during the 5-week program and good adherence at 3-month follow-up.⁽³⁰⁴⁾

Traditional care vs eHealth

Two studies that compared traditional face-to-face methods with eHealth presented opposing favourability in completion rates in face-to-face vs eHealth groups.^(253, 303) In the Hayes et al (2023) study, on average, participation in the face-to-face group was 88% (14 of 16) of scheduled sessions compared to the eHealth telephone group of 81% (13 of 16) of scheduled telephone calls. In the Omid et al (2020) study, group-based education was completed by 91% (32 of 35), while the eHealth social media group intervention was completed by 97% (34 of 35).

Discussion

Patients living with LE are a population with complex health care needs where it was previously unknown if eHealth could support their care. This review is the first to conduct a broad systematic review on the impact of various types of eHealth and mHealth interventions on patients with LE. The primary objectives of this research were met, resulting in: a) identification of 9 studies on eHealth, 2 of which involved mHealth interventions for patients living with LE; b) evaluation of the feasibility and efficacy of such interventions; and c) an understanding of whether adherence to the intervention was affected by utilizing eHealth.

Efficacy of various eHealth and mHealth modalities was demonstrated in areas such as health and LE outcomes, self-care, psychosocial outcomes, and disease comprehension. No adverse events were reported, with eHealth modalities being generally well accepted or preferred over conventional methods.

Key insights

Three key insights emerged from this review, including: 1) eHealth interventions have been shown to assist in adherence across a small number of studies; 2) the design of the eHealth tool should be considered to optimize adherence; and 3) eHealth can be used as an adjunct to support traditional care.

Adherence

Research indicates that the use of mobile devices by health care professionals is transforming clinical practice.⁽³¹⁰⁾ Researchers have stated, “Although text messaging and mHealth technologies may not work for all patients with chronic diseases, they represent a unique opportunity in health care. There is no other existing technology that could potentially improve human health that is already used many times per day by billions of people and whose use will assuredly increase over the coming years. Our challenge now is to figure out how to capitalize on its potential”.⁽³¹¹⁾ Some of this “potential” in LE care has been illustrated in section 3.8 across a small number of studies.

Adherence as a topic in eHealth-related research has been described as “...an underdeveloped and often improperly used concept in the existing body of literature. When defining the intended use of a technology and selecting valid measures of adherence, the goal or the assumed working mechanisms should be leading”.⁽³¹²⁾ When designing future RCTs that intend to examine adherence, how the technology specifically aims to increase treatment adherence should be described. There was heterogeneity across the studies for how treatment adherence was reported on with further research being required.

Design

There are varied opinions on the definitions of pilot and feasibility studies among researchers. It has been proposed that, “...feasibility as an overarching concept, with all studies done in preparation for a main study open to being called feasibility studies, and with pilot studies as a subset of feasibility studies” and “...that a feasibility study asks whether something can be done, should we proceed with it, and if so, how”.⁽³¹³⁾ It makes sense that if feasibility testing has occurred prior to a RCT that there may be less chances of an eHealth tool failing because of design faults.

The Fu et al (2022) group, for example, had conducted thorough feasibility testing of their eHealth tool prior to undertaking their RCT. The preliminary usability and feasibility tests were completed with thirty breast cancer survivors who evaluated the ease, difficulties, and feasibility of using the tool on a computer, mobile phone or tablet device.⁽²⁴⁹⁾ Their research group also conducted a feasibility clinical trial with a pre- and post-test design to evaluate the effects of the tool.⁽³⁰⁷⁾

In section 3.8 the reported deficits in the design of the eHealth tool by Ridner et al (2020) highlighted that the design of the eHealth tool itself could impact adherence and completion.⁽²⁹⁹⁾ This suggests planning for, and inclusion of feasibility testing and user acceptance testing of an eHealth technology in the early stages of design and development is an important consideration. Van Velsen et al (2018) state that "Having a clear overview of the facilitators and barriers towards use is crucial for technology design and the development of a successful implementation strategy".⁽³¹⁴⁾ We propose that the strategies of chunking content and keeping time to complete at a minimum be considered with early user acceptance testing being conducted prior to studies progressing to RCT stage.

eHealth as an adjunct

The concept of using eHealth as an adjunct or replacement for standard care has been debated in the literature. eHealth supported self-management programs offer a way to change the traditional approach to person-centred care where "High quality management of chronic illnesses can only be achieved if patients take responsibility. Therefore, it is important to empower them to take charge of their own health".⁽³¹⁵⁾

"eHealth is generally considered to have a positive effect on health care quality and to be a promising alternative to face-to-face health care contacts. Surprisingly little is known about possible adverse effects of eHealth apps".⁽³¹⁶⁾ In this review, no adverse effects were reported.

The concept of examining the value of eHealth over standard care then arises. Section 3.4 presented the study results by Omidi et al (2020) which concluded that while the social network-based education method was effective, the group-based education method was more effective. Health services should consider that traditional models of care may still have more value over eHealth interventions in some circumstances. One perspective is to consider eHealth as an adjunct that can provide opportunities to maintain and enhance face to face interactions.⁽³¹⁷⁾

The study by Hayes et al. discusses looking toward the future in regard to more widely implementing eHealth delivered services.⁽³⁰³⁾ They state, "While the telephone delivery of exercise prescription does not reflect standard practice, Cancer Councils throughout Australia commonly deliver support on a range of healthy behaviours via their telephone helpline, highlighting that the necessary infrastructure to deliver exercise prescription via this mode already exists." The authors highlight that equity of service provision can be addressed through eHealth, especially for vulnerable patients who live in rural and remote areas. The authors stated: "Also, delivering an exercise intervention using the telephone has the advantage of reaching all women, irrespective of place of residence, and thus can accommodate the 30% of Australian women with breast cancer who live in rural, regional areas, and/or areas with limited access to specialist services."

Review limitations

Despite best efforts, the number of studies included in the search was limited. Although the search was comprehensive, there is the possibility that some articles may have been missed. Research in this field, specifically in terms of RCTs appropriate for inclusion in a systematic review, was in its infancy. Given the number of excluded pilot studies, future reviews may be able to include more RCTs as maturity of the research in this area grows.

Of the included articles, the risk of bias assessment demonstrated that most studies (55%) had some or high-risk methodological concerns, but despite this, they were still included for assessment. There was considerable heterogeneity in the type of LE of the participants, the intervention, the reported results, and the methods used to assess these results in the studies. This necessitated a narrative data synthesis, in lieu of more robust meta-analytic procedures.

Conclusion

Several distinct categories of eHealth and mHealth interventions were shown to improve disease comprehension, psychosocial and lymphoedema outcomes. Findings from this systematic review may have an impact on the design of future studies in this domain, including consideration of early user acceptance testing when developing eHealth tools. With the ongoing progress in eHealth technology, further investigation into eHealth is warranted given the encouraging results observed in a limited number of studies.

Table 11 - Summary of studies included for analysis

#	Author, Country and Year	eHealth Role and Modality	Objective	Primary Intervention	Duration of Intervention	Study Design	Participants	Outcome(s)	Feasibility/ Acceptability	Adherence
1	Atef et al., (Egypt), 2020	Primary focus; Digital gaming	Compare virtual reality-based exercises and usual care [intervention] to proprioceptive neuromuscular facilitation and usual care [control].	Exercise with a Nintendo Wii® video game and usual care two times per week. Games: tennis, triceps extension, and rhythmic boxing.	4-week intervention : 30-minute exercise program	Quasi-RCT	Women with Breast CRL (N = 36): intervention (N = 18), control (N = 18). Age range 40 to 65 years. Gender: Female (100%).	Excess arm volume significantly decreased in both the virtual reality group (p = 0.001) and the proprioceptive neuromuscular facilitation group (p = 0.005). The mean percentage improvement values in the QuickDASH-9 score were 33.66 ± 16.87 and 19.81 ± 20.14 for the VR group and the PNF group, respectively. The difference between groups was statistically significant (p = 0.045).	"...virtual reality was found to be superior to proprioceptive neuromuscular facilitation in motivating patients and providing visual feedback".	6 dropouts out of 36 (16.7%).

#	Author, Country and Year	eHealth Role and Modality	Objective	Primary Intervention	Duration of Intervention	Study Design	Participants	Outcome(s)	Feasibility/ Acceptability	Adherence
2	Fu et al., (U.S.A.), 2022	Primary focus; Instructive Online Information	Compare 2 types of web- and mobile-based systems: The-Optimal-Lymph-Flow (TOLF) [intervention] vs Arm Precaution Group (inclusive of videos on therapeutic limb mobility exercises and risks for LE) [control].	Web- and mobile-based platform to learn about LE, diagnosis, self-care, including 8 avatar videos with step-by-step instructions to perform lymphatic exercises to promote lymph flow and optimize shoulder and limb mobility. Arm Precaution group provided access to less content.	12 week program.	RCT	People with cancer (N = 120) randomised: intervention (N = 60), control (N = 60). Mean age 56.7 years (SD = 10.6). Gender: Female (100%).	Participants who received the TOLF intervention were more likely to experience a complete reduction in chronic pain (50% [23/46] vs 22% [11/51]). Significantly fewer participants in the TOLF group reported arm/hand swelling (P=0.04), heaviness (P=0.03), redness (P=0.03), and limited movement in shoulder (P=0.02) and arm (P=0.03).	Tested prior to this study. "The TOLF intervention is safe, efficacious, and affordable as a replacement or complement therapy for chronic pain management for millions of breast cancer survivors. The low-cost, detailed description of interventions, and technologically driven delivery model of the TOLF make it relatively easy to implement TOLF in clinical practice or at home".	All participants adhered to the study protocol. Adherence to performing exercises twice a day: 87% (52/60) TOLF lymphatic exercises vs 83% (50/60) for limb mobility exercises.

#	Author, Country and Year	eHealth Role and Modality	Objective	Primary Intervention	Duration of Intervention	Study Design	Participants	Outcome(s)	Feasibility/ Acceptability	Adherence
3	Hayes et al., (Australia), 2013	Used as part of intervention; Telehealth	Compare Face-to-Face (FtF) and telephone-delivered (Tel) exercise [intervention] vs Usual Care (UC) [control].	16 scheduled sessions (in person or via telephone) with a designated Exercise Physiologist, starting weekly and tapering to monthly contacts after 4 months.	1 year	RCT	Women with BC (N = 194): intervention (Tel) (N = 67), (FtF) (N = 67), control (UC) (N = 60). Mean age 52 years (age range 29 - 70). Gender: Female (100%). Participants with LE: 194 (100%).	There were significant (P < 0.05) interaction effects on QoL, fitness and fatigue with differences being observed between the intervention groups and the control group.	Feasible and safe for women to participate in an exercise intervention delivered FtF or Tel, commencing 6-weeks post-surgery. Nil exacerbation of initiating common treatment-related side effects.	On average, participation was: FtF group 88 % (14 of 16) of scheduled sessions; Tel group 81 % (13 of 16) of scheduled telephone calls.
4	Li et al., (China), 2022	Primary focus; Instructive Online Information	Compare social media based education [intervention] to group-based education [control].	Supplementing information about the prevention of postoperative complications of BC via social media platforms (WeChat, Weibo, Kuaishou, and Douyin).	1 year	RCT	People with BC (N = 50): intervention (N = 25), control (N = 25). Mean age 43.67 years, intervention (43.56±5.74), control (43.78±5.63). Gender: NA. Participants with LE: 7 (14%) (2 intervention, 5 control).	Nursing satisfaction and the degree of mastery of disease knowledge in the intervention group was significantly higher (P<0.05) than in the control group on both measures. There were 2 cases of oedema in the intervention group compared to 5 cases in the control group.	"Internet home nursing can effectively prevent postoperative lymphoedema, improve patients' negative emotion and improve patient satisfaction, which is worthy of clinical application."	-

#	Author, Country and Year	eHealth Role and Modality	Objective	Primary Intervention	Duration of Intervention	Study Design	Participants	Outcome(s)	Feasibility/ Acceptability	Adherence
5	McClure et al., (U.S.A.), 2010	Used as part of intervention; Instructive Online Information: video used as part of intervention	Compare Breast Cancer Recovery Program [intervention] vs usual recommendations [control].	Each structured session included participation in the video "From Lymphoedema Onto Wellness" (FLOW), as well as verbal instructions with accompanying written educational material. Participants were instructed to complete the FLOW video and relaxation techniques at home daily.	3 month program: 10 biweekly, 1-hr structured sessions for 5 weeks, followed by a 3-month self-monitored home program. Participants were tested at entry, 2.5 weeks, 5 weeks, and 3 months.	RCT	Women with BCRL (N = 32): intervention (TG) (N = 16) mean age 57.0 (SD = 2.9); control (CG) (N = 16) mean age 59.7 (SD = 2.1). Gender: Female (100%). Participants with LE: 32 (100%). Mean age of combined groups 58.4	Intervention group participants demonstrated significant treatment effects for improved bioimpedance z, arm flexibility, quality of life, mood at 3 months, and weight loss, versus the control group.	No adverse events reported.	Adherence scores representing the number of times intervention participants practiced Exercise (E) and relaxation (R) techniques during a 7-day week demonstrated excellent adherence at 5 weeks (E = 7.9 ± 1.6, R = 8.7 ± 1.7) and good adherence reported at 3-month follow-up (E = 5.3 ± 1.0, R = 5.4 ± 1.1).

#	Author, Country and Year	eHealth Role and Modality	Objective	Primary Intervention	Duration of Intervention	Study Design	Participants	Outcome(s)	Feasibility/ Acceptability	Adherence
6	Okutsu et al., (Japan), 2014	Primary focus; Telehealth: mHealth	Compare telephone-assisted support [intervention] to routine self-care support [control].	Video, text, and voice functions used for mobile phone consultations on self-care.	12 week program: Five phone calls with each participant over three months, one every 2 weeks.	RCT	Women with Genital CRL (N = 30) randomised: intervention (N = 15), control (N = 15). Age 20 to 69 years. Gender: Female (100%).	The intervention group was significantly better than the control group for self-care implementation, and Functional Assessment of Cancer Therapy-General (FACT-G) mental status at three months after the initial interview, better in psychological, social, and physical items in the Mental Health Pattern (MHP) testing (P < 0.005).	"Mobile phone communication once every two weeks enabled quick response to each patient's differing symptoms, inquiries, and concerns, which led to psychological stability in the patients, and thus the patients were able to deal appropriately with their given conditions".	Full adherence other than a control group member being excluded due to development of cellulitis and requiring frequent support.

#	Author, Country and Year	eHealth Role and Modality	Objective	Primary Intervention	Duration of Intervention	Study Design	Participants	Outcome(s)	Feasibility/ Acceptability	Adherence
7	Omidi et al., (Iran), 2020	Primary focus; Instructive Online Information	Compare social network-based education (SNE) [intervention] vs group-based education (GE) [intervention] vs self-paced education delivered via a CD after the study.	Social media based education (Telegram™ messenger channel, and WhatsApp™ messenger).	2 - 3 weeks	RCT	Women with BC (N = 105): intervention (SNE) (N = 35), (GE) (n = 35), control (N = 35). Mean age 51 years. Gender: Female (100%). Participants with LE: 97 (92%).	Results showed improvement of most QoL aspects after three months of intervention. The social network-based education method was effective, however the group-based education method was more beneficial.	Applying these educational methods in LE treatment protocols needs cost-effectiveness studies.	Control=31/35 (81%) completed SNE=34/35 (97%) completed GE=32/35 (91%) completed. "Due to the particular design of the present study, the adherence rate could not be appropriately investigated".

#	Author, Country and Year	eHealth Role and Modality	Objective	Primary Intervention	Duration of Intervention	Study Design	Participants	Outcome(s)	Feasibility/ Acceptability	Adherence
8	Ridner et al., (U.S.A.), 2020	Primary focus; Instructive Online Information	Evaluate the effects of a Web-based Multimedia Intervention (WBMI) [intervention] on symptom burden, function, psychological well-being, costs, and arm volume vs only receiving a hard copy of an educational pamphlet [control].	Online content of interviews with patients sharing stories about living with LE, basic physiology of LE and self-care, goal setting, diet and exercise strategies, methods of dealing with negative emotions, body image changes, uncertainty, and social support.	4 week program: WBMI group completed 12 sessions of videos, each 20–45 minutes long. 1 month allowed to complete the intervention .	Two stage study: Focus Groups followed by RCT.	People with BCRL (N = 160) randomised: intervention (N = 80), control (N = 80). Mean age 57.6 years (SD = 9.1). Gender: Female (100%).	WBMI was perceived as providing better self-care information than the Pamphlet group (P = 0.001). 25% of the WBMI group had 2 or fewer mood symptoms at 1-month assessment whereas most in the Pamphlet group had not reduced those symptoms at all (P < 0.05, effect size = 0.53).	Intervention group reported statistically significantly more time to complete than the control group (WBMI: median = 525 minutes, Pamphlet: median = 60 minutes; p < 0.001). If completed, the WBMI group were more likely than the Pamphlet group to strongly agree that the WBMI provided good examples of self-care (p = 0.001).	A statistically significant difference (P = 0.011) was observed for rates of intervention completion, WBMI (58.8%), and Pamphlet (77.5%).

#	Author, Country and Year	eHealth Role and Modality	Objective	Primary Intervention	Duration of Intervention	Study Design	Participants	Outcome(s)	Feasibility/ Acceptability	Adherence
9	Sherman et al., (Australia) , 2018	Used as part of intervention; Instructive Online Information	Compare the impact of My Changed Body (MyCB) [intervention] on Body Image–Related distress (BID) and body appreciation in BC survivors (BCSs) vs expressive writing [control].	MyCB is a web-based psychological intervention involving a self-compassion focused writing activity.	Single session	RCT	Women with BC (N = 304): intervention (N = 149), mean age 57.50 years (SD = 8.98); control (N = 155) mean age 57.23 years (SD = 9.97). Participants with LE: 98 (32%).	Participants who received MyCB reported significantly less BID (P = .035) and greater body appreciation (P = .004) and self-compassion (P < .001) than expressive writing participants.	Tested prior to this study. This study supports the efficacy of MyCB for reducing BID and enhancing body appreciation among BCSs.	Compliance with the MyCB intervention was 88%, and attrition was 9.2%.

Abbreviations: BC = Breast Cancer, BCRL = Breast Cancer Related Lymphoedema, CD = Compact Disc, CRL = Cancer Related Lymphoedema, FtF = Face to Face, LE = Lymphoedema, N = Number, NA = Not Available, OR = Odds Ratio, P = Probability, QoL = Quality of Life, RCT = Randomized Controlled Trial, SD = Standard Deviation, Tel = Telephone, UC = Usual Care.

Table 12 - Summary of eHealth modality and technology type

Publication	eHealth modality	eHealth technology type
Fut al. (2022)	instructive online information	web and mobile-based platform with videos and text
Ridner et al. (2020)		web based platform with videos and text
McClure et al. (2010)		video
Sherman et al. (2018)		digital writing program
Li et al. (2022)		social media-based education
Omidi et al. (2020)		
Okutsu et al. (2014)	telehealth	video, text, and voice functions used on a mobile phone
Hayes et al. (2013)		telephone-delivered exercise intervention
Atef et al. (2020)	digital gaming	video game / virtual reality

CHAPTER TEN: A MIXED METHODS ANALYSIS OF HEALTH SYSTEM CHALLENGES

Chapter overview

This chapter presents the results of mixed methods analysis of health system challenges faced by a small sample of Australian lymphoedema practitioners. The investigation utilised the World Health Organization's (WHO) classification model, described in Chapter Five, to describe and categorise these health system challenges.⁽¹³⁹⁾

Highlights

The key highlights of this research include:

- This research commenced the secondary thesis objective of examining contemporary issues impacting the use of digital health in lymphoedema care
- This research successfully achieved a working understanding of some of the health system challenges face by Australian lymphoedema practitioners and how digital health was being used to address these issues.

Research

Aim

To understand if Australian lymphoedema practitioners were experiencing health system challenges and if so, how digital health was being utilised to overcome such challenges. This research would elucidate the potential motivators underpinning the utilisation of digital health technologies.

Background

Digital health technologies may be used to overcome health system challenges. The World Health Organization (WHO) classification system (V1.0) was presented in Chapter Five. Apart from classifying digital health interventions the classification system also outlines health system challenges and how digital health may be used to overcome such challenges. In the model there are eight health system challenges including information, availability, quality, acceptability, utilisation, efficiency, cost and accountability. The WHO suggests that implementing digital health interventions, such as "targeted communication to clients," can help address health system challenges like "lack of service utilisation." By providing clients with tailored information about available services, targeted communication may increase awareness and encourage greater use of healthcare resources.

Research applying the WHO classification system to lymphoedema care has previously been performed by Mangion and Piller (2023) (presented in Chapter Six).⁽³¹⁸⁾ This research sought to further apply the WHO classification system and use it to understand lymphoedema related health system challenges from Australian lymphoedema practitioners. It was unknown if health system challenges were being faced and if digital health technologies were being used to overcome such challenges.

Method

Mixed-methods research was designed to capture both qualitative and quantitative data through an electronic survey. A survey was designed and hosted within Qualtrics.⁽²⁶⁹⁾ The survey included some pre-qualification questions and then questions pertaining to health system challenges faced by practitioners, challenges perceived to be faced by patients, and questions about the application of eHealth to overcome challenges. Descriptive statistics would be used to describe quantitative data. Qualitative data would be analysed by thematic analysis.⁽²⁷⁰⁾

The project was approved by Flinders University's Human Research Ethics Committee (HREC project number 7454). The survey was sent to members of the Australian Lymphoedema Professionals Google Group (researched in Chapter Fourteen). There are approximately four-hundred and fifty (450) members across Australia, New Zealand (NZ) and the United Kingdom (UK). All members of the Australian Lymphoedema Professionals Google Group are health practitioners, and the survey asked a pre-qualification question which excluded practitioners who worked outside of Australia. Further demographic information of the respondents is reported in Chapter Eight in the results section. Data was collected from the 18th of May 2024 to the 31st of July 2024.

Results

A total of 24 respondents participated. The majority of respondents reported using eHealth to overcome health system challenges (64%). The reported health system challenges included quality, utilisation, accountability, efficiency, cost, information, availability and acceptability challenges (Figure 52).

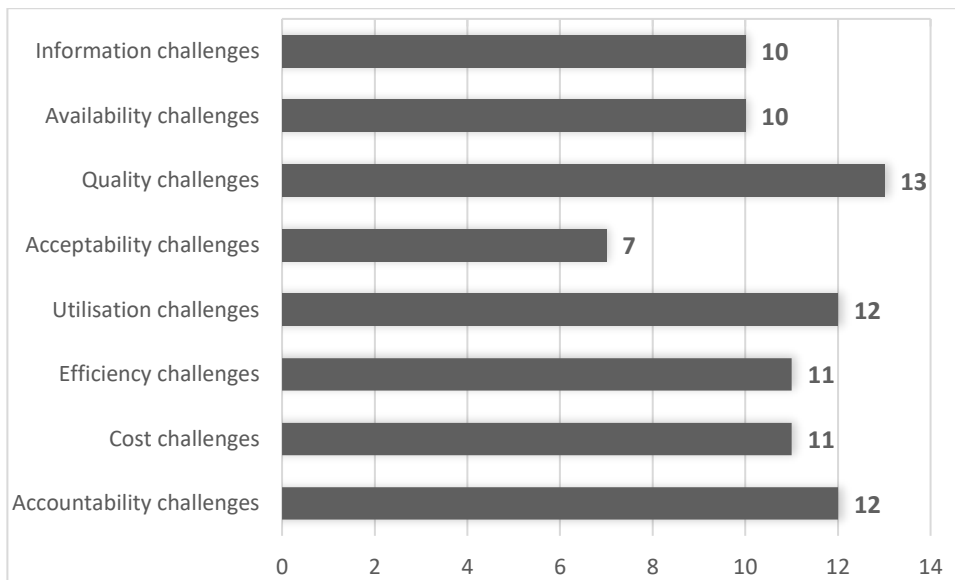


Figure 52 - Health system challenges encountered by Australian lymphoedema practitioners

The types of health system challenges perceived to be faced by patients, reported by the responding health practitioners, were cost, quality, availability, acceptability, efficiency, utilisation, accountability and information challenges, presented diagrammatically in Figure 53.

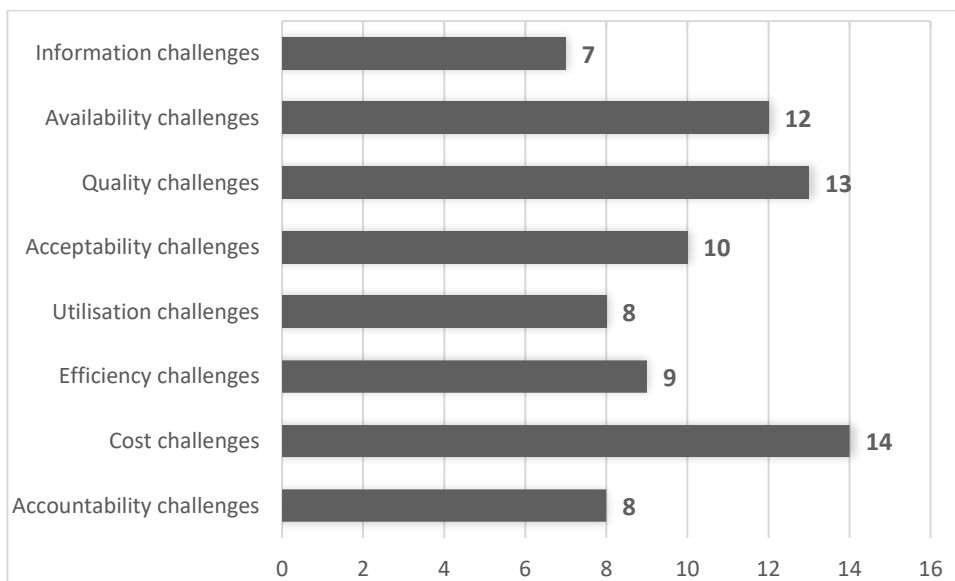


Figure 53 - Health system challenges reported by lymphoedema patients to their lymphoedema practitioner

Digital health was being used to overcome health system challenges in a variety of ways (Table 13) including overcoming distance preventing access to care, reducing administrative burden, improving patient adherence and patient education. The eHealth modalities used to overcome these challenges were instructive online information, mHealth, telehealth, clinical decision support systems, eHealth records and ePrescribing.

Table 13 - Examples of qualitative responses to illustrate the use of digital health for health system challenges

How have you used digital health interventions in lymphoedema care for overcoming health system challenges?	eHealth Modality	Challenges overcome
"Educational videos and bioimpedance information to engage people in their care and compliance to treatment over time."	Instructive Online Information	Patient adherence
"Links to suppliers or products or local services." "Access to indocyanine green online." "Digital ordering systems to track orders." "Digital applications for funding." "Digital tracking of applications for funding."	ePrescribing	Administrative burden
"Lymbase supports the workflow and has been valuable for helping engage patients to address the challenge of treatment adherence." "eMR [electronic medical records] addresses some of the administrative burden of scheduling and supports up to date communication with the wider health team - photo sharing and getting a full history."	Clinical decision support system, eHealth records	Patient adherence, Administrative burden
"Using video conferencing avoiding patients having to travel long distances."	Telehealth or video conferencing	Distance preventing access to care
"Mainly through decreasing the distance between the patient and carer e.g. it is so easy to text a patient and have them reply over social media or through messages."	Using mobile phones	Distance preventing access to care
"To enable access to care closer to home for people in metro, rural and remote locations. Used to reinforce education provided in clinic by sending electronic handouts or videos."	Instructive Online Information	Patient education, Distance preventing access to care

Lymphoedema practitioners reported several means in which DHIs were being used to impact clients including targeted client communication, client to client communication, on demand information, client financial transactions, untargeted client communication and personal health tracking (Figure 54). Citizen health reporting was not reported.

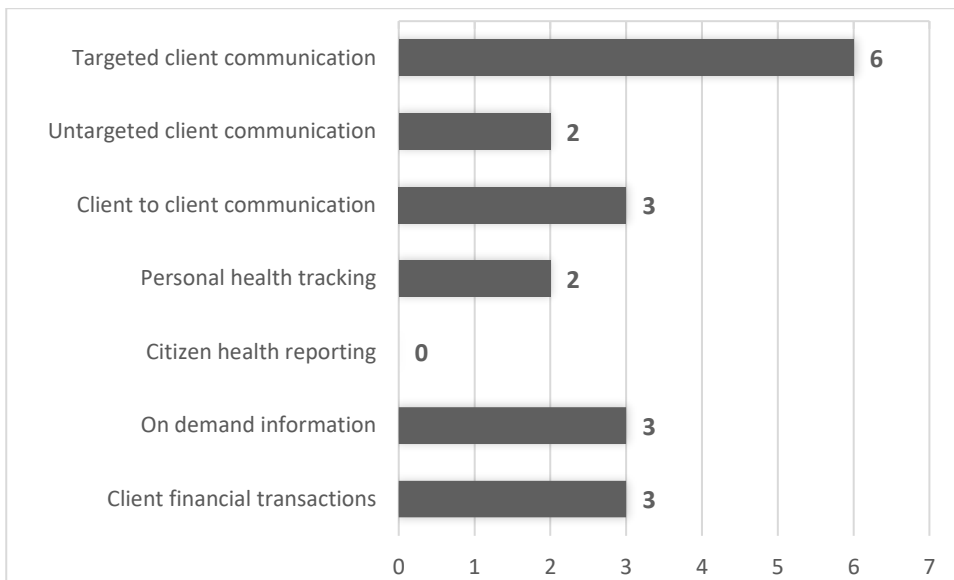


Figure 54 - The ways in digital health interventions were being used to impact clients

Lymphoedema practitioners reported several ways DHIs were being used to impact healthcare practitioners (Figure 55). These included client identification and registration, referral coordination, healthcare provider training, client health records, healthcare provider decision support, healthcare provider communication, health worker activity planning and scheduling and laboratory and diagnostic image management. Prescription medication management was not reported.

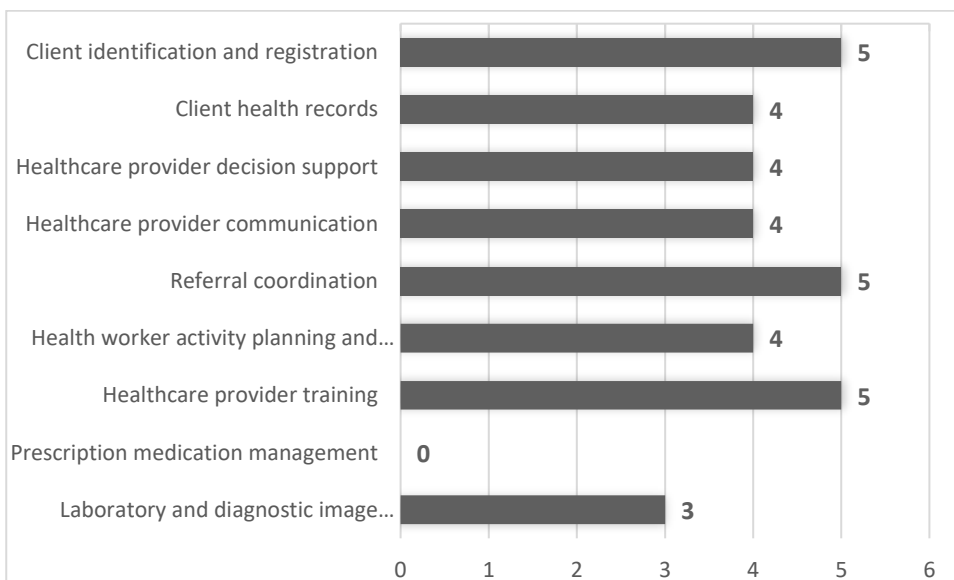


Figure 55 - The ways in which lymphoedema practitioners reported digital health interventions were impacting healthcare practitioners

Lymphoedema practitioners reported several ways DHIs were being used to impact health system managers including health financing, human resource management, equipment and asset management, facility management, supply chain management and public health event notification (Figure 56). Civil registration and vital statistics were not reported.

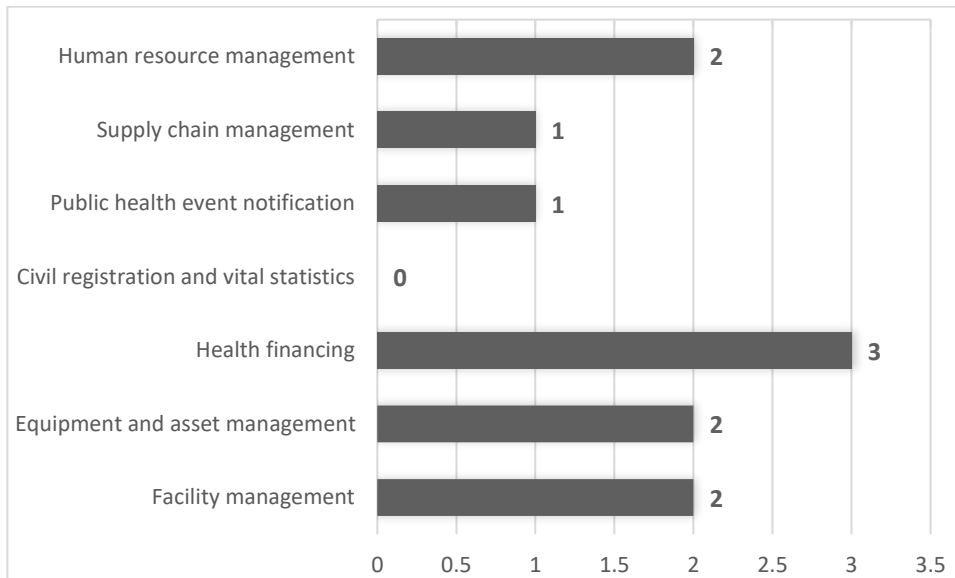


Figure 56 - The ways lymphoedema practitioners reported digital health interventions were impacting health system managers

Lymphoedema practitioners reported several ways DHIs were being used to impact data services including data collection and management use, location mapping and data coding (Figure 57). Data exchange and interoperability were not reported.

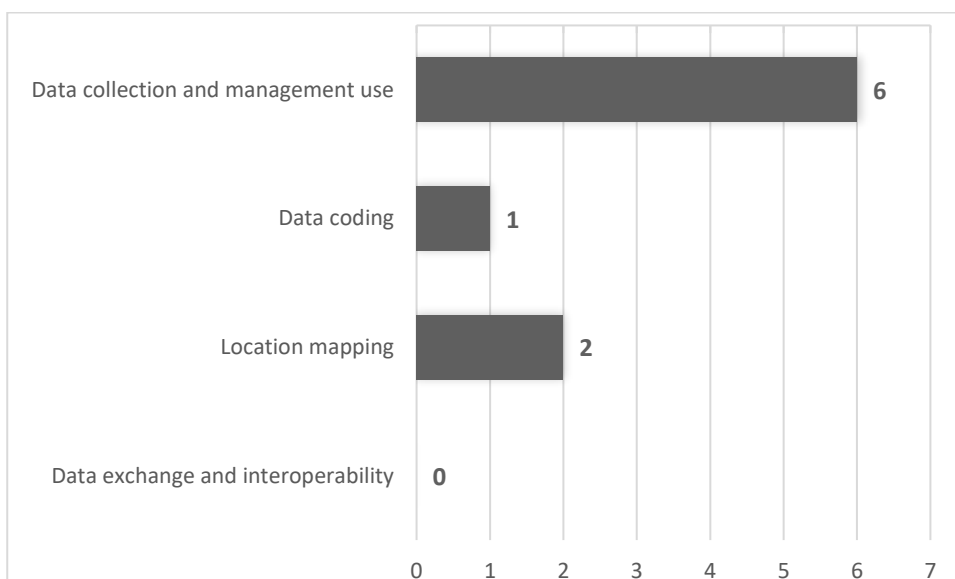


Figure 57 - The ways in which lymphoedema practitioners reported digital health interventions were impacting data services

Examples of responses for the contemporary ways in which eHealth was used to overcome health system challenges is presented below (Table 14).

Table 14 - Examples of responses for contemporary ways eHealth is being used to overcome health system challenges

Contemporary ways eHealth is being used to overcome health system challenges?	eHealth Modality	Challenges Overcome
"Emailing client information such as clinical findings or care status between practitioners."	Clinical decision support system	Sharing patient data
"Education, such as videoing the client doing their own exercises or self-management." "Videos provided via private YouTube for real time guidance of carers in, for example, massage."	Instructive Online Information	Accessibility to training and education
"HL7 and FHIR [Fast Healthcare Interoperability Resource] to support interoperability" "MyHealth Record is developing in maturity and has turned its focus now to allied health"	eHealth records	Sharing patient data
"Telehealth providing access to specialist skills." "Unfortunately, lymphoedema treatment does not easily lend itself to a virtual delivery."	Telehealth	Geographic inaccessibility
"My guess would be use of artificial intelligence."	Applications of Artificial Intelligence	Lack of access to information or data
"The location mapping for filariasis is interesting."	Infoveillance	Lack of population denominator
"Use for communication to broader patient and health professional groups to make information and training more accessible to a wider audience."	Health knowledge management, Instructive Online Information	Accessibility to training and education

Discussion

This research achieved its aim of understanding if Australian lymphoedema practitioners were experiencing health system challenges and how they were using digital health to overcome such challenges. Lymphoedema practitioners reported utilising a range of eHealth modalities to overcome various health system challenges. Modalities being used included instructive online information, mHealth, telehealth, clinical decision support systems, eHealth records and ePrescribing, applications of artificial intelligence and health knowledge management.

The integration of these DHIs assisted in overcoming various health system challenges. Many of the responses were anticipated, such as the use of telehealth and instructive online information to reduce accessibility issues. The ways in which DHIs were and were not being used to impact clients, health providers, health system managers and data services was also anticipated. Data exchange and interoperability, which fall under the impact of DHIs on data services, were not reported. However, these functions generally require both users with data to share and established systems for data exchange. As digital health usage matures within the field of lymphoedema, these aspects may evolve over time.

Responses which were not anticipated included recognition of the value of online clinical decision support through emailing client information between practitioners. Another unanticipated response was recognition of eHealth to assist with the prescription of garments. Lastly, the other unanticipated response was the mentioning of My Health Record as "...growing in maturity". My Health Record is Australia's national digital personal health record system, designed to store and manage individuals' health information electronically. Every Australian has a record in this system unless they actively choose to opt out. Research by Holt et al (2023) demonstrated that knowledge of the system by the general public is lacking.⁽³¹⁹⁾ Privacy concerns have also been reported in the literature.⁽³²⁰⁾ The positive reference to "growing in maturity" suggests that further inquiry is needed on whether lymphoedema practitioners use and advocate for the system.

In regard to barriers for use, one individual remarked, "Unfortunately, lymphoedema treatment does not easily lend itself to virtual delivery." This statement underscores the challenges associated with providing lymphoedema care via telehealth. While telehealth may not be ideal for all aspects of lymphoedema treatment, there are numerous instances where it has been effectively utilised, particularly during the COVID-19 pandemic.^(1, 196, 252) Telehealth has facilitated continued care, patient education, and support, demonstrating its potential to enhance healthcare delivery in challenging circumstances. Encouraging the adoption of telehealth for lymphoedema care may lead to improved accessibility, cost savings and continuity of care, even if it may not fully replace in-person treatment.

Interestingly, some practitioners did not perceive themselves as using DHIs to overcome health system challenges. This discrepancy could stem from a lack of recognition or awareness of the broader implications and benefits of eHealth technologies. These practitioners may not view their use of digital tools and platforms as part of a larger strategy to address systemic issues within the healthcare system. This finding highlights the need for increased education and awareness among healthcare providers regarding the potential of eHealth to transform and improve healthcare delivery. Enhanced understanding and recognition of the role of DHIs could further encourage their adoption and effective implementation, ultimately benefiting both practitioners and patients.

A limitation of this research is the small sample size. Future research should consider examining the benefits of digital health on a larger sample of lymphoedema practitioners. Detailed exploration of the most effective ways to leverage telehealth through rigorous research and subsequent publications could provide a model of care which lymphoedema practitioners could utilise.

Future research should consider examining the benefits of digital health on a larger sample of health professionals. Detailed exploration of the most effective ways to leverage telehealth through rigorous research and subsequent publication can provide valuable models of care. As technology continues to evolve, the methods by which digital health is utilised will require ongoing investigation. We know that "...the most frequently quoted statistic on the gap or 'chasm' between researchers and practitioners is that 'it takes 17 years to turn 14% of original [clinical] research to the benefit of patients'."⁽³²¹⁾ This is too long for lymphoedema patients to wait. Therefore, it is crucial that research efforts focus on translational research to ensure that the latest findings are quickly and effectively communicated to practitioners. This approach will help to prevent significant delays in the adoption of new knowledge and techniques, thereby enhancing the overall quality and efficiency of healthcare delivery.

Conclusion

A small sample of Australian lymphoedema practitioners reported using several types of eHealth to overcome a variety of health system challenges. Ongoing research, with a larger sample of practitioners, is needed in this area with a focus on translational research to ensure that the latest findings are quickly and effectively communicated to practitioners.

CHAPTER ELEVEN: DIGITAL ACCESSIBILITY IN LYMPHOEDEMA TRAINING AND CLINICAL PRACTICE

Chapter overview

Digital accessibility involves the design of digital systems and services to enable access for individuals, including those with disabilities, including visual, auditory, motor, or cognitive impairments.⁽¹²⁾ Research has confirmed “...the existence of an eHealth disability digital divide” with people with impairments experiencing varied challenges in engaging with eHealth.⁽³²²⁾

This research aimed to answer the question, “What digital accessibility factors could stop digital health from being used?” It was unknown within the context of lymphoedema care whether an impairment, such as blindness, could impact lymphoedema training or clinical practice. It was decided that the most effective way to explore this was by understanding the perspectives of individuals who face significant barriers when digital content is not accessible. To gain firsthand insight, case studies were designed to document the experiences of Kate, a blind health professional, navigating both lymphoedema training and clinical practice. Learning directly from someone affected by accessibility challenges provided a unique research opportunity. Similar to patient-centred research, this approach allowed for an authentic perspective on these challenges, enriched by lived experience. Kate was also invited to participate as an author due to her background advocating for those with disabilities.

This chapter has two sections which each include a published case study. The first section [Eleven(i)] presents a case study of Kate’s experiences undergoing lymphoedema training. The second section [Eleven(ii)] presents a case study of Kate’s experiences working as a lymphoedema practitioner.

Eleven(i) - Publication title – Accessibility in Accredited Lymphoedema Training: Digital and Practice Training Considerations

Reference

Mangion A, Murdoch K, Piller N. Accessibility in Accredited Lymphoedema Training: Digital and Practical Training Considerations: A Case Study. *Wounds International*.2024;15(4). In press.

Credit

Conceptualisation, methodology, writing—original draft, review, and editing by A.M. Writing – review and editing by K.M. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 90% of the data collection and analysis and 90% of the writing and editing.

Kate attended the 2024 Australasian Lymphology Association and co-presented with the author on the information contained within this publication. Numerous audience members approached afterwards to commend the quality of the presentation and to convey how much they had learned from it. One audience member remarked that she "...would revamp her entire website with the knowledge learned to better consider those with disabilities."

Highlights

This publication aimed to elucidate relevant accessibility factors in accredited lymphoedema training through exploring Kate's experiences as a blind remedial massage therapist. Kate was initially denied participation in other Australasian Lymphology Association (ALA) accredited training programs before seeking training with the Australia Institute of Lymphoedema, due to accessibility issues. Although anti-discrimination laws are designed to prevent such exclusion, Kate posited that exclusion is nonetheless anticipated.

Kate's blindness underscores the necessity of accessible digital content; without it, she would have been unable to engage with the training material. This scenario brings to the forefront the critical need for inclusivity and the real challenges faced by health practitioners with disabilities.

Accessibility should not be considered solely for individuals with disabilities but for everyone.

Lymphoedema practitioners, dedicated to helping people, must ensure that lymphoedema courses, patient education resources, and clinical environments are accessible to all.

The key highlights of this research include:

- This research contributed to the thesis secondary objective of demonstrating what digital accessibility is
- This research contributed to a comprehensive understanding of digital accessibility, highlighting the significant barriers which are faced by those who are disabled when content is not accessible
- This research answered the question, "What accessibility factors can stop digital health being used?" If digital content is not accessible, for someone with blindness, it can't be accessed. Blind people cannot understand digital content if pictures, for example, do not have Text Alt descriptions or descriptive captions.
- This publication is, to the authors' knowledge, the first to address digital accessibility in lymphoedema training

- Providing practical guidance for other lymphoedema trainers on steps that can be taken to increase accessibility in lymphoedema training courses.

Publication

Abstract

Accessibility to goods, services, and environments is fundamental to the protection of human rights. With the increasing availability of online learning, digital accessibility must be considered in order to improve access to education for students who are blind or visually impaired or who may find using computers challenging. Practical, face-to-face training also necessitates consideration to ensure that it is inclusive, appropriate, and enjoyable for all participants. This paper examines what digital accessibility is, accessibility standards in Australia, and Kate Murdoch's experience, as a blind healthcare professional, in becoming an accredited lymphoedema practitioner in the Casley-Smith method. The authors propose lessons learned from the lymphoedema training and potential solutions to improve accessibility and inclusion.

Background

Digital accessibility is a fundamental principle of contemporary healthcare especially as digital communication, through using the internet, has become a primary tool for communicating and engaging patients.⁽³²³⁾ According to the International Organization for Standardization (ISO, 2021): "Over a billion people around the world have some form of disability, so ensuring products, services and environments are accessible to everyone is fundamental to human rights."⁽³²⁴⁾

Digital accessibility is the practice of designing and developing digital content and technology, such as websites, online courses, software applications, digital documents, and multimedia content, so that it is accessible and usable by all users, regardless of ability and environment. Digital accessibility involves the elimination of barriers that prevent people from accessing and using digital content and technology.

According to the Digital Transformation Agency of the Australian Government (2017): "You need to make sure everyone who needs your service can use it. This includes people with disability and older people, and people who can't use, or struggle with, digital services. Your service must be accessible to users regardless of their digital confidence and access to a digital environment. This includes users in remote areas and users with different devices."⁽³²⁵⁾

Digital accessibility involves a wide range of considerations, including:

- Providing alternative text (Alt Text) descriptions for visual content, such as images and videos, for people who are blind or have low vision.
- Ensuring that web content and software can be accessed using keyboard navigation for people who cannot use a mouse.
- Providing captions and transcripts for audio and video content for people who are deaf or hard of hearing.
- Providing audio descriptions for video content.
- Using colour contrast and other design techniques to make content more readable for people with visual impairments.
- Ensuring technology is compatible with assistive technologies, such as screen readers and text-to-speech software.

What are the standards for digital accessibility in Australia?

According to the Australian Human Rights Commission (2014): “One in five Australians has a disability, and the proportion is growing. The full and independent participation by people with a disability in web-based communication and online information delivery not only makes good business and marketing sense but is also consistent with our society’s obligations to remove discrimination and promote human rights.”⁽³²⁶⁾

Under Australian federal legislation of the Disability Discrimination Act of 1992, it is a legal requirement to make sure services are accessible and usable for people with disabilities.⁽³²⁷⁾

Government agencies in Australia must also adhere to the Web Content Accessibility Guidelines (WCAG) 2.1.⁽³²⁸⁾

The WCAG 2.1 provides a set of technical and non-technical guidelines for making digital content accessible to people with disabilities, including those with visual, auditory, physical, speech, cognitive and neurological disabilities. The guidelines are organised into four principles:

1. Perceivable - this means that users must be able to perceive the information being presented and it must not be invisible to all senses.
2. Operable – this means that users must be able to operate the interface, and the interface cannot require interaction that a user cannot perform.
3. Understandable - this means that users must be able to understand the information as well as the operation of the user interface. Therefore, the content or operation cannot be beyond understanding.
4. Robust – this means that the content must be interpreted reliably by a wide variety of user agents, including assistive technologies.

Lessons learned from the lymphoedema training programme

Kate Murdoch is an experience remedial massage therapist and has worked for more than six years in massage therapy. Kate owns a successful private practice, Resolve Penrith, in New South Wales, Australia (Figure 58). She is blind and is an advocate for accessibility with past workplace experience including working for NSW Health, for 14 years, with diversity and inclusion as focus areas.



Figure 58 - Kate performing low level laser therapy

[In this photo, Kate is smiling and performing low level laser therapy on a male patient in her private practice. Kate has the laser in her right hand and is applying the laser to her patient's left arm.]

In 2022, Kate undertook an Australasian Lymphology Association accredited course to become an accredited lymphoedema practitioner in the Casley-Smith method (CANpractice, Australian Institute of Lymphoedema).⁽³²⁹⁾ The course involved a month of self-directed online learning through a learning management system, four virtual classroom sessions via a video conferencing product (Zoom Video Communications, San Jose, California, US) and a week of practical, face-to-face training in Sydney, Australia.

Some of the lessons learned during the lymphoedema training programme from an accessibility perspective included the following.

The online learning content needed to be accessible through the learning management system. This was addressed by ensuring that text copying was enabled to allow for screen reading technology to scan the words. Free access to the online portal was allowed to test the suitability of Kate's screen reader prior to enrolling in the course.

In the design of the course content, Andrea Mangion had ensured that videos were accompanied by a transcript and that Alt Text image descriptions were completed on figures and images.

Resources usually provided in printed form needed to be provided in electronic format. This allowed Kate's screen reader to detect the content.

There was a need for continuous evaluation of the practicability of course components given that there were no prior publications that could be sourced on the topic.

Overall, Kate excelled in the course. She demonstrated high levels of competence in lymphatic drainage and compression bandaging, when compared to her peers, which was likely due to the skills being highly assisted through tactile feedback.

The most challenging tasks were circumferential measures and garment prescription, given that these tasks rely heavily on visual cues and an ability to read the measurements from the tape measure at the required measurement points. Kate used silicon dots to provide tactile feedback of where the required measurement points were. She used a Braille tape measure to read the circumferential measurements.

Additional support was appropriate throughout the course. Kate was able to bring Wylie, her black Labrador and accredited guide dog (Figure 59).

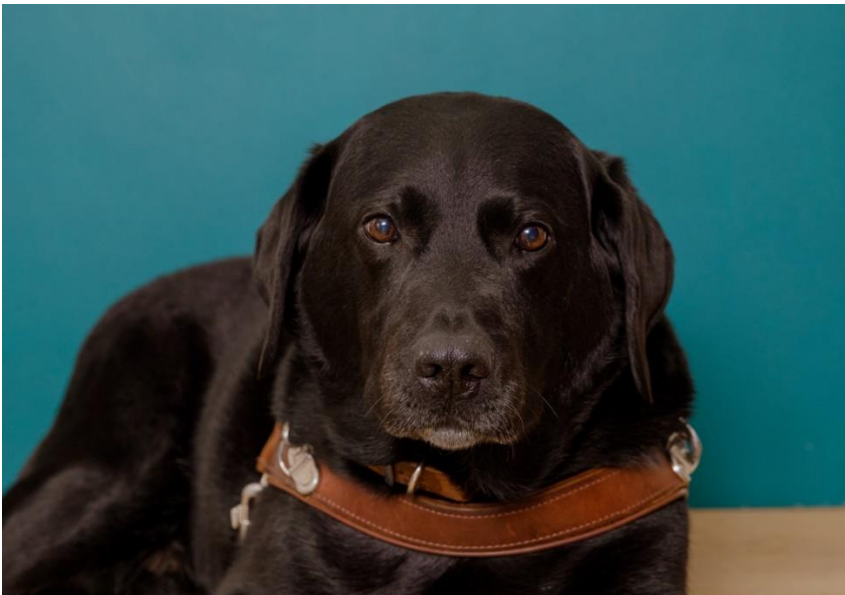


Figure 59 - Wylie Kate's guide dog

[Pictured is a black labrador guide dog wearing its brown harness. Wylie is looking at the camera and is comfortably lying on the ground.]

Kate was accompanied by an experienced support worker, John, who attended for the entire week (Figure 60).



Figure 60 - Kate and her support worker John

[Kate and John, an experienced support worker, who attended the course. In this photo John is smiling while Kate has applied a pneumatic compression pump device. The device is on his legs and extends to his abdomen.]

Anne, a registered nurse and lymphoedema trainer, also attended the course to provide additional support and further verbal instructions, as well as tactile feedback in the practical sessions.

Potential solutions for improving accessibility and inclusion

Some solutions for improving accessibility and inclusion in lymphoedema training courses are outlined below.

- Following accessibility standards when authoring and deploying online learning

Screen readers should be enabled, images and figures should have Alt Text descriptions completed, and videos should include transcriptions and detailed descriptions of practical tasks as well as audio descriptions. Allowing additional time for students to undertake online learning may be helpful.

- Solutions for printed material

Blind students may not be able to access printed material, such as handouts, textbooks and course readings. Alternative formats, such as Braille, large print or electronic formats, may be required.

- Access to visual content

Blind students may not be able to access visual content, such as videos, images and diagrams, that are presented in class. Audio descriptions or tactile graphics may be needed to provide equal access to this content.

- Navigation and mobility

Blind students may face difficulties navigating the physical space of the classroom, locating classrooms, and finding their way around. The use of tactile paving, clear signage, assistive technology, support/guide animals and support staff can be helpful.

- Visual aids

Blind students may not be able to see visual aids such as whiteboards, chalkboards, and overhead projectors. Alternative options, such as audio descriptions, can be used to provide equal access to this content. Assistive apps, such as text-to-speech applications, can also be used.

- Practical lymphoedema tasks

Tape measures that include Braille may assist with circumferential measures. While not suitable in courses (due to the weight and expense), solutions for use in the clinic, such as perometry and 3D scanners, may be suitable alternatives to using a tape measure for circumferential and garment measures. Technology that allows practitioners to measure patients independently and accurately will assist in providing high standards of reliable clinical care.

- Allowing further practice time

Additional time allocated to practise skills may be required.

- Allowing time to debrief and manage fatigue

For all healthcare practitioners, regardless of ability, undertaking lymphoedema training can be tiring. Time to debrief after the end of the day and having strategies to allow for rest during the programmes may be beneficial.

- Support staff and animals

Support staff and animals should be encouraged to attend courses. Having a support healthcare professional who can provide additional auditory and tactile feedback may be beneficial.

- Encouraging use of supportive professional networks

Upon finishing initial accreditation training, next steps for Kate include consideration of ongoing training through continuous professional development and being involved in supportive peer networks. Continuing education is essential in the field of lymphology to ensure that Kate stays up to date with the latest techniques and technologies. Furthermore, actively participating in peer networks that consist of other healthcare professionals who share the same level of enthusiasm for lymphoedema can offer reciprocal assistance and facilitate the exchange of practical strategies.

Conclusion

Although lymphoedema training requires a high level of practical proficiency in demanding tasks, such as compression bandaging, it can be completed by blind healthcare professionals who are proficient in remedial massage prior to attendance.

Accessibility factors should not discourage healthcare professionals from pursuing training in this specialised field. Further research is required into digital accessibility in healthcare and how both training and lymphoedema clinical practice can be enhanced, regardless of ability or environment.

Eleven(ii) - Publication title – Accessibility in Lymphoedema Practice: Digital and Practical Therapy Considerations

Reference

Mangion A, Murdoch K, Piller N. Accessibility in Lymphoedema Practice: Digital and Practical Therapy Considerations. *Journal of Lymphoedema*.2024;19(1):30-33

Credit

Conceptualisation, methodology, writing—original draft, review, and editing by A.M. Writing – review and editing by K.M. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 85% of the data collection and analysis and 90% of the writing and editing.

Highlights

This publication was designed to highlight both the successes and challenges Kate faced after becoming a lymphoedema practitioner. It underscores accessibility considerations in the workplace for both individuals with and without disabilities, offering valuable insights for product manufacturers to better accommodate the needs of practitioners and patients with disabilities. The key highlights of this research include:

- This research also addressed the question, “What accessibility factors can stop digital health being used?” For individuals with blindness, in clinical practice, if digital health tools are not accessible they may not be able to be utilised independently. Given that lymphoedema care frequently involves specialised medical equipment, it is essential to consider the accessibility of such equipment. Accessibility, therefore, plays a critical role in determining whether health practitioners with disabilities can effectively work as lymphoedema practitioners.
- This research concluded to the thesis secondary objective regarding demonstrating accessibility issues in clinical practice
- This publication is, to the authors' knowledge, the first to address accessibility challenges encountered by a blind lymphoedema practitioner within the workforce.

Publication

Abstract

Accessibility is a broad concept that considers the capacity of individuals to autonomously and easily utilise and derive benefit from a physical environment, equipment, technology, and services. Accessibility, in the context of a blind massage practitioner specialising in lymphoedema therapy pertains to the necessary modifications and supports required to deliver clinical services effectively and safely without the sense of sight.

This case study explores Kate's successes and challenges, in the 12 months since becoming an accredited lymphoedema practitioner in the Casley-Smith method, in working as a lymphoedema practitioner.

Background

Lymphoedema therapy, under the Casley Smith method, is focused lymphatic drainage compression bandaging, and the prescription of compression garments and encompasses various clinical assessment methods and techniques, including limb circumferences and volume measurement.⁽⁶²⁾

Accessibility

According to the World Health Organisation in 2023, globally at least 2.2 billion people have a near or distance vision impairment.⁽³³⁰⁾ Research has shown that visual dysfunction substantially limits career and occupational options.⁽³³¹⁾ Other research has shown that lack of assistive technology is a barrier to employment and that "society needs to support the inclusion of each individual and ensure equal participation."⁽³³²⁾

In educational settings, ensuring accessibility for students with disabilities entails making necessary adjustments to the learning experience, including the content and teaching methods, to provide equitable learning opportunities for all.⁽³³³⁾ In employment settings, the Australian Human Rights Commission (2024) refers to accessible and inclusive workplaces considering the following four factors:

- physical workplace including internal and external accessibility and signage
- workplace attitudes including positive and harmful sentiments
- workplace technology to ensure all employees are empowered to effectively undertake their work duties independently

- reasonable adjustments including changes to work processes, practices or environments, to ensure employees with disability can perform their job free from barriers.⁽³³⁴⁾

Kate is a blind remedial massage and lymphoedema practitioner and has a strong desire to work independently and help others (Figure 61).



Figure 61 - Kate from Resolve Penrith

[Kate is smiling at the camera in this photo which shows Kate's torso. Kate is wearing her Resolve Penrith polo top.]

The authors recently explored Kate's ability to become a qualified accredited lymphoedema practitioner in the Casley-Smith method.⁽³³⁵⁾ The case study demonstrated that although lymphoedema training requires a high level of practical proficiency in tasks, such as compression bandaging, it could be completed by blind health professionals who were proficient in remedial massage prior to attendance at the training course. The case study also demonstrated that accessibility factors should not discourage health care professionals from pursuing training in this specialised field.

After completing the training, Kate has offered lymphoedema services through a private practice model, leveraging off the success of her remedial massage therapy business (Resolve Penrith).⁽³³⁶⁾ Since becoming an accredited lymphoedema practitioner, Kate has experienced both successes and challenges in her role.

Successes

Kate's successes are highlighted in the domains of establishing a safe working space, access to funding, delivering manual lymphatic drainage (MLD) and delivering compression therapy using pneumatic compression pumps and wraps.

i) Safe working space

Kate successfully established a safe and accessible work environment. The physical layout of the clinic is navigable and safe for a blind practitioner and patients with disabilities. This was achieved through selecting a suitably accessible premises, organising tools and equipment in consistent places, using tactile floor markings and navigation aids that help orient Kate within the space, and adopting accessible technology systems for scheduling, patient records, and communication. Wylie, Kate's guide dog, (Figure 62) is also in attendance at the clinic for the purpose of providing not just mobility assistance but also confidence and companionship.



Figure 62 - Wylie Kate's guide dog

[Wylie, Kate's guide dog, is a black Labrador. In this photo Kate is smiling whilst hugging Wylie. Wylie is sitting and wearing a brown collar. One of Kate's arms is under Wylie's left paw and Kate's other arm is wrapped around Wylie.]

Other specific resources such as wheelchair-accessible facilities, adjustable examination tables, and auditory diagnostic devices have been considered for anyone with disabilities. These tools not only ensure that medical care is accessible but also that dignity and needs of all patients, regardless of their physical abilities, has been considered.

ii) Access to funding

There are various government programs and non-profit organisations which offer grants for blind or visually impaired people which can be used to purchase specialised equipment for improved accessibility. Kate was successful in acquiring funding through Job Access (Employment Assistance Funding Program, Australian Government) to cover the costs of adaptive technology.⁽³³⁷⁾

Under the Employment Assistance Funding Program financial assistance allows individuals with disabilities to obtain funded equipment that is considered "necessary to perform a job". An essential aspect of a lymphoedema practitioner's responsibilities, for example, is the utilisation of a tape measure for the measurement of limb circumferences and determination of limb volume for the choosing of the appropriate compression garments. Hence, it is crucial for a visually impaired practitioner to recognise substitute tools and processes that can fulfil the same purpose as a tape measure, given its indispensable nature in the profession. Allocation of funding is limited to tools that are necessary for professional responsibilities, rather than for items that are merely preferred. Consequently, without appropriate funding, the practitioner is rendered incapable of practicing.

iii) Manual lymphatic drainage

Manual lymphatic drainage (as taught by the Casley-Smith method) is a gentle massage technique that enhances lymph circulation and drainage and helps reduce lymphoedema by manually directing lymph flow towards healthy lymph vessels and nodes.⁽³³⁸⁾ A practitioner who is blind or visually impaired must heavily depend on their tactile abilities to palpate swelling and compare between sides as well as perceive subtle variations in body temperature, skin texture, and tissue fluid. To improve these tactile cues, one can train their sensory skills through the practice of massage therapy, as can non-disadvantaged practitioners.

Kate, with her extensive background as a remedial massage practitioner, finds manual lymphatic drainage (MLD) to be the least difficult lymphatic modality to deliver. Kate's adeptness with MLD stems from her refined tactile sensitivity. This sensitivity enables her to tailor manual techniques based on patient feedback, such as reports of swelling and discomfort in a particular area will allow a focus on this area. Additionally, Kate adjusts her approach to meet the specific needs of the tissues involved, recognising conditions like fibrosis which require firmer decongestion strategies before proceeding with effleurage. This nuanced understanding allows Kate to provide highly personalised and effective treatment to suit the unique needs of each patient.

iv) Compression therapy via pneumatic compression

Kate has successfully integrated pneumatic compression pumps into her practice. Pneumatic compression devices automate the process of applying consistent pressure to affected limbs, a method that is crucial for managing lymphoedema but challenging to execute with traditional bandaging techniques for someone who is visually impaired. This technological adaptation enhanced Kate's ability to treat lymphoedema effectively and for Kate's patients, allows them to have an effective strategy for managing lymphoedema on an ongoing basis at home through an affordable rental option (Medi-Rent, 2024).⁽³³⁹⁾

Results of one patient's results are shared below. A 74-year-old female presented to Kate with bilateral lower limb lymphoedema (Figure 63 and Figure 64). The patient had Type 2 diabetes, coronary artery disease and a pacemaker. The patient reported an eleven-year history of hypersensitivity and pain on palpation along the medial aspect of both lower limbs from ankles up to inner thigh. Chronic swelling began approximately 6 years ago and, the clinical diagnosis was made by the patient's general practitioner 12 months prior.



Figure 63 - Kate's patient before treatment (front view)

[A front view photo of the patient's legs below the knee. The patient's trousers are pulled up. Both legs are shown as very swollen up to the knee. The left leg appears slightly more swollen than the right leg. Both legs appear patchy and pink in places which represent chronic inflammation in both legs.]



Figure 64 - Kate's patient before treatment (side view)

[A side view photo of the patient's legs below the knee. The patient's trousers are pulled up and she has bare feet. The left leg is closest to the camera. The dorsum of the foot shows prominent swelling except for the toe area which was compressed by her shoes.]

Pneumatic compression (Bio Compression Pants, Medi-Rent) was implemented on a daily basis (Figure 65). The settings are shown in Figure 66. After 3 months the results are shown in Figure 67 whereby there is a visible reduction in limb volume. The patient also reported a 50% reduction in pain sensitivity on light touch.



Figure 65 - Kate with one of her patients

[Kate and a representative from Medi-Rent are pictured smiling and looking at a patient wearing Bio Compression pants up to the waist. The Bio Compression device operates with a bright blue garment. Kate has her right hand over the top of the pump garment, on her patient's lower leg.]

Pressure	60 mmHg
Cycle time	75
Duration	45 min
Frequency	1 x daily
Other	<ul style="list-style-type: none"> Knee highs Comfiwave (Haddenham Healthcare) were also introduced 3 weeks after the Bio Compression pants were initiated

Figure 66 - Pneumatic compression pump pressure settings

[The pressure settings for the pump are shown as 60mmHg, cycle time of 75 sec, duration of 45 minutes, once daily. Other compression that was added to her therapy regime included knee high Comfiwave garments (Haddenham Healthcare) three weeks after the Bio Compression pants were initiated.]



Figure 67 - Kate's patient after treatment (front view)

[A front view photo of the patient's legs below the knee three months after treatment with the pneumatic compression device commenced. The patient's lower legs are bare. Both legs are shown as minimally swollen up to the knee. Both legs appear normal colour except for one patch of pink skin on the right anterior ankle area. Residual marks, derived from using Haddenham Healthcare's Comfiwave garments, are present on the patient's legs.]

v) Compression therapy via wraps

Compression bandaging is used in lymphoedema care to apply graduated pressure on swollen limbs, helping to move lymph fluid to areas where it can be more effectively drained. Vision aids practitioners in this process by allowing them to ensure the bandages are applied smoothly and consistently, to observe any proximal or distal skin changes such as discoloured toes or fingers, and to adjust the pressure accurately. Blind or visually impaired therapists need to develop a highly refined sense of touch to gauge tension and pressure accurately and to rely on verbal feedback from their patient regarding the comfort of the bandages.

Recognising these difficulties, an alternative approach using compression wraps has been adopted by Kate with great success. This option appears to be more advantageous for patients in terms of reduced therapy costs and practicality of use.

In the last 6 months, over 50 garments have been prescribed and not one patient has complained of ill-fitting garments. Kate has found Haddenham Healthcare and Medi to have been particularly helpful in providing Kate with customer service and clinical reasoning support.^(340, 341)

Kate employs an administrative assistant in her clinic who helps with measuring for garment prescriptions and completing paperwork. While Kate provides the clinical advice and determines the prescription, her fully sighted assistant measures the limb, reads the numbers, and accurately transfers this information onto the order form. However, employing an additional administrative assistant to compensate for visual impairment, though beneficial for operational efficiency, proves to be cost-prohibitive. The financial burden of hiring extra staff to perform tasks a sighted practitioner would typically manage independently adds significant overhead. This situation highlights broader challenges faced by blind therapists in the healthcare field.

Challenges

A practitioner who is visually impaired encounters distinct obstacles when compared with their full sighted peers. The subsequent sections will address some of the accessibility considerations impacting limb volume assessment, the prescription of compression garments and continuing professional development.

i) Limb volume assessment and garment prescription

Assessing limb volume and prescribing garments is a crucial component of managing lymphoedema, yet it poses significant challenges for a blind or visually impaired therapist. Initially, an approach using silicone dots to mark specific landmarks on the skin, combined with a braille tape measure, was attempted by Kate. However, this method proved overly cumbersome and time-consuming, complicating rather than streamlining the process.

In search of a more efficient solution, a substantial investment was made in a perometer—a sophisticated piece of equipment designed to measure limb volume electronically (Pero-System, Germany). A stand-up perometer typically consists of a frame that the patient stands in (Figure 68). The frame is equipped with infrared sensors that run along its length. As the patient inserts their limb into the cylindrical frame, the sensors measure the distance across various points of their limb, effectively mapping out its circumference at multiple intervals. The perometer then uses these measurements to calculate the volume of the limb by integrating the circumferential data along its length, often visualised through a software interface that provides a detailed profile of the limb's shape and size.

From an accessibility perspective, the stand-up perometer has the potential to provide digital output of the circumference measures which is made accessible through screen reading technology. Screen reading technology allows the device's digital outputs, typically displayed on a monitor, to be accessed by a user who is blind or visually impaired.

Unfortunately, this high-tech device also brought its own set of difficulties. The rarity of its use in Australia meant that the manufacturer was unfamiliar with accessibility considerations, leaving the practitioner needing to source additional guidance to utilise the equipment effectively. As a strategy, a scripter familiar with screen reading technology has been engaged to connect the device's electronic output to Kate's text to audio technology.

The lack of the manufacturer's consideration of accessibility highlighted the reality that without readily available technical support from the suppliers, even high-tech technology can be underutilised or non-utilisable. The practical implementation of such technologies, therefore, does not merely rest on acquiring the latest equipment but also ensuring that there is a robust and mature framework for training, maintenance, and troubleshooting for contextualised integration. It is contextualised integration which transforms what is theoretically a powerful accessibility tool into a practical and effective solution for specific clinical settings.

Ideally, Kate would like to use the perometer pre and post every treatment session, for measuring the impact of treatment, as well as for garment prescription. At this point in time, the perometer needs to be used with a support person to read the screen and utilise the machine effectively. A scripter is currently working with Kate to test if a screen reader can be integrated.



Figure 68 - Stand-up perometer

[A photo of the stand-up perometer. Kate is standing in front of the perometer looking at a woman standing full clothed inside the perometer. The woman is demonstrating how her right leg would be measured.]

ii) Continuous improvement

The field of lymphatic therapy is continually evolving, such as through the use of indocyanine green lymphography to map superficial lymphatic flow in real time.⁽³⁴²⁾ Kate would like to keep up-to-date with the latest research, but it is difficult to access the resources because they are often delivered through diagrams and videos. Such diagrams in research papers are usually represented with little detail to explain the illustration, such as short or no descriptive captions. Videos of the indocyanine green lymphography often lack detailed audio descriptions of what is being presented on the screen.

The workaround for this is that Kate is aiming to build up a local team who can provide mentoring to each other, shared learning and also provide support at lymphology conferences. Kate also experiences difficulties when attending in-person lectures. Attending the 2024 Australasian Lymphology Conference (ALA), for example, has meant that Kate needed to fund not only her time, conference fee, flights and accommodation but also provide the same for a support worker who would attend and translate information received throughout the conference. The decision was made not bring her guide dog to the ALA conference due to difficulties associated with toileting and access to areas for feeding Wylie.

Conclusion

Accessibility in this field is about ensuring that blind or visually impaired practitioners have the means to provide effective and professional care just as their sighted peers do. It's about creating a level playing field where the focus is on ability and quality of care, transcending physical limitations through training, technology, physical resources and funding.

Working as a lymphoedema therapist does present obstacles for blind or visually impaired practitioners. The provision of digital technologies alone is not enough and there is the need to ensure that digital technologies are contextually integrated with consideration of a robust framework for training, maintenance, and troubleshooting. Further awareness of the obstacles faced by visually impaired or blind practitioners needs to occur with more research conducted in this area.

CHAPTER TWELVE: APPROPRIATENESS OF GENERATIVE ARTIFICIAL INTELLIGENCE

Chapter overview

This thesis aimed to answer the question, “Can artificial intelligence (AI) driven chatbots deliver suitable responses contextualised to lymphoedema care?” To investigate this a series of investigations were designed to test emerging AI driven chatbot technology.

This chapter has four sections which each include a publication on generative AI. The first section [Twelve(i)] presents a publication which provides a foundational overview of generative AI, establishing the context for its definition and subsequent exploration. The second section [Twelve(ii)] presents a publication which tested the appropriateness of the information being derived from ChatGPT by using a complex case of lymphorrhoea. The third section [Twelve(iii)] presents a publication which tested the appropriateness of the information being derived from ChatGPT for promoting patients to seek early care for breast cancer-related lymphoedema. The fourth and final section [Twelve(iv)] tested the appropriateness of the information being derived from Bard and ChatGPT for the differential diagnosis of lymphoedema vs lipoedema.

Twelve(i) - Publication title - Generative Artificial Intelligence in Lymphoedema Care

Reference

Mangion A, Piller N. Generative Artificial Intelligence in Lymphoedema Care. *Journal of Lymphoedema*. 2024;19(1):57-59

Credit

Conceptualisation, methodology, writing—original draft, review, and editing by A.M. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 100% of the data collection and analysis and 95% of the writing and editing.

Highlights

The key highlights of this research include:

- This publication aimed to educate health practitioners on what generative artificial intelligence is. The publication achieves this through documenting early versions of two generative AI chatbot brands (Bard and ChatGPT).
- That lymphoedema practitioners would benefit from being aware of emerging technology which may impact their patients, such as the intention of Google to release Derm Assist. Such technology could possibly allow for lymphoedema to be diagnosed through photographs.

Publication

Abstract

Generative artificial intelligence is a type of artificial intelligence that can create new content, such as text, images, or music. Generative artificial intelligence may revolutionise health care communication through changing the way that health education is delivered to both patients and health practitioners. Chatbots, as one implementation example of generative artificial intelligence, interact with users via text-based or voice-based conversations and employ natural language processing techniques to comprehend and interpret user inputs and generate suitable responses. This clinical practice piece provides an overview of generative artificial intelligence and explores the characteristics of two brands of chatbot systems – ChatGPT and Bard. This research will serve as an important historical record of the early versions of these chatbots, and potential future research directions are described for lymphoedema care.

Background

Artificial intelligence (AI) is integrated to our everyone day lives. “Netflix knows which films and series people prefer to watch, Amazon knows which items people like to buy when and where, and Google knows which symptoms and conditions people are searching for”.⁽³⁴³⁾ The capability of these ubiquitous software applications understanding our viewing, buying and searching preferences originates from AI.

AI that can generate new and original content, such as text, images, and music, rather than relying solely on pre-existing data or predetermined rules, is called generative artificial intelligence. Generative AI is still under development, but it has the potential to revolutionize the way healthcare is delivered through assisting in digital communication.⁽³⁴⁴⁾ One such means of revolutionising digital communication, is through chatbots being used to assist both patients and practitioners in information delivery.

A chatbot is an artificial intelligence-driven computer programme that imitates human conversation to communicate with users via text or voice. It employs sophisticated language processing techniques to interpret user input and generate pertinent responses.

Chatbots have applications in customer service, information retrieval, virtual assistance, and entertainment. They can be implemented on a variety of platforms and channels to provide automated and effective responses to user queries and tasks, without the need for ongoing human intervention. Some chatbots adhere to predefined rules, while others use machine learning to enhance their conversational skills over time. In the context of generative artificial intelligence, a chatbot would be used to generate responses in a creative and contextually relevant manner.

Chatbot systems

Two experimental chatbot system brands that are freely accessible to the general public are:

- A) ChatGPT (OpenAI; California / Version 3.0)⁽³⁴⁵⁾
- B) Bard (Alphabet Inc. (Google's parent company) Version 2.0.1; California)⁽³⁴⁶⁾

Both systems can generate human-like responses to natural language input by predicting the most likely next word in a sequence of text. Both systems disclose on the user interface that they are in experimental stages.

A) ChatGPT

ChatGPT can be described as an advanced AI language model that engages in conversation, answer questions, offer explanations, and can assist users in different areas of interest based on text input (Figure 69).

 Describe yourself


 I am ChatGPT, an advanced AI language model developed by OpenAI. I have been trained on a diverse range of text sources to assist with generating human-like responses and providing information on various topics. My purpose is to engage in conversation, answer questions, offer explanations, and assist users in different areas of interest. Please feel free to ask me anything, and I'll do my best to help you!

Figure 69 - ChatGPT response to being asked “Describe yourself”

The ChatGPT interface mentions some capabilities and limitations of Version 3.0 of the software including the fact that the software may occasionally generate incorrect information and occasionally produce harmful instructions or biased content.⁽³⁴⁷⁾ The capabilities and limitations of ChatGPT Version 3.0 (Figure 70) are the technology:

- Remembers what users have said earlier in the conversation
- Allows the user to provide follow-up corrections
- Is trained to decline inappropriate requests
- May occasionally generate incorrect information
- May occasionally produce harmful instructions or biased content
- Has limited knowledge of the world and events after 2021.



Figure 70 - ChatGPT interface with stated capabilities and limitations

ChatGPT has gained widespread popularity for its ability to generate realistic, coherent, and sometimes even witty responses to open-ended questions and prompts. It has been used in various applications, such as chatbots, virtual assistants, and language-related research. As Homolak (2023) states, "...the hype surrounding ChatGPT is not unjustified: the model is (still) free, easy to use, and able to authentically converse on many subjects in a way that is almost indistinguishable from human communication".⁽¹³⁾

Research on ChatGPT is in its early stages. For clinical utility one researcher stated, "Some patients could find ChatGPT a handy and approachable method to get information and assistance while figuring out how to manage their disease".⁽³⁴⁸⁾

B) Bard

"Google officially debuted Bard, its AI technology, with the goal of competing with Open AI's well-known ChatGPT-3 language model".⁽³⁴⁹⁾ Bard can also be described as an advanced AI language model that engages in conversation, answer questions, offer explanations, and can assist users in different areas of interest based on text input The Bard interface is similar to ChatGPT (Figure 71).

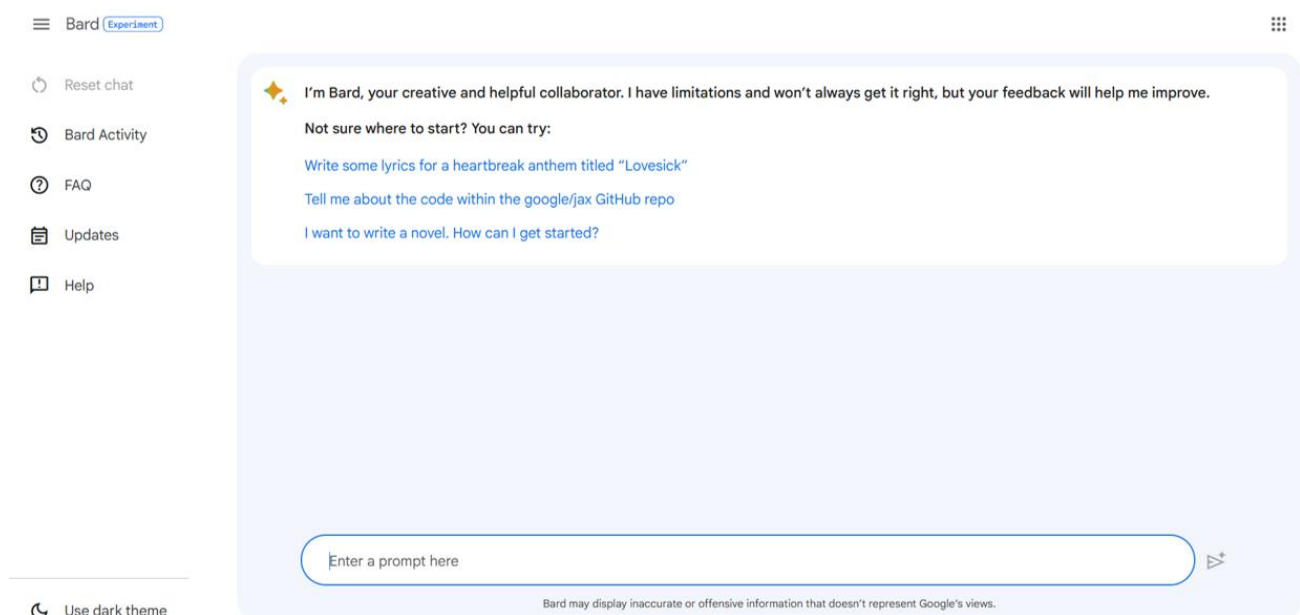


Figure 71 - Bard interface

Bard's limitations are stated on the website.⁽³⁵⁰⁾ One of the frequently asked questions is, "Does Bard give accurate and safe responses?" The answer acknowledges that Bard is an experimental system and cautions that some of the responses it provides may be inaccurate. Users are encouraged to double check the information obtained from Bard (Figure 72).

Does Bard give accurate and safe responses? ^

Bard is experimental, and some of the responses may be inaccurate, so double-check information in Bard's responses. With your feedback, Bard is getting better every day. Before Bard launched publicly, thousands of testers were involved to provide feedback to help Bard improve its quality, safety, and accuracy.

Accelerating people's ideas with generative AI is truly exciting, but it's still early days, and Bard is an experiment. While Bard has built-in safety controls and clear mechanisms for feedback in line with our [AI Principles](#), be aware that it may display inaccurate information or offensive statements.

Figure 72 - Bard frequently asked question about whether or not Bard produces accurate and safe responses

Google has published principles for AI which include several objectives. "While we are optimistic about the potential of AI, we recognize that advanced technologies can raise important challenges that must be addressed clearly, thoughtfully, and affirmatively".⁽³⁵¹⁾

1. Be socially beneficial.
2. Avoid creating or reinforcing unfair bias.
3. Be built and tested for safety.
4. Be accountable to people.
5. Incorporate privacy design principles.
6. Uphold high standards of scientific excellence.

Future research directions

In the context of lymphoedema care, future research possibilities include investigating generative AI for:

- **Health education purposes:** ChatGPT or Bard may be used to provide information about the causes, symptoms, and treatment of lymphoedema. This information can help patients and health practitioner to understand the condition.
- **Virtual support:** ChatGPT or Bard may be used to provide virtual support. Ayers et al (2023) compared the responses of physicians and chatbots to patient questions posed on a public social media forum.⁽³⁵²⁾ The quality and empathy ratings of chatbot responses were significantly higher than those of physician responses. Whilst this is a promising result there needs to be further studies on a much larger population group to validity and reliability of responses.

- **Condition tracking and health condition diagnosis:** Google Health, for example, is a personal health record platform that uses generative AI to help patients manage their health (Figure 73). Google Health can be used to track health data, set goals, and find information about health conditions. “We’re developing technology solutions to enable care teams to deliver more connected care. And we’re exploring the use of artificial intelligence to assist in diagnosing cancer, preventing blindness and much more”.⁽³⁵³⁾

Considering that lymphoedema is known to cause skin abnormalities, an example of a relevant application under Google Health may be Derm Assist (Figure 74) which is currently being researched. The use case is that patients can diagnose skin conditions through taking photos of their skin.

Advertised as a Class 1 medical device undergoing research Google states the technology is, “... a guided skin search app from Google Health that helps you find personalized information about your skin concerns after a few questions and three quick photos.” Applications such as this, in the future, may allow patients to take photos of their limbs and receive information on a likely diagnosis. As generative AI technologies continue to develop, further innovative and effective ways to use AI to improve healthcare may be developed.

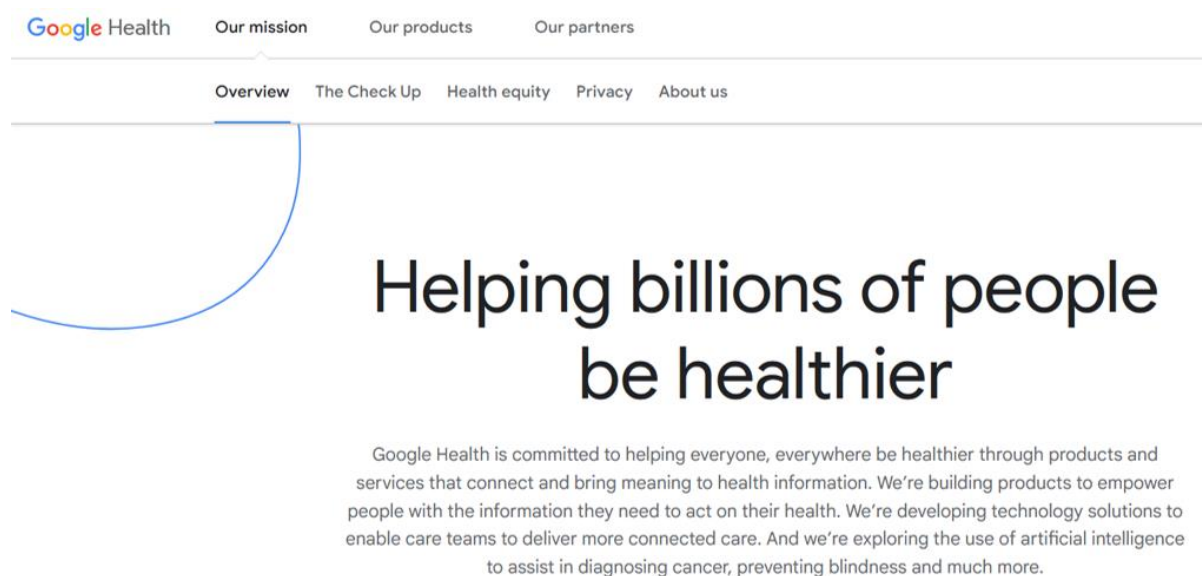


Figure 73 - Google Health



A whole new way to help identify your skin conditions

Learn more about skin conditions in minutes with DermAssist, a guided skin search app from Google Health that helps you find personalized information about your skin concerns after a few questions and three quick photos.

DermAssist is [CE-marked](#) as a Class 1 Medical Device, and is currently undergoing further market testing through a limited release. If you're interested in trying DermAssist, [sign up here](#) to be notified when the tool is available in your region or to contribute to our research.



Figure 74 - Derm Assist by Google

Conclusion

Generative AI is a rapidly advancing area of digital technology. Further research is warranted in this innovative area for assisting in the care of lymphoedema.

Twelve(ii) - Publication title - Generative Artificial Intelligence and ChatGPT for Chronic Oedema Information

Reference

Mangion A, Piller N. Generative Artificial Intelligence and ChatGPT as a Chatbot for Chronic Oedema Information. *Wounds International*. 2024;15(2):14-17

Credit

Conceptualisation, methodology, writing—original draft, review, and editing by A.M. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 100% of the data collection and analysis and 95% of the writing and editing.

Highlights

The key highlights of this research include:

- This paper aims to educate lymphoedema practitioners on the meaning of AI related terms such as "Natural Language Processing"
- This is a new kind of publication comparing the advice that would be given by an experienced lymphoedema practitioner (control) to that produced through generative artificial intelligence (experiment)
- The findings suggest that quality of information derived from the AI driven chatbots does not surpass that which can be provided by an experienced lymphoedema practitioner
- The finding that one of the responses, whilst being technically correct, was not appropriate. Instructing a patient who is complaining of lymphorrhoea to "keep their wound moist" may be confusing, as the concept of "moist wound healing" is well-known to wound care practitioners but not typically understood by patients.
- That given the rapid growth of AI, it is imperative for health practitioners to understand the functioning of these technologies, their value, and the associated risks for patients. This publication contributes significantly to this knowledge.

Publication

Abstract

Digital health assists in healthcare by allowing for more convenient and accessible patient access to information. ChatGPT is an application of artificial intelligence, known as generative artificial intelligence, which can contribute to the ongoing development of digital health solutions by utilising natural language processing and machine learning algorithms to generate healthcare communication. This paper introduces concepts of digital health, including generative artificial intelligence, discusses natural language processing, and demonstrates the use of ChatGPT using a scenario of a patient using the chatbot to understand a complex clinical presentation of lymphorrhoea with an eczematous ulcerated lesion.

Background

Digital health encompasses a vast array of electronic technologies and methods for improving healthcare delivery and outcomes. Some common forms of digital health technology are as follows.

- Electronic health records (EHRs), which are digital versions of patients' medical records, including their medical history, diagnoses, medications, and test results. They can be used for large, population-based studies to better understand chronic oedemas.⁽³⁵⁴⁾
- Telemedicine and telehealth refer to the use of digital technologies, such as video conferencing, to provide remote medical and health consultations and care. Telehealth can improve access to care, particularly for patients in rural or underserved areas, and can reduce costs associated with in-person visits.⁽¹⁹⁶⁾
- Mobile health (mHealth) refers to the use of mobile devices, such as smartphones and tablets, to support healthcare.⁽¹⁶⁸⁾
- Health information websites or databases that provide information on health topics and conditions.⁽¹⁷⁵⁾
- Virtual doctors are where generative artificial intelligence is used to create patient communication. Ayers et al (2023) compared physician and chatbot responses to patient questions posed on a public social media forum. The quality and empathy ratings of chatbot responses were significantly higher than those of physician responses.⁽³⁵²⁾
- Social media platforms, such as Instagram, can be used for health communication and education, providing opportunities to share information, resources, and support for health issues.⁽²⁴⁴⁾

Natural language processing

Natural language processing (NLP) is a subfield of computer science and artificial intelligence (AI) that focuses on enabling computers to understand, interpret, and generate human language.

Leeson et al (2019) state: "NLP uses algorithmic approaches rooted in statistical techniques to ascertain semantic meaning from textual data".⁽³⁵⁵⁾ NLP involves developing algorithms and models that allow computers to process, analyse, and generate natural language data, such as text or speech.

In healthcare, NLP can be used to analyse electronic health records, assist in medical diagnosis, and provide automated communication and support to patients.

Hao et al (2021) provide further applications of NLP to health research and delivery including:

- NLP models for medical or social web data (e.g. literature, EHRs, clinical trials and social media about healthcare processing).
- Health information retrieval and extraction.
- NLP techniques for medicine personalisation.
- Novel tools for medical, clinical or social web data interpretation and visualisation.
- Innovative NLP systems for mobile environments for healthcare applications.
- NLP for clinical decision support and informatics.
- Question-answering technologies for health applications.⁽³⁵⁶⁾

Generative artificial intelligence and ChatGPT

ChatGPT is an application of question-answering technologies.⁽³⁴⁵⁾ The program can be considered a type of electronic health technology (also known as eHealth) that falls under the categories of digital health communication and generative artificial intelligence.⁽³⁴⁴⁾ Specifically, ChatGPT can be used as a chatbot or virtual assistant to provide health-related information, support, and advice to users.

ChatGPT (OpenAI; San Francisco, CA/Version 3.0) is a NLP model based on generative pre-trained transformer (GPT) architecture. GPT refers to a series of pre-trained language models.⁽³⁵⁷⁾ ChatGPT can generate human-like responses to natural language input by predicting the most likely next word in a sequence of text. The model has been trained on a large amount of text data from the internet, including books, articles and websites, allowing it to understand and generate responses in a wide range of topics and styles. It can also perform a variety of language-related tasks, such as summarising, translation and answering questions.

Demonstration of ChatGPT for questions pertaining to lymphorrhoea with an eczematous ulcerated lesion

In the context of chronic oedema management, ChatGPT could be used to develop a conversational agent or chatbot that can help patients manage their condition by providing information, answering questions, and offering support.

Chronic oedema affects millions of people around the world and, if left untreated, can have severe health consequences. One such consequence, as discussed by Karnasula (2012) is ulceration, which is more common in venous disease, but can also occur in severe cases of lymphoedema, such as in association with lymphorrhoea.⁽³⁵⁸⁾

Lymphorrhoea, the weeping of lymph through the skin, is a complication of chronic oedemas.⁽³⁵⁹⁾ As MacLaren (2001) explains, lymphorrhoea typically manifests as beads of fluid trickling down the swollen limb.⁽³⁶⁰⁾ This can lead to maceration of the surrounding skin, soaked clothing, fluid pooled in footwear, and extreme coldness and discomfort for the patient.

Below is a hypothetical case study of a patient with ulceration and lymphorrhoea who uses ChatGPT to understand their health condition. The patient understands that they have a chronic ulcer on their left leg, which is leaking clear fluid. The patient has already seen two healthcare providers, but the wound has failed to heal.

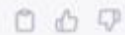
The first question posed to the AI was: “I have a big leaky ulcer on my leg. It won’t heal. What should I do?”

A

I have a big leaky ulcer on my leg. It won't heal. What should I do?



I'm sorry to hear about your ulcer. It's important to seek medical attention as soon as possible as ulcers can become infected and cause further complications.



Here are some general steps you can take:

1. See a healthcare professional: It is important to have your ulcer assessed by a medical professional, such as a doctor or wound care specialist, who can properly diagnose the ulcer and recommend appropriate treatment.
2. Keep the area clean: Clean the affected area with mild soap and warm water, and pat it dry gently.
3. Keep the ulcer moist: Keeping the ulcer moist can help to promote healing. Ask your healthcare provider for recommendations on topical ointments or dressings that can help with this.
4. Elevate your leg: Elevating your leg can help to reduce swelling and improve circulation to the affected area.
5. Follow your healthcare provider's instructions: Your healthcare provider may recommend additional steps to help promote healing and prevent further complications.

Remember, untreated ulcers can become serious, so it's important to seek medical attention promptly.

Regenerate response

Figure 75 - Initial question and ChatGPT response

The first AI-generated response (Figure 75) involved:

- Acknowledgement of their condition: "I'm sorry to hear about your ulcer."
- Recommendation to seek medical help: "It's important to seek medical attention as soon as possible as ulcers can become infected and cause further complications."
- Practical steps that could be taken including seeing a healthcare professional, keeping the area clean, keeping the ulcer moist, elevating the leg and following your healthcare provider's instructions.
- Further caution that help may be required: "Remember, untreated ulcers can become serious, so it's important to seek medical attention promptly."

Patients attempting to heal their "leaking legs" may not be familiar with the concept of moist wound healing, which is well-known to experienced wound practitioners. Therefore, a follow-up question was posed: "What do you mean by keep the wound moist? It's already leaking fluid".

A

What do you mean by keep the wound moist? It's already leaking fluid.



You're right that in some cases, a wound may produce a significant amount of fluid and may not require additional moisture. However, in general, it is important to keep wounds moist to promote healing.

When we say "keep the wound moist," we are referring to the use of a moist wound healing approach, which involves applying a moist dressing to the wound. This can help create an optimal environment for wound healing by promoting the growth of new tissue, preventing scarring, and reducing pain and inflammation.

In some cases, if a wound is producing a significant amount of fluid, it may be necessary to use an absorptive dressing to manage the excess fluid. This type of dressing can help wick away excess moisture while still maintaining a moist environment for healing.

It's important to work with a healthcare provider to determine the best approach for managing your wound, as different wounds require different types of dressings and treatments.

Figure 76 - Second question and ChatGPT response

The second AI-generated response (Figure 76) involved:

- Clarification of the point: "You're right that in some cases, a wound may produce a significant amount of fluid and may not require additional moisture. However, in general, it is important to keep wounds moist to promote healing. When we say 'keep the wound moist,' we are referring to the use of a moist wound healing approach, which involves applying a moist dressing to the wound. This can help create an optimal environment for wound healing by promoting the growth of new tissue, preventing scarring, and reducing pain and inflammation."
- Information on the solution: "In some cases, if a wound is producing a significant amount of fluid, it may be necessary to use an absorptive dressing to manage the excess fluid. This type of dressing can help wick away excess moisture while still maintaining a moist environment for healing."

- Recommendations to seek medical help: “It’s important to work with a healthcare provider to determine the best approach for managing your wound, as different wounds require different types of dressings and treatments.”

In this hypothetical scenario, even after being bandaged by community nurses, the clear fluid continued to leak down the leg and into the patient’s shoe. They expressed their frustration towards the AI, writing: “That’s not very helpful, just telling me to see a healthcare professional. I have seen two already”.

The third AI-generated response (Figure 77) involved:

- Acknowledgement of their disappointment: “I apologise if my previous response did not provide you with the information you were hoping for.”
- Recommendations to seek medical help: “Remember, chronic ulcers can be complex and difficult to treat. It may take time to find the right treatment approach for your specific situation. It’s important to continue working with your healthcare provider and following their recommendations to promote healing and prevent further complications.”
- Practical steps that could be taken, including seeing a wound care specialist or a dermatologist, trying different treatments such as compression therapy, topical medications, and debridement (removing dead tissue), considering lifestyle factors and keeping a wound diary.

A

That's not very helpful, just telling me see a healthcare professional. I have seen two already.



I apologize if my previous response did not provide you with the information you were hoping for. Since you have already seen two healthcare professionals and your ulcer is not healing, here are some additional suggestions:

1. **Get a referral to a specialist:** If you haven't already, you may want to ask your healthcare provider for a referral to a wound care specialist or a dermatologist who can provide specialized care for chronic ulcers.
2. **Try different treatments:** Depending on the underlying cause of your ulcer, different treatments may be effective. Some options to consider include compression therapy, topical medications, and debridement (removing dead tissue).
3. **Consider your lifestyle factors:** Certain lifestyle factors can contribute to the development and slow healing of ulcers. For example, smoking can impair circulation and slow healing, so quitting smoking can be helpful. Additionally, maintaining a healthy diet and getting regular exercise can promote healing.
4. **Keep a wound diary:** Keeping track of your ulcer and its healing progress can be helpful. You may want to document the size of the ulcer, any changes in color or drainage, and any treatments you have tried.

Remember, chronic ulcers can be complex and difficult to treat. It may take time to find the right treatment approach for your specific situation. It's important to continue working with your healthcare provider and following their recommendations to promote healing and prevent further complications.

Figure 77 - Third question and ChatGPT response

Then the patient tried to seek further understanding of what the fluid leaking from their leg was. They wrote, "There is clear fluid leaking out of the wound. What could the fluid be?" The AI generated response (Figure 78) noted that the clear fluid could be lymphatic fluid or serous fluid with valid definitions of the type of fluid being provided. A reminder to seek medical help was again provided.

A

There is clear fluid leaking out of the wound. What could the fluid be?



The clear fluid that is leaking from the ulcer could be lymphatic fluid or serous fluid. Lymphatic fluid is a clear fluid that circulates in the lymphatic system and helps to remove waste and bacteria from tissues. Serous fluid is a clear, yellowish fluid that is produced by the body's tissues and helps to lubricate and protect them.

In the case of an ulcer, clear fluid may be a sign that the wound is producing excess fluid, which can delay the healing process. It could also indicate an infection or inflammation in the affected area.

If you notice any changes in the color, amount, or odor of the fluid, or if you experience any pain or other symptoms, it's important to seek medical attention as soon as possible. Your healthcare provider can properly diagnose the underlying cause of the fluid and recommend appropriate treatment.

Figure 78 - Fourth question and ChatGPT response

The patient questioned further: "The fluid leaks out of my leg into my shoe, even after I have been bandaged by the community nurses. What is this called?" The AI responded that the fluid must be wound exudate (Figure 79).

A

The fluid leaks out of my leg into my shoe, even after I have been bandaged by the community nurses. What is this called?



The clear fluid leaking from your ulcer that is saturating your bandages and leaking into your shoe is commonly known as wound exudate. Wound exudate is a natural fluid that is produced by the body in response to tissue damage, inflammation, or infection. The amount and type of exudate can vary depending on the type of wound and the stage of healing.

Excessive wound exudate can cause the bandages to become saturated, which can delay the healing process and increase the risk of infection. To manage wound exudate, healthcare providers may use different types of dressings or bandages that are designed to absorb the excess fluid and promote healing.

It's important to monitor the amount and appearance of the wound exudate, as changes in color or odor may indicate an infection or other complication. If you notice any changes in your wound exudate or have any concerns, it's important to notify your healthcare provider as soon as possible so that they can evaluate the wound and recommend appropriate treatment.

Figure 79 - Fifth question and ChatGPT response

The patient questioned further (Figure 80). "Are you sure it is wound exudate? It drips down my leg. I think there is something else wrong with my leg." The AI responded with an acknowledgement: "It's possible that there may be a more serious underlying issue beyond wound exudate." A valid response was provided including that the reason could possibly involve a range of conditions such as lymphoedema, venous insufficiency or an infection.



Are you sure it is wound exudate? It drips down my leg. I think there is something else wrong with my leg.



If the clear fluid is dripping down your leg and your bandages are becoming soaked, it's possible that there may be a more serious underlying issue beyond wound exudate.

It's important to see a healthcare provider as soon as possible to have your leg assessed, especially if you are experiencing pain, fever, or other symptoms. The healthcare provider may perform tests or imaging studies to identify the cause of the fluid leakage and recommend appropriate treatment.

Some potential causes of fluid leakage from the leg include lymphedema (swelling due to a buildup of lymphatic fluid), venous insufficiency (poor blood flow in the veins), or an infection. It's important to get an accurate diagnosis so that you can receive appropriate treatment and prevent complications.

I hope you are able to see a healthcare provider soon to get the care you need.

Figure 80 - Sixth question and ChatGPT response

Limitations

An experienced lymphoedema practitioner composed the questions posed to the chatbot in an effort to elucidate a diagnosis of lymphorrhoea. Poorly worded questions, misspellings and the reliability of responses necessitate additional research.

Conclusion

Forms of digital health communication, such as generative AI, are rapidly expanding. In this paper the use of ChatGPT elucidated valid responses for questions pertaining to a hypothetical case of lymphorrhoea. As AI technology continues to advance, there may be further integration of AI language models into virtual doctors and other digital healthcare services. Further research of AI specifically on patients with chronic oedema is required.

Twelve(iii) - Publication title - Generative Artificial Intelligence via ChatGPT for the Early Intervention of Breast Cancer-Related Lymphoedema

Reference

Mangion A, Piller N. Generative Artificial Intelligence via ChatGPT for the Early Intervention of Breast Cancer-Related Lymphoedema. *Wounds International*. 2024;15(3):10-13 .

Credit

Conceptualisation, methodology, writing – original draft, review, and editing by A.M. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 100% of the data collection and analysis and 95% of the writing and editing.

Highlights

The key highlights of this research include:

- This publication contributes significantly to understanding the value of information produced by a generative artificial intelligence (AI) driven chatbot for the early intervention of lymphoedema
- That the AI generated responses were of similar standard with online information contained on two well-known Australian websites. This suggests that a future appropriate use case might be the utilisation of chatbots as an alternative option to lymphoedema patients searching the web for information. Future research is required.

Publication

Abstract

Virtual chatbots are one example of how generative artificial intelligence can be applied. These chatbots utilise natural language processing and machine learning algorithms to provide virtual health communication. This paper examines the practicality of utilising a chatbot to gather information on the early detection and treatment of breast cancer-related lymphoedema through a single case study design. The chatbot responses were assessed for their accuracy by a knowledgeable Lymphoedema Practitioner and compared to information found on two reputable Australian health websites.

The responses were determined to be valid and provided comparable information to what was accessible online. Additional research is necessary to continue in the exploration of this innovative technology.

Background

Early intervention of breast cancer related lymphoedema (BCRL) through a prospective system of monitoring and screening has demonstrated significant clinical effectiveness. Since Stout et al's (2012) publication on the prospective surveillance and early intervention model of care, numerous studies have been published with meta-analyses demonstrating the model's efficacy.^(49, 361-363)

Two elements comprise the prospective surveillance and early intervention model of care for lymphoedema: lymphoedema screening and education. The model includes the following:

- An education protocol involving delivering early information on what lymphoedema is and what the evidence-based risk factors are for the development of lymphoedema.
- A screening protocol, every three (3) to six (6) months, assessing for signs of lymphoedema with a tape measure and bioimpedance spectroscopy (BIS) for the first few years following breast cancer treatment. Screening should occur before breast and lymph node surgery such as a sentinel lymph node biopsy.
- If lymphoedema is diagnosed, compression garments, scar management, graduated exercise prescription, and additional education are prescribed as treatment.

The importance of online education

Fu et al (2023) in a systematic review on the experiences of breast cancer survivors stated that, "...timely self-management education and access to lymphoedema treatment and related resources are important for survivors to prevent and manage lymphoedema."⁽³⁶⁴⁾ Research has shown that patients with breast cancer search online for information and they desire accurate and factual information that is easy to understand.⁽³⁶⁵⁾ Digital health communication therefore warrants investigation to understand if the information being provided is factual and easy to understand.

Digital health communication technologies are evolving rapidly. The application of artificial intelligence to healthcare is one such technology undergoing rapid development. ChatGPT (OpenAI; San Francisco, CA / Version 3.0) is an application of artificial intelligence (AI), which can simulate human responses to natural language input by predicting the most probable next word in a string of text. With this sophistication, ChatGPT can be used as a chatbot, whereby despite being a computer program it can simulate conversation with human users.^(347, 366)

One application of ChatGPT is in the answering of common health questions.⁽³⁴⁴⁾ Ayers et al (2023) compared the responses of physicians and chatbots to patient questions posted on a social media forum accessible to the public.⁽³⁵²⁾ The ratings for the quality and empathy of chatbot responses were significantly higher than those for physician responses.

ChatGPT may however have limitations, such as providing inaccurate information. The software provider includes a warning on the dashboard stating that the technology has limited access to data after 2021 which may impact the validity of the responses.⁽³⁴⁷⁾ The utility of ChatGPT in providing accurate information on the early intervention of breast cancer-related lymphoedema (BCRL) had not been investigated. A case study was designed to test response validity.

Method:

Four queries, well-written and typed by an experienced lymphoedema practitioner, were entered into ChatGPT. On the same day in May 2023, response validity was assessed in two ways. Initially, a Lymphoedema Physiotherapist and Casley-Smith Recognised Trainer (A.M) assessed the information against common clinical knowledge and the type of information that would be expected from a trained lymphoedema practitioner. Secondly, the online information contained on two well-known Australian websites was compared with the generative artificial intelligence responses (Table 15).

Table 15 - Initial chatbot responses for risk reduction contrasted against the information contained on the BCNA and ALA websites

Chatbot Recommendation for Risk Reduction	Response validity as assessed by a Lymphoedema Physiotherapist. Is the response valid and is this response evidence based?	Is the information comparable to that contained on the BCNA website?	Is the information comparable to that contained on the ALA website?
Maintaining a healthy weight	Valid. High Body Mass Index is an evidence-based risk factor.	Yes (in lymphoedema factsheet).	Yes. High Body Mass Index listed as a risk factor on the page designed for medical practitioners.
Avoiding tight clothing and jewellery	Valid. Common sense measure to avoid sustained proximal constriction.	Yes "...clothes that are tight around your chest or arm, and tight jewellery or watches may reduce lymph flow."	Yes
Protecting arms and legs from injury and infection	Valid. Infection is an evidence-based risk factor. Protection from injury is a commonsense measure.	Yes, "infections in your arm – infections can start from cuts, scratches, injections, insect bites, burns or sunburn; anything that causes the skin to break."	Yes

The Australian websites were selected based on their ranking prominence on popular search engine results (i.e., placement on the first page of Google Search) and monthly website visits. The websites were the Breast Cancer Network Australia (BCNA) website (BCNA Homepage) and the Australasian Lymphology Association (ALA) website (ALA Homepage).^(367, 368)

The BCNA website provided breast cancer patients with information pertinent to their treatment. The website stated that the “Breast Cancer Network Australia (BCNA) is Australia’s leading breast cancer consumer organisation.” The website had 62.6K visits in April 2023.⁽³⁶⁹⁾ The website had a global rank of 1,356,089, country rank of 32,810 and is ranked 157th in the category of health conditions and concerns in Australia.

The ALA website provided health practitioners with information on lymphoedema. The website was ranked globally 3,995,851, had a country rank of 127,584 and category rank of 1,662 for health conditions and concerns in Australia. It had a total of 11.2K visit in April 2023.⁽³⁷⁰⁾

Website content was searched by using the search function on each site. The presented pages were then scanned for key words pertaining to the early intervention of BCRL including the terms lymphoedema, breast cancer, diagnosis, early intervention and risk factors.

Results

A) Breast Cancer Network Australia (BCNA) website

The BCNA website provided information directed to patients on:

- The definition of lymphoedema
- Tips for reducing the risk of lymphoedema by partaking in skin care and keeping active
- Symptoms of lymphoedema
- How to manage lymphoedema
- Emerging treatments
- How to find a lymphoedema practitioner. A link was provided to the ALA’s National Lymphoedema Practitioner Register.⁽¹⁷⁶⁾
- Compression garments
- Lymphoedema facts(BCNA factsheet, 2020)⁽³⁷¹⁾

B) Australasian Lymphology Association (ALA) website

The website provided some information on what lymphoedema is, “the importance of early diagnosis” and “early warning signs”.⁽³⁷²⁾ The information was positioned towards health practitioners, including a webpage on “the importance of early diagnosis of lymphoedema for medical practitioners” and a Position Paper on the “Early detection of breast cancer-related lymphoedema”.^(372, 373)

C) Artificial intelligence

The initial query entered into ChatGPT was, “I have been diagnosed with breast cancer. I am scared of getting lymphoedema. What should I do?”

The first AI generated response (Figure 81) involved:

- Acknowledgement of their condition. “I’m sorry to hear about your diagnosis.”
- Recommendation to seek medical help. “Remember that lymphoedema can be managed with proper treatment and self-care. Don’t hesitate to reach out to your doctor or a lymphoedema specialist for support and guidance.”
- Practical steps that could be taken including understanding what lymphoedema is and how it can be caused, talking to their doctor about their concerns, taking steps to reduce their risk, being aware of the signs and symptoms and following a lymphoedema management plan if diagnosed.

A

I have been diagnosed with breast cancer. I am scared of getting lymphoedema. What should I do?



I'm sorry to hear about your diagnosis. Lymphoedema is a common concern for people who have undergone breast cancer treatment, but there are steps you can take to reduce your risk and manage your symptoms.

Here are some tips that might be helpful:

1. Understand what lymphoedema is and how it can be caused: Lymphoedema is a swelling of the arms or legs caused by a build-up of lymphatic fluid. Breast cancer treatment, such as surgery or radiation, can damage the lymphatic system and increase the risk of developing lymphoedema.
2. Talk to your doctor about your concerns: Your doctor can provide you with information about your risk of developing lymphoedema and recommend ways to reduce your risk. They may also refer you to a lymphoedema specialist for additional support.
3. Take steps to reduce your risk: There are things you can do to reduce your risk of developing lymphoedema, such as maintaining a healthy weight, avoiding tight clothing and jewelry, and protecting your arms and legs from injury and infection.
4. Be aware of the signs and symptoms: Early detection of lymphoedema is important for effective treatment. Look for signs of swelling, heaviness, or tightness in your arms or legs, and report any changes to your doctor right away.
5. Follow a lymphoedema management plan: If you are diagnosed with lymphoedema, your doctor or lymphoedema specialist can help you develop a management plan. This may include exercises, compression garments, and other therapies to reduce swelling and manage symptoms.

Remember that lymphoedema can be managed with proper treatment and self-care. Don't hesitate to reach out to your doctor or a lymphoedema specialist for support and guidance.

Figure 81 - First question and chatbot response

The second question asked for further information on how someone undergoes early intervention (Figure 82), "Can you please define the early detection of lymphoedema? What is involved with lymphoedema being detected early?"

A

Can you please define the early detection of lymphoedema? What is involved with lymphoedema being detected early?



Early detection of lymphoedema involves identifying the signs and symptoms of the condition as soon as possible. This is important because early intervention can help to manage symptoms, prevent complications, and improve outcomes.

The signs and symptoms of early lymphoedema may include:

- Mild swelling or heaviness in the arm, hand, breast, or chest after breast cancer treatment
- A feeling of tightness, tingling, or numbness in the affected area
- Changes in the texture or appearance of the skin, such as redness or thickening
- Difficulty fitting into clothes or jewelry that previously fit well
- A decrease in the range of motion of the affected limb

If you notice any of these signs or symptoms, it's important to report them to your doctor as soon as possible. Early detection of lymphoedema can help to prevent the condition from progressing to a more severe stage, which may be more difficult to manage.

If you are at risk of lymphoedema due to breast cancer treatment, your doctor may recommend regular monitoring for signs of the condition, such as measuring the circumference of your arm or using other diagnostic tools. They may also provide you with self-care tips to help reduce your risk of developing lymphoedema or managing symptoms if they occur.

Figure 82 - Second question and chatbot response

The second AI generated response spoke about signs and symptoms of lymphoedema including looking out for swelling. The chatbot included appropriate advice to receive monitoring, "If you are at risk of lymphoedema due to breast cancer treatment, your doctor may recommend regular monitoring for signs of the condition, such as measuring the circumference of your arm or using other diagnostic tools. They may also provide you with self-care tips to help reduce your risk of developing lymphoedema or managing symptoms if they occur."

The third query (Figure 83) included asking what is meant by other diagnostic tools from the chatbot's second response.

The AI generated response replies with a list of other technology including lymphoscintigraphy, bioimpedance spectroscopy (BIS), circumferential measurements and water displacement. BIS, being the most appropriate response in addition to circumferential measures.



What other diagnostic tools can be used?



There are several diagnostic tools that can be used to detect and monitor lymphoedema. Some of these include:

1. **Lymphoscintigraphy:** This is a nuclear medicine test that uses a small amount of radioactive material injected into the affected limb. A special camera is used to track the movement of the material through the lymphatic system and identify any blockages or abnormalities.
2. **Bioimpedance spectroscopy (BIS):** This is a non-invasive test that measures the fluid content in the affected limb. It involves placing electrodes on the skin and measuring the resistance to a small electrical current. BIS can detect changes in fluid content before visible swelling occurs.
3. **Circumferential measurements:** This involves measuring the circumference of the affected limb at specific points to detect changes in size or shape. This method can be used to track changes over time and monitor response to treatment.
4. **Water displacement:** This is a simple test that involves placing the affected limb in a container of water and measuring the amount of water displaced. This method is less precise than other diagnostic tools but can provide a rough estimate of the amount of swelling.

Your doctor or lymphoedema specialist will determine which diagnostic tool is most appropriate for your individual case based on your medical history, symptoms, and other factors. Early detection and regular monitoring can help to manage lymphoedema and prevent complications.

Figure 83 - Third question and chatbot response

The fourth query then sought to ascertain whether the chatbot would recommend medical help by asking, "I am still scared about developing lymphoedema. I am based in Sydney, Australia. Can you tell me where I can get help?" (Figure 84).

A

I am still scared about developing lymphoedema. I am based in Sydney, Australia. Can you tell me where I can get help?



There are several resources available to help you manage your risk of developing lymphoedema and provide support if you are diagnosed with the condition. Here are some options in Sydney, Australia:

1. **Your doctor:** Your primary care physician or oncologist can provide you with information about your risk of developing lymphoedema and recommend ways to reduce your risk.
2. **Lymphoedema clinic:** A lymphoedema clinic is a specialized center that provides diagnostic, treatment, and management services for lymphoedema. The Australian Lymphology Association maintains a directory of lymphoedema clinics in Australia, including several in Sydney.
3. **Physiotherapist or occupational therapist:** A physiotherapist or occupational therapist with experience in lymphoedema management can provide exercises, education, and other therapies to help reduce your risk of developing lymphoedema or manage symptoms if they occur.
4. **Support groups:** There are several support groups in Sydney for people with breast cancer and lymphoedema. These groups can provide emotional support, information, and practical tips for managing the condition.
5. **Online resources:** There are several online resources available for people with lymphoedema, including the Lymphoedema Support Network and the National Lymphedema Network. These organizations provide information, resources, and support for people with lymphoedema and their families.

Remember that you are not alone in this. Reach out to your healthcare provider or one of these resources for support and guidance.

Figure 84 - Fourth question and chatbot response

The AI generated response included several resources available for help including recommendations for the patient to see their doctor, a lymphoedema clinic, physiotherapist or occupational therapist, support groups and visit online resources. Specific information was included such as using the ALA website to search for a lymphoedema clinic.

Conclusion

In addition to searching websites for online information, in the future patients may use chatbots to acquire online information. In this single case study, chatbot responses encouraged a user to seek early care for their lymphoedema by seeing a suitably trained health professional and looking out for signs of swelling. The AI generated responses were of similar standard with online information contained on two well-known Australian websites. Further research is warranted on generative artificial intelligence technologies including validity and reliability of responses when questions contain misspellings and lack context.

Twelve(iv) - Publication title - Generative Artificial Intelligence for Differential Diagnosis of Lipoedema and Lymphoedema

Reference

Mangion A, Piller N. Generative Artificial Intelligence for Differential Diagnosis of Lymphoedema and Lipoedema. Wounds International. 2024;15(3):21-26

Credit

Conceptualisation, methodology, writing – original draft, review, and editing by A.M. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 100% of the data collection and analysis and 95% of the writing and editing.

Highlights

The key highlights of this research include:

- This publication contributes significantly to understanding the value of generative artificial intelligence driven chatbots for differential diagnosis of lymphoedema
- This research answered, “Can AI driven chatbots deliver suitable responses contextualised to lymphoedema care?” AI chatbots can delivered contextualised information but the information derived may not be correct
- That at this time the chatbots did not outperform an experienced lymphoedema practitioner in differential diagnosis
- The observation that some of the information derived from the chatbot was incorrect
- The finding that ChatGPT outperformed Bard.

Publication

Abstract

Artificial intelligence which employs natural language processing techniques to comprehend user inputs and generate appropriate responses is known as generative artificial intelligence.

Practitioners can utilise generative artificial intelligence to aid differential diagnosis.

This paper explores pilot validity testing of two brands of generative artificial intelligence products (Bard and ChatGPT) for the differential diagnosis of lymphoedema and lipoedema. The findings indicate that skilled lymphoedema practitioners should continue to depend on their expertise until there is a significant improvement in generative artificial intelligence responses. The flow charts within the results exemplify the complexity and high level of understanding required to comprehend chronic oedemas.

Background

Artificial intelligence (AI) will have a significant impact on the healthcare industry as its use increases.⁽¹¹⁴⁾ Healthcare practitioners can use AI to their advantage for the purpose of aiding clinical diagnosis. Miller and Brown (2018) in their paper on AI in medical practice highlight that the integration of clinical reasoning and AI improves traditional clinical results, “AI is being successfully applied for image analysis in radiology, pathology, and dermatology, with diagnostic speed exceeding, and accuracy paralleling, medical experts. While diagnostic confidence never reaches 100%, combining machines plus physicians reliably enhances system performance”.⁽³⁷⁴⁾

Practitioners can demonstrate the integration of clinical reasoning and AI by employing generative AI to aid differential diagnosis. Both Bard and ChatGPT have been trained on large datasets of medical information and are therefore able to access and process text queries quickly. For the purpose of differential diagnosis, both systems can provide the practitioner with a list of possible diagnoses based on text input.

The use of generative artificial intelligence for this purpose had not been studied in lymphoedema and lipoedema. A pilot study was designed to test response validity of two brands of generative artificial intelligence products to aid in differential diagnosis.

Method

An experienced lymphoedema practitioner (A.M) assessed two brands of Generative AI: Bard (Alphabet Inc, Google's parent company, California, Version 2.0.1) and ChatGPT (Open AI, California, Version 3.01, 2023).^(346, 347) Response validity, being the extent to which the output from the generative AI involves the same construct as responses would have been provided by the practitioner for the same question. Response validity was assessed on a subjective scale from not valid, potentially valid and valid based on clinical knowledge and available clinical evidence.

To allow for comparison of responses between brands, the identical scenario and text queries that were first entered in Bard were then entered into ChatGPT on the same day in May 2023. Given that generative AI learns over time, the responses may change as the technology evolves.

Screenshots of the responses were therefore taken for recording purposes.

A scenario was employed to allow for consistent questioning of the AI chatbots and to provide the researcher with a suitable model of assumed practitioner knowledge.

Scenario

A 66-year-old female patient presents to a newly trained lymphoedema practitioner. The patient's chief complaint is bilateral leg swelling with some pain and discomfort. There are some signs of chronic fatty tissue deposition in the lower legs. The practitioner asks the patient about their medical history, their family history, and their lifestyle habits. The practitioner also performs a physical examination of the patient's legs.

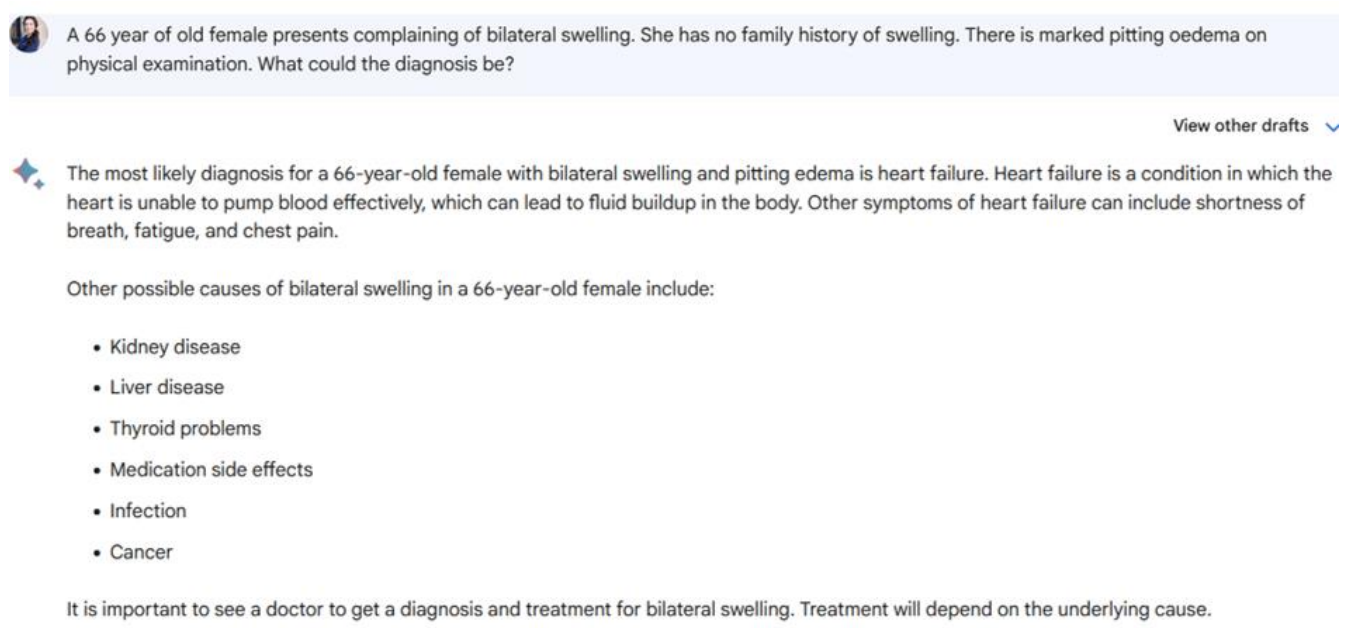
Whilst suspecting lymphoedema, the practitioner is unsure of the diagnosis. The practitioner is concerned about the report of "some pain" and questions whether the patient could have lipoedema. The practitioner decides to consult with generative AI. Along with clinical reasoning, and further tests, the practitioner then attempts to provide a possible diagnosis for the patient.

Results and Discussion

A) Bard

The practitioner types the following initial query into Bard, "A 66 year of old female presents complaining of bilateral swelling. She has no family history of swelling. There is marked pitting oedema on physical examination. What could the diagnosis be?"

The initial Bard response did not include lymphoedema as a possible diagnosis (Figure 85).



The screenshot shows a user query in a light blue box: "A 66 year of old female presents complaining of bilateral swelling. She has no family history of swelling. There is marked pitting oedema on physical examination. What could the diagnosis be?". Below the query, the AI response is displayed. It starts with a star icon and states: "The most likely diagnosis for a 66-year-old female with bilateral swelling and pitting edema is heart failure. Heart failure is a condition in which the heart is unable to pump blood effectively, which can lead to fluid buildup in the body. Other symptoms of heart failure can include shortness of breath, fatigue, and chest pain." This is followed by a list of other possible causes: "Other possible causes of bilateral swelling in a 66-year-old female include:" followed by a bulleted list: "Kidney disease", "Liver disease", "Thyroid problems", "Medication side effects", "Infection", and "Cancer". At the bottom, a disclaimer reads: "It is important to see a doctor to get a diagnosis and treatment for bilateral swelling. Treatment will depend on the underlying cause." A "View other drafts" link is visible in the top right corner of the response area.

Figure 85 - Initial Bard query and response

The possible causes of swelling were proposed as:

- Heart failure
- Kidney disease
- Liver disease
- Thyroid problems
- Medication side effects
- Infection
- Cancer

With the following health conditions being proposed, the clinician would need to use their own clinical reasoning to exclude the conditions above. A pathway for such clinical reasoning is proposed (Figure 86).

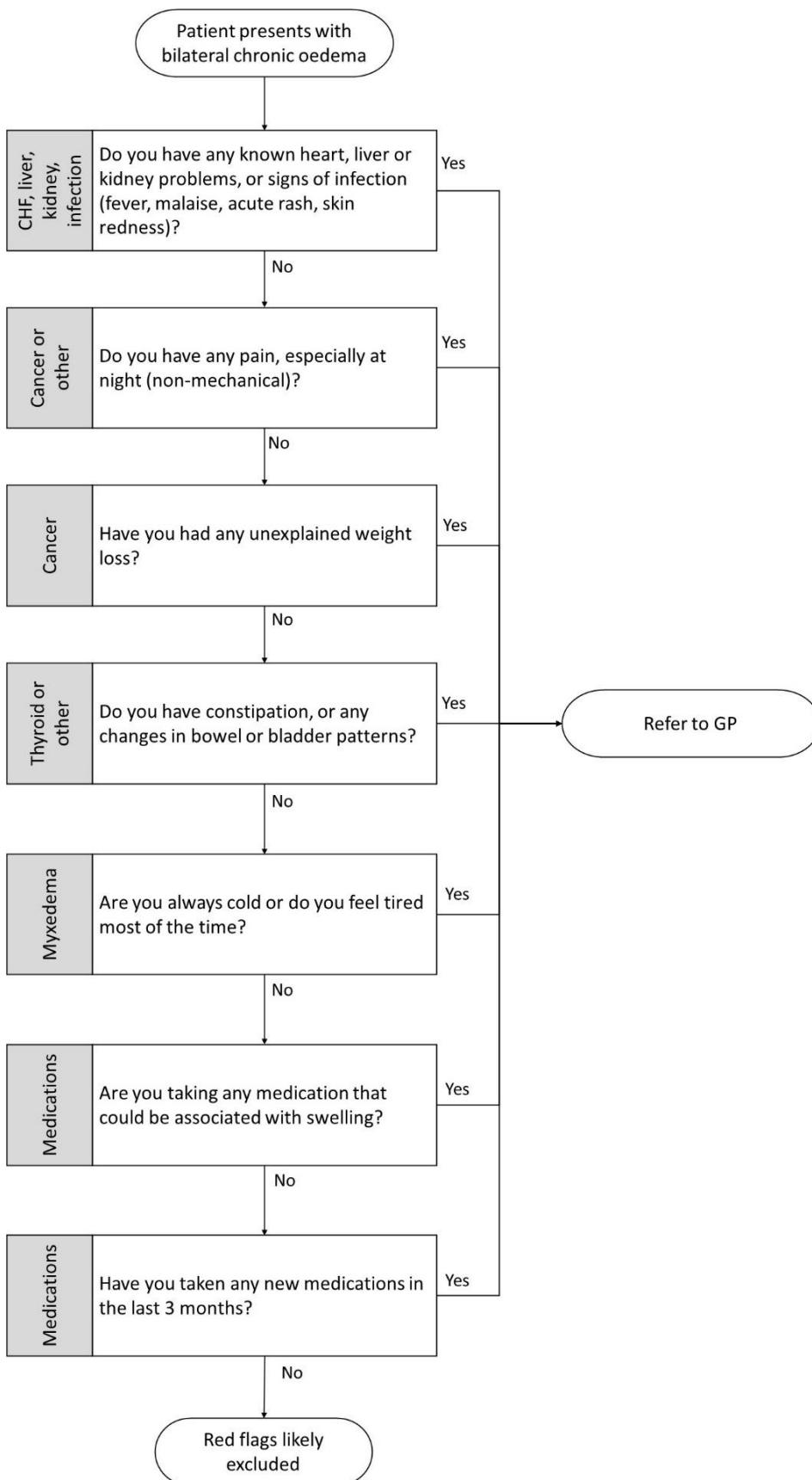


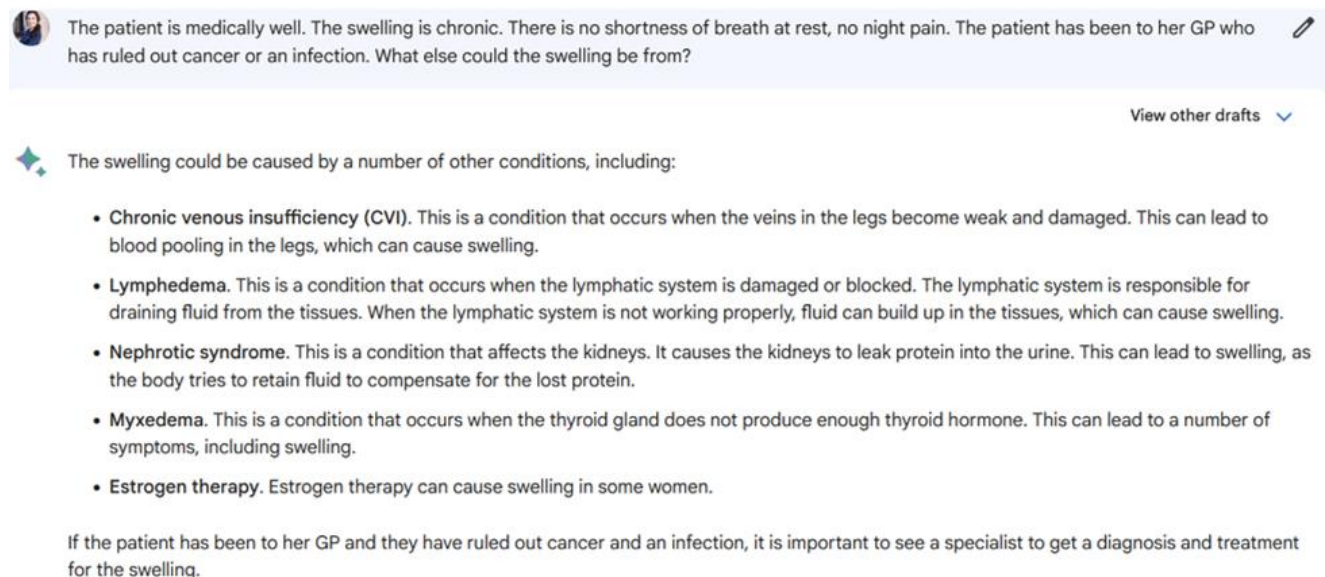
Figure 86 - Differential diagnosis flowchart

[Consideration of heart failure, kidney disease, liver disease, thyroid problems, medication side effects, infection, and cancer]

The practitioner types a second query into Bard, “The patient is medically well. The swelling is chronic. There is no shortness of breath at rest, no night pain. The patient has been to her GP who has ruled out cancer or an infection. What else could the swelling be from?”

The chatbot provides the following health conditions as possible diagnosis (Figure 87)

- Chronic venous insufficiency (CVI)
- Lymphoedema
- Nephrotic syndrome
- Myxedema
- Estrogen therapy.



The patient is medically well. The swelling is chronic. There is no shortness of breath at rest, no night pain. The patient has been to her GP who has ruled out cancer or an infection. What else could the swelling be from?

[View other drafts](#)

The swelling could be caused by a number of other conditions, including:

- **Chronic venous insufficiency (CVI).** This is a condition that occurs when the veins in the legs become weak and damaged. This can lead to blood pooling in the legs, which can cause swelling.
- **Lymphedema.** This is a condition that occurs when the lymphatic system is damaged or blocked. The lymphatic system is responsible for draining fluid from the tissues. When the lymphatic system is not working properly, fluid can build up in the tissues, which can cause swelling.
- **Nephrotic syndrome.** This is a condition that affects the kidneys. It causes the kidneys to leak protein into the urine. This can lead to swelling, as the body tries to retain fluid to compensate for the lost protein.
- **Myxedema.** This is a condition that occurs when the thyroid gland does not produce enough thyroid hormone. This can lead to a number of symptoms, including swelling.
- **Estrogen therapy.** Estrogen therapy can cause swelling in some women.

If the patient has been to her GP and they have ruled out cancer and an infection, it is important to see a specialist to get a diagnosis and treatment for the swelling.

Figure 87 - Second Bard query and response

The practitioner then types in, “There are no signs of venous disease. Kidney problems have been excluded. A thyroid problem is unlikely, but the patient will be encouraged to have tests from her GP. She is not on estrogen therapy. The lymphoedema diagnosis may be possible. Apart from swelling, the patient’s legs are painful to touch. What could be the cause?”

The chatbot provides confirmation that there could be a possible diagnosis of lymphoedema (Figure 88).



There are no signs of venous disease. Kidney problems have been excluded. A thyroid problem is unlikely but the patient will be encouraged to have tests from her GP. She is not on estrogen therapy. The lymphoedema diagnosis may be possible. Apart from swelling, the patients legs are painful to touch. What could be the cause?



[View other drafts](#) ▾



The patient's symptoms are consistent with lymphedema. Lymphedema is a condition that occurs when the lymphatic system is damaged or blocked. The lymphatic system is responsible for draining fluid from the tissues. When the lymphatic system is not working properly, fluid can build up in the tissues, which can cause swelling. In addition to swelling, lymphedema can also cause pain, redness, and warmth in the affected area.

The pain in the patient's legs may be caused by inflammation of the lymphatic vessels. The inflammation can cause the vessels to become swollen and tender. The pain may also be caused by pressure from the fluid buildup.

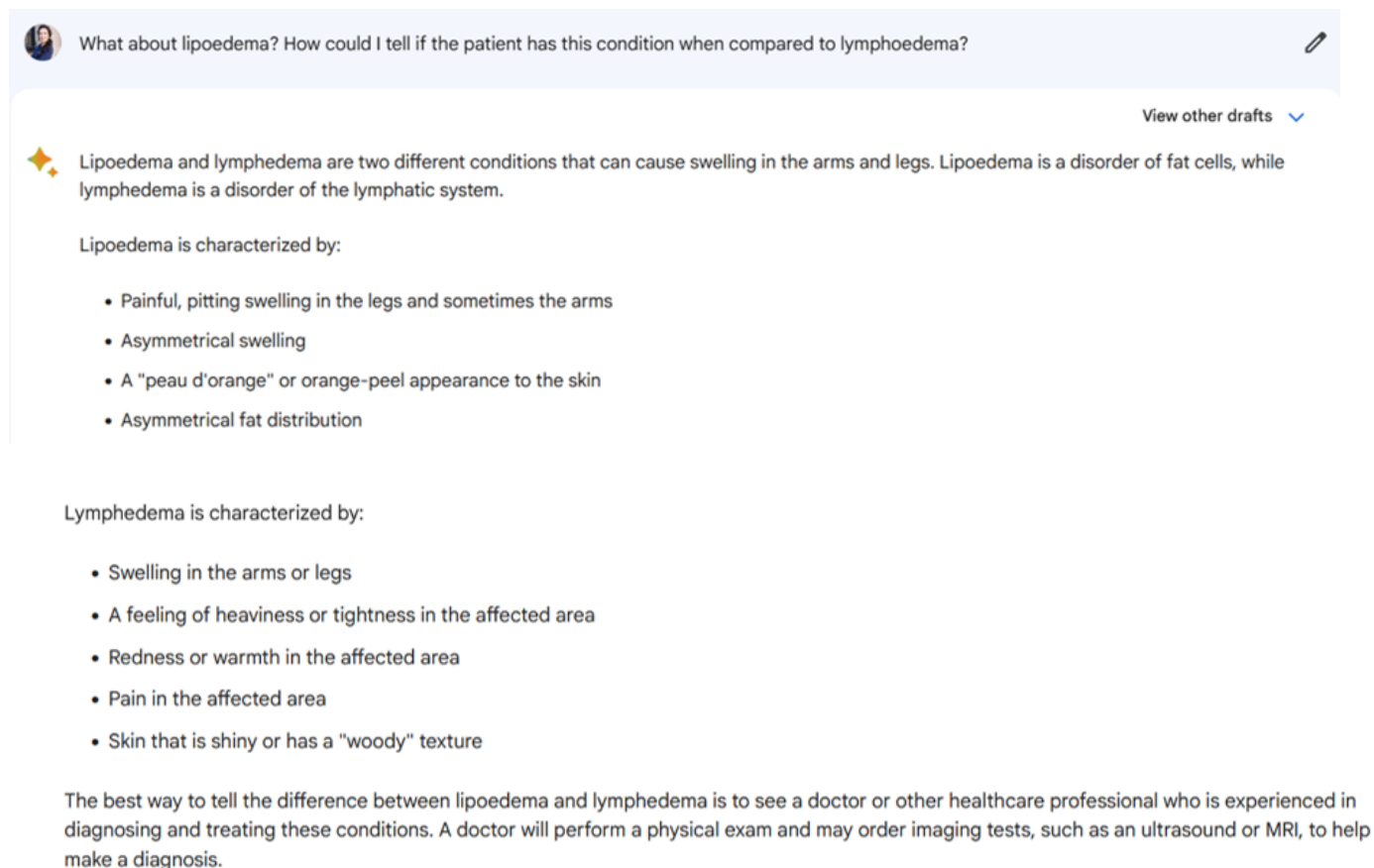
If the patient is diagnosed with lymphedema, there are a number of treatments that can help to manage the condition. These treatments include:

- **Compression therapy.** Compression therapy uses elastic bandages or compression garments to apply pressure to the affected area. This pressure helps to reduce swelling and improve lymphatic drainage.
- **Manual lymphatic drainage.** Manual lymphatic drainage is a massage technique that helps to move fluid through the lymphatic system.
- **Elevation.** Elevating the affected area can help to reduce swelling.
- **Exercise.** Exercise can help to improve lymphatic drainage and reduce swelling.

Figure 88 - Third Bard query and response

Having undertaken lymphoedema training and having a reasonable understanding of differential diagnosis of types of chronic oedemas, the practitioner queries whether or not the patient could have lipoedema due to the symptoms of pain sensitivity. The question that is proposed is, "What about lipoedema? How could I tell if the patient has this condition when compared to lymphoedema?"

Bard then provided responses that were not factually correct (Figure 89).



The screenshot shows a chat window with a user query and a Bard response. The query asks for the difference between lipoedema and lymphoedema. The response explains that lipoedema is a fat cell disorder and lymphoedema is a lymphatic system disorder. It lists characteristics for both and advises seeing a doctor for diagnosis.

What about lipoedema? How could I tell if the patient has this condition when compared to lymphoedema?

View other drafts

Lipoedema and lymphedema are two different conditions that can cause swelling in the arms and legs. Lipoedema is a disorder of fat cells, while lymphedema is a disorder of the lymphatic system.

Lipoedema is characterized by:

- Painful, pitting swelling in the legs and sometimes the arms
- Asymmetrical swelling
- A "peau d'orange" or orange-peel appearance to the skin
- Asymmetrical fat distribution

Lymphedema is characterized by:

- Swelling in the arms or legs
- A feeling of heaviness or tightness in the affected area
- Redness or warmth in the affected area
- Pain in the affected area
- Skin that is shiny or has a "woody" texture

The best way to tell the difference between lipoedema and lymphedema is to see a doctor or other healthcare professional who is experienced in diagnosing and treating these conditions. A doctor will perform a physical exam and may order imaging tests, such as an ultrasound or MRI, to help make a diagnosis.

Figure 89 - Final Bard query and response

The response also encouraged referral to a qualified healthcare practitioner by stating, "The best way to tell the difference between lipoedema and lymphoedema is to see a doctor or other healthcare professional who is experienced in diagnosing and treating these conditions. A doctor will perform a physical exam and may order imaging tests, such as an ultrasound or MRI, to help make a diagnosis."

The characteristics of lipoedema that Bard proposed were:

- Painful, pitting swelling in the legs and sometimes the arms
- Asymmetrical swelling
- A "peau d'orange" or orange-peel appearance to the skin
- Asymmetrical fat distribution.

The responses were found not to be valid (Table 16). Lipoedema is most frequently experienced in the legs with an association with non-pitting oedema. Asymmetrical swelling would show a tendency towards lymphoedema.

In terms of treatment, weight loss was proposed as possible solution for lipoedema, which was also not valid. "There is no evidence that lipoedema leads to weight gain."⁽³⁷⁵⁾ Lipedema adiposity is resistant to weight loss diets.^(376, 377)

Table 16 - Bard responses and judgement of validity for lipoedema

Symptom response from Bard	Judgement of validity by an experienced lymphoedema physiotherapist	Alternative diagnosis / or notes
Painful, pitting swelling in the legs and sometimes the arms	Not valid	Whilst lipoedema is painful, pitting swelling is usually present in lymphoedema, mixed cases of lipolymphoedema or if the patient has lipoedema and is also obese.
Asymmetrical swelling	Not valid	Swelling is not a primary symptom of lipoedema, rather painful fat deposition is with pressure sensitivity.
A "peau d'orange" or orange-peel appearance to the skin	Potential validity	A "peau d'orange" or orange-peel appearance to the skin is usually present in more severe lymphoedema or in cases of malignancy where the lymphatics are obstructed (Shukla and Suman, 2022, Tefferi and Colgan, 2004).
Asymmetrical fat distribution	Not valid	The fat distribution is usually symmetrical (Wiedner et al., 2020).

[Validity from not valid, potential validity or valid response by an experienced lymphoedema practitioner]

The characteristics of lymphoedema that Bard proposed were:

- Swelling in the arms or legs
- A feeling of heaviness or tightness in the affected area
- Redness or warmth in the affected area
- Pain in the affected area
- Skin that is shiny or has a "woody" texture.

The responses were found to be valid or potentially valid (Table 17). Swelling is the main symptom in lymphoedema where it can be accompanied by a feeling of heaviness or tightness in the affected area.

Table 17 - Bard responses and judgement of validity for lymphoedema

Symptom response from Bard	Judgement of validity by an experienced lymphoedema physiotherapist	Alternative diagnosis / or notes
Swelling in the arms or legs	Valid response	Chronic swelling is the primary symptom in lymphoedema.
A feeling of heaviness or tightness in the affected area	Valid response	Swelling will make an area feel tight and heavy.
Redness or warmth in the affected area	Potential validity	This response could indicate an infection (cellulitis). Other conditions can be associated with redness (e.g., stasis dermatitis).
Pain in the affected area	Potential validity	Pain should not be the <i>primary</i> symptom in lymphoedema. If it is, another condition is likely.
Skin that is shiny or has a "woody" texture"	Potential validity	Woody texture occurs in later stages of lymphoedema. The validity of this response depends therefore on how long the oedema has been present.

[Judgement of validity from not valid, potential validity or valid response by an experienced lymphoedema practitioner]

B) ChatGPT

The identical initial query was entered into ChatGPT. The response suggested that “Based on the information provided, the diagnosis that could be considered in this case is congestive heart failure (CHF)”. The response also included recommendations to have “...thorough medical evaluation, including a detailed history, physical examination, and possibly additional tests, would be necessary to confirm the diagnosis.”

From the second query, ChatGPT provided the following possible diagnosis:

- Venous insufficiency
- Chronic kidney disease
- Liver disease
- Hypothyroidism
- Medications:
- Lymphoedema
- Certain autoimmune disorders.

Notably the medication explanation included a broad range of possible medications: “Certain medications, such as calcium channel blockers, nonsteroidal anti-inflammatory drugs (NSAIDs), or hormones, may cause fluid retention and edema.”

The third query produced the following likely causes:

- Cellulitis
- Deep vein thrombosis (DVT)
- Arthritis
- Peripheral neuropathy
- Fibromyalgia
- Chronic regional pain syndrome (CRPS)

A flow chart, reliant on practitioner knowledge, explaining how these conditions would need to be excluded by differential diagnosis is provided (Figure 90).

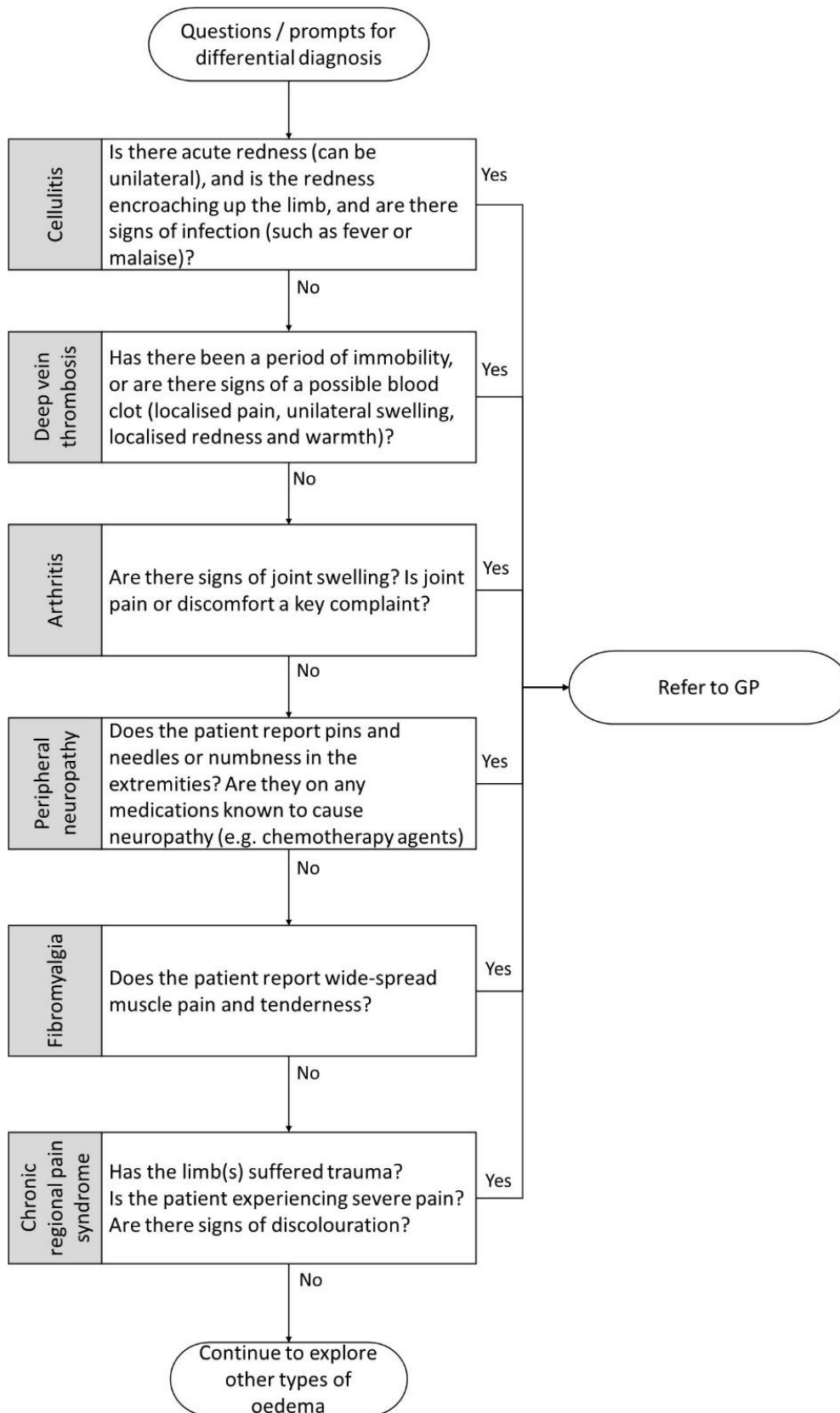


Figure 90 - Differential diagnosis

[Questions and prompts that a practitioner would need to ask themselves to exclude conditions presenting with oedema]

Conclusion

Neither Bard nor ChatGPT suggested a possible diagnosis of lipoedema for a presentation of chronic bilateral leg swelling with pain. Only ChatGPT suggested lymphoedema as a possible diagnosis. ChatGPT provided more comprehensive responses than Bard. The generative artificial intelligence responses did not assist the clinician in differential diagnosis. Trained lymphoedema practitioners need to rely on their own training at this stage and have a high level of understanding of chronic oedemas in order to be able to diagnose their patients correctly. Further research on AI is warranted as the technology continues to evolve.

CHAPTER THIRTEEN: SOCIAL MEDIA FOR PATIENT ADVOCACY

Chapter overview

Patient advocacy plays a vital role in modern healthcare, providing a platform for patient voices to be heard. Social media serves as a powerful tool to amplify patient voices, expanding the reach and impact of individual experiences. After a brief background on social media and patient advocacy this chapter presents a publication on the use of social media for patient advocacy.

This chapter explores qualitative research, gathering data through an in-depth interview to document the lived experiences of Monique, a person living with breast cancer-related lymphoedema. The interview highlighted how Monique strategically used social media to share her journey, advocate for awareness, and support others facing similar challenges.

Social media

Social media platforms have billions of active users globally, providing a vast audience for the dissemination of health information. Millions of new posts can occur each day on social media platforms ⁽²⁴⁴⁾ and every day, millions of people search the Internet for health-related information ⁽³⁷⁸⁾. Images, infographics, and videos offer short and entertaining means of learning. “Sharable content,” which is small in data size, short to consume and interesting, offers an opportunity to simplify complex health information and contribute to behaviour change and decision making.^(379, 380)

Social media facilitates the sharing of health information in numerous ways including visual storytelling, feedback and interaction on topics and sharing and reposting content that users find valuable. Since social media platforms do not require lengthy peer-reviewed processes prior to publication and do not cost users publication fees, real-time updates are available. This enables the immediate sharing of breaking news, health crisis updates, and emerging health trends. Not surprisingly, research has shown that “1 in 5 Americans turn to TikTok before their doctor when seeking treatment for a health condition.”^(74, 75)

Patient advocacy

Collaborative approaches are needed whereby patient voices and the lived-experience are embedded.⁽³⁸¹⁾ A patient or consumer advocate is an individual that works to promote the rights, interests, and well-being of patients and aims to ensure that the voices of patients' interests are heard by relevant parties. Brickley et al state, "Patient advocates are those who participate in health consumer engagement, advisory or consultant groups and 'advocate' on the behalf of others."⁽³⁸²⁾

The National Health and Medical Research council (NHMRC) specifically mentions consumer and community involvement in health and medical research. They state, "NHMRC recognises that involving consumers and community members can add value to health and medical research... Appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers."⁽³⁸³⁾

This leads into research on an exploration of patient advocacy via social media through the lived-experience of a person living with breast cancer-related lymphoedema.

Publication title – Social Media and Patient Advocacy in Lymphoedema Care; A Perspective Piece with Australian of the Year, South Australian Local Hero 2022

Reference

Mangion A, Bareham M, Piller N. Social media and patient advocacy in lymphoedema care; A Perspective Piece with Australian of the Year, South Australian Local Hero 2022 Informatics and Health. 2024. Informatics and Health. Submitted July 2024

Credit

Conceptualisation, methodology, writing—original draft, review, and editing by A.M. Data and Writing – review and editing by R.F. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 90% of the research design, 75% of the data collection and analysis and 60% of the writing and editing.

Highlights

The key highlights of this research include:

- This publication is the first of its kind to document lymphoedema-related patient advocacy efforts using social media
- The documentation of Monique's remarkable advocacy achievements and recognition by being awarded Australian of the Year, South Australian Local Hero 2022
- Three examples of social media utilisation are described, providing insights into the strategies that contributed to their success
- In the process of writing this paper, it became evident that the content and timing of social media posts across various platforms must be strategically considered. Monique, for example, utilised Facebook as a 'newsletter' to connect directly with her consumer base, crafting longer, more descriptive posts with multiple images to engage individuals affected by lymphoedema. She also leveraged Facebook's newer features, such as stories and reels, to capture attention and share short-form content. Through these strategies, Monique effectively used Facebook to celebrate past and present achievements, promote upcoming events, and drive consumer advocacy campaigns.

Monique used X for high-level communication, promoting her advocacy to politicians, researchers, and media personalities through tagging. She noted preferring to follow up offline rather than using the platform for direct communication. LinkedIn similarly was also beneficial for broader networking with community groups, researchers, industry representatives, and stakeholder organisations.

Publication

Abstract

Social media, an accessible and multifaceted eHealth modality, allows for virtual interactions and the rapid dissemination of health-related information by both patients and health practitioners. The perspective of a breast cancer survivor's strategic use of social media for patient advocacy in lymphoedema care is explored. Named the 2022 South Australian Local Hero for her outstanding service, Monique's decade-long advocacy contributed to the establishment of a lymphoedema compression garment subsidy scheme in South Australia, increasing government and policy-maker awareness of lymphoedema. Her perspective on advocating through the lens of lived experience via social media offers insight into effective advocacy strategies.

Introduction

Electronic health (eHealth) refers to modalities such as telehealth, social media, robotics, and artificial intelligence which are being used to transform the way patients and practitioners communicate with one another.⁽¹⁰⁵⁾ Eysenbach in defining eHealth stated, “eHealth is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies”.⁽¹¹⁶⁾

Alongside the wide adoption of eHealth technologies, is the promotion of inclusion of the lived-experience of patients in health research, translation, and implementation.⁽³⁸⁴⁾ The lived-experience of patients refers broadly to the experience(s) of people on whom a social justice issue, or combination of issues, has had a direct impact. A formal definition includes, “Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.”⁽³⁸⁵⁾

Recognising health providers and patients “...as partners that both make vital contributions to produce good health and to improve quality of life for patients, caregivers and family” is regarded as a successful strategy for effectively and authentically engaging patients.⁽³⁸⁶⁾ Social media, as a digital medium for communication exchange and information sharing, is one form of eHealth empowering patients to share their lived-experiences.⁽³⁸⁷⁾

Social media platforms are online digital platforms or websites that enable users to create profiles, share content, connect with others, and engage in various forms of communication and interaction concerning health and healthcare topics.⁽³⁸⁸⁾ Social media platforms, such as Facebook and Instagram® (Meta Platforms, Inc. formerly Facebook, Inc.), X (X Corp, formerly Twitter) and LinkedIn (Microsoft Corporation), provide a variety of ways for users to engage in content and use the software for advocacy efforts.^(389, 390)

Research on social media and lymphoedema care is in its infancy. In an example of effective use, in a study by Omidi et al (2021), Telegram was used to deliver educational content.⁽²⁵³⁾ Telegram (Telegram Messenger Inc) is primarily known as a cloud-based instant messaging service. Unlike traditional social media platforms that encompass a broader range of features like content sharing, profile creation, and social networking, Telegram is primarily focused on enabling messaging and secure communication. A channel was created called “Lymphoedema Self-Management Education.” Educational content was uploaded on the channel twice a week for 3 weeks and presented to the channel as 20 audio and photo messages at different times of the day. The intervention was found to positively impact lymphoedema patient’s quality of life.

Further research on the quality of information shared through social media is required. A 2021 study by Tuğral et al on Instagram hashtags found that “Overall, our results show that it is not possible to say that Instagram® is the right platform for engaging with individuals and obtaining information about lymphoedema due to the abundance of misinformation arising despite its easy accessibility”.⁽²⁴⁴⁾ This highlights the needs for sharing of information by informed sources. This is where patient advocacy has a role as they can offer an “expert” perspective.^(382, 391)

There is little information on patient advocacy in lymphoedema. The authors were not aware of any other published perspective pieces on the strategic use of social media for lymphoedema patient advocacy at the time of writing.

Monique (Figure 91) was diagnosed with breast cancer-related lymphoedema in 2010. Being under forty years of age and otherwise fit and healthy when diagnosed with breast cancer, it was a shock when her arm and hand suddenly started to swell during chemotherapy. Monique stated, “I was more frightened of my lymphoedema than I was of my cancer.”



Figure 91 - Monique Bareham winning South Australian of the Year, Local Hero 2022

[Photo credited to National Australia Day Council (NADC) and Salty Dingo. Published with permission.]

Monique was diagnosed by Professor Neil Piller (Flinders University) with Stage Two early lymphoedema, with just over a litre of fluid volume difference between her right and left arm and was told that lymphoedema was likely to be a lifelong consequence of the breast cancer treatment. Monique privately funded compression bandaging, which was effective in initially reducing the size of her arm, but without regular access to appropriate care and compression garments, her symptoms worsened.

Monique's journey as a patient advocate began when she realised that lymphoedema was a condition that lasted a lifetime and required compression therapy to stop the worsening of symptoms. South Australia (SA) was the only Australian jurisdiction at the time which did not have a government funded garment subsidy programme. Monique stated "due to the financial toxicity of cancer treatment I could not afford compression garments or paying for treatments privately. I lost my job. All I could see was a life with a progressive chronic condition which I could not afford to manage. This was very frightening and isolating and led to a period of depression and anxiety which made me question why I bothered to survive the cancer treatment at all."

Monique began her advocacy journey in 2012 by joining the Lymphoedema Support Group of South Australia Inc. (LSGSA). Monique quickly assumed leadership roles becoming President of LSGSA in 2013. Monique also created the role of 'Lymphoedema Advocate' in LSGSA holding both positions until 2022. Monique's advocacy efforts were formally recognised as part of the prestigious Australian of the year awards, being awarded 2022 SA Local Hero.

Methods and Results

Via a qualitative, patient-centred interview approach, an in-depth recorded interview was conducted and analysed to capture the experiences and perspectives of Monique. Responses were gathered through open-ended questions to allow Monique to share personal insights and provide a detailed account of her experience.

Monique used social media strategically to support her advocacy efforts. Specifically, Monique concentrated her efforts with social media pages on Facebook (commenced in June 2015), X, LinkedIn and Instagram.⁽³⁹²⁻³⁹⁵⁾ Monique also utilises her blogging website to record advocacy activities [www.lymphadvocate.com].⁽³⁹⁶⁾ Three examples of strategic use are described below.

i) Using social media to advocate to former Australian Minister for Health and Aged Care

Before the 2019 Federal Election, Monique learned via social media that Health Minister Greg Hunt would attend a community forum in Mt Gambier, SA. She drove for six hours to attend and organised members of the Mt Gambier Breast Cancer Awareness Group to join her. Together they raised the issue of the lack of a compression garment subsidy with the Federal Health Minister, the Local Federal Member, and the Local State Member.

The social media post on Facebook read, "Last night, Monique Bareham joined with Mt Gambier LSGSA and Breast Cancer Support Group members to attend the Mt Gambier Community Q and A Forum hosted by Federal Member for Barker - Mr Tony Pasin MP with Special Guest, Federal Minister for Health Mr Greg Hunt MP.

Monique raised the lack of public lymphoedema services and a compression garment subsidy in Mt Gambier and Statewide. Monique also raised the concern that Lymphoedema Services have not been included in the Repat Master Plan even though Lymphoedema Services were listed as the No. 1 service missing in the initial proposal.

Minister Hunt gave an undertaking to raise these issues with SA Health Minister Wade today acknowledging that there is a 'GAP' in lymphoedema services and subsidies in SA.

We eagerly wait to hear the outcome of this meeting!"

Following this event, Monique launched a lymphoedema awareness campaign in March 2019, which included letters to all South Australian Parliament members and a targeted social media campaign. This advocacy prompted Member of the Legislative Council (MLC) Ms Connie Bonaros to reach out and facilitate a roundtable meeting on May 10, 2019, with the SA Health Minister and representatives from SA Health and LSGSA. This meeting resulted in the establishment of the South Australian Lymphoedema Compression Garment Subsidy Scheme Advisory Group and a working party, tasked with launching the subsidy program in July 2020.

ii) Public service delivery promotion in a rural town

Monique stated, "I am a firm believer in "Nothing about us, without us" which means consumers must be front and centre and meaningfully engaged in all elements of health provision and health and medical research."

On August 12, 2023, a free lymphoedema patient information and screening day was held in the rural town of Whyalla, South Australia, organised with the support of the Whyalla Pink Spirits Breast Cancer Support Group, led by Rae Williams. The event was attended by Monique, Professor Neil Piller, Toni Piller, Andrea Mangion, Dr. Vani Prasad, Lymphoedema Association Australia (LAA) members, representatives from garment companies, 30 health professionals, and 90 patients. Monique used social media before and after the event to raise awareness of a gap in public service delivery of lymphoedema services in the local area (Figure 92). Following the event, she met with Local Federal and State Members to discuss the issue which assisted in prioritising the training of a new lymphoedema practitioner in the local area to enable the support of public patients.



Figure 92 - Whyalla Lymphoedema Expo Facebook post including evidence of the Whyalla News article on the event

iii) Awareness of lymphoedema through public quick response codes

Monique was chosen to be one of the 100 power portraits for the 2024 SA history festival (Figure 93). The theme was “power” and Monique chose to use this unique opportunity to help destigmatise the wearing of compression garments for lymphoedema and send a message that with the right treatment and support individuals affected by lymphoedema can live a healthy and productive life. On a public street power pole (referred to in SA as a “Stobie pole”) portraits of Monique wearing garments were displayed with a Quick Response (QR) code that linked to Monique’s patient advocacy message. Social media posts encouraged commenting, sharing and engaging with the QR code. The message was, “I think you never really know the power you have within yourself until you are faced with a personal crisis. For me the collateral damage caused by my cancer treatment left me totally depleted and devastated to the point that I questioned why I had bothered to endure it. It was in the re-inventing of myself as a lymphoedema patient advocate that I truly learned how much power I held within myself to rebuild and shape who I wanted to be.

As I learned more about the suffering of others I was further strengthened. Each interaction galvanised my resolve to do my best to improve the health outcomes for other affected by lymphoedema, including normalising and destigmatising garments and building recognition and awareness.”



Figure 93 - Monique with her mother (Ursula Legierski) at the Welbourne Street Stobie pole

During the campaign, members of parliament directly reached out to Monique. One comment on Facebook and Instagram by Connie Bonaros (MLC) read “Proud to see Monique Bareham – Leading Lymphoedema Advocate 2022 SA local hero, feature on Welbourne Street in Mitcham as part of SA histories festival. Through this initiative she hopes to raise awareness and foster understanding about the importance of compression garments for many individuals. Monique’s words resonate deeply.”

Discussion

Monique's perspective highlights the value of consumer and community advocacy for improved lymphoedema care, with social media serving as an effective eHealth tool. The approach of involving community members is supported at a national level with the National Health and Medical Research Council (NHMRC) stating we understand "... the importance of engaging with consumers and the community on its role and activities, whilst also providing leadership and guidance to the health and medical research sector on the meaningful engagement of consumers throughout all stages of research and health care".⁽³⁹⁷⁾

Fourteen years after Monique's lymphoedema diagnosis, her condition is well managed, but lymphoedema remains a constant reminder of her breast cancer treatment and the initial struggles she faced in sourcing necessary compression garments. Compression therapy has been shown to be necessary for lymphoedema, not only through maintaining limb volume measures but also through decreasing the incidences of cellulitis.^(398, 399) In Australia, government-funded garment subsidy programs aim to reduce hospitalisations for cellulitis. The Agency for Clinical Innovation noted that two sets of custom-made compression garments cost only 14% of a typical hospital admission for lower limb lymphoedema, highlighting their cost-effectiveness.⁽³⁷⁾ Access to garment subsidy schemes however, varies across jurisdictions, leading to inequalities in types, quality, and eligibility for compression garments. In July 2020, after years of advocacy, the South Australian government announced a subsidy program for compression garments, dedicating millions of public health dollars to support South Australians with lymphoedema.⁽⁴⁰⁰⁾ Monique's efforts, along with other patients and other stakeholder organisations advocating over many years for lymphoedema patients, made this achievement possible.

Conclusion

Further research on the impact and benefits of social media and patient advocacy for patients living with lymphoedema is required. This perspective piece highlights the value of consumer and community involvement in influencing government and policy-maker awareness of lymphoedema and how social media can be an effective tool to amplify the patient voice.

CHAPTER FOURTEEN: DIGITAL COMMUNITY OF PRACTICE

Chapter overview

This chapter presents the results of a collaborative descriptive analysis of a digital lymphoedema community of practice. This publication aimed to document the characteristics, roles, and dynamics successfully sustaining this community of practice. Initiated twenty years ago by co-author and occupational therapist Brenda Svensson-Florida, this community is an effective and well-administered group that provides international professional development and peer support at no cost to its members.

Highlights

The key highlights of this research include:

- The formal documentation of a long-lasting digital lymphoedema community of practice
- An analysis of the administrative strategies and practices which have contributed to the longevity of the community
- The recording of an example of a clinical digital resource created by the community.

Publication title - A Digital Community of Practice in Lymphoedema Care

Reference

Mangion A, Svensson-Florida B, Piller N. A digital community of practice in lymphoedema care. Informatics and Health. Submitted July 2024.

Credit

Conceptualisation, methodology, writing—original draft, review, and editing by A.M. Data curation and Writing – review and editing by B.S. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 95% of the research design, 50% of the data collection and analysis and 85% of the writing and editing.

Publication

Abstract

Professional groups and communities of practice play an essential role in the advancement of knowledge, innovation, and professional development across various fields. Health related groups in particular provide a structured forum for health professionals to engage in meaningful exchanges about current and future trends, challenges, and practices.

This paper details the history, technology, governance and utilisation of the digital Australian Lymphoedema Professional Google Group, successfully initiated and administered for over twenty years by an Australian occupational therapist.

This paper examines how the group functions as a digital community of practice, broadly describing its impact on professional development, knowledge sharing, and the collective advocacy efforts of its members.

Background

Communities of practice (CoPs) can be defined as "groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise by interacting on an ongoing basis".⁽¹³⁶⁾ CoPs can be used for learning, exchanging information and knowledge and improving clinical practice for the implementation of evidence-based practice.⁽⁴⁰¹⁾

A Google Group functions as an online forum where members can communicate through email or a web interface.⁽⁴⁰²⁾ Users can start discussions by posting messages, which are then emailed to all group members or accessible via the group's webpage. Members can respond directly from their email inboxes or through the group interface, facilitating a continuous and interactive dialogue. The group administrator can customize settings, such as whether to moderate posts, manage membership approvals, and decide who can view or contribute to the discussions. This platform supports a variety of uses, from simple information sharing to more complex collaborative efforts among its members.

The Australian Lymphoedema Professionals Google Group began as an initiative of Australian occupational therapist, Brenda Svensson-Florida (group administrator and owner, Australasian Lymphology Association accredited lymphoedema practitioner), who recognised the need for a dedicated free digital platform where health professionals with an interest in lymphoedema can exchange knowledge, share clinical experiences, and discuss advancements in treatment methodologies. This group was originally founded in 2004 with the aim of bridging the distance between rural and metropolitan Australian occupational therapy lymphoedema-related services. From 2007 to 2024, the group evolved to bridge gaps between research, training, advocacy and

provide a platform to seek advice or opinion to enhance clinical intervention, enabling therapists from various backgrounds (such as Medicine, Physiotherapy, Occupational Therapy, Nursing, Massage Therapy and other Allied Health Services) to collaborate and enhance their clinical skills and knowledge. Most members are lymphoedema practitioners however some are researchers, medical practitioners and other health professionals with a special interest in lymphoedema.

Initially starting with a small group of nine (9) health professionals in 2004 and the group quickly grew as the value of shared expertise and support became evident, attracting a wider membership that spans multiple disciplines involved in management, education and research. The membership has grown to approximately four-hundred and fifty (450) with membership across Australia, New Zealand (NZ) and the United Kingdom (UK).

Method

Administration of the Australian Lymphoedema Professionals Google Group is managed by the group owner who retains the responsibility for maintaining the data collection on the community and the integrity and purpose of the group. Data on the community, such as the list of members, shared digital content and the group's conversation history, is stored within the Google Groups administration portal.

Membership is restricted to health professionals, with membership achieved through completion of a membership application that is emailed to the group owner. The group owner has the authority to adjust settings that control membership, posting privileges, and visibility of discussions. This includes approving or denying membership requests, moderation of posts to limit inappropriate content, and set guidelines for discussions to ensure they remain productive and respectful. All new members are provided with instructions regarding how to interact with the group, change their membership settings and the need to provide disclosures regarding interests.

Users of the group are identified by their email address or google account nickname name. To address potential challenges and provide some clarity around conflicts of interest and bias of interest, the owner has implemented clear guidelines that require members to disclose any potential interests or biases when posting about products, services, or research. Members are required to declare interests at the top of applicable emails in a form similar to "Nothing to declare" or "Declaration: I have..." This transparency helps to promote integrity in the discussions and ensures that advice or information shared is not unduly influenced by personal or commercial interests.

All conversations of topics are allowed to promote free speech and open discussion. To prevent disruptive behaviour, such as unproductive complaining, the administrator also enforces a code of conduct that promotes professionalism and courtesy. Discussions that veer off-topic or become contentious, result in reminders of the group's purpose and the expectations for respectful communication.

Results

The group has an average of one hundred and eleven (111) emails per month with one hundred and twenty-three (123) emails in February, one hundred and twenty-eight (128) emails in March and eighty three (83) in April 2024. Most emails are posed as clinical questions to the group. One example of a clinical query, inclusive of brief clinical case history, was "Dear All. I am hoping to get some guidance. I have a lovely 50-year-old lady who is now 2 years on from lumpectomy with sentinel node biopsy/radiation/chemo. She is complaining of on/off stabbing pain in her breast (right under her scar line). On ultrasound (US) there is a visible seroma there and the lymph scanner measures a very low-grade difference (52% compared to 45% on the other side).

There is no palpable pitting. There is some deep scar tissue palpated. Her function and range of movement (ROM) are perfect. I have done some laser on her and manual lymphatic drainage (MLD), nothing has helped with the pain. Is there anything else anyone can suggest?"

Four (4) responses to this query were received from the group and included ideas such as targeting scar tissue release around the seroma and scaring, considering muscular adhesions in muscles such as pectoralis major and rib cage mobility exercises as well as lymphoedema and neuromuscular taping. Responses were received within four business days with the author posting gratitude for the group's high quality collective input. Such responses then allow lymphoedema practitioners to seek further assistance, continue or modify assessments and treatments with confidence based on feedback.

The group also develops or improves shared assessment or patient education resources. Expressions of interest for development of a particular resource is sent to the group, then members volunteer to participate in working groups to work on the project. Resources are then shared for the benefit of the entire group through Google Drive links. One example of developed resources is a comprehensive four-page Breast Lymphoedema Assessment form (Figure 94).⁽⁴⁰³⁾ The third page of the form is pictured. On the form there are areas where clinicians can document information on coding, fluid levels, scar tissue and clinical impression notes.

Conclusion

The Australian Lymphoedema Professionals Google Group represents an effective and well administered digital community of practice. The free group allows members to stay connected with other lymphoedema practitioners across Australia, NZ and the UK and share advancements in advocacy efforts, technology, treatment, and best practices for the care of their patients.

Cording:

Location axilla, side of chest, breast

Thickness of cord: non-visible, visible, thin, thick, band

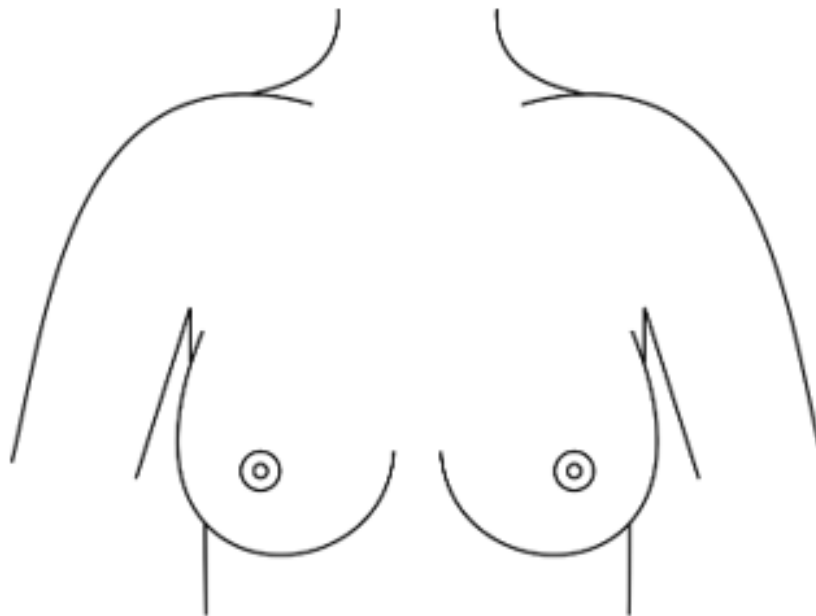
Effect on movement/AROM: nil impact, tightness, pain, reduce AROM,

Breast moisture measurements

Measurement of breast oedema completed with _____ (device).

Position of measure	Approx. distance from areola border	Left Moisture %	Right Moisture %	Threshold (unaffected/affected)
Lateral chest	NA			1.4
Medial upper breast				1.34
Medial lower breast				1.34
Lateral lower breast				1.34
Lateral upper breast				1.34
Patient reported "most swollen area"				

Breast Diagram



Scars: ++++ Tissue firmness: Adhesion:

Digital Photography

Photographs taken: Yes No

If yes, photograph storage location:

client phone, client file, etc

Client position in photographs:

standing, seated, reclined, lying

arm position (by side, abducted x degrees, shoulder height, above head)

Clinical Impression:

Presence/absence of oedema, location and extent of breast oedema

Figure 94 - Extract from the community created breast lymphoedema assessment form

CHAPTER FIFTEEN: DIGITAL TRAINING OF STAFF IN THE ENCORE PROGRAM

Chapter overview

This chapter explores the Encouragement, Normalcy, Counselling, Opportunity, Reaching Out, Energies Revived (ENCORE) breast cancer rehabilitation program. The ENCORE program has had a significant impact on the lives of thousands of patients. Together with other members of the ENCORE advisory board, ENCORE management and facilitators, this Participatory Action Project involved collaborative research to collect program data, retrospectively analyse data from past ENCORE programs, and highlight the value of evidence-based exercise and rehabilitation programs in caring for people with, or at risk of, lymphoedema post-breast cancer.

From a digital health perspective, this chapter examines the use of instructive online information for staff training. Given that ENCORE facilitators were distributed across Australia, it was necessary to establish a method for ensuring consistency in staff training delivery. Virtual training achieved this through online videos which allowed ENCORE facilitators to observe how exercises should be performed and taught, ensuring consistency in program delivery across all facilitators.

Highlights

This publication was completed as part of the author's role as a volunteer on the ENCORE board. Professor Piller suggested that volunteering could help increase the author's professional networks, improve opportunities to educate others on digital health and how to leverage it, and contribute to the lymphoedema community.

The key highlights of this research include:

- The documentation of the success of the ENCORE program as an evidence-based exercise and rehabilitation program
- Demonstration of the practical implementation of instructive online information, through online videos, to support staff training.

Publication title – Encouraging Exercise: The role of the ENCORE Program in Supporting Breast Cancer Care

Reference

Mangion A, Freeland R, Piller N, Hayes S, Treadgold C, Koelmeyer L, Reul-Hirche H. Encouraging exercise: The role of the ENCORE program in supporting breast cancer care. *Journal of Lymphoedema*. 2024;19(1):52-56

Credit

Conceptualisation, methodology, writing—original draft, review, and editing by A.M. Data and Writing – review and editing by R.F. Writing – review and editing, and supervision by N.P.

Contribution

A.M. completed 100% of the research design, 75% of the data collection and analysis and 80% of the writing and editing.

Publication

Abstract

The Encouragement, Normalcy, Counselling, Opportunity, Reaching Out, Energies Revived (ENCORE) program is a community based, multi-modality evidence-based education and exercise program designed to aid the physical and emotional recovery of women who have undergone breast cancer treatment. ENCORE provides a package of tailored education, therapeutic exercises, relaxation techniques, and supportive community engagement. Funded through a combination of government funding, private donations, and community support, ENCORE represents a significant achievement in the application of evidence-based practice within the realm of cancer care. ENCORE has demonstrated improved clinical outcomes relating to participants' physical strength, mobility, and quality of life. The program's achievements underscore the critical value of exercise and peer support in cancer rehabilitation.

Background

Every four minutes an Australian is diagnosed with cancer.⁽⁴⁰⁴⁾ Physical activity and exercise has increasingly been recognized as a crucial component in the comprehensive care of individuals diagnosed with cancer. Misiag et al (2022) stated, "...physical activity decreases the severity of side effects of cancer treatment, reduces fatigue, improves quality of life, has a positive impact on mental health and improves aerobic fitness in cancer patients. Moreover, it reduces the risk of cancer recurrence and death".⁽⁴⁰⁵⁾ Research demonstrates that individuals diagnosed with cancer participating in regular physical activity (with exercise being a major component of this) have a 21–35% lower relative risk of cancer recurrence, a 28–44% reduced relative risk of cancer-specific mortality and a 25–48% decreased relative risk of all-cause mortality when compared with insufficiently active or sedentary patients (typically those who do little or no exercise).⁽⁴⁰⁶⁾ Higher levels of physical activity have been associated with reduced overall mortality and cancer-related mortality in individuals diagnosed with breast, colorectal, or prostate cancer. The relative risk reductions ranged from approximately 40 to 50 percent.⁽⁴⁰⁷⁾

Considering the positive impact of physical activity, exercise should be regarded as an essential component in a comprehensive approach to cancer care.

Physical activity vs exercise

Physical activity, defined as any bodily movement resulting in energy expenditure, encompasses a spectrum of activities from daily routines to structured exercises.⁽⁴⁰⁸⁾ This includes occupational tasks, sports, conditioning, household chores, and more.

Exercise is a subset of physical activity characterised by its planned, structured, and repetitive nature, aimed at enhancing or maintaining physical fitness.⁽⁴⁰⁹⁾ In the context of breast cancer care, both physical activity and exercise play vital roles in supporting individuals during and following cancer treatment.

Physical activity and exercise guidelines

Extensive evidence in scientific and medical literature indicates that physical inactivity is a significant public health issue, causing a variety of detrimental effects. Mounting, convincing evidence shows exercise is beneficial in brain health, cancer care, cardiometabolic care, and for general health through lowering all-cause mortality risk.⁽⁴¹⁰⁾

Evidence from cohort studies and trials have informed patient and practitioner directed physical activity and exercise guidelines endorsed by leading organisations such as the Clinical Oncology Society of Australia (COSA), Exercise and Sports Science Australia (ESSA), Cancer Council and the Breast Cancer Network Australia (BCNA).⁽⁴¹¹⁻⁴¹⁷⁾ Evidence-based programs which adhere to such guidelines ensures that exercise programs are scientifically vetted, tailored to the specific needs of cancer patients, and designed to safely maximize the benefits of physical activity during and after treatment.

ENCORE

The Encouragement, Normalcy, Counselling, Opportunity, Reaching Out, Energies Revived (ENCORE) is an evidence-based education and exercise-based cancer rehabilitation program designed to support women in breast cancer care.⁽⁴¹⁸⁾ The program is open to anyone with a history of breast cancer or preventative surgery of any age. The program can be commenced as soon as 8 weeks post-surgery once an online an online registration process, including a medical history questionnaire and a medical approval form signed by treating doctor, has been completed.

The program

ENCORE is a community based, multi-modality program which consists of two-hour sessions every week for eight weeks along with a home exercise program. The sessions, led by trained facilitators, incorporate land (Figure 95) and water-based exercises (Figure 96) and provide general support, guest speakers and information on breast cancer recovery, lymphoedema, prosthesis, nutrition, massage, complementary exercise, psychological welfare, mindfulness, meditation and connection to community resources and support.



Figure 95 - ENCORE exercises

[An example of land-based exercises within an ENCORE program. A facilitator is in the centre demonstrating stretching her arm over her head. Some participants are on the floor exercising on yoga mats and others are exercising in chairs.]



Figure 96 - ENCORE hydrotherapy

[An example of pool-based exercises within an ENCORE program. A facilitator is in the side of the pool demonstrating how to run through water. Six participants are in the water jogging through the water.]

Graduated and carefully progressed exercises are added every fortnight with the aim being to gradually increase fitness and strength over the eight-week program. Land exercises include deep breathing (Figure 97), mobility exercises of the arms, shoulder, neck and trunk and stretches for the upper and lower body. Pool exercises include aerobic exercises, resistance exercise and a cool down.

Deep Breathing combined with arm exercise

Starting position

Either sitting or standing with shoulders relaxed and arms at sides

Motion

Standing with shoulders relaxed, fingertips pointing to sternum (breast bone), elbows are slightly lifted to the side and below shoulder height. Take a deep breath in and extend your arms to the side. Once your elbows are fully extended hold your breath for one to two seconds, then breath gently out and at the same time return the arms back into the starting position, repeat 3-5 times



Caution

Maintain good posture, **shoulders relaxed**, core engaged (tummy in and back straight)
Start with 1-2 repetitions as deep breathing can cause dizziness.

Figure 97 - Deep breathing exercises

[Deep breathing combined with arm exercise. In this image the starting position, motion and cautions are included with a picture of how to start deep breathing and then how to finish. The motion includes standing with shoulders relaxed, fingertips pointed to the sternum with elbows bent. A big breath is taken and then arms are extended outwards.]

The exercises include progressions to allow for graduation (Figure 98). Participants are also encouraged to undertake a minimum of two additional unsupervised sessions between the ENCORE sessions. Participants are provided with take home exercise sheets providing step by step instructions in written and photographic format for both land and pool-based exercises. The exercise sheets are reviewed at the end of in-person sessions and participants are encouraged to continue performing exercises at home.

Cycling

Basic

Starting position

Stand with feet together, tummy tight, knees soft.

Motion

Marching on the spot, always keeping one foot on the ground. Keep knees soft.



Level 1

Starting position

Stand with feet together, tummy tight, knees soft.

Motion

On the spot lean forward so that shoulders are just underwater. Begin a cycling motion by bringing knees to chest and keep shoulders under the water.

Level 2

Starting position

Stand with feet together, tummy tight, knees soft.

Motion

Same as level 1 with added cycle arm movement. Ensure knees are coming up to the chest hard and fast. Increase intensity of arm movement and legs.

Level 3

Starting position

Stand with feet together, tummy tight, knees soft.

Motion

Same as level 2 with modified arm movements (See above).

[Pool exercise example of cycling. In this picture the starting position, motion on three levels of exercises for the activity of cycling in the pool are demonstrated. The basic movement is to march on the spot. It is made harder by adding bigger arm and leg movements.]

Figure 98 - Hydrotherapy exercises example

To offer opportunities to advance their ability to participate in exercise, participants can enrol in the program up to four times. Participants are also encouraged to take advantage of their increased physical capacity and self-confidence to participate in other activities that they find appealing and that are best suited to their physical abilities, such as yoga, walking groups, swimming or wading groups.

Research has shown that individuals recovering from cancer treatment report psychological needs, health system/informational needs, physical and daily activities, and interpersonal/intimacy needs.⁽⁴¹⁹⁾ The design of the ENCORE program reflects the desire to meet a diverse range of supportive care needs. ENCORE offers group information presentations conducted by guest speakers, specifically tailored to address various information requirements related to breast cancer. These presentations are then followed by group discussions centred around these topics. Although this forum does not offer counselling or supportive care, engaging in interpersonal interaction with women facing similar circumstances has been shown to result in improvements in quality of life, therefore extending beyond the effects of exercise alone.⁽⁴²⁰⁾ Additional support through psychological support and tailored information classes for any women with metastatic disease has been considered to take care of the needs of all women with breast cancer regardless of stage of disease at diagnosis.

Training of facilitators

Each ENCORE session is performed in small groups, with a maximum of 14 participants, and led by two trained facilitators. Many of the facilitators engaged in delivery of the ENCORE program have been previous participants of the program or have lived experience personally or through close association with someone who has had breast cancer. All ENCORE team members, including facilitators, are educated by healthcare professionals, researchers, and experienced breast care nurses, either in person or through webinars, on topics relevant to program participants, such as lymphoedema, metastatic breast cancer and the psychosocial impacts of living with breast cancer.

Training is provided to staff in person and electronically as part of robust measures to ensure consistency in program delivery. In addition to being provided with an extensive training manual that includes step by step instructions on all aspects of program delivery, online videos of exercises allow ENCORE facilitators to watch how exercises should be performed and taught to ensure consistency in program delivery. The online videos aim to communicate how exercises should be delivered and what the safety considerations are. It is also a requirement that facilitators refresh their exercise delivery skills using these videos, prior to delivery of each week's program.

In addition to program debriefs, facilitators are supported in their psychosocial being through access to employee assistance counselling support when needed. All staff also complete digital training in, and adhere to, state and federal Privacy Act requirements as confidential participant information is received through the enrolment process and may be disclosed during the program.

History

The ENCORE program was arguably ahead of the times, as it was originally developed in the United States by ballet teacher, Helen Glines Kohut in 1972. Having experienced breast cancer surgery herself, Helen saw a need to assist other women with similar experiences to rebuild their physical and emotional strength following treatment. Despite the presence of support programmes, none specifically addressed the physical limitations and discomfort caused by breast cancer, particularly the post-operative effects.

In consultation with the National Young Women's Christian Association (YWCA) of USA, a pilot project was set up in 30 YWCAs in the USA to test the program's effectiveness. A Committee of Medical and Health Consultants reviewed the findings from this project and recommended Encore to be a safe and effective program for women following treatment for breast cancer, and in 1977 the National YWCA ENCORE program was launched.

ENCORE was brought to Melbourne, Australia in 1983 under license from the YWCA of the USA. Since then, YWCA Australia became a registered ENCORE provider and has held the international license for the program, successfully delivering the program for over 40 years in Australia. Following the successful pilot in Melbourne, ENCORE eventually expanded to all states in Australia, making it available in over 50 metropolitan and regional locations. With increased recognition of the importance of exercise following a breast cancer diagnosis, YWCA Australia was approached and supported the granting of licenses and training to self-funded licensees, YWCA of Japan, YWCA of New Zealand, and YWCA of Canada. While the program has been delivered for over 40 years in Australia, records show that since 1997, across all states in Australia, more than 1,948 programs have been delivered and 17,522 participants have benefited from ENCORE.

Notable recognition of the program occurred in 2005 when the ENCORE program was the National Winner in the Prime Minister's Business and Community Partnership Awards, Longevity Category, together with Avon Australia and the Australia New Zealand Breast Cancer Trials Group. In 2022, ENCORE was recognized in the Centenary Anniversary celebration video of YWCA Princeton, New Jersey, and in Memoria of Helen Glines Kohut who passed away in April 2022 at the age of 101 years.

Outcomes

National clinical outcomes demonstrated increases in strength, mobility, flexibility and emotional wellbeing (Table 18).

Table 18 - ENCORE results

Outcome Indicators/Measures	July - Dec 2022		
	% reported improvement	Number of Responses	
The number of individuals who reported that their knowledge, confidence and skills about managing the after effects of breast cancer had improved. (Respondent evaluation of individuals)	I have a better understanding of all the benefits of exercise in relation to breast cancer (knowledge)	100%	44
	I know more about the services, resources and activities in my community (knowledge)	90%	44
The extent to which individuals were supported to develop their knowledge, confidence and skills to manage the after effects of breast cancer. (Progress Report)	I feel more confident in managing the after effects of breast cancer (confidence)	100%	44
	Measured Physical Improvement (skills)		
	- Chair stand	89%	42
	- Sit reach (left)	55%	44
	- Sit reach (right)	44%	44
	- Back scratch (left)	61%	44
	- Back scratch (right)	44%	44
	- Arm curl	89%	44
	- Step test	100%	41
	The number of individuals who reported that their physical care and well-being had improved (Respondent evaluation of individuals)	Physical benefits felt by Participants (physical care)	
- Increase in flexibility		89%	44
The extent to which individuals were supported to develop their knowledge, confidence and skills to manage the after effects of breast cancer (Progress Report).	- Increase in mobility and ability to do everyday tasks	96%	44
	- Emotional well-being has improved	100%	44
	- Increase in energy	98%	44
	- Increase in strength	90%	44
	I am more committed to looking after health and wellbeing (well-being)	100%	44
	I feel part of a supportive community (well-being)	100%	40

[Results from the ENCORE program in Western Australia across July to December 2022 as an example of captured national outcome data.]

A study by Sherman et al explored the feasibility and psychological impact of ENCORE on Australian post-surgical breast cancer patients (N = 162) by comparing the program to a waitlist control.⁽¹⁷⁾ Overall adherence and satisfaction with the program were high with the authors stating, “Our data support the feasibility of the Encore program with high levels of user satisfaction and acceptability evident along with low dropout and high adherence rates...”

Regarding quality of life and the value of the overall program the authors stated, “Significant enhancements at follow-up for quality of life and social support were evident for intervention compared with control participants. Familiarity with exercise and self-efficacy satisfied the requirements for mediation of quality of life. These findings provide evidence for psychosocial benefits of YWCA Encore multi-component program and support the use of such community-based programs for breast cancer survivors.”

Funding

Designed to be free to participants, expansion of the program was originally funded through Avon's Breast Cancer Awareness Crusade. Programs have since been funded through public and community donations, patient support groups, City of Onkaparinga (South Australia), Women's Health Tasmania, The Prostate and Breast Cancer Foundation (New South Wales), Landsdale Roses (Western Australia), the New South Wales Department of Health, South Eastern Sydney Local Health District; Government of Western Australia, Department of Health; and the Commonwealth Department of Health, Driving Social Inclusion through Sport and Physical Activity.

Advisory and operational structure

The program is overseen by an advisory committee consisting in 2024 of six breast cancer specific health professionals. Members of the committee have strong backgrounds in lymphology, epidemiology, physiotherapy and exercise science, and are dedicated to promoting breast cancer rehabilitation. The operational structure is shown in Figure 99.

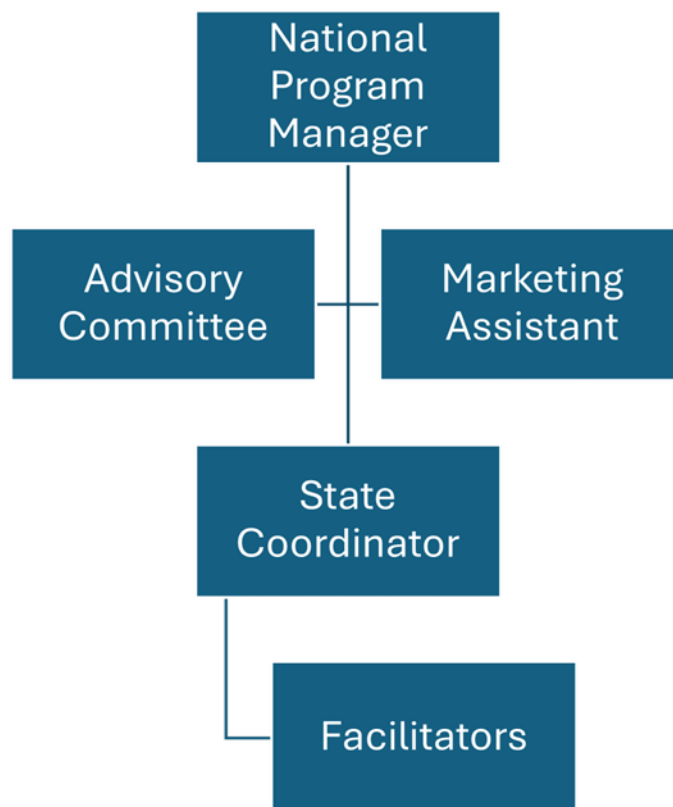


Figure 99 - ENCORE organisational structure

[A flow chart that shows the organisational structure. A national program manager is supported by state coordinators and a team of facilitators. The advisory committee provides input to the national manager. A marketing assistant also assists with program and promotional activities.]

Conclusion

Exercise programmes, like ENCORE, are crucial in aiding the recovery and improving the overall health outcomes of individuals diagnosed with cancer. ENCORE represents the implementation of an evidence-based exercise and rehabilitation program which has improved clinical outcomes and psychosocial wellbeing of women following breast cancer.

CHAPTER SIXTEEN: DIGITAL TRAINING VIA YOUTUBE FOR PATIENTS AND PRACTITIONERS

Chapter overview

This chapter explores the use of YouTube as a platform for digital training of both patients and practitioners. Following an overview of research on YouTube for lymphoedema education, a case study is presented which highlights the innovative use of YouTube to deliver accessible, lymphoedema-specific information on a bandaging product.

YouTube for Instructive Online Information

Instructional online information is an eHealth modality whereby training and education is provided online. Training and education can be posted on online websites, on social media, within video platforms and can also be hosted in Learning Management Systems (LMS). A Learning Management System (LMS) is a digital platform that allows educators to deliver, manage, and track educational content and training programs online. Educational providers, such as universities, use a LMS to streamline course delivery, monitor learner progress, and enhance engagement.⁽⁴²¹⁾ LMS systems often involve significant hosting fees and are designed to limit accessibility through password protection.

Several social media and video hosting platforms offer free access to information. It is not surprising that patients are increasingly turning to digital solutions for health information. Comp et al (2020) highlight the role of digital technology by stating that "...with 72% of the public participating in at least one social media platform, technology has become influential in allowing online communities to interact and share information surrounding similar problems, solutions, and insights."⁽⁴²²⁾

The use of video-based platforms like Vimeo and YouTube for medical education is well-established, and TikTok is increasingly being encouraged for similar purposes. Although the author does not have a TikTok account, there is a concern about being left behind if one does not stay up to date with the latest trends in digital education. Comp et al (2020) state "...in an age where the use of social media is becoming more pervasive in our lives, the medical community should consider harnessing the unique characteristics of TikTok to deliver information to patients as well as for targeted training for medical education".⁽⁴²²⁾

Research on instructional online information for lymphoedema across various video hosting and social media platforms is lacking. Prior research in this thesis, helped the author to learn that YouTube had been investigated as an educational tool in lymphoedema rehabilitation. Kūçükakkaş and İnce (2022) investigated 90 videos uploaded by mostly private healthcare institutions or healthcare professionals (65.6%).⁽¹⁷⁵⁾ The mean duration of the videos was 8.9 ± 10.5 min. Educational quality was assessed using a subjective five point Global Quality Scale, designed by other authors in a separate investigation of online information for inflammatory bowel disease.⁽⁴²³⁾ The scale provides a framework for subjectively assessing the quality and usability of online content in terms of its content and structure.

The authors conclude, “The biggest obstacle for YouTube to be an excellent source of information is that it hosts large volumes of uncontrolled and low-quality data. When YouTube content related to lymphoedema rehabilitation was examined, it was observed that many videos were quite insufficient and incomplete even though there were useful videos. If careful controlling measures are implemented and if medical videos aim to meet reliability and Global Quality Scale criteria, YouTube can become an effective and useful source of information for lymphoedema rehabilitation.”

This research highlights several key points. First, it raises the need to consider the concept that some videos may be useful while others may not. Research in other areas of health, such as YouTube videos about chemotherapy, has found similar results. Sahin and Seyyar (2023) found “...most YouTube videos about chemotherapy were helpful to patients, content quality and reliability were moderate-low.”⁽⁴²⁴⁾ This suggests that variability of information quality is not unique to lymphoedema.

Secondly, consideration of how much video content is required to be assessed in order for a representative sample of data to be analysed. The examination of 90 videos arguably constitutes a small proportion of the extensive video content available on YouTube on the lymphatic system, lymphoedema and chronic oedema. There is also new content added every day. According to an online statistics website, “As of June 2022, more than 500 hours of video were uploaded to YouTube every minute. This equates to approximately 30,000 hours of newly uploaded content per hour.”⁽⁴²⁵⁾ Ongoing research of emerging online education is therefore required.

Thirdly, careful consideration is needed regarding the tools available to researchers for assessing content quality. Instruments like the Global Quality Scale offer a means for rapid subjective assessment of content flow which can help health practitioners determine whether online information is suitable for patients. However, more comprehensive digital assessment frameworks specific to lymphoedema instructional online information could be developed to enable a thorough evaluation.

Among the criteria, more definitive binary indicators could be included, such as assessing the accuracy of lymphoedema definitions within the content (for example “Was there an accurate definition of lymphoedema?": Yes / No) and verifying content alignment with peer-reviewed literature available at the time of publication (for example “Was all content in alignment with published peer reviewed research at the time of publication?": Yes / No).

Finally, the notion of “careful controlling measures” being implemented. The author cautions that such measures are not aligned with YouTube’s intended use. YouTube, as a video hosting platform, is primarily designed to host short, discrete videos on singular topics, allowing open access where anyone can upload content. Consequently, the data is uncontrolled and may vary in quality. Platforms specifically designed for comprehensive educational programs, with built-in quality control mechanisms, are more appropriately aligned with the structure of an LMS.

Social media platforms like YouTube offer the ability to easily share information with other users, making online videos an accessible tool for distributing scientific information to the general public. Kohler et al (2021) support this by stating, “Since social media platforms like YouTube offer the possibility of easily sharing information with other users, online videos are also considered accessible tools for distributing scientific information to the general public.”⁽⁴²⁶⁾ This aligns with the definition of accessibility provided in Chapter One, which includes the concepts of affordability, acceptability, availability, geographic accessibility and the appropriateness and suitability of health services.⁽¹¹⁾

Given YouTube’s free access and the lack of quality control at upload, the platform meets several key dimensions of healthcare accessibility. Its open access makes educational content available to users regardless of their financial situation or geographic location, addressing both affordability and geographic accessibility. YouTube’s widespread popularity and ease of use further support acceptability and availability, enabling individuals to easily access information. However, as previously discussed, the lack of quality control raises concerns about the appropriateness and suitability of health-related content. This lack of oversight may affect the reliability and professional standards of the content.

This leads into an exploration of a case study presenting the use of YouTube as an accessible eHealth modality for disseminating information about a lymphoedema-specific product.

Publication title – An Innovative Approach of Fast'n Go for Lymphoedema Self-Care

Reference

Mangion A, Quach H, Piller N. An Innovative Approach of Fast'n Go™ for Lymphoedema Self-Care. *Journal of Lymphoedema*. 2024;19(1):28-29

Credit

Conceptualisation, methodology, writing – original draft, review, and editing by A.M. Data collection and Writing – review and editing by H.Q. Writing – review and editing, supervision by N.P.

Contribution

A.M. completed 100% of the research design, 90% of the data collection and analysis and 95% of the writing and editing.

Highlights

The key highlights of this research include:

- A demonstration of the use of YouTube to support accessible training of a lymphoedema product for both patients and practitioners
- The documentation of an innovative product designed to improve lymphoedema treatment.

Of importance to note is that the objective of this publication was not to assess the quality of video content or to measure accessibility, but rather to formally document the use of YouTube for lymphoedema education, a topic for which there is a notable lack of published literature.

Publication

Abstract:

Traditional lymphoedema bandaging is time consuming and must be applied by experienced accredited lymphoedema practitioners limiting accessibility. However, the emergence of innovative technologies, such as the patented Fast'n Go™ hybrid bandaging system, offers a solution to enhance patient self-treatment options. The single-layer, multi-component short-stretch bandaging system was developed to empower patients with self-bandaging. Online training, hosted on YouTube, supports the education of accredited lymphoedema practitioners and patients in how to effectively use the system.

Introduction

Lymphoedema is a chronic inflammatory condition that affects millions of people worldwide. It is characterized by the abnormal accumulation of tissue fluid resulting in oedema, fibrosis, and fatty tissue deposition.⁽²⁰⁾

Under the Casley-Smith method of treating lymphoedema, bandaging is a core component of care.⁽⁵⁶⁾ Traditional bandaging can be time-consuming, labour-intensive, and requires specialised training, knowledge and skills. However, advances in technology have led to the development of innovative approaches, such as the patented Fast'n Go™ (Thonic Innovation) hybrid bandaging system

The Fast'n Go™ hybrid bandaging system includes a single-layer, multi-component short-stretch bandage system. The system consists of two components; 1) the bandaging material consisting of a long stretch elastic bandage inserted into an inelastic cotton bandage. When assembled with transversal seams every 10 cm, the stretchability of the elastic bandage is mechanically limited to 30%.to deliver a short-stretch effect and 2) a closure system with a fastening hook. The system is designed to apply around 30mmHg of pressure at rest when applied at full stretch (Figure 100).



Figure 100 - The Fast'n Go™ system

[The Fast'n Go™ system pictured with the two components. The bandage material is white and the closure system is bright blue on one side and white on the other with the words Fast'n Go typed onto the white side.]

The system was designed to overcome two problems associated with self-bandaging: 1) difficulty with self-anchoring of bandages and 2) fast, effective, and safe self-application.

i) Self-anchoring of bandages

Patients self-fastening bandages with traditional bandaging systems is problematic, especially for patients self-bandaging their upper limb, with just one hand to hold the bandage in place and then apply tape to hold the bandage in place (Figure 101). Fast'n Go™ solves this issue through a patented fastening system consisting of a single, soft material band which hooks and loops together when the material is stretched. The closure has been designed to be easy to apply and to remove. It attaches to the bandage with a hook and can be removed very easily if needed.



Fast'n Go Compression Bandage - Application Options

Figure 101 - Online training of Fast'n Go™ showing the anchoring mechanism at the thumb

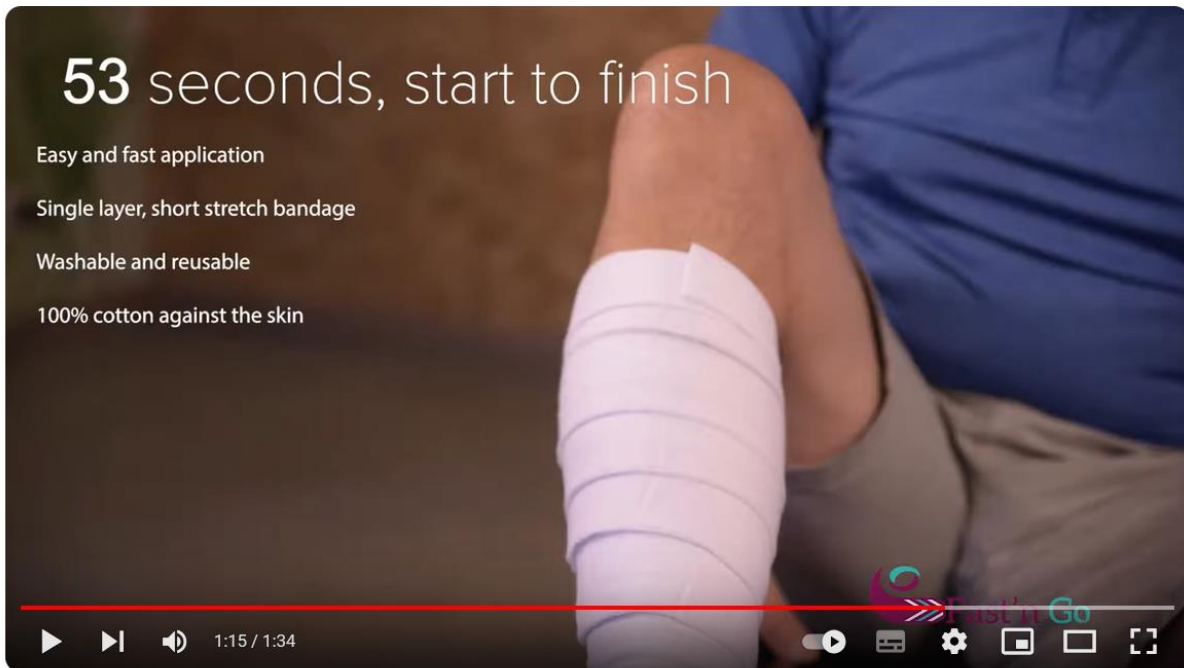
ii) Fast, effective and safe self-application

Patients self-bandaging with traditional bandaging systems, involving two or multiple layers of products that need to be applied in correct order and technique, has risks including skin irritation, discomfort and pain. Rabe and colleagues state, "Severe medical compression therapy-associated adverse events are very rarely encountered if compression is used correctly and contraindications are considered".⁽⁴²⁷⁾ Fast'n Go™ offers a means of providing safe and fast patient application as only one bandage needs to be applied minimising confusion about which product should be applied first. The system includes identical sides of the bandage product removing the need for patients to be concerned with which side of the material is in contact with their skin. There is also a visual guide to assist with bandaging the product at 50% overlap (demonstrated as the blue line in Figure 101).

Virtual Training

Training for Fast'n Go™ is facilitated through digital videos hosted on YouTube, providing a convenient and accessible platform for both accredited lymphoedema practitioners and patients to learn how to effectively utilize the bandaging system.⁽⁴²⁸⁾ Instructional videos offer step-by-step guidance on the setup, operation, application and standard application time of Fast'n Go™, ensuring users have the necessary knowledge and skills to integrate the device into their treatment routines (Figure 102).

By leveraging YouTube the training can be easily accessed from anywhere with an internet connection on computers and mobile devices, empowering both patients and practitioners with the flexibility to learn at their own pace and reinforcing proper techniques for optimal lymphoedema management.



Fast'n Go Compression Bandage - Leg Application

Figure 102 - Online training of the leg application of Fast'n Go™

[Demonstrating that a knee-high self-application can occur in 53 seconds]

Conclusion

The Fast'n Go™ bandaging system represents an innovative means of supporting self-patient care. Free and accessible virtual product training supports both patients and practitioners. As technology continues to advance, innovative technologies which may improve patient care warrant further research. Digital health technologies which allow for accessible lymphoedema education, such as platforms like YouTube, also warrant further research.

Disclosures

No funding was provided for this publication. Hugh Quach is the Australian Distributor of Fast'n Go™.

CHAPTER SEVENTEEN: QUALITATIVE PERSPECTIVES ON VIRTUAL WOUND AND LYMPHOEDEMA SERVICES

Chapter overview

This chapter presents the results of a publication containing qualitative perspectives on issues concerned with running a virtual wound and lymphoedema service.

Highlights

The key highlights of this research include:

- A demonstration of the successful implementation of telehealth services within New South Wales (NSW) Health
- The provision of key insights from two experienced virtual wound care practitioners
- The creation of a helpful checklist designed to empower lymphoedema practitioners in setting up their own virtual services within NSW Health.

Publication title – Virtual Wound and Lymphoedema Services – An Exploration of Qualitative Perspectives From Virtual Practitioners

Reference

Mangion A, Leahy C, McCormack B, and Piller N. Virtual Wound and Lymphoedema Services – An Exploration of Qualitative Perspectives From Virtual Practitioners. Informatics and Health. Submitted August 2024.

Credit

Conceptualisation, methodology, and writing original draft, review, and editing by A.M.
Methodology, investigation, and writing review and editing by C.L
Methodology, investigation, and writing review and editing by B.M.
Writing - editing and supervision by N.P.

Contribution

A.M. completed 50% of the research design, 50% of the data collection and analysis and 50% of the writing and editing.

Publication

Abstract:

Virtual wound care nursing is revolutionising healthcare delivery by leveraging digital technologies to provide accessible, timely, and efficient care to patients, regardless of their geographic location. This approach allows healthcare providers to remotely assess and manage wounds, offering real-time guidance on wound care practices, and monitoring the healing progress through telehealth platforms.

This paper explores the rationale behind setting up a public virtual wound and lymphoedema service and provides qualitative perspectives of the role of virtual services from two experienced wound care practitioners. This paper also explores considerations for accessible and efficient virtual services through a virtual care delivery framework. A checklist has been created to serve as a helpful tool for virtual service providers in the consideration of people, processes and technology which impact wound and lymphoedema virtual services.

Background

Lymphoedema is a chronic inflammatory condition characterised initially by the accumulation of tissue fluid arising from impaired lymphatic drainage.⁽⁴²⁹⁾ Impaired lymphatic drainage alters wound healing pathophysiologically and immunologically with impairment of tissue remodelling, increased internal tissue pressure leading to microcirculatory ischemia, and accumulation of cell debris.⁽⁴³⁰⁾

Lymphoedema necessitates wound care nursing due to its association with complications like lymphorrhoea and cellulitis, as well as in conditions such as venous insufficiency or phlebolymphoedema, where venous ulceration is common.^(30, 33, 431, 432) Embedding specialist lymphoedema services into community nursing and wound services has been shown to offer significant reductions in resource allocations including staff visits, cellulitis admissions, compression consumables and wound dressing costs.⁽⁴³³⁾

Broader than lymphoedema and chronic oedema care alone, it is estimated that 345 000 people in Australia live with chronic wounds, costing the health care system \$2.85 billion annually.⁽⁴³⁴⁾ Both cost effective and clinically effective models of care for delivering wound care services are therefore required.

Virtual wound care services have become increasingly essential, particularly in the post-pandemic era, as the pandemic accelerated the adoption of telehealth technologies.⁽⁴³⁵⁾ In an example of Australian research by Barakat-Johnson and colleagues (2022), the viability and acceptability of virtual wound care services was demonstrated through the provision of cost effective and clinically effective care.⁽⁴³⁶⁾ In the study a total of 61 wounds were analysed over seven months. Patients received, on average, an occasion of service every 4.4 days, with direct queries responded to in a median time of 1.5 hours. During the study period, 26 (42.6%) wounds were healed, and all patients reported high satisfaction with their wound care.

Methods

Qualitative data was gathered through interviews with two experienced wound care practitioners from New South Wales (NSW) Health, who contributed as both subject matter experts and co-authors. The practitioners provided descriptive statistics on the outcomes of their virtual wound care services. Since this study did not involve direct collection of patient data, ethics approval was not required.

For the development of a checklist NSW Health guidance on digital health was reviewed. The NSW Virtual Care Strategy (2021-2026) was selected due to its currency and relevance to services within NSW Health.⁽⁴³⁷⁾

The rationale behind setting up a public virtual wound and lymphoedema service

Western NSW Local Health District (LHD), located in Australia, is a uniquely challenging healthcare environment characterised by its vast geographical expanse, encompassing a mix of rural, remote, and Indigenous communities. Covering an area of approximately 250,000 square kilometres, it is one of the largest health districts in NSW, yet it has a relatively small and dispersed population.⁽⁴³⁸⁾ The district faces significant health challenges, including a higher prevalence of chronic diseases such as diabetes, cardiovascular conditions, and respiratory illnesses. Mental health issues are also more common, exacerbated by social isolation and limited access to mental health services. The Indigenous population in the region experiences significant health disparities, with higher rates of chronic disease, lower life expectancy, and poorer overall health outcomes compared to the non-Indigenous population. Additionally, the district grapples with higher rates of preventable conditions due to limited access to early intervention and preventive care.

Given these challenges, the need for telehealth and virtual care services is critical. These services help overcome the barriers posed by geographic isolation and workforce shortages by providing timely access to healthcare expertise that would otherwise be unavailable.^(439, 440) Telehealth allows patients to receive specialist consultations, follow-up care, and ongoing monitoring without the need for long distance travel, which is often not feasible for many residents. This approach is particularly important in managing chronic diseases, where regular monitoring and early intervention can prevent complications, long term chronicity and reduce hospital admissions.^(130, 441)

Catherine, a Wound Prevention and Management Clinical Nurse Consultant established the virtual wound service for Western NSW LHD in 2018, bringing her extensive expertise in wound care to the forefront of this innovative service. Bonnie, who joined Catherine's team in 2022, is a Transitional Nurse Practitioner. In 2023, she further expanded her expertise by becoming a certified lymphoedema therapist. Together, they are dedicated to advancing virtual wound care, ensuring that patients across the district receive high-quality, accessible care regardless of their location.

The Virtual Wound Consultancy Service (VWCS) has treated 100 patients in 2023 and 54 patients January to July in 2024. The service was established to address the challenge of accessing wound care expertise in rural and remote regions, where a lack of wound specialists contributed to poor patient outcomes and higher healthcare costs.⁽⁴⁴²⁾ The goals of the service included supporting clinicians in community and residential aged care settings, providing expert consultancy, building wound management capacity across the health district, and guiding clinicians in delivering evidence-based care.

By helping clinicians assess wounds, identify causes, select appropriate treatment pathways, and escalate care when necessary, the service has enhanced the quality of care for people living with wounds. Additionally, it has minimised the need for patients to travel to centralised facilities, creating more efficient escalation pathways.

Telehealth enhances healthcare in rural and remote regions by improving access to services, reducing costs, and enabling timely healthcare interventions.^(439, 440, 443) It ensures continuity of care, especially for chronic conditions, and provides access to specialists who are not available locally. Telehealth fosters collaboration between local providers and specialists, enhancing continuity and quality care.⁽⁴⁴³⁾ This modality enables real time education for consumers and healthcare professionals alike, assisting with the delivery of high-quality accessible care to all individuals, no matter their geographical location. Telehealth is a crucial tool for improving healthcare outcomes and ensuring equitable access in rural and remote areas worldwide.⁽⁴⁴⁴⁾

In 2022, the VWCS expanded from focusing solely on chronic and complex wound care to also include lower limb lymphoedema management. This strategic expansion reflects our commitment to providing comprehensive care that addresses a broader spectrum of patient needs. By integrating lymphoedema management into our virtual care model, we are enhancing our ability to offer timely, specialised and targeted treatment and support for patients dealing with both chronic wounds and lymphoedema wounds, provide treatment recommendations, and adjust care plans as needed. This continuity of care helps prevent complications, promotes faster healing, and enhances patient outcomes.

The widespread use of telehealth during the pandemic has proven that virtual healthcare can be both effective and efficient. Patients and healthcare providers have become more comfortable and proficient with digital health platforms, leading to greater acceptance and integration of these technologies into routine care. Virtual wound care services also offer the advantage of reducing healthcare costs by minimising the need for emergency visits and hospital admissions. They enable healthcare professionals to provide personalised care and education, empowering patients to manage their conditions more effectively at home. As the healthcare landscape continues to evolve, virtual wound care services are set to play a crucial role in delivering accessible, high-quality care, meeting the growing demand for innovative and flexible healthcare solutions.^(441, 445) This extension of services not only improves care coordination and patient outcomes but also ensures that individuals with complex conditions receive the holistic and integrated care they require.⁽⁴⁴⁵⁾

Qualitative perspectives on the role of virtual services

As an experienced wound care practitioner, Catherine believes the role of the Virtual Wound Consultancy Service is to bridge the gap between patients and specialised care, particularly in rural and remote areas. She views virtual services as essential for expanding access to high-quality wound care, reducing healthcare disparities, and enhancing the efficiency of care delivery. Catherine sees these services as pivotal in empowering clinicians with the tools and support they need to deliver evidence-based care, all while ensuring that patients receive timely, effective treatment regardless of their geographic location. Additionally, she believes that virtual services play a crucial role in fostering innovation in healthcare, enabling more flexible, patient-centred approaches that can adapt to the evolving needs of the population.

Bonnie believes that telehealth can address health system challenges by improving access, patient engagement, clinician empowerment and the delivery of specialised care to those who need it. A significant concern in Australia is the lack of lymphoedema services, particularly in rural and remote communities.⁽⁴⁴⁶⁾ This shortage often forces individuals with lymphoedema in non-metropolitan areas to either forgo necessary treatment or travel long distances at considerable cost to access care.⁽³⁷⁾

Expanding the Virtual Wound Consultancy Service to include lower limb lymphoedema assessment and management offers several key benefits. It enhances clinician education and training, ensuring healthcare professionals are well-equipped to manage complex cases.

Continuity of care is strengthened through the integration of comprehensive management of both chronic wounds and lymphoedema, while consumer education and engagement are fostered by accessible virtual resources on mobile or computer devices. This expansion not only improves access to specialist assessments and recommendations, leading to better health outcomes, but also promotes preventative care by enabling remote assessments and encouraging patients to take proactive steps in their health management.⁽⁴⁴⁷⁾

Virtual wound care services allow patients to receive timely, cost-effective expert care without the need to travel, which is especially beneficial for those with mobility issues or those living in remote areas. These services facilitate regular monitoring and consultation through video calls, digital images, and other telecommunication tools, ensuring that wound care teams can suitably care for their patients.

Considerations for accessible and efficient quality of care for patients

The NSW Virtual Care Strategy (2021-2026) published by NSW Health sets out guidance for telehealth and virtual wound services to achieve accessible and efficient quality of care for patients irrespective of where they live.⁽⁴³⁷⁾ The Strategy outlines a virtual care delivery framework which can be used by services as a basis for planning for effective virtual services. The framework has been modified into a checklist to empower anyone using this paper to understand considerations for wound and lymphoedema virtual services (Table 19).

Catherine and Bonnie's application of this framework to their virtual service is reflected in their strategic investment in people, processes, and technology. Their approach underscores the importance of a comprehensive and multifaceted strategy to running a successful virtual service. This involves addressing various complexities, such as recruiting and training suitably skilled staff, ensuring robust and user-friendly technology platforms, and establishing streamlined processes that support both clinicians and patients. Fundamentally the focus on continuous improvement and adaptability has enabled the service to evolve in response to emerging challenges and needs.

“The running of a successful virtual service involves many complexities, including not only the technical aspects of telehealth but also the human elements, such as building trust with patients and fostering a culture of collaboration among healthcare providers. The service must be agile, responsive to feedback, and committed to ongoing education and support for both staff and patients,” explains Catherine. This qualitative perspective highlights the intricate balance required to maintain high standards of care while navigating the unique challenges of virtual healthcare delivery.

The need to provide culturally appropriate care to diverse populations, while maintaining the quality and consistency of services, adds another dimension to the complexity. These factors, combined with the ongoing need to measure outcomes, gather data, and refine the service based on evidence and patient feedback, make the management of a virtual wound and lymphoedema service a highly dynamic and challenging endeavour.

Conclusion

Virtual wound and lymphoedema services allow patients to receive timely, targeted and cost-effective rural and remote care. Virtual services are established to overcome health system challenges including insufficient supply of services in rural areas and high costs associated with in-person care. They are also established due to provide a service to multiple communities simultaneously, allowing resources to be used more effectively across a broader range of areas. Running and effective virtual service involves many factors such as having suitably trained staff, effective marketing, technology and systems.

Table 19 - Checklist for a wound / lymphoedema virtual service based on the NSW Government's Virtual Care Strategy

Virtual care delivery framework component	Considerations for wound and lymphoedema virtual services	Check box (tick)
Invest in people	Develop a virtual capability framework for staff which includes the values, behaviours, confidence, and digital skills required for the wound/lymphoedema service. Invest in training staff to have specialised skills through wounds and lymphoedema specific training. For lymphoedema training, consider the Australasian Lymphology Association's (ALA) framework for suitable qualifications such as the completion of an ALA recognised lymphoedema course in the Casley-Smith method of lymphatic therapy.	
	Support consumer involvement in virtual care service design and delivery through engaging consumer representatives. Patient advocates that have experienced chronic wounds and patients living with lymphoedema should be consulted with.	
	Build and strengthen partnerships with education providers or build capability in your team to develop wound and lymphoedema educational resources.	
	Raise awareness of virtual wound and lymphoedema care, address misconceptions, and promote benefits of virtual wound/lymphoedema with patients, carers, families and communities	
	Promote the benefits of virtual wound/lymphoedema care and build acceptance amongst clinicians and health staff.	
	Optimise the efficiency and flow of virtual care consultations, as well as giving it a human face, through a moderator or concierge, rather than relying on self-management from day one.	
	Support equitable access including for people with disability, older people and people from culturally and linguistically diverse backgrounds. Accessibility guidelines should be followed such as the international Web Content Accessibility Guidelines (WCAG).	
	Support Aboriginal populations to use wound/lymphoedema virtual care and ensure virtual care is considered culturally safe.	
	Engage and strengthen the skills of local champions to support local staff.	
Consider internet connectivity and general accessibility for those living in rural and remote areas.		

Virtual care delivery framework component	Considerations for wound and lymphoedema virtual services	Check box (tick)
Designing processes	Re-orientate funding models towards wound/lymphoedema virtual services.	
	Embed wound/lymphoedema virtual care into clinical governance frameworks.	
	Support decision making to use wound/lymphoedema virtual care.	
	Prioritise the roll-out of wound/lymphoedema virtual care across the system based on the highest value for patients and clinicians.	
	Ensure virtual wound/ lymphoedema devices are suitable, integrated and simple.	
	Enable effective wound/lymphoedema digital system scaling.	
	Enable effective wound/lymphoedema change management.	
	Initiate wound/lymphoedema monitoring and evaluation.	
	Consolidate Patient Reported Measures/	
	Facilitate Safety Intelligence for wound/lymphoedema virtual care.	
	Integrate wound/lymphoedema virtual care into local planning contexts/	
	Develop guidance/policy that enables and supports people, process and technology to deliver dynamic integrated shared wound/lymphoedema care management in partnership with the patient.	
	Collaborate with stakeholders on initiatives that support wound/lymphoedema virtual care delivery.	
Build technology	Drive the technology roll-out to meet the needs of the system, patients and clinicians for wound/lymphoedema virtual care.	
	Manage health care record integration through moving or recording wound/lymphoedema virtual care occasions of service into patient records.	
	Address data privacy and device security risks.	
	Leverage innovation by looking out for technology advances for wound/lymphoedema virtual services.	
	Build a central portal to coordinate existing and new wound/lymphoedema virtual care apps.	
	Create a virtual care simulation unit for testing new wound/lymphoedema virtual care technologies.	

CHAPTER EIGHTEEN: DEVELOPMENT OF A LYMPHOEDEMA CHATBOT

Chapter overview

This chapter details the processes and lessons involved with building a lymphoedema-related chatbot.

Highlights

The key highlights of this research include:

- A prototype of a rules based and artificial intelligence-driven chatbot was successfully developed
- An in depth understanding of factors influencing chatbot development were obtained
- The prototype was able to accurately select specific lymphoedema products (such as a pink armsleeve).

Prototype development - chatbot

Aim

The objective of this research was to build a prototype of a chatbot. The questions the research aimed to answer were: “What are the processes involved with building a lymphoedema specific chatbot?” and “Can the chatbot retrieve lymphoedema specific queries?”

Background

“Chatbots consist of software that can establish a sequential conversation looking for a certain result as a facilitating tool for humans with whom it interacts.”⁽⁴⁴⁸⁾ ELIZA (Figure 103) was an early natural language processing computer program developed by Joseph Weizenbaum.⁽⁴⁴⁹⁾ ELIZA was created to explore communication between humans and machines by simulating conversation.

```

Welcome to
          EEEEE  LL      IIII  ZZZZZ  AAAAA
          EE     LL      II     ZZ     AA  AA
          EEEEE  LL      II     ZZZ   AAAAAA
          EE     LL      II     ZZ     AA  AA
          EEEEE  LLLLLL IIII  ZZZZZ  AA  AA

Eliza is a mock Rogerian psychotherapist.
The original program was described by Joseph Weizenbaum in 1966.
This implementation by Norbert Landsteiner 2005.

ELIZA: Is something troubling you ?
YOU:   Men are all alike.
ELIZA: What is the connection, do you suppose ?
YOU:   They're always bugging us about something or other.
ELIZA: Can you think of a specific example ?
YOU:   Well, my boyfriend made me come here.
ELIZA: Is it important to you that your boyfriend made you come here ?
YOU:   He says I'm depressed much of the time.
ELIZA: I am sorry to hear that you are depressed.
YOU:   It's true. I am unhappy.
ELIZA: Can you explain what made you unhappy ?
YOU:

```

Figure 103 - ELIZA

[Public domain image obtained from https://commons.wikimedia.org/wiki/File:ELIZA_conversation.png. No changes made.]

Other famous chatbots through time include Alice, Clippy, Alexa, Cortana, Watson, Bixby and most recently ChatGPT (Figure 104).

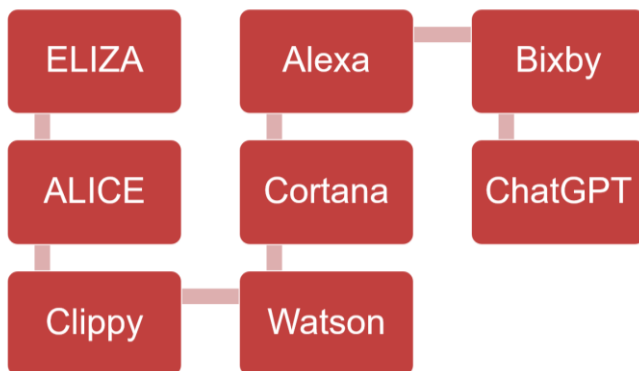


Figure 104 - Famous chatbot names

There are three different types of chatbots:

- Rules-based - give a specific reply based on the rule e.g. query XYZ equals ABC
- Smart - rely on large data sets to inform their responses.
- Hybrid - use a combination of rules based systems and hybrid systems.⁽⁴⁴⁸⁾

Ayers et al (2023) compared the responses of physicians and chatbots to patient questions posed on a public social media forum (Reddit's r/AskDocs).⁽³⁵²⁾ The quality and empathy of chatbot responses were rated. Ratings were significantly higher for the chatbot responses than those of physician responses (3.6 times higher prevalence of good or very good quality responses for the chatbot). Further research is therefore warranted.

Method

A prototype chatbot was developed to facilitate learning during its creation and to produce a research prototype. The project development considerations (Figure 105) were:

- Solution mapping - What is the problem I am trying to solve?
- Building - How do I build the chatbot? What software do I use?
- Testing - How do I test it? (The prototype build did not go into the testing phase. Testing considerations did however inform the build.)
- Deployment - How would I deploy the solution? (The prototype was not formally deployed further testing was required prior to this.)
- Continuous improvement (CI) - How could I ensure it was continuously improved? (The prototype went through several rounds of CI in its development. Further CI would be required after testing and on an ongoing basis after deployment.)

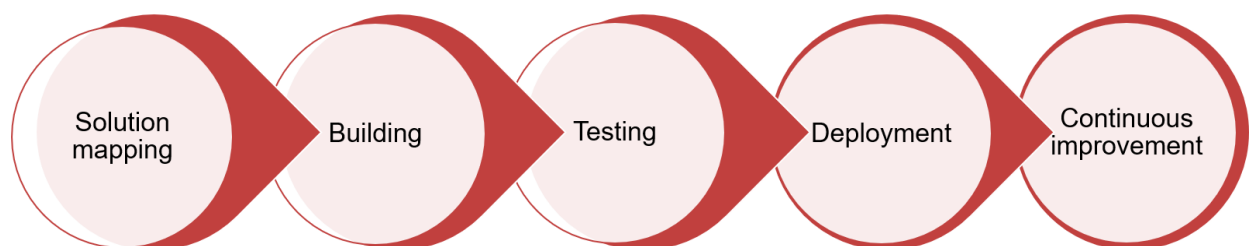


Figure 105 - Product development considerations)

Solution mapping

The chatbot looked this on the home screen (Figure 106). It was designed to solve four common query types:

- Training - I need to be trained and where can I find lymphoedema training?
- Searching - I need help searching for information on the website
- Sourcing - I need help sourcing a product
- A therapist - I need help finding a therapist

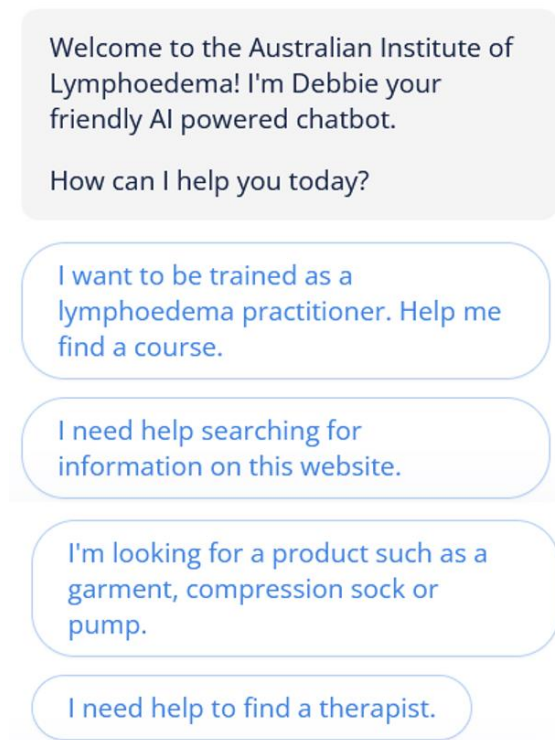


Figure 106 - Chatbot home screen

Building

A hybrid chatbot was used which relied on both rules as well as AI. Several software pieces were used:

- Chatbot building software (Voiceflow)⁽⁴⁵⁰⁾
- Electronic database (Airtable)⁽⁴⁵¹⁾
- Artificial intelligence source (ChatGPT)⁽³⁶⁶⁾
- JavaScript code.⁽⁴⁵²⁾

The rules were entered into the Chatbot building software. The responses were generated through a mixture of rules based (pulling from the electronic database) as well as AI (pulling from the AI source).

A. Database

A database was built in Airtable. A sample of the database is below showing the first few columns (Figure 107). For feasibility testing, the database was built out with 41 different products. This allowed testing of specific queries for scar products, skin care products, low level lasers, compression garments and compression pumps.

The columns were designed to allow the chatbot to pull data based on rules-based queries (e.g. if the condition is “true” for colour pink, pull all pink options “and” if the condition is “true” for arm sleeve, exclude other garment options which are not arm sleeves.) The rules involved consideration of several factors such as the category of garment, the garment style, body part, colour, purpose, symptoms and what the product was suitable for. The database allowed for an image of the relevant product to be uploaded which would then display to the patient as an available solution.

A sample of the database where “true” conditions were entered is shown (Figure 108). Each product was linked to whether it was relevant to lymphoedema, pregnancy, diabetes, ulcers and lipoedema. Lymphoedema symptoms-based queries were also entered through key terms such as swelling or varicose veins.

B. Mapping

A screenshot showing the complex mapping for each of the 4 questions is below (Figure 109).

<input type="checkbox"/>	productname	category	buy	garmentstyle	bodypart	descriptiontext	color
10	Sigvaris Traditional Armsleeve - Wrist to Top of Arm	Arm sleeve	If you don't have much or any swelli...	armsleeve	arm	Armsleeve designed for swelling of...	Beige
11	Sigvaris Traditional Armsleeve - Knuckles to Top of ...	Arm sleeve	If you don't have much or any swelli...	armsleeve	arm	Armsleeve designed for swelling of...	Beige
12	Sigvaris Secure Lite Armsleeve - Wrist to Armpit	Arm sleeve	If you don't have much or any swelli...	armsleeve	arm	Armsleeve designed for swelling of...	Pink
13	Sigvaris Wrap - knee high for lower leg venous ulce...	Wrap	If you don't have much or any swelli...	knee high garment	leg		Black
14	Sigvaris Wrap - knee high for lower leg lymphoede...	Wrap	If you don't have much or any swelli...	knee high garment	leg		Black
<input type="checkbox"/>	Sigvaris Wrap - knee high for diabetes and poor cir...	Wrap	If you don't have much or any swelli...	knee high garment	leg		Black
16	Sigvaris Wrap Liner without compression - for diab...	Wrap	If you don't have much or any swelli...	knee high garment	leg	A grey sock designer to keep your ...	Grey
17	Sigvaris Wrap Liner without compression	Wrap	If you don't have much or any swelli...	knee high garment	leg	A grey sock designer to keep your ...	Grey
18	Sigvaris Secure Glove	Glove	If you don't have much or any swelli...	glove	hand		Pink
19	Sigvaris Style Silhouette Leggings	Stocking	If you don't have much or any swelli...	pantyhose or waist height	leg	Stylish, subtle ribbed design looks ...	Black
20	Sigvaris Microfibre Shades Calf - knee high socks	Stocking	If you don't have much or any swelli...	knee high garment	leg	Knee highs socks offering 15-20m...	Black
21	Sigvaris Athletic Recovery Calf - white knee high soc...	Stocking	If you don't have much or any swelli...	knee high garment	leg	Knee high sports socks offering 15...	White
22	Sigvaris Athletic Recovery Calf - black knee high soc...	Stocking	If you don't have much or any swelli...	knee high garment	leg	Knee high sports socks offering 15...	Black
23	Sigvaris Eversoft diabetic sock	Stocking	If you don't have much or any swelli...	knee high garment	leg	These socks are designed for ever...	White
24	Sigvaris Flat Knit garments	Garment	If you don't have much or any swelli...		leg		Beige
25	Haddenham Comfiwave armsleeve	Arm sleeve	These garments must be purchased...	armsleeve	arm		Grey
26	Haddenham Comfiwave breast	Bra	These garments must be purchased...	breast garment	breast		Grey
27	Medi-Rent pneumatic compression pump	Medical device	You can rent a pump from Medi-Re...	pump garment			
28	Jobst Bella Lite armsleeve	Arm sleeve	These garments should be prescrib...	armsleeve	arm		Beige
29	MooGoo cream	Cream	You can buy direct from MooGoo o...				
30	Siltape scar tape	Tape	You can buy from a distributor calle...				

Figure 107 - Sample of data entered into the database

	productname	lymphoedema	pregnant	diabetes	ulcers	lipoedema	symptoms	
10	Sigvaris Traditional Armsleeve - Wrist to Top of Arm	true				true	swelling	lym
11	Sigvaris Traditional Armsleeve - Knuckles to Top of ...	true				true	swelling	lym
12	Sigvaris Secure Lite Armsleeve - Wrist to Armpit	true				true	swelling	lym
13	Sigvaris Wrap - knee high for lower leg venous ulce...	true		true	true		wound	ulce
14	Sigvaris Wrap - knee high for lower leg lymphoede...	true		true	true		swelling	lym
15	Sigvaris Wrap - knee high for diabetes and poor cir...	true		true	true		wound	dial
16	Sigvaris Wrap Liner without compression - for diab...	true		true	true		swelling	dial
17	Sigvaris Wrap Liner without compression	true		true	true		swelling	ulce
18	Sigvaris Secure Glove	true				true	swelling	lym
19	Sigvaris Style Silhouette Leggings		true				varicose veins	vari
20	Sigvaris Microfibre Shades Calf - knee high socks	true				true	varicose veins	
21	Sigvaris Athletic Recovery Calf - white knee high soc...						swelling	spo
22	Sigvaris Athletic Recovery Calf - black knee high soc...						swelling	spo
23	Sigvaris Eversoft diabetic sock			true			wound	dial
24	Sigvaris Flat Knit garments	true					swelling	
25	Haddenham Comfiwave armsleeve	true					hardness	swc

Figure 108 - Linking products to the overarching health condition

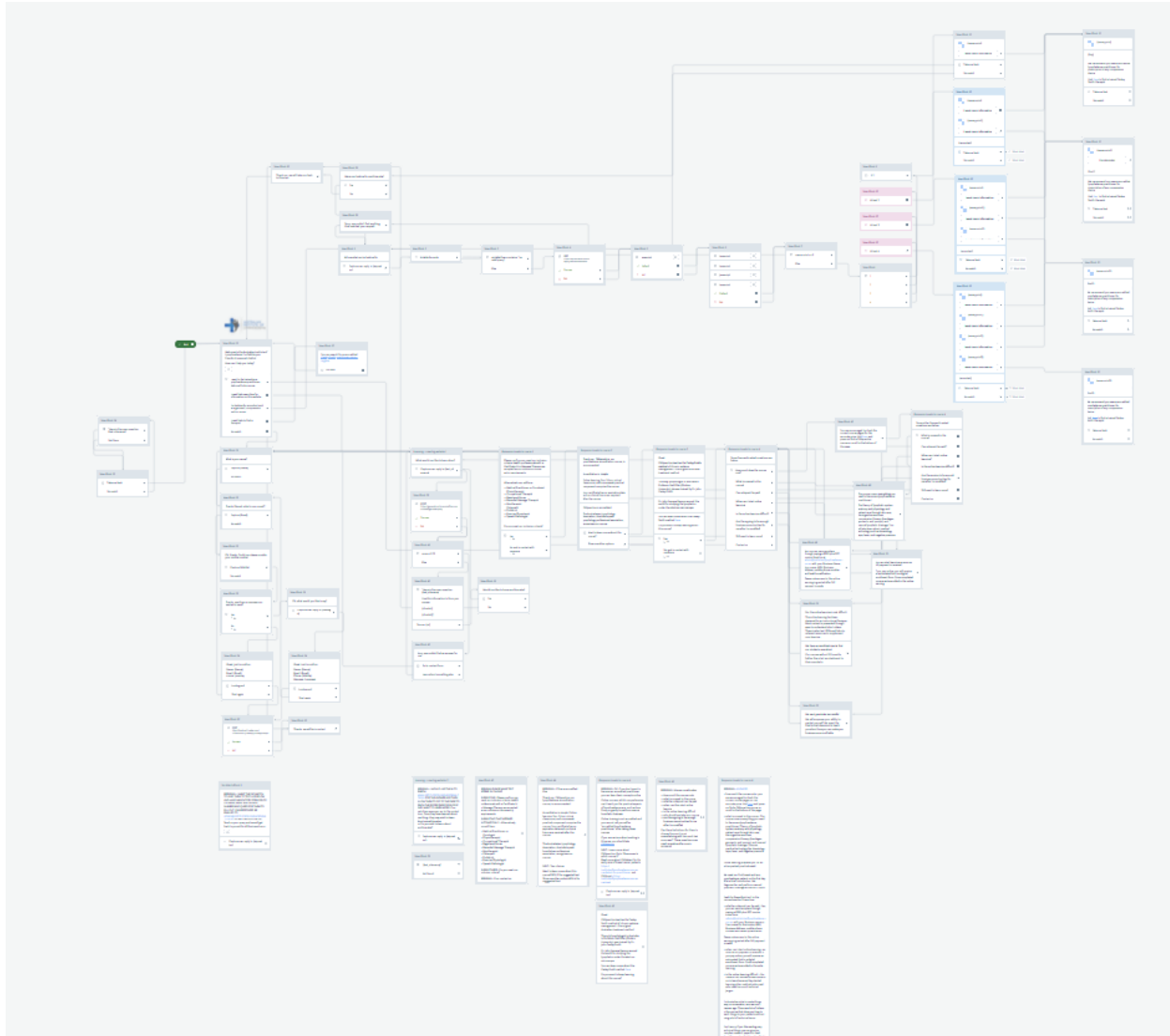


Figure 109 - Mapping for each of the four chatbot questions

[Note – this picture is not designed to be read. It is designed to allow for a bird’s eye view of the complexity of the mapping involved.]

The mapping for each question varied in complexity. The least complex was the first query "I need help to find a therapist" (Figure 110).

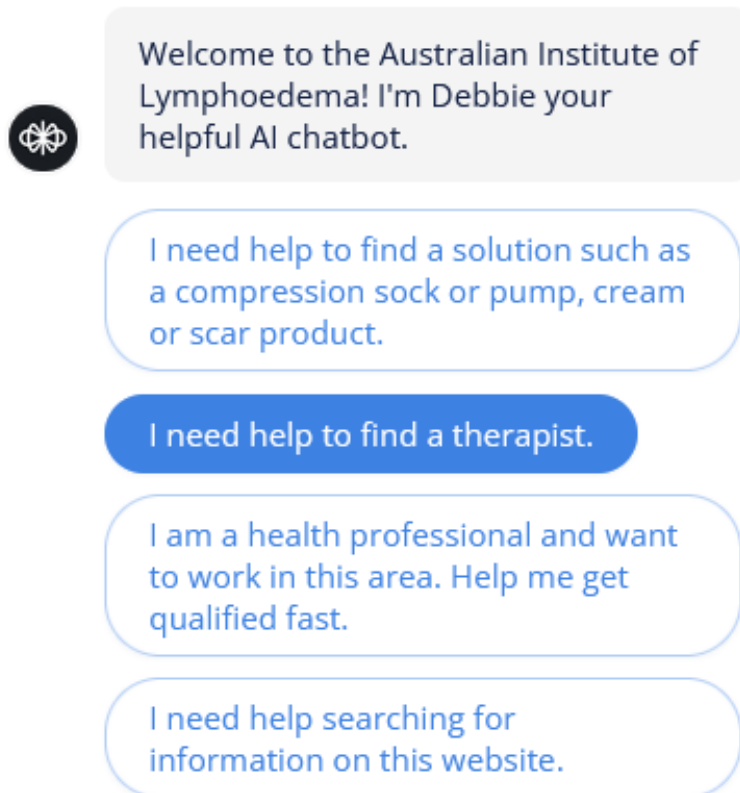


Figure 110 - Query of "I need help to find a therapist"

The chatbot was programmed to provide one option only for this response (Figure 111). By design the chatbot was to send the patient to either a database of Casley-Smith trained therapists or to the Australasian Lymphology Association's National Lymphoedema Practitioner Register (NLPR) database.

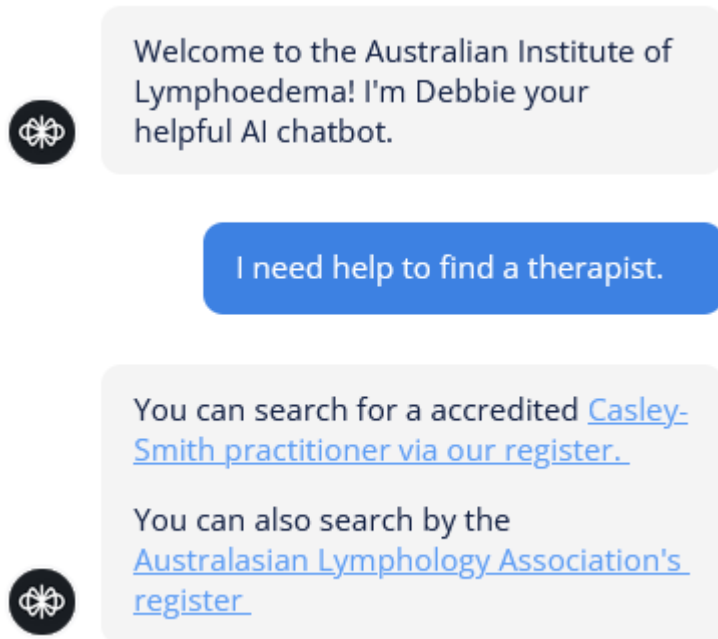


Figure 111 - Chatbot response to "I need help to find a therapist"

In the backend of the chatbot, the mapping was simple with one arrow to the suitable response (Figure 112).

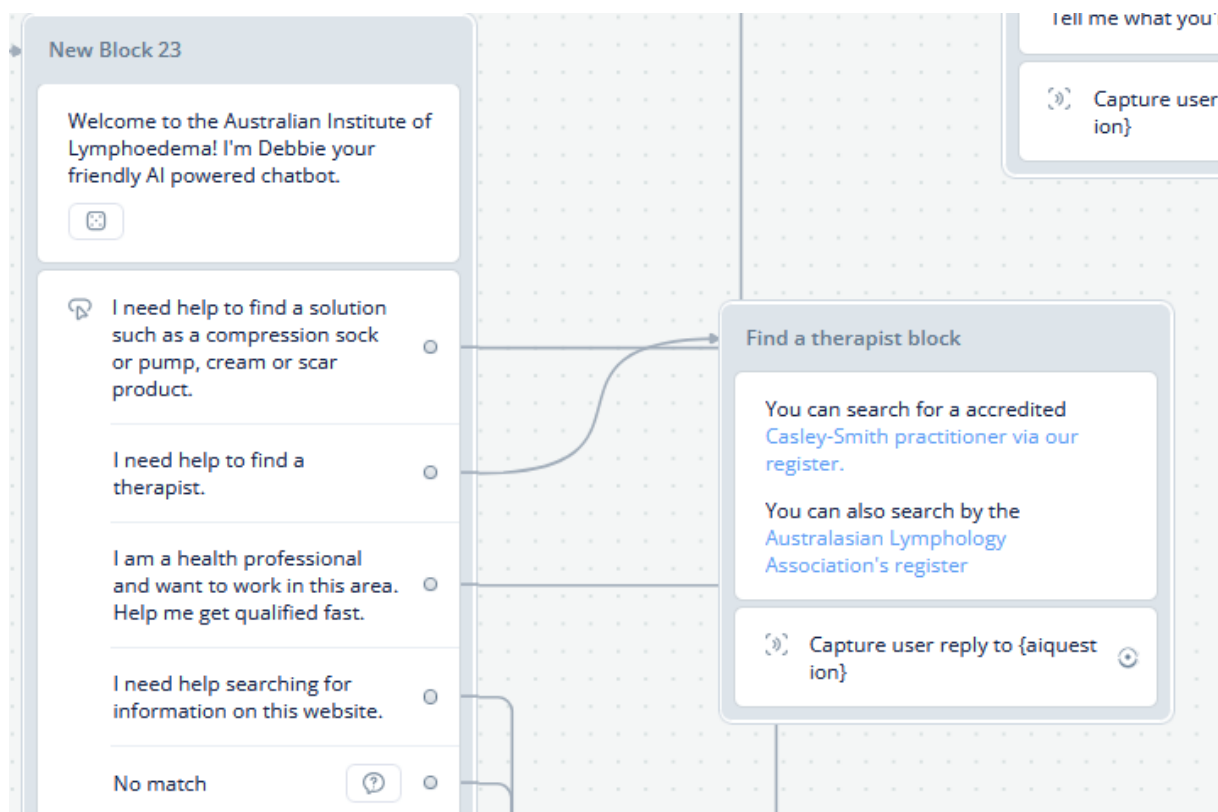


Figure 112 - Find a therapist block

Another block which did not involve complex mapping, was the second query, “I need help searching for information on this website.” For this query, we asked the chatbot to rely on a separate database created within Voiceflow, a Knowledge Base (KB) relying on sourcing data from the sitemap of a website (<https://www.instituteoflymphoedema.com.au/sitemap.xml>). The KB is a vector database allowing own documents and website data to be leveraged to power answers and define variables.

How to set up the KB through a sitemap as the source of information is shown in Figure 113.

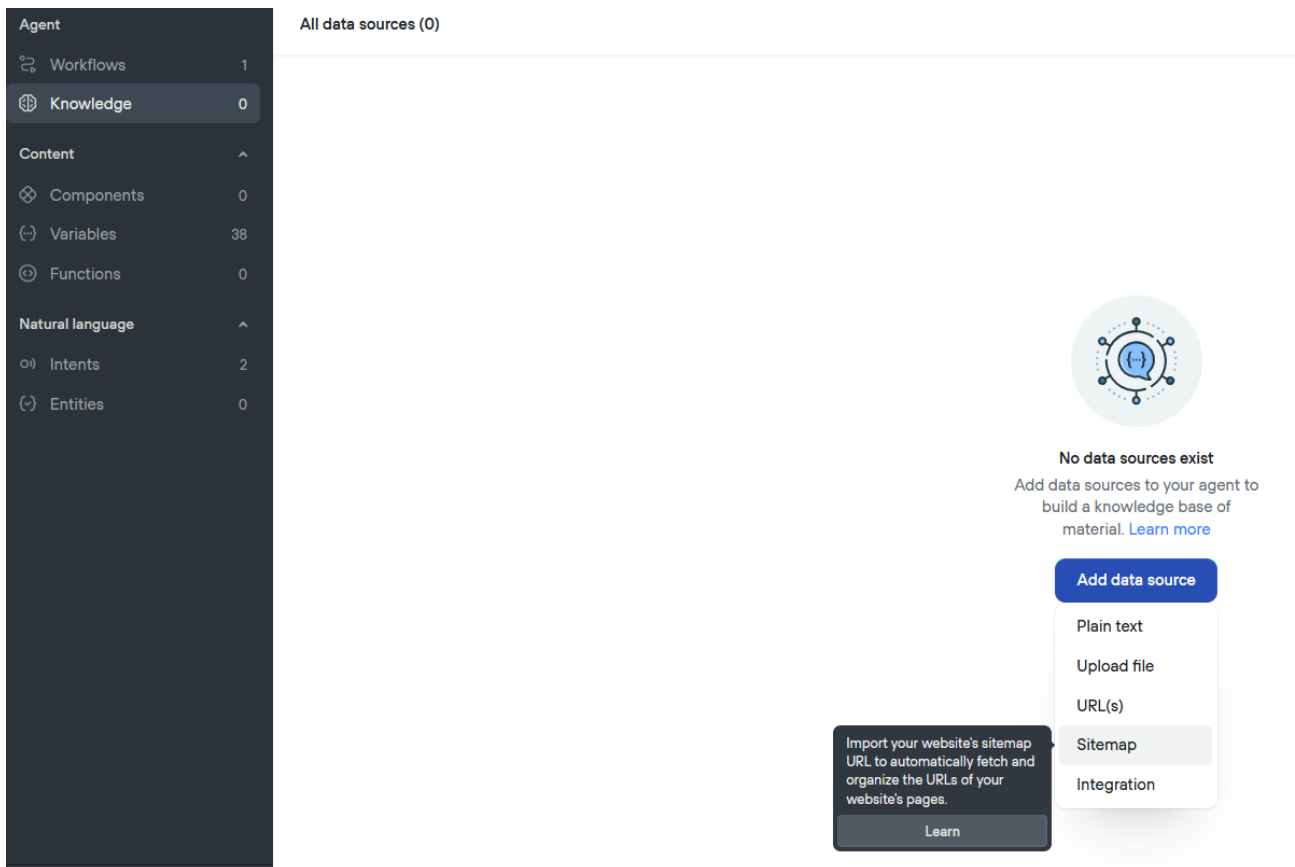


Figure 113 - How to pull data from a website through the sitemap of a prepopulated website

The third query was “I am a health professional I am a health professional and want to work in this area. Help me get qualified fast.” As response accuracy was required, specific answers were put into the chatbot as opposed to relying on a KB or AI. A sample of the detailed responses are included below (Figure 114). Similar to how a salesperson would run through a series of pre-qualification questions, the chatbot asked the same questions, in the same order, which would have been asked over the phone.

Questions such as:

“Please confirm you meet our inclusion criteria. Health professionals with a Certificate IV in Massage Therapy are accepted as our minimum course entry requirements. Alternatively, you will be a:

- Medical Practitioner or Oncologist
- Physiotherapist
- Occupational Therapist
- Registered Nurse
- Remedial Massage Therapist
- Myotherapist
- Osteopath
- Podiatrist
- Exercise Physiologist
- Speech Pathologist

Do you meet our inclusion criteria?”

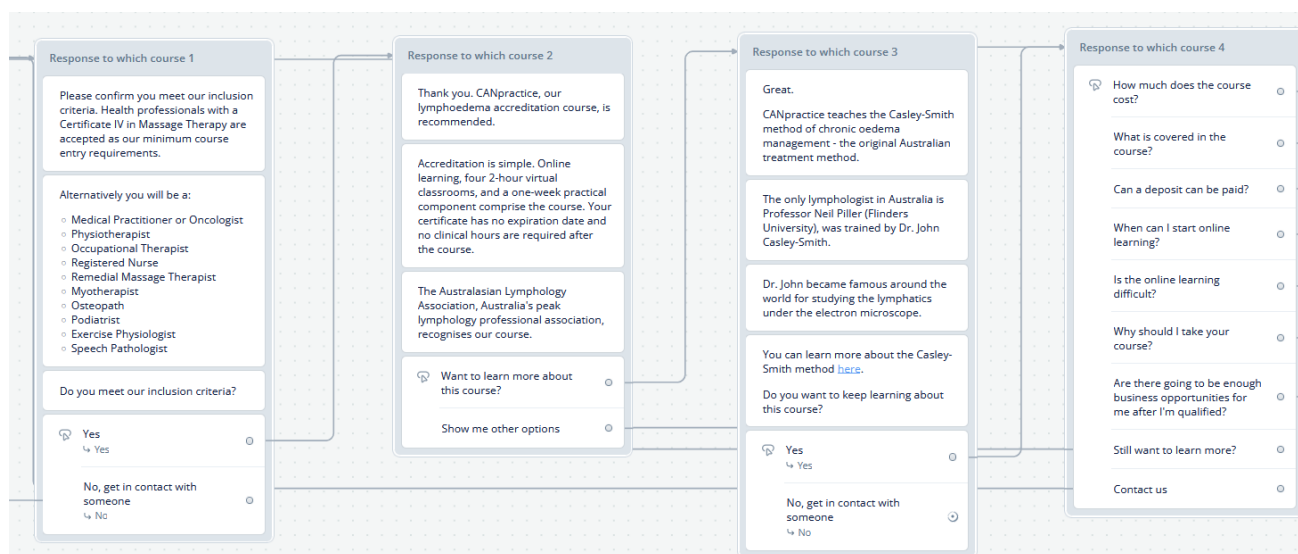


Figure 114 - Sample of responses for finding a lymphoedema course

The most complex mapping was for the fourth query, “I need help to find a solution such as a compression sock or pump, cream or scar product.” The chatbot replied on pulling information from Airtable and AI. A sample of the mapping is below involving the chatbot being told to pull data from Airtable (Figure 115).

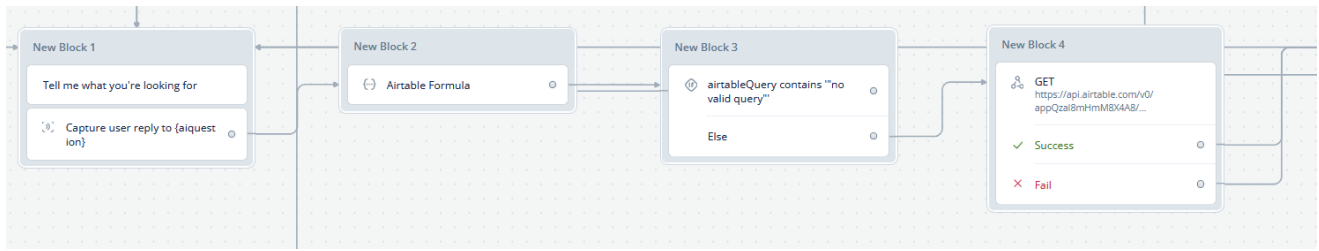


Figure 115 - Mapping for data being pulled from Airtable

C. Writing in Plain English

Through conducting the narrative and systematic review, the author identified research which highlighted that health literacy is a significant issue affecting the use of digital products. Seth et al (2016) found “Patient information found through an Internet search for lymphoedema is too difficult for many American adults to read. Websites queried had a range of readability, and surgeons should direct patients to sites appropriate for their level.”⁽⁴⁵³⁾

Considerable time was invested into writing in plain English. For example:

“If you are at risk of swelling or have mild to severe swelling you can look after yourself by seeing an accredited lymphoedema practitioner for prescription of a pressure garment.”

This text could be shortened to

“See an accredited lymphoedema practitioner for a pressure garment prescription if you are concerned about swelling or lymphoedema.”

D. Deployment

After development, to “play” the chatbot it had to be hosted on the website hosting software. The chosen software was WordPress, a website hosting software.⁽⁴⁵⁴⁾ For the chatbot to appear, a code snippet needed to be entered before the closing `</body>` tag on all website pages (Figure 116).

```
<script type="text/javascript">
  (function(d, t) {
    var v = d.createElement(t), s = d.getElementsByTagName(t)[0];
    v.onload = function() {
      window.voiceflow.chat.load({
        verify: { projectID: 'XXXXXXXXXXXXXXXXXXXX' },
        url: 'https://general-runtime.voiceflow.com',
        versionID: 'production'
      });
    }
    v.src = "https://cdn.voiceflow.com/widget/bundle.mjs"; v.type = "text/javascript";
  })(document, 'script');
</script>
```

Figure 116 - JavaScript code for deployment on a website

Results

A chatbot prototype was successfully developed and subsequently presented at a 2024 Phlebology conference held in Fiji.

Example of output

The chatbot was able to successfully pull responses from both a database, screen the entire website for suitable information as well as rely on AI.

For example, a patient needing a pink garment is quite specific request (Figure 117).

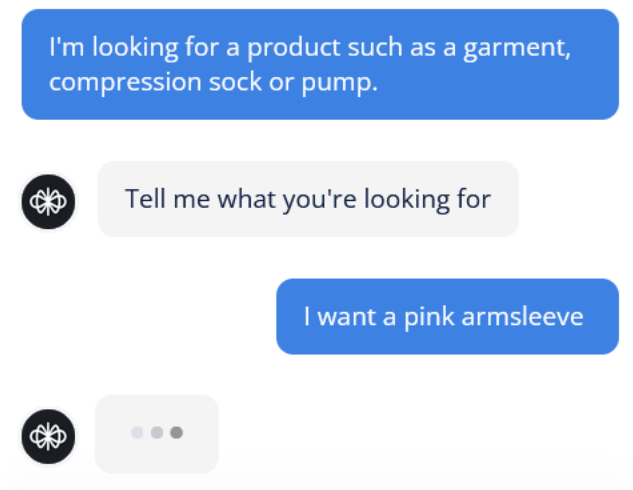


Figure 117 - Chatbot query for a pink garment

In the picture below detail is provided as to the chatbot relying on “gpt 3.5 turbo” as the AI engine and using a certain amount of tokens to pull this data (Figure 118). Large amounts of token use are how billing occurs for this type of software. Hundreds of patient queries would incur significant token usage.

Condition matched - taking path 1

AI Set
Model: gpt-3.5-turbo
Token Multiplier: 0.6x
Token Consumption: {total: 210, query: 174,
answer: 39}
Post-Multiplier Token Consumption: {total: 126,
query: 104, answer: 23}



Figure 118 - GPT engine information in the back end of the chatbot interface

What the person saw using the chatbot is pictured below (simply the garment and where to source the product from without any of the GPT engine information) (Figure 119).

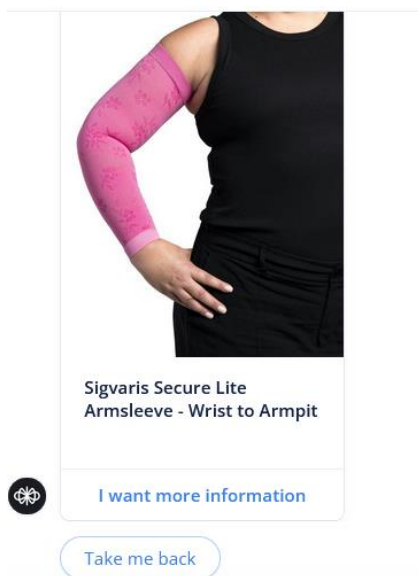


Figure 119 - Patient view in the chatbot

Details were then provided to the patient as to where they could source the relevant products from.

**Sigvaris Secure Lite
Armsleeve - Wrist to Armpit**

If you don't have much or any swelling, you can buy from [Garnet Medical](#) or other leading [Sigvaris store](#).

We recommend you see an accredited lymphedema practitioner for prescription of any compression device.

Visit [here](#) to find a trained Casley-Smith therapist.

Figure 120 - Where to source the lymphoedema products from

In a second example a “patient” searches for a wrap for a leg ulcer (Figure 121).

Welcome to the Australian Institute of Lymphoedema! I'm Debbie your friendly AI powered chatbot.

How can I help you today?

I'm looking for a product such as a garment, compression sock or pump.

Tell me what you're looking for

A wrap for a leg ulcer

Figure 121 - Query for a wrap

The chatbot pulls information from the database on wraps. It shows the patient the options of the wrap (Figure 122) as well as liners (Figure 123).



Figure 122 - Wrap option



Figure 123 - Liner option

Then the chatbot showed the “patient” how to source the products (Figure 124).

We have found some products that are similar to what you are looking for. The Sigvaris Wrap - knee high for lower leg venous ulcers, Sigvaris Wrap - knee high for lower leg lymphoedema, Sigvaris Wrap - knee high for diabetes and poor circulation to the foot and lower leg, and Sigvaris Wrap Liner without compression - for diabetes and ulcers may be suitable alternatives for your leg ulcer.

If you don't have much or any swelling, you can buy from [Garnet Medical](#) or other leading [Sigvaris store](#).

We recommend you see an accredited lymphedema practitioner for prescription of any compression device.

Visit [here](#) to find a trained Casley-Smith therapist.

Figure 124 - Responses for how to source the products

Discussion

Both research questions were answered through the process of building this prototype. The first question of, “What are the processes involved with building a lymphoedema specific chatbot?” was answered through building the prototype and experiencing solution mapping and the build of the chatbot. The build of the chatbot involved several key considerations. First, there was the design and creation of a database to store relevant information that would be used by the chatbot to respond to user queries. This required careful planning to ensure that the data could be easily retrieved and updated as needed. Next, the flow of data retrieval was mapped out, ensuring that the chatbot could access the correct information in a structured and efficient manner. Additionally, great attention was paid to writing in plain English, ensuring that the language used by the chatbot would be accessible and easily understood by users with varying levels of literacy. Finally, deployment considerations were taken into account, including hosting and whether the chatbot could be smoothly integrated into the existing digital infrastructure.

The second research question of, “Can the chatbot retrieve lymphoedema specific queries?” was answered through the testing of retrieval of specific information, such as a pink armsleeve.

Lessons learned

Lessons from building this chatbot prototype included:

- **Ease of build:** Software such as Voiceflow significantly simplifies the creation of chatbots, though some technical expertise, such as JavaScript coding experience, is still necessary. Mapping out the responses is where the complexity in the initial build comes into play. Building out the database is also incredibly time consuming.
- **Types of chatbots:** Chatbots which are rule-based and AI-based tend to provide more accurate responses. A very specific request, such as I want a “pink armsleeve” can garner a suitable response with rules-based responses.
- **Possibilities:** Chatbots could provide commercial benefits by guiding patients to purchase specific products. Rather than struggling to find a particular solution on a website, patients can receive direct recommendations from chatbots.
- **Scanning entire websites as a knowledge base:** Chatbots can be utilised to scan entire websites quickly, offering patients a more efficient alternative to reading individual blogs. The feature of being able to upload an entire website as a knowledge base, warrants further research, especially on lymphoedema-related websites where information may be difficult to find. A well-designed lymphoedema chatbot could empower patients by providing them with timely, accurate information pulled from a vetted website or database of responses. This could stop patients struggling to find information on websites.
- **Various technical, clinical, user-experience challenges and ethical issues** which illuminate broader issues within the digital health landscape. Each will be briefly explored below.
 - i) Technical challenges
- Developing a chatbot that accurately understands and responds to user queries requires sophisticated Natural Language Processing (NLP) algorithms. These algorithms must be trained to recognise medical terminology specific to lymphoedema, understand context, and provide accurate, relevant responses. Relying on an AI model which already understands this terminology is helpful. This is why the prototype relied on OpenAI’s GPT model.
- The chatbot must integrate seamlessly with existing systems, such a website which can host the chatbot. In this prototype case, this process was simple using WordPress as the hosting platform.

ii) Clinical validation

- The chatbot needed to provide clinically accurate information. This requires rigorous validation of the chatbot's responses by healthcare professionals. Any content which was rules based would need to keep being updated on an ongoing basis to reflect the latest clinical guidelines and research. Further research is needed in this regard.

iii) User experience and accessibility

- The chatbot needed to be easy to use. Designing a user-friendly interface and using plain language, were strategies considered to enable this. Providing support for multiple languages as well as a text to speech function would enhance accessibility. Further research is needed in this regard.

-

iv) Ethical and privacy considerations

- Protecting patient data is paramount. The chatbot was designed to ask questions which were about products or learning. Patients were not directed to type in clinical queries. A chatbot which was designed for this function would need legal review, such as suitable medical and privacy disclaimers, and careful consideration of where the data was stored.
- Informed consent was not considered in the use of this chatbot. Per the mention of privacy considerations above, depending on the type of data collected, users should be informed about how their data will be used and provide consent before interacting with the chatbot.

Implications for future research

The implementation examples of AI previously discussed in this thesis, using ChatGPT and Bard in Chapter Twelve, demonstrate the need for future research into the utilisation of chatbots by practitioners, particularly for assistance with tasks such as differential diagnosis.

Building this chatbot highlighted how future research is needed to explore the efficacy of chatbots in serving patients with lymphoedema. Adequate funding and a dedicated research team/s are essential to advance this field.

Ayers et al (2023) found that chatbot responses were perceived as more empathetic than those of physicians, suggesting the possibility that chatbots may eventually outperform practitioners in tasks involving question-and-answer interactions.⁽³⁵²⁾ To remain relevant, the field of lymphoedema must keep pace with such technological advancements. In the short term, chatbots could assist with administrative tasks, allowing clinicians to concentrate on patient care and physical interventions.

CHAPTER NINETEEN: DEVELOPMENT OF A SERIOUS GAME ON THE LYMPHATIC SYSTEM

Chapter overview

This chapter details the processes and lessons involved with building a serious game on the lymphatic system.

Highlights

The key highlights of this research include:

- A prototype of a serious game educating on the lymphatic system was successfully developed
- A considerable number of lessons were learned in the process, such as the need to involve different team members with different skill sets (e.g. instructional design involves a separate skill set to game board development).

Prototype development – serious game

Aim

The aim was to build a serious game on the lymphatic system and learn from this process. The research question was “Can a serious game be produced on the lymphatic system?” A prototype of a serious game aimed to be developed to facilitate learning during its creation and to produce a research prototype.

Background

“An extraordinary number of species—from squid to lizards to humans—engage in play.”⁽⁴⁵⁵⁾

Playing serves as a standard of excellence in childhood education. “Play is essential to development because it contributes to the cognitive, physical, social, and emotional well-being of children and youth.”⁽⁴⁵⁶⁾ In childhood, games are leveraged as a primary platform for fast and intensive learning utilizing elevated biochemistry to maximise learning potential. “When children play in an adventurous way, climbing trees, riding their bikes fast downhill and jumping from rocks, they experience feelings of fear and excitement, thrill and adrenaline.”⁽⁴⁵⁷⁾

Play serves as a crucial mechanism through which children develop intrinsic interests and competencies, earn decision-making, problem-solving, self-control, and rule-following, regulate their emotions, form friendships and learn to interact with peers as equals, and experience joy. Collectively, these benefits of play significantly contribute to the promotion of mental health.⁽⁴⁵⁸⁾

It is not unexpected then that adults experience depression when they cease engaging in play. Although, according to Emslie “it is not possible to assume that what works or does not work in children will have the same efficacy and adverse effect profile in adults”, it is reasonable to consider the fundamental role of play and explore ways to incorporate it into chronic healthcare rehabilitation.⁽⁴⁵⁹⁾

Digital games

Digital games have increasingly become an important component of digital health, offering various benefits. Haaranen et al (2014) found in a systematic review, “...games for health are suitable for all-ages and promote their short-term health behaviour.”⁽⁴⁶⁰⁾ Hall et al (2012) found in their systematic review, “...significant positive effects on health outcomes associated with digital videogame play among older adults. With current advancements in technology, including advanced motion sensing, digital game platforms have significant potential for positive health impact among older populations.”⁽⁴⁶¹⁾

Serious games

Serious (or Applied) games are a type of digital game that employs “serious” learning content as well as elements of fun and entertainment.⁽¹³⁵⁾ They are less about entertainment alone and more about achieving a certain outcome such as solving a problem.⁽⁴⁶²⁾ In such games the learner can be invited to actively participate in problem solving, simulations, repeated practice with real-time feedback, branching scenarios based on real-time choices, role playing by choosing an avatar, competitions, testing logic and knowledge tests. This is contrasted to lecture or classroom style learning in which the learner is passive and receives disseminated information with little or no real-time testing of knowledge or skill acquisition.

Serious games are interactive digital applications created for the purpose of imparting knowledge or skills. They incorporate an element of scoring as well as challenging goals and engaging design. They are designed to improve a learner’s knowledge, skills, or attitudes in the “real” world.⁽⁴⁶³⁾

Serious gaming in medical education is a modality that continues to grow with best practices for its use, development and evaluation, still being defined.⁽⁴⁶⁴⁾

Types of serious games

There are several types of serious games. The types according to Wang and colleagues ⁽⁴⁶⁴⁾ are:

- Adaptation
- Adventure
- Board game
- Simulation

- Platform
- Puzzle
- Quiz

Each type of game has its own technical parameters, complexities, advantages and disadvantages that strive to challenge the learner in different ways. Alves et al (2018) published on the use of flow adaptation in serious games for health.⁽⁴⁶⁵⁾ They developed a first-person shooter video game that adapts its in-game difficulty and environmental settings based on the representation of the mental state of the learner. This game methodology aims to keep a balance between the skills of the player and the challenge of the game by mental state of the learner being measured with their physiological signals, namely the heart rate and the beta band of the brainwaves. In addition to the basic game structure this type of game requires technology that can measure the real-time mental state of the learner. This adds a layer of complexity to the game when compared to other types of serious games such as digital board games, puzzles or quizzes. Such types of serious games require complex game structures without the integration of real-time physiological feedback from the learner.

Design factors which produce an effective serious game

Serious game designers in health must decide whether the game will be safe and effective enough to be used for their intended purposes.⁽⁴⁶³⁾ The five factors identified by Graafland and colleagues (2014) are:

- **Game Description** – including an accurate description, sources of revenue and costs.
- **Rationale** – defines the purpose of the game. Both the external purpose (e.g., understanding the lymphatic system) may differ from the actual goal in the game (egg, getting to the finish line on a gameboard).
- **Functionality** – “a game requires the user to operate or interact with the content, with the ultimate goal to change ones behaviour in real life (i.e., learning)”. The game’s content, how the instruction is delivered, how performance is assessed and how these aspects are integrated in the gameplay need to be described.
- **Validity** – whether the serious game adequately resembles the construct it aims to educate on. Content, face, construct, concurrent and predictive. Predictive validity is the ultimate goal as it determines if performance in the game leads to better outcomes in reality
- **Data protection** – data storage and patient privacy must be considered.

Six facets of effective game development are described by Bouroumane et al (2020)⁽⁴⁶⁶⁾:

- Educational goals – what is going to be taught to the learner and educational objectives?
- Domain simulation – the model for responding to the learner's interactions with the game
- Interaction with simulation – how to ensure pleasure for the learner. What responses will the learner receive once they interact?
- Problems and progression – the problems that the learner should solve and how the game will progress
- Decorum – the script and multimedia elements designed to build pleasure for the learner
- Terms of use – how will educational content and playful qualities be used together?

The criterion for serious gaming includes:

- **Content with an intended outcome or purpose.** This is opposed to content that may only be intended for entertainment purposes and therefore may not be aimed at achieving a specific educational outcome. Other types of traditional video games, card games or board games, for example, can be intended for entertainment purposes only. This is why for the purpose of this paper we refer to “learners” as opposed to “players” demonstrating the active difference in the role of the person participating in a serious game.
- **Computer-based.** Serious Games are computer games which differentiates them from other games such as physical board games.
- **Element of scoring.** Serious Games include an element of scoring and therefore are differentiated from screen animations, educational videos or pictures that provide education but do not have inbuilt testing functionality of some kind.
- **Engaging design.** Serious games include an engaging design and therefore are differentiated from other types of digital applications such as apps or health eLearning courses that provide content but may not provide a creative learning experience.⁽¹³⁵⁾

Caserman et al (2020) explain that there needs to be a balance of the serious side vs the game side (Figure 125).

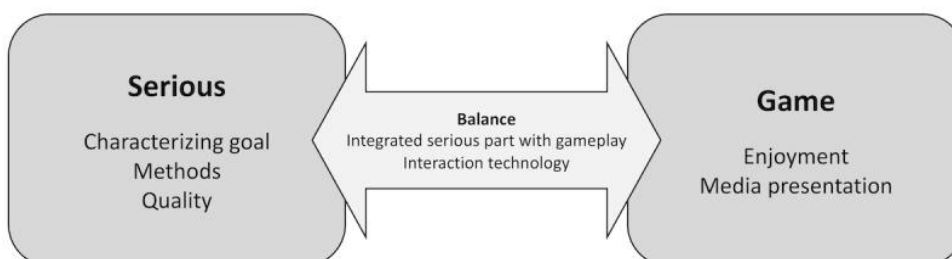


Figure 125 - The balance between the serious and game components of serious games

[From Caserman et al 2020. Distributed under a Creative Commons Attribution License <https://creativecommons.org/licenses/by/4.0/>. No changes made.](¹³⁵)

Caserman et al (2020) more formally set out a quality criterion which includes the following elements (Table 20):

Table 20 - Quality criterion for serious games

Serious Part	
	Focus on the characterizing goal
	Clear goals
	Indispensability of the characterizing goal
	Correctness of the domain expert content
	Appropriate feedback on progress
	Appropriate rewards
Proof of effectiveness & sustainable effects	
Enjoyment	
	Ensure player engagement and experience
	Ensure flow
	Establish an emotional connection
	Sense of control
	Support social interactions
	Ensure immersive experience
	Attractive graphics
Appropriate sound	
Balance between serious side and fun	
	Embedding characterizing goal into the gameplay
	Scientific foundation
	Appropriate interaction technology
	Intuitive game mechanics and natural mapping
	No simplifying of the learning and/or training process due to technical features
Avoid adverse effects	

The rationale for serious game education

More research is required on the physiology of serious games. The physiology of traditional video games, on the other hand, has been investigated. Video games have been shown to activate different parts of the brain. They activate the cortical regions of the brain such as the frontal cortex, the sensory-motor cortex, the visual cortex, and the subcortical areas (such as the amygdala and hippocampus).⁽⁴⁶⁷⁾

A systematic review of the biochemistry of traditional gaming by Krarup and Krarup (2020) concluded via investigation of heart rate variability that gaming increases activity in the sympathetic nervous system with heart rate being used as a measure of arousal.⁽⁴⁶⁸⁾ How heart rate may be increased during gaming is explained by the body releasing adrenaline which is a hormone produced within the adrenal gland, in response to stress, that increases heart rate.⁽⁴⁶⁹⁾

Stress is a complex concept to define as there may be different types of stress such as mental stressors and biopsychosocial stress. Cortisol, as a stress hormone, has been investigated in video gaming. Video games have been shown to affect the stress of players with the type of stress depending on the game style. The effect of the stress may be positive or negative.^(467, 470)

The development of serious games for health and lymphatic education therefore must account for learner stress, ensuring that the cognitive, auditory, and visual demands are not overwhelming or detrimental to the learner.

Utilisation of serious games in lymphatic education

Limited research is available on the use of serious games in lymphatic education. Konstantara and Xinogalos (2018) reported on a serious game, called Cells of War, which was designed to educate on the immune system.⁽⁴⁷¹⁾ The game included information on diseases coming from viruses, bacteria, parasites or fungi and explained how daily habits may affect health. The pilot evaluation of Cells of War showed that the game appeared to be fun, well-designed and was able to educate the players.

Bouroumane et al (2020) developed a serious game designed to strengthen the immune system against Covid-19.⁽⁴⁶⁶⁾ This game aimed at providing information on the link between food, immunity and the spread of the virus within the human body in order to raise awareness of the modifications to be adopted to improve the immune system. The game was called “The Magic Soldier of the Human Body.” A castle was used as the human body, and the organs of the human body were represented as the living families within the castle in the form of houses. The cells of the human body were represented as members of the family and the molecules as protection weapons of each family. In the castle there were stations that showed the learner healthy eating habits to strengthen the soldiers during the war against the enemy.

The systematic review, referred to in Chapter Nine of this thesis, found Atef et al. (2020) compared virtual reality-based exercises and usual care with proprioceptive neuromuscular facilitation and usual care. The digital gaming intervention achieved statistically significant clinical results for reducing LE symptoms.⁽³⁰¹⁾

Method

A digital game on the lymphatic system, called Journey to the Lymph Node, was developed (Figure 126). The development software was self-funded, the prototype was developed, and hosting was tested. The project was then ceased due to a lack of funding for ongoing development and hosting.

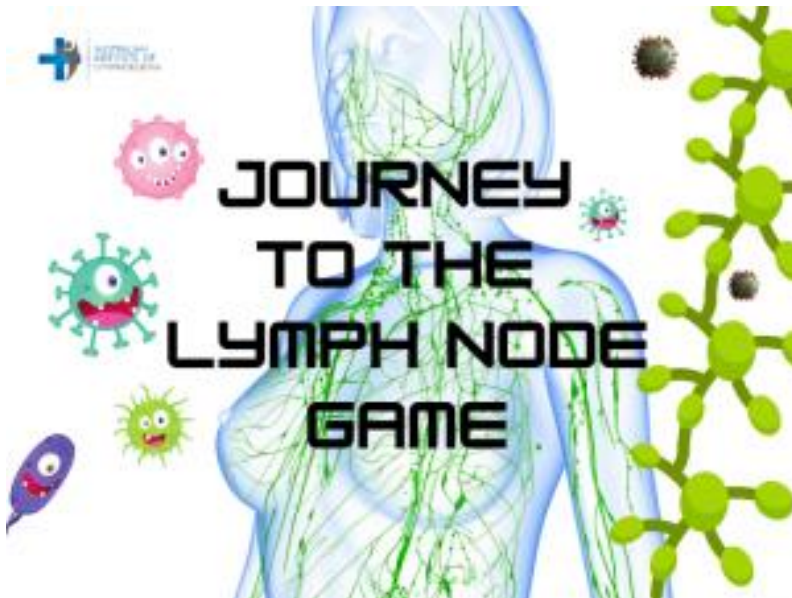


Figure 126 - Journey to the Lymph Node serious game cover

Objectives of the serious game

Journey to the Lymph Node Game was designed to be a fun, free, digital game for educating the general public, patients, practitioners and researchers about the immune system. The learning objectives were:

- 1/ Understand the role of lymph nodes in the context of immune surveillance
- 2/ Describe the role of white blood cells in immune surveillance
- 3/ Explain the role of the lymphatic system in immune surveillance

The aim of the game

The aim of the game was to “...take Harry - a bug invader, through the lymphatic system (by rolling the die) and reach the finish line (representing a lymph node.) During your travels you may land on a green square (representing a lymphangion) and be presented with interesting facts about the immune system. Answer the quiz questions correctly to gain points and increase your score (representing the host's immune response).”

The playboard is pictured below, which featured as an interactive Graphics Interchange Format (GIF) for ongoing entertainment.

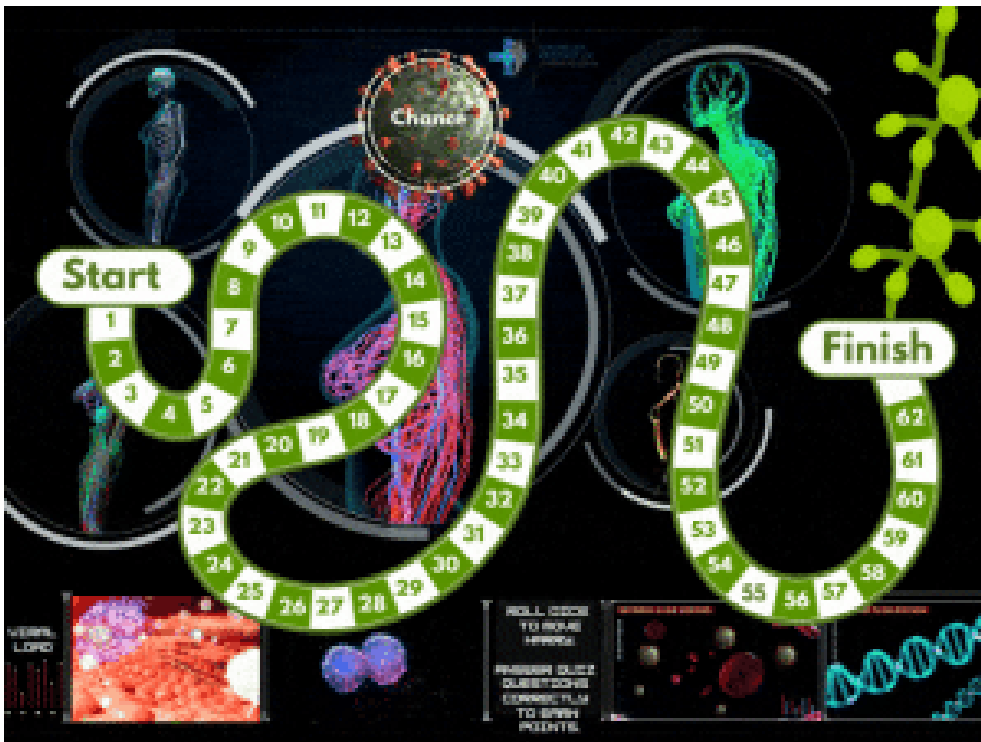


Figure 127 - Journey to the lymph node game board

The game included educational content on the lymphatic system including a video on lymph nodes by Professor Neil Piller, Lymphologist, from Flinders University. Included were digital animations, pictures, videos and quiz questions to test the learners understanding of the immune system.

Two examples of content are below (Figure 128, Figure 129).

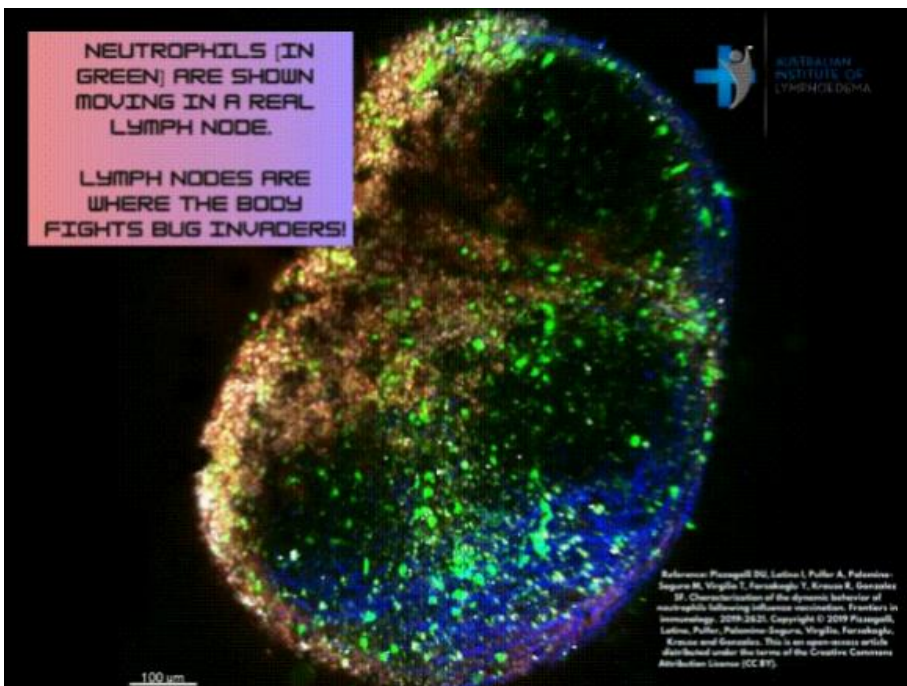


Figure 128 - Serious game content example one

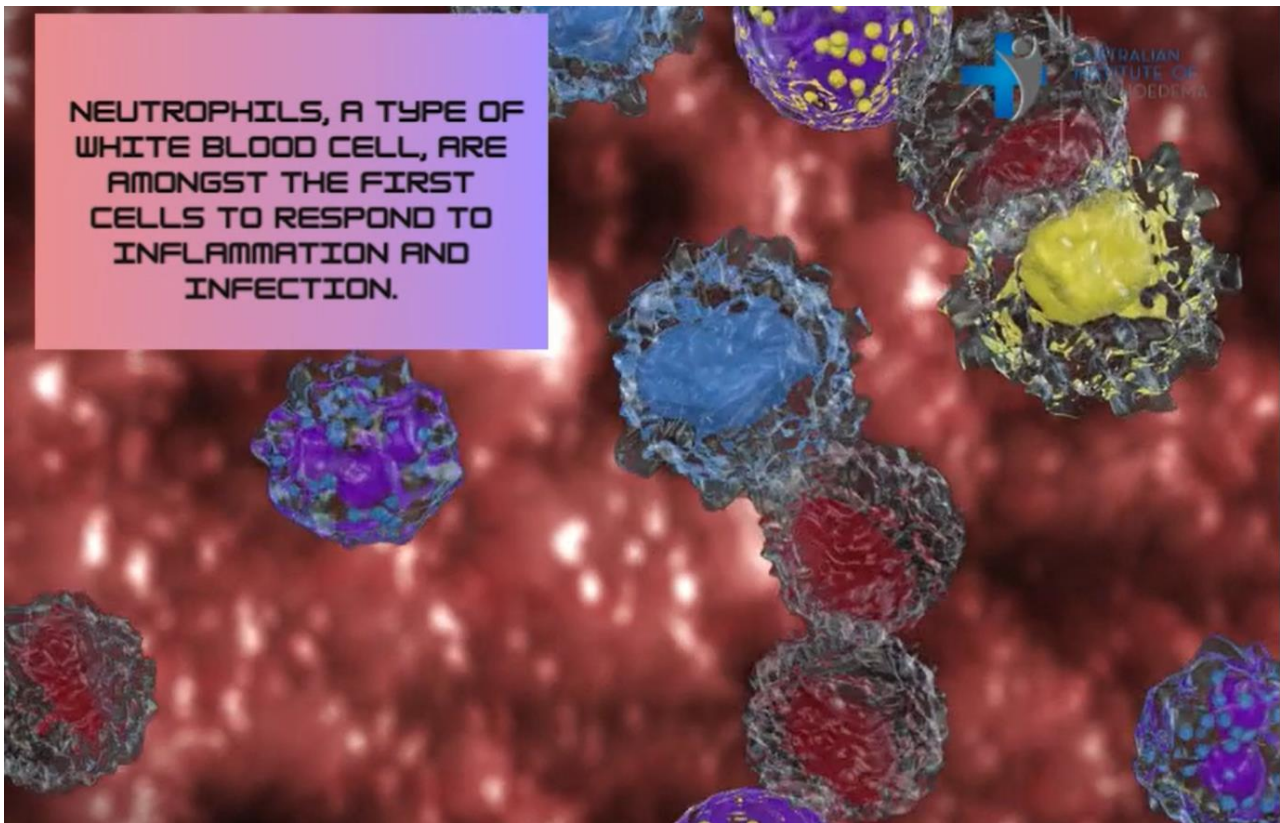


Figure 129 - Serious game content example two

Authoring software

The authoring software was Storyline by Articulate 360.⁽⁴⁷²⁾ The export format was as a Sharable Content Object Reference Model (SCORM) file.

Variability

In the Journey to the Lymph Node game variability was a desired factor and implemented by way of a simulated die, the roll of which determining the number of spaces forward the learner's piece would be moved. Each click of the die ("roll") triggered a call to a custom pseudo random number generator ("PRNG") function returning an integer between 1 and 6 (representing each face of a die) with approximately uniform distribution over that range.

During testing of the first iteration it was observed the results from the die rolls, although supposedly random, returned the same sequence each time the game was started. Limitations in the platform PRNG necessitated additional algorithms to seed (vary) the numbers returned from the PRNG using the seconds component of the real-time clock to ensure the rolls were not identical each time the game was restated.

For a die-based serious game, consideration needs to be given to how many die rolls (and potentially quiz questions) the learner must endure to completion before the game becomes monotonous or overwhelming or the learner loses their attention span. Theoretically, in the absence of an approximately uniform distribution of the die roll, it would be possible to roll a certain number repeatedly - in the worst-case scenario rolling "ones" and best case scenario rolling "sixes" repeatedly. In the case of Journey to the Lymph Node game, which has a game board of 62 numbered spaces and a "Finish" space, it could theoretically take 63 rolls of the die in a worst-case scenario if "ones" were repeatedly rolled, or 11 rolls if "sixes" are repeatedly rolled. Such factors contributed to where quiz questions were placed on the board. Thankfully, approximately uniform distribution of the PRNG results was confirmed by observing over a series of 100 simulated games (Table 21) which gave the indication that the range in that instance was 13 to 24 rolls with an average of 19 rolls.

Table 21 is based on the following JavaScript code simulating the die rolls from the example game: The JavaScript program logic simulates playing the board game of 63 squares 100 times to determine the number of times in each game how many rolls of the dice it took to complete the game

Table 21 - Sample of 100 games and die rolls

Game #	Die Rolls	Game #	Die Rolls	Game #	Die Rolls	Game #	Die Rolls	Game #	Die Rolls	Game #	Die Rolls	Game #	Die Rolls	Game #	Die Rolls	Game #	Die Rolls	Game #	Die Rolls		
1	19	11	21	21	21	31	23	41	18	51	17	61	20	71	21	81	17	91	21		
2	24	12	17	22	18	32	13	42	17	52	20	62	18	72	19	82	22	92	18		
3	17	13	20	23	17	33	19	43	18	53	20	63	19	73	18	83	19	93	19		
4	18	14	17	24	16	34	18	44	20	54	20	64	16	74	18	84	20	94	14		
5	18	15	18	25	21	35	21	45	18	55	19	65	18	75	16	85	20	95	21		
6	20	16	18	26	19	36	18	46	20	56	17	66	18	76	18	86	22	96	20		
7	15	17	18	27	18	37	18	47	16	57	16	67	18	77	18	87	18	97	17		
8	17	18	16	28	20	38	23	48	20	58	20	68	23	78	17	88	14	98	19		
9	20	19	18	29	20	39	18	49	17	59	22	69	22	79	18	89	18	99	18		
10	15	20	20	30	19	40	19	50	17	60	19	70	19	80	18	90	19	100	16		
Min.	15		16		16		13		16		16		16		16		14		14	13	Min of Mins
Max.	24		21		21		23		20		22		23		21		22		21	24	Max of Maxes
Avg.	18.3		18.3		18.9		19		18.1		19		19.1		18.1		18.9		18.3	18.6	Avg over 100 rolls

[Sample of a series of 100 games showing how many die rolls were needed to complete the example game]

```

let pos = 0; // position on simulated board

let rolls = 0; // number of die rolls, reset after each new game

let rn = 0; // random number

console.log("Game # \t Die Rolls" )

for (var i=0; i<100; i++) {

  pos = 0;

  rolls = 0;

  while (pos < 63) {

    rn = Math.floor((Math.random()*6)+1); // fetch random number between 1 and 6

    rolls++;

    pos += rn;

  }

  console.log( (i+1) + "\t" + rolls )

}

```

[Sources used included

https://developer.mozilla.org/en-US/docs/Web/JavaScript/Reference/Global_Objects/Math/random

<https://yourbasic.org/algorithms/random-number-generator-seed/>].

Testing of the die roll sequences at the start of each new game gave confidence that extensive variation was being achieved (Table 22). For example, the first simulated roll of the die in game 1 produced a “5”, whereas on game 2 the simulated dice roll was a “4” etc.

Table 22 - Verifying variation of die roll results between new games

Dice Roll Sequence #	Game 1 Result	Game 2 Result
1	5	4
2	2	3
3	5	4
4	5	4
5	5	1
6	4	4
7	1	6
8	3	1
9	3	2
10	6	1
11	6	6

Further, in the Journey to the Lymph Node game, for additional variability, specific quiz questions were allocated to specific squares and only alternate (even numbered) squares trigger a quiz question to avoid overwhelming the learner.

Yet another means by which variability can be introduced in order to maintain the learner’s interest, is by varying and spreading the question type (e.g., fill in the blanks, vs multiple choice, vs True / False, vs drag and drop etc). Table 23 represents an early design intention for the types, frequency (count) and distribution (spread) of questions in the example game. This was subsequently modified to alternate through a series of fill in the blanks, true or false, and multiple-choice type questions, whilst also reducing the total number of questions to 31 in order to avoid overwhelming the learner.

Table 23 - Example of question type spread from the example game

Question Type	Count	%	Spread
Fill in blank	11	18%	5.6
Label	10	16%	6.2
Match Drag & Drop	18	29%	3.4
Multiple Choice	10	16%	6.2
True / False Choice	12	19%	5.2
Other	1	2%	
Total	62	100%	

Variability also introduces certain aspects of complexity and potentially unintended outcomes. The Journey to the Lymph Node game had to account for a learner reaching the finish line without having landed on a question, and therefore attaining a score of zero at the end. In this case the learner was credited playfully as “a ninja having evaded the body’s immune response” and asked to play the game again. An alternative approach could have been to require the learner to start over, but this might not respect the learner’s time constraints.

Play time for learning benefit

The game was designed to be suitable as part of an adult education program in alignment with education on basic lymphatic anatomy and physiology. This game was not intended to be a standalone education piece requiring the full curriculum to be completed.

The play time for learning benefit was not tested. In the design the learner would have had to play the game several times to encounter all of the learning curriculum. This is because the roll of the die introduced randomness and since different learning objectives were associated with different positions on the board, in rolling the die the learner had a 1 in 6 chance of encountering the next lot of board spaces.

This could have introduced monotony as the learner may have been presented with the same question again. If the game was able to save previous results and knew who the learner was, programming could be written in to exclude previously asked questions. In the Storyline software, used for Journey to the Lymph Node Game, this was not able to be accommodated.

For removing monotony, question places on the board could have been associated with a question bank (as opposed to one question) to increase randomness, however this may have led to the curriculum objectives not being fully represented. This would have increased the development complexity.

Results

Assessment of the game as a Serious Game

The criteria described by Caserman et al (2020) was applied to the game (Table 24). The game successfully met the criteria for being a serious game.

Learner autonomy

The game was designed to be run when it was convenient to the learner and on a device which suited them, allowing them to save their progress.

Game information for learners

The instructions included frequently asked questions with two examples as follows:

A. Why should I play this game?

“Without a heart, blood cannot pump around the human body.

Without lymph nodes, the human body cannot effectively fight disease. Lymph nodes can be thought of as the little hearts of the human body's lymphatic system. We have 600-1000 of them all over the human body to try to ensure that disease can be eliminated.

For people that live with conditions such as cancer and for those suffering from conditions whereby the lymphatic system does not function correctly (such as lymphoedema, lipoedema and venous disease) it is important that a basic understanding of how the lymphatic system works is acquired. Lymph node removal, for example, such as sentinel lymph node biopsies and node dissections are common treatments for cancer. In order to understand why cancer is detected at the lymph node, patients and health practitioners need to understand the role of lymph nodes in immune surveillance.”

B. Why should I learn about the immune system?

“All human beings face bug invaders including viruses, parasites and bacteria. It is important that both patients and practitioners understand the basics of how the immune system functions in order to keep the human body healthy. White blood cells are constantly trying to battle bug invaders!

Let's look at a real case study that was published by Ran et al (2016).⁽⁴⁷³⁾ This 28 year old presented for investigation of itching, multiple erythema, papules and multiple pustule lesions on their nose and cheek.

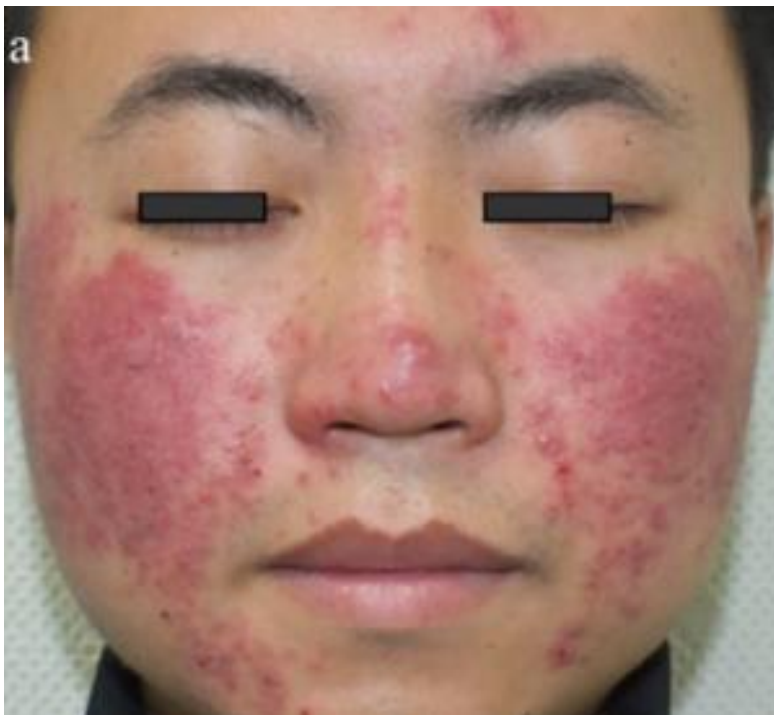


Figure 130 - Case of demodicosis due to Demodex mites (parasites)

[Figure by Ran et al (2016). Distributed under a Creative Commons Attribution 3.0 License <https://creativecommons.org/licenses/by/3.0/>. No changes made.]⁽⁴⁷³⁾

When his skin was investigated with an electron microscope the parasite below was found. There were four pairs of feet on the side of the head of the parasite!

Most people can explain why we have a heart and how it pumps blood through the human body. However, many cannot describe why we have lymph nodes and lymph fluid, or how the body filters it. White blood cells play a crucial role in responding to invaders like parasites and eliminating them. Lymph fluid allows these invaders to travel through the body. Lymph nodes are the sites where the body detects and fights these invaders, using white blood cells to eliminate them and protect the body from infection.”



Figure 131 - Four pairs of feet on this parasite

[Figure by Ran et al (2016). Distributed under a Creative Commons Attribution 3.0 License <https://creativecommons.org/licenses/by/3.0/>. No changes made.](⁴⁷³)

Discussion

The research question of, “Can a serious game be produced on the lymphatic system?” was answered. A serious game was successfully produced. Several lessons were learned in this process.

Lessons learned

Several lessons were garnered in this process of prototype development:

- Hosting considerations
- Concept definition
- Capabilities required for building a serious game
- Development methodology
- Factors for variability and engagement.

Each will be explored in more detail below.

i) Hosting of the game

Consideration of game access significantly impacts what authoring and hosting software must be chosen. The Journey to the Lymph Node game was designed to be free to access. The game was to be hosted on the Amazon S3 cloud server in a bucket. The learner could therefore access the game via a link to a web address. Through this form of hosting, there was not going to be a certificate of completion awarded. Rather the internal game metrics determined the score at the end.

Consideration of how the learner would access the game influenced the game design in the following ways:

- If the game was to be hosted in a password protected Learning Management System (LMS), which could provide statistics on user completion rates and interactivity with content, then the game needed to be developed in SCORM compliant software.
- If the game was to be hosted on a publicly available web site, the game could have built in software allowing for export as web-file format, such as HTML. With this style of export, tracking of the engagement with content and completion statistics would not be available.

In the Journey to the Lymph Node game, export considerations were for both an LMS hosted version and web-hosted version. The web-hosted version could have been used to raise awareness of the lymphatic system, whilst the LMS hosted version could have been used for research purposes or embedded as part of university teaching programs on the lymphatic system.

ii) Concept definition

Design of Serious Games involves broad consideration to ensure an effective game is produced. The first steps involve deciding on the educational aims of the game and then the type of serious game, such as a digital board game. Using a board game as the model, which was chosen in Journey to the Lymph Node, considerations include:

- **Design of the board game itself.** Factors such as the number of dice, if any, and how many steps there are on the board itself will impact how long it will take for the learner to complete the game, the number of questions and test opportunities and the complexity of the digital board game design. The overall theme and story that is told to the learner also needs to be considered. A medical and serious theme was chosen for the Journey to the Lymph Node game, with an interactive GIF and music to keep engagement high.
- **The types of quiz and knowledge testing** that will be incorporated and how information will be presented throughout the learning journey. Multiple choice questions were implemented in the Journey to the Lymph Node game.
- **How enjoyment and excitement will be created** such as through die rolling, making the next step random, visually appealing graphics and video resources. All of these strategies were implemented into the Journey to the Lymph Node game
- **How feedback will be provided** and how repeated practice will be allowed for.
- **Whether there is dependency** on acquisition of knowledge. This was not embedded into Journey to the Lymph Node game. The roll of the die determined when the learner would finish.

iii) Capabilities in producing a serious game

The development platform may influence the constitution of the delivery team, however, generally, a serious game should typically include skilled people with the following roles:

- **Product owner** to set the vision and define product requirements.
- **Project manager** to create an implementation plan and manage resources including budget.
- **Technical analyst** to elaborate detailed functional and non-functional requirements.
- Subject matter expert (SME) to provide learning content.
- **Computer programmer(s)** to write programming code (e.g., Java, C#, .NET etc) that implements aspects of the required functionality.
- **Graphic designer(s)** and sound / video engineer(s) to create custom content (e.g., artwork, music etc) if ready-made stock images and soundtracks are inadequate.

- **Testers** including technical and non-technical personnel to document and execute a comprehensive set of tests to ensure the minimum acceptable standards of quality are achieved. Such tests should include functional testing (e.g., unit testing, system testing, integration testing, acceptance testing) and non-functional testing (performance testing, security testing, usability testing, compatibility testing) as appropriate.
- **Operations and support engineers**, if necessary, to establish and maintain the hosting platform as applicable
- **Educators** to create the educational content.

Depending on an individual's capability and capacity, some team members may be able to fulfill one or more of the above-mentioned roles.

iv) Development methodology

Product owners may not necessarily be experienced in the technical aspects of delivering a serious game. Therefore, the delivery team should adopt a software development methodology that is iterative, provides incremental deliveries, and is tolerable to change, such as Agile (Figure 132) or DevOps rather than Waterfall. This will allow for frequent showcasing, engagement of the non-technical stakeholders and adjustments if necessary, facilitating delivery of the desired product.

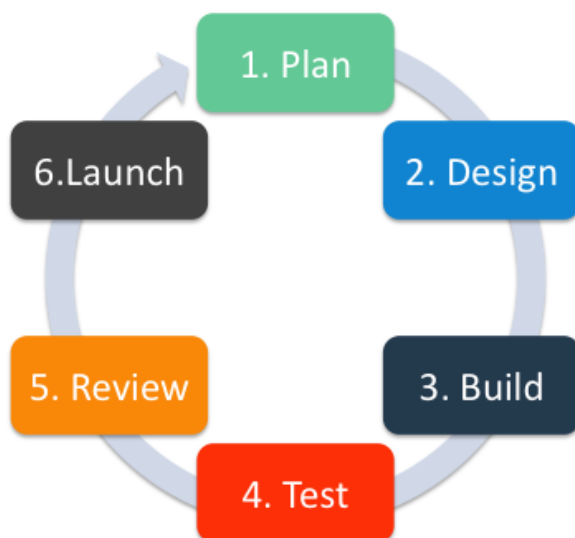


Figure 132 - Agile methodology

The author, serving as the sole developer of the game and fulfilling multiple roles, recognised the significant potential for technical specifications to evolve throughout the development process. Relying on a waterfall approach may lead to challenges in achieving the intended research objectives, particularly when final approval rests with a product owner whose perspectives may diverge from those of the developers.

v) Factors for variability and engagement

Implementation of variability in the design of a serious game is dependent on whether the type of game chosen is conducive to such, and if so, whether variability is at all desired. Variability may lead to complexity in game design, especially if there is dependency on acquired knowledge.

Progress indication

An indication of the learner's progress and performance in the serious game is important in keeping interest and is fundamental in monitoring the learner's achievement outcomes.

Various methods can be applied, which may include one or more of the following:

- Gaining points for correct answers. For example, allocating a nominal value to each quiz question and awarding points only for correct, partially correct or even incorrect answers. This approach lends itself to awarding higher points for more difficult questions, if desired. In the Journey to the Lymph Node game, no points were awarded for partially correct answers. Each correct answer gained 10 points, and incorrect answers gained zero points.
- Progress questions attempted and the number of correct versus incorrect being displayed. In the Journey to the Lymph Node game a counter was kept of the number of quiz questions attempted and those answered correctly from which a percentage score was calculated and shown on the game board.
- Level indicator where the game offers increasing levels of difficulty as the game progresses. In the Journey to the Lymph Node game this was not implemented. In a more complex future iteration, different levels could be built. An innovative idea would be to start with basic lymphatic terminology on level 1, then level two could teach of basic lymphatic anatomy and level 2 could teach more complex lymphatic anatomy and so forth.

Advancement method

Advancement throughout a serious game is dependent on the type of game itself and may be offered in a number of dimensions. For example, a first-person shooter game may advance a level by reaching a destination on a map but may also advance their score by collecting tokens along the journey.

In the Journey to the Lymph Node game, the learner's avatar progressed along the winding path towards the finish line based on the die roll, irrespective of whether their quiz question was answered correctly or not (Figure 133). Consideration was given to only advancing the avatar if a quiz question was answered correctly, however in the interest of the learner it was deemed impractical to do so.

Metrics

Capturing statistics on game usage contributes to measuring the success of the learning module and potentially the learner's progress. Platforms offering a secure user login can determine for specific learners the frequency and history of visits, duration to completion, and overall progress. Platforms where the learner is anonymous can still capture useful statistics albeit obviously anonymously but may also use the learner's Internet Protocol (IP) address to potentially distinguish different players. There may be some margin of error (since different users could be originating from the same IP address).

Implications for future research

Future research can leverage off the many lessons garnered through the development of this serious game. Authoring and hosting considerations, concept definition, learner autonomy, capabilities required for building a serious game, development methodology, factors for variability and engagement, progress indication, advancement method and metrics are some of the considerations for future research projects on serious games.

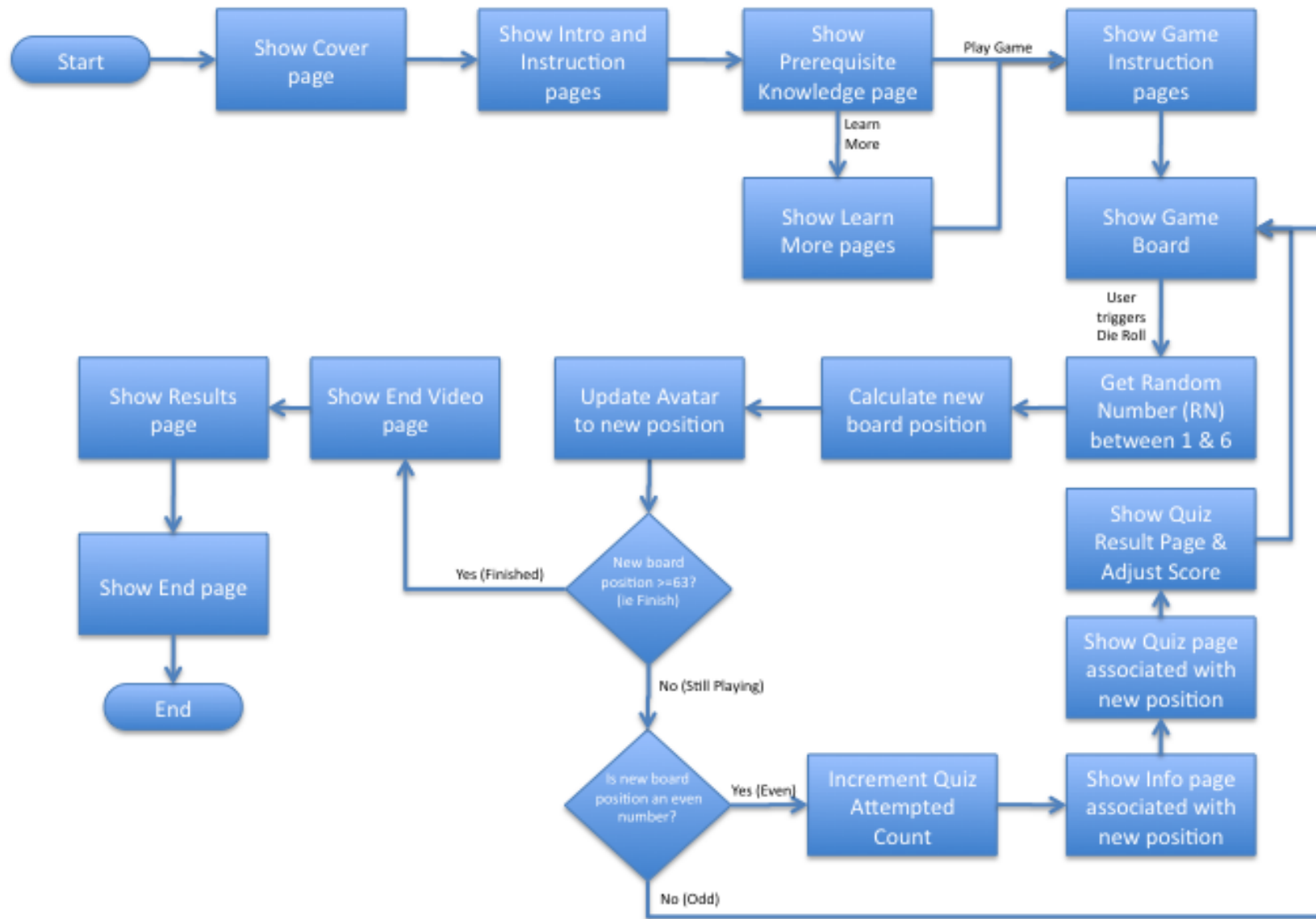


Figure 133 - Game logic

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Table 24 - Application of the Caserman et al (2020) classification of serious games to the Journey to the Lymph Node prototype game

Serious Part		Journey to the Lymph Node Game
	Focus on the characterizing goal	The learning/training goal remained in focus
	Clear goals	Clear goals were provided
	Indispensability of the characterizing goal	Training and learning tasks were not a hurdle to reaching the main goal
	Correctness of the domain expert content	Content was technically correct
	Appropriate feedback on progress	Learners receive feedback on their performance and progress. Performance at the end and progress by how the moved along the board.
	Appropriate rewards	Positive reinforcement was given
	Proof of effectiveness & sustainable effects	Not achieved. We could not prove that the characterising goal was achieved i.e. no formal test afterwards
Enjoyment		
	Ensure player engagement and experience	The game aimed to ensure a positive experience during playing. Pilot testing then further testing would have needed to occur to test this.
	Ensure flow	The variability could have been improved if more complex development software was used. There was some variability with the roll of the dice.
	Establish an emotional connection	Not tested if the game allowed emotions and aroused a feeling of instinct.
	Sense of control	It appeared that learners had control over their actions in the game
	Support social interactions	Collaborative and competitive game modes were not enabled. The play could only try to beat their own score if playing again.
	Ensure immersive experience	Visual and audio included
	Attractive graphics	Attractive graphics were designed
	Appropriate sound	Sound was of suitable quality with music to keep engagement high
Balance between serious side and fun		
	Embedding characterizing goal into the gameplay	Learning/training tasks were related to the game and connected to the game elements
	Scientific foundation	Relevant evidence-based information
	Appropriate interaction technology	Interaction technology was suitable for a target group of adults
	Intuitive game mechanics and natural mapping	Intuitive use of game controls
	No simplifying of the learning and/or training process due to technical features	Accurate tracking to prevent cheating
	Avoid adverse effects	Adverse events very unlikely

CHAPTER TWENTY: THERAPEUTIC PATIENT EDUCATION IN LYMPHOEDEMA CARE

Chapter overview

This chapter has three sections. The first section [Twenty (i)] defines and presents the relevance and benefits of therapeutic patient education in lymphoedema care. The second section [Twenty(ii)] presents the results and lessons learned from the development of a prototype of an online educational course on the early detection of lymphoedema for patients. The third section [Twenty(iii)] describes research on the development of a prototype of an educational app for patients on the early detection of lymphoedema which hosts short educational videos.

Twenty(i) - Publication title - Relevance and Benefits of Patient Education about Lymphology and Lymphoedema

Reference

Mangion A, Piller N. Relevance and Benefits of Patient Education about Lymphology and Lymphoedema (Chapter). Textbook of Lymphatic Surgery and Clinical Lymphology: From Basic Science to Diagnosis and Integrated Treatment. Editors Michele Maruccia and Corrado Campisi, Meteor- Springer. In-press.

Credit

Conceptualisation, methodology, writing – original draft, review, and editing by A.M.

Conceptualisation, methodology, writing – original draft, review, and editing and supervision by N.P.

Contribution

A.M. completed 50% of the research design, 50% of the data collection and analysis and 50% of the writing and editing.

Highlights

The key highlights of this publication include:

- This chapter establishes the framework for understanding the delivery of education with a therapeutic focus. The author learned of the concept of Therapeutic Patient Education (TPE), which is examined in detail, providing essential information for anyone seeking to deliver educational tools effectively.

- This chapter represents the author's first publication in a textbook, marking a significant achievement in their academic career. Publishing in a textbook broadens the content's reach, making it accessible to a larger audience.
- Application of the World Health Organization's introductory guide on TPE to lymphoedema care.

Publication

Abstract

Many of our national and international clinicians and patient centered groups provide education and information to patients and the chance of continuing professional development for professionals and each has unique needs according to the country. Sometimes, the information while well-meaning can be difficult or confusing for the patient to absorb and apply to their condition.

Also, some surveys of our medical curricula have indicated that 30 minutes or less about lymphatics and lymphoedema is common. Certainly, this is not enough for any clinician to be confident and competent in giving patients advice so we must address this problem.

From all of our perspectives, we are moving into the artificial intelligence (AI) age in which AI and its associated chatbots will be advising all of us and this may become an issue of accuracy, relevance and appropriateness of the information provided. However, no matter how or when educational information is provided, several basic principles must be acknowledged to gain the best outcome for those at risk of or with lymphoedema. These principles are assessment, planning, implementation and evaluation. Continuous evaluation ensures that patient education remains an ongoing, adaptive process that supports the patient's health journey!

In particular, Therapeutic Patient Education (TPE) goes beyond providing patients with information about their health. TPE is an approach towards empowering patients through education which aims to empower patients to effectively manage their health. These programs are tailored to the holistic needs of the individual, considering psychological, social, and physical factors, and objectives being structured around specific and achievable goals.

Our international lymphological area is a generally coherent and communicative one and together we can improve patient education dealing with its core principles but being locally relevant. The issue is now very important due to the increasing availability and use of AI for information gathering and decision making for patients and sometimes our health professionals.

To use such tools well we all need to be better educated and aware in the first place. We have the ability, the knowledge, the information so it's time to do it – ensure we have the confidence to assess, plan, implement and evaluate for the optimal outcomes and for patients to live life well with their condition.

Introduction

Throughout our lives we learn from those around us, our parents, teachers, friends and colleagues, through what we discuss, hear, see and read. These experiences make us what we are today but along the way perhaps there were times when we have doubted or questioned the information, its sources, its accuracy and relevance to ourselves and the benefits that this information will provide. We must of course still do that today.

In the medical field, however, only those well experienced and qualified should be the ones a patient listens to or whose advice they act on. The information they provide should always be the basis of any actions in terms of health and wellbeing, the lymphoedema and any co-morbidities associated with it.

For a patient at risk of or with lymphoedema, medical opinions and clinical trial outputs and associated web sites are not always able to provide the information and evidence to make a firm informed decision in terms of what you ideally need. Sometimes we want to reach outside of the medical horizon for information and advice, sometimes we reach out to others in our field who have more experience with the patients with the problems or issues in question and sometimes we use our prior experience and knowledge of diagnosing or treating patients with similar problems to the one in front of us now. On other occasions we might link one patient with another to tell of their lived experience of what they are going through or have gone through. This is most often an eye-opening and valuable experience and shows the patient that they are not alone in what they are going through.

Around the world we have many legitimate health systems/government agencies and professional and patient groups and patient advocates, who aim to direct us towards suitable information sources to help with any condition the patient may have. As an example in South Australia we have the Governmental Health “Pathways” Guide for general practitioners, we have the Lymphoedema Association of Australia (LAA) who promote and provide information for patients and we have an overarching Australasian Lymphology Association (ALA) from which clinicians, therapists and patients can seek guidance and recommendations for best practice and models of care and from whom patients can seek the appropriately trained therapist.^(474, 475) But at a local level sometimes the guidance and information can be at variance to that of the overarching statements and so there is often patient (and practitioner) confusion or uncertainty.

The question commonly arises among all of us – which source do we use, which is most accurate and most appropriate?

As we health professionals search through the literature, we will read of clinical trial outputs from randomised controlled trials and other levels of research about the outcomes of various strategies and interventions from sites like pub-med which may be at odds with the other existing recommendations and earlier research. National and International Consensus documents, however, can help with many uncertainties.

Nevertheless, it all can become rather confusing sometimes leading to no action or the wrong reaction and advice to the patient or the wrong action by the patient.

Is knowledge across the disciplines of medicine our basic problem?

The basic problem here is often that as specialists, clinicians diagnosing and making recommendations about the treatment of lymphoedema as well as making recommendations about the types of treatment whether surgical or conservative, we do not have enough core training or awareness of the lymphatic system, and issues associated with it such as what genetics may impose on its functioning, the impact of other risk factors such as obesity, diet, activity and the optimal pathways for treatment suggestions.

But patients with good outcomes through good advice from a clinician will recommend that person to other patients through patient networks. And so, through experience they become an “expert” in the area of the lymphatic system, its structure, functioning, reasons for its failure and how to remediate the problems. They may then present that at a professional association meeting so others can learn from them. They may also present at groups who train therapists with the goal of empowering patients to best treat and manage their condition. But there still remains a basic issue for many clinicians, and that is a lack of education in our medical education programs as well as a paucity of Continuing Professional Development programs to learn and be updated in a coordinated informed matter.^(476, 477)

Vuong et al (2011) in a survey of physiology chairs found that half of the respondents indicated that the time devoted to lymphatics was 30 mins or less in the first two years of their programs, about 40% indicated it to be 1-3 hours while the rest indicated it was 15 mins or less!⁽⁴⁷⁶⁾ Scarily just over 60% thought the time spent was enough! So, if this situation still exists, we can see why our problems still exist!

Rockson (2004) emphasised the global nature of the problem and commented that most individuals with forms of primary and secondary lymphoedema encounter responses from medical caregivers which encompass, ignorance, disbelief and frustration with education running far behind our research-based knowledge.⁽⁴⁷⁷⁾

So, this and other research shows that our education of clinicians is inadequate and that this is the core of our problem. But we have to live with it. And what follows are some current and future avenues along which we might progress in a partnership with our patients.

Knowledge pathways

So, let's consider the modes of information delivery which we all use and learn from but which at times we may not consider or know their appropriateness for us, or the patient or their accuracy with respect to the patient's situation/condition. Nevertheless, some can be very beneficial and appropriate, especially those from reputable sources.

The first and most personal is that of patient-to-patient advice. The Spring edition of "Pathways" Bowman et al (2024) reported on the benefits of this following a patient-to-patient advice workshop. Why patient to patient advice? They stated, "people already have within them the wisdom and creativity to confront even the most difficult of challenges; that the answers we need are available to us and that we are wiser together than when alone!" The outcomes from the workshop were strong and included advice such as "be your own advocate", keep being curious and learning, connect with others, listen to oneself and do what one feels best for the body" and "still live your life".⁽⁴⁷⁸⁾

Taking from the recent workshop though is the point of "keep being curious and learning" we arrive at a situation where nowadays many more of us seek advice from the web. And a trending focus of information provision, as the second form of information delivery, AI.

Well, how do we know the information we gain from it is accurate, appropriate, and helpful for our condition? That comes from knowledge about it, how it sources information and how it uses this to present what one might call a "fait accompli" to us about our condition or situation (or if we are a professional), about the patient we are trying to gain the best outcomes for.

AI ChatGPT and other sources of digital health information

Mangion and Piller (2024) indicated that generative artificial intelligence and Chat GPT can be used as a chatbot for information about chronic oedema/lymphoedema.⁽⁴⁷⁹⁾ Digital health can assist all of us by allowing easy, convenient access for patients to a range of information about their condition/situation. But what are its limitations when dealing with a complex clinical presentation such as lymphoedema with associated co-morbidities in terms of suggesting directions to take to improve outcomes?

Certainly generative artificial intelligence and ChatGPT or similar chatbots are going to help improve knowledge and awareness and perhaps lead to improved self-care in chronic conditions such as lymphoedema, especially for those in rural or remote locations where access to therapists and other medical care is poor, but there is still at the moment a danger in an assumption that its accurate, appropriate and actionable in terms of the patient taking more control of their condition (ideally still in concert with their therapist or other health professional), but it's on its way so the more we know about its strengths and limitations the better for all of us.

What's critically important for all of us to be aware of is that when we use it the Chatbots can only reply based on what we ask and that poorly worded questions and misspellings will lead to poor information and that even if we ask the right ones the information response still may not always be reliable or accurate.⁽³⁵²⁾ But AI and its language models may soon become part of our virtual digital health care system. Let's get well prepared, but at the same time we must still be involved in the personal side of things, linking into patient groups, going to education and awareness sessions keeping up with current research and especially consensus documents and absorbing the practicality and importance of patient-to-patient information sharing!

The basic and broader context

Patient Education (PE) involves healthcare practitioners providing health education to patients about their state of health, the significance of healthcare care, various alternative forms of care and their effects, and about other factors related to healthcare.⁽⁴⁸⁰⁾ Patients are empowered through education by being provided with the necessary knowledge to understand their health status, being encouraged to participate actively in their own self-care, and make informed decisions about treatment options.

The process for providing patient education

The process of providing patients with education requires specific teaching skills and follows a logical process. Cutilli (2020) describes that the execution of excellent patient education is an “art” and “science” needing to be both nuanced and evidence based.⁽⁴⁸¹⁾ The four step process of assessment, planning, implementation, and evaluation needs to be addressed by the healthcare providers (Figure 134). Each stage plays a vital role in ensuring that the education provided is tailored to the patient's needs and is effective in promoting positive health outcomes.

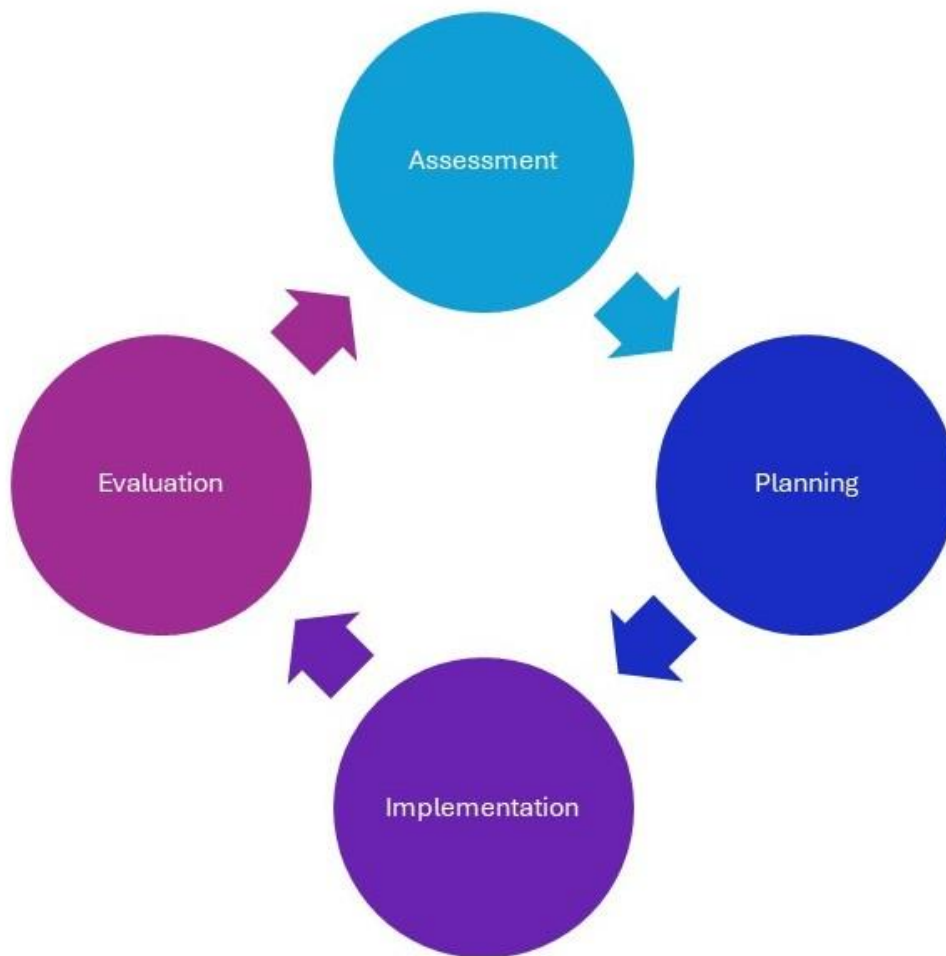


Figure 134 - Four step process of patient education involving assessment, planning, implementation, and evaluation

1. Assessment

The first stage, assessment, involves gathering comprehensive information about the patient and sets the stage for a personalized education plan that addresses the unique needs of the patient. This includes understanding the patient's current knowledge, health literacy level, learning preferences, cultural background, and readiness to learn. The healthcare provider assesses the patient's physical, emotional, and psychological status to identify any barriers to learning. For instance, if a patient is blind then accessibility factors need to be considered for both online and face to face education. Digital education needs to be compatible with screen readers and any illustrations need to have alternative text descriptions to ensure that the content can be understood.

2. Planning

In this stage healthcare providers develop an education plan tailored to the patient's specific needs and preferences. The plan outlines the educational objectives, content to be covered, teaching methods, and resources needed. Goals should be realistic, measurable, and achievable, ensuring they align with the patient's abilities and lifestyle. For example, if a patient is managing lymphoedema, the plan might include learning how to perform self-manual lymphatic drainage, care for their garments and recognise signs of cellulitis.

3. Implementation

The implementation stage involves putting the education plan into action. Healthcare providers deliver the educational content using the methods and resources identified in the planning stage. This could include one-on-one teaching, group sessions, printed materials, digital tools, or interactive activities. Effective communication skills are crucial during this stage to ensure the patient understands the information. Providers should encourage questions, provide feedback, and use teach-back methods to confirm understanding. The implementation stage is where the patient actively engages with the educational material, applying new knowledge and skills to their daily routine.

4. Evaluation

The final stage, evaluation, focuses on assessing the effectiveness of the education provided. Healthcare providers evaluate whether the educational objectives were met and if the patient has successfully integrated the knowledge and skills into their self-care practices. This can be done through follow-up appointments, surveys, or observing changes in the patient's behaviour and health outcomes.

If the evaluation reveals gaps in understanding or application, the education process may need to be revisited, starting with a reassessment. Continuous evaluation ensures that patient education remains an ongoing, adaptive process that supports the patient's health journey.

Therapeutic Patient Education

Therapeutic Patient Education (TPE) goes beyond providing patients information about their health. TPE is an approach towards empowering patients through education which aims to empower patients to effectively manage their health, any diseases and prevent complications, especially in chronic health condition management such as occurs with lymphoedema.

The World Health Organisation defines TPE as “.... a structured person-centred learning process that supports individuals living with chronic conditions to self-manage their own health by drawing on their own resources, supported by their carers and families.”⁽⁴⁸²⁾ The term “Therapeutic Patient Education” is described by the WHO to include three key elements (Figure 135):

- therapeutic whereby there is an impact on clinical outcomes;
- delivered for a patient and/or their partners/carers and offered as part of the health-care pathway; and
- educational through a structured process which is adapted to the patient to support them to acquire or maintain competencies to be self-managing through setting goals and sharing information about the health condition, health risks and management options and providing training in practical skills (including self-monitoring of the condition).

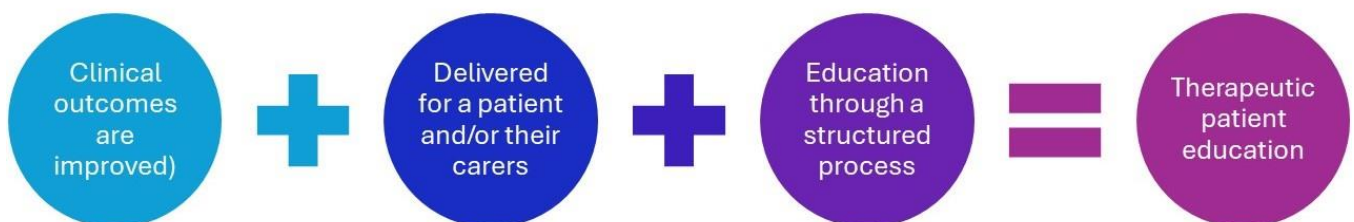


Figure 135 - Therapeutic Patient Education

[The definition of Therapeutic Patient Education involving an improvement in clinical outcomes, delivered to a patient and or their partner/carers and involves education through a structured process]

Unlike general PE which may broadly aim to inform patients about their health, TPE focuses intensely on enabling patients to manage their conditions such as lymphoedema daily (Figure 136). It encompasses not just educational components about lymphoedema itself but also includes training in practical skills necessary for effective self-management.

TPE typically involves an interdisciplinary team of health professionals—including doctors, nurses, dietitians, psychologists, physiotherapists and lymph therapists—who contribute their collective expertise to provide a comprehensive education about all facets of the patient’s condition. But as you have seen previously still we have issues of enough of these health professionals being educated about our issue of lymphoedema and this issue needs to be dealt with as a matter of priority.^(476, 477)

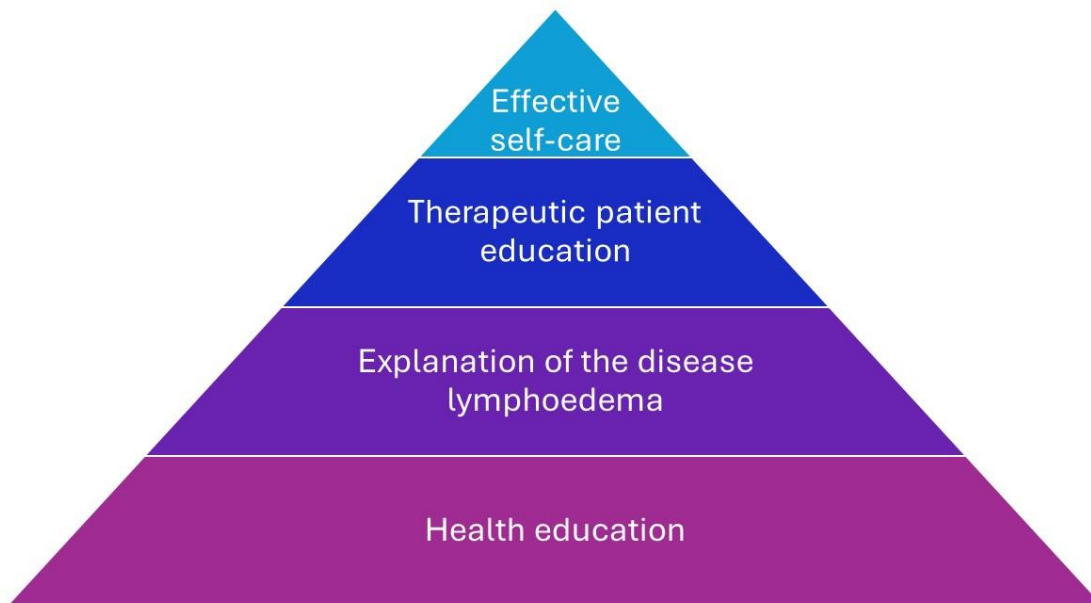


Figure 136 - Health education progression through to Therapeutic Patient Education and effective self-care

TPE is characterised by its collaborative and ongoing nature, involving regular and structured interactions between patients and healthcare providers. This ongoing dialogue adapts to changes in the patient’s condition and treatment needs over time, making TPE a dynamic component of chronic disease management.

TPE programs are tailored to the holistic needs of the individual, considering psychological, social, and physical factors, and objectives being structured around specific and achievable goals.

Amat (2011) described three types of objectives.

- **Health objectives** where the goal is to improve is to improve physical wellbeing by improving, for example, the extent of swelling.
- **Behavioural objectives** where the goal is to improve activities conducive to improved health for example, wearing compression garments on a daily basis. A key objective of TPE is to empower patients, enhancing their capacity to make informed decisions about their care and effectively self-manage. TPE involves awareness training, and the prescription of specific exercises or aids that will assist patients in their care.
- **Psycho-social objectives** where the goal is to adjust factors which influence the behaviour of patients by analysing unhealthy sociocultural, environmental, and financial influences so as to effectively improve their lymphatic systems functioning. One example could be removing financial stress through applying for garment funding through a government funded garment subsidy program.⁽⁴⁸³⁾

Therapeutic Patient Education in lymphoedema care

TPE has been shown to improve chronic disease management. Correia et al (2022) state that TPE “...programs have been shown to alter health behaviours positively, and thus improve biological, psychological, and quality of life outcomes for many chronic disorders.”⁽⁴⁸⁴⁾

Lymphoedema, a chronic condition marked by the accumulation of lymph fluid and swelling in various parts of the body, requires lifelong management to control symptoms and prevent progression. The complexity of lymphoedema management, which often includes the use of compression therapy, meticulous skin care, manual lymphatic drainage and physical exercises, demands a well-informed patient who understands the intricacies of the condition and the triggers for worsening of the condition.

Education needs will vary based on the type of lymphoedema and the individual needs of the patients. For breast cancer -related lymphoedema, for example, individualised education via a multi-modal approach, repeated at multiple time points, and assessment of the patients knowledge acquisition is recommended.⁽⁴⁸⁵⁾ The means by which these education sessions could be delivered would be through a prospective surveillance and monitoring model of care whereby patients are regularly seen by their healthcare practitioner for screening and education sessions.^(49, 362)

The World Health Organization (2023) published a comprehensive introductory guide aimed at policy-makers, health professionals, and educational bodies involved in TPE.⁽⁴⁸²⁾ This resource focuses on the critical aspects of commissioning, designing, and delivering TPE services and training programs for health professionals, addressing a vital component of healthcare that enhances patient engagement and disease management.

The guide explains that there are three subdomains of TPE which require consideration:

- **Self-management** intervention characteristics such as what is the support technique, what type of healthcare provider is providing the support and where
- **Expected patient/caregiver self-management behaviours** such as lifestyle, clinical and psychological management
- **Outcomes** such as have clinical outcomes been improved and has adherence to self-management behaviours improved.

Application of this guide to lymphoedema care is provided in Table 25. The remainder of this chapter will focus on aspects of each domain.

Self-management intervention characteristics in lymphoedema care

Dr Judith Casley-Smith was a prominent advocate for patient self-management. Recognising the chronic nature of lymphoedema and the necessity for ongoing care, she emphasised the importance of empowering patients to take an active role in managing their condition. In the Casley-Smith textbook they included comprehensive chapters dedicated to self-management strategies.⁽⁵⁶⁾ These chapters provided detailed instructions on various techniques and practices that patients could adopt to control their symptoms and improve their quality of life. Their approach encouraged qualified lymphoedema practitioners to teach patients:

- I. **Self-Massage and Lymphatic Drainage:** Detailed techniques on how patients could perform lymphatic drainage massages on themselves to reduce swelling and promote lymphatic flow.
- II. **Compression Therapy:** Guidance on the proper use of compression garments and bandaging, which are crucial in managing lymphoedema.
- III. **Decongestive Exercises:** Specific exercises tailored to help maintain lymphatic flow and reduce fluid buildup, along with tips on how to integrate these exercises into daily routines.
- IV. **Skin Care:** Essential tips on maintaining skin health to prevent infections and complications associated with lymphoedema.
- V. **Lifestyle Adjustments:** Practical advice for avoiding factors, such as poor diet and hydration, and other lifestyle factors which could influence the management of lymphoedema.

The encounter type and delivery method of TPE in lymphoedema care includes various means to ensure comprehensive understanding and accessibility.

- i) **Individual Counselling:** Patients often receive one-on-one education sessions from healthcare providers such as nurses, physiotherapists, or specialists in lymphoedema treatment. These sessions are tailored to the individual's specific needs. Individual counselling is usually performed in person through clinic visits or is also performed online through telehealth appointments. Noble Jones et al (2021) published guidelines for management lymphoedema patients remotely which offers practical guidance on when clinic appointments vs face to face appointments should be considered.⁽¹⁾
- ii) **Group Education Sessions:** Many healthcare facilities offer group education sessions where patients can learn from healthcare providers and share experiences with other patients. These sessions often cover general topics such as the importance of regular exercise, skin care to prevent infections, and how to correctly apply compression garments. ENCORE is one such educational program initiated in Canada and now taught in many countries including Australia. It provides a tailored program of education, therapeutic exercises, relaxation techniques and supportive community and professional engagement.⁽⁴⁸⁶⁾
- iii) **Printed Materials and Online Resources:** Brochures, books, and online articles provide valuable resources for patients. These materials can be accessed easily and revisited as needed, allowing patients to refresh their knowledge and stay informed about the latest treatments and strategies in lymphoedema management.
- iv) **Workshops and Seminars:** Occasionally, workshops or seminars are conducted by Lymphology Associations through patient education seminars, providing updates on new research, advancements in treatment options, and practical demonstrations of care techniques. These events also offer opportunities for patients to ask questions and interact with specialists who are not regularly available.
- v) **Digital Tools and Apps:** With the advancement of technology, several apps have been developed to assist in the management of lymphoedema. These digital tools can help track swelling, remind patients to perform lymphatic drainage exercises, or monitor the skin condition to prevent infections. Examples of these tools which can help those with lymphoedema include Lymphtrack™ which can play an active role in managing your lymphoedema. Patients can record key lymphoedema symptoms and self-care treatments and create charts that show how they are progressing over time.

There are other programs and patients should talk with their health professionals about which is best for them in their area, and which are best for them sharing information with those health professionals. Through these diverse educational approaches, patients with lymphoedema can gain a robust understanding of their condition and learn practical skills necessary for effective self-management. This comprehensive educational support not only helps in managing the condition day-to-day but also contributes to long-term health outcomes and a better quality of life.

Expected patient/caregiver self-management behaviours

Enhanced self-management practices include various aspects of lymphoedema care such as:

- diligent adherence to compression therapy
- regular performance of lymphatic drainage exercises
- meticulous skin care routines to prevent infections
- patients and caregivers reporting becoming more adept at recognizing early signs of complications and being empowered to take proactive measures to address them.

Outcomes

The effectiveness of TPE in lymphoedema care can be measured through various key outcomes that reflect the patient's or carers improved ability to manage their condition. Examples include:

- reduction in limb volume or circumference measures quantified through volume measurements
- consistent reports of adherence to recommended self-care practices such as wearing compression garments and performing lymphatic drainage exercises
- Improvements in quality of life assessed through validated questionnaires
- a decrease in the frequency of complications such as cellulitis occurrence rates and reduced healthcare utilization including fewer emergency visits and hospital admissions
- enhancements in functional status and daily activities through patient self-reported outcomes.

TPE is crucial for effective lymphoedema management, empowering patients with the knowledge and skills necessary to control their condition. By learning proper self-care techniques such as compression therapy, lymphatic drainage exercises, and meticulous skin care, patients can significantly reduce swelling, prevent complications, and improve their overall quality of life.

Education also enhances patient adherence to treatment protocols, increases confidence in self-management, and reduces the frequency of emergency healthcare interventions. Ultimately, well-informed patients are better equipped to manage their symptoms, leading to improved health outcomes and greater independence in their daily lives.

Conclusions

There is a huge diversity of sources of information for patients about how to manage their lymphoedema. Care needs to be taken particularly when consulting online resources as some may contain dubious often unchecked information and recommendations. While patient to patient, activities, sharing and communication is great it's not always possible so often is no other option than to go to the web for information. If this is done it should be confined to reputable sites that are recommended by national and international patient and practitioner groups. The other side to information sourcing is one of limitations in terms of well-educated and aware general practitioners, family doctors, clinicians and specialists able to give advice and direct care and management for the patient. Despite these issues there are some very good recommendations for TPE in general terms and that is a focus of our chapter. What needs to be done however is that the patient (ideally in concert with their selected health professional) needs to be led to these programs and assisted in their progress through them, to give them the opportunity and confidence to manage their lymphoedema.

Table 25 - Subdomain elements and application to lymphoedema care

Domain	Component	Examples for World Health Organisation Guide	Examples of application to lymphoedema care
Self-management intervention characteristics	1.1 Support technique	Sharing information, skill training, stress and/or emotional management, shared decision-making, goal setting and action planning, problem-solving skill enhancement, self-monitoring training and feedback, using prompts and reminders, encouraging the use of services, providing equipment, social support, coaching and motivational interviewing	Sharing information on lymphatic anatomy and physiology, giving self-monitoring tips to look out for signs of swelling and cellulitis
	1.2 Delivery method	Clinic visit, support session and self-guided intervention, telephone calls, smart phones, Internet and specific devices	eHealth and mHealth (online courses, telehealth), clinic sessions, group face to face education sessions
	1.3 Encounter type	Face-to-face intervention, distance/remote interventions	Face to face and remote through telehealth appointments
	1.4 Recipient	Individual, group and specific populations	Lymphoedema patients, patient's carers
	1.5 Provider type	Physician, nurse, pharmacist, physiotherapist, occupational therapist, social worker, psychologist, dietitian/nutritionist, healthcare assistant, peer, layperson and service provider	Qualified lymphoedema practitioners, breast care nurses, oncology practitioners, lymphologist
	1.6 Location workplace	Hospital (inpatient care), long-term centre/nursing home care, community-based care, home care, primary care, outpatient setting	Inpatient, outpatient and community settings
Expected patient/caregiver self-management behaviours	2.1 Lifestyle related	Eating behaviours, physical activity/exercise, smoking cessation or reduction, cessation or reduction of the consumption of alcohol or other harmful substances, healthy sleep habits	Information on risk factors for poor lymphatic function
	2.2 Clinical management	Condition-specific behaviours, self-monitoring, medication use and adherence, early recognition of symptoms, asking for professional help or emergency care when needed, device management and physical management	Information on how to self-monitor limb volume
	2.3 Psychological management	Handling/managing emotions	Encouragement to use a journal

Domain	Component	Examples for World Health Organisation Guide	Examples of application to lymphoedema care
	2.4 Social management	Fitting in at work, social roles and being able to work	Garment management techniques for work (such as prescription of a separate arm and glove rather than all in one to assist in removing an upper limb garment at work for hand washing)
	2.5 Working with a healthcare/social care provider	Communicating with a healthcare and/or social care provider	Encouraging open communication and structuring opportunities through regular telehealth appointments
Outcomes	3.1 Basic empowerment/competencies	Level of knowledge, level of health literacy, level of skill acquisition, level of self-efficacy and level of patient activation	Understanding of lymphatic anatomy and physiology, reporting when a concept is not understood and seeking clarification
	3.2 Adherence to self-management behaviours	Lifestyle, clinical, psychological, social, interactions and communication with healthcare/social care providers	Reporting being able to leave the house more often and feeling more confident in society
	3.3 Clinical outcomes	Disease progression (clinical markers, symptoms) complications, adverse events and mortality	Improved limb volume measures, softening of areas of fibrosis
	3.4 Patient/caregiver quality of life	Overall quality of life, physical functioning, psychological and emotional functioning, social functioning, sexual functioning and burden of treatment	Improvements in quality of life reported through validated lymphoedema quality of life questionnaires
	3.5 Care perception/satisfaction	Overall satisfaction with self-management interventions, perceptions of being well and sufficiently informed (quality of information provision), perceptions of the patient-provider relationship, and personalized care	Reporting being highly motivated and empowered in their own lymphoedema self-care
	3.6 Healthcare use	Type and number of visits, hospital admissions and readmissions, and emergency care	Decreased number of admissions to public hospital services for cellulitis
	3.7 Costs	Healthcare costs for patients, health-care costs, direct nonmedical costs and societal costs	Decreased cellulitis recurrence rates

Twenty(ii) - Prototype development – online course

Highlights

The key highlights of this research include:

- A prototype of an online course designed for patients was successfully developed
- Appreciation of the fact that developing an effective online course can be a complex process
- The prototype development demonstrated the feasibility of creating an online course designed to help patients learn about the early intervention of lymphoedema
- Before this tool could be made available it would need to undergo thorough testing, necessitating research funding. The cost of funding the course and hosting need to be carefully considered.

Aim

The objective of this research was to develop a prototype of an online course for patients on lymphoedema and learn from this process. The research question was, “What factors need consideration in the building of an online course for patients with lymphoedema?”

Background

There is a need for high-quality, current, evidence-based educational resources for Australian lymphoedema patients, as such resources are not freely available. The Australasian Lymphology Association (ALA), as the peak professional lymphology body in Australia, provides two video resources known as the Survive and Thrive series (S&TS). The S&TS was developed 11 years ago, and while the videos were exceptional resources at the time, they are now outdated. They no longer align with the advancements in manual lymphatic drainage (MLD) techniques with advent of indocyanine green imaging having improved practitioners understanding of how MLD should be performed. They also lack crucial information on the importance of nutrition and early intervention.

Mt Wilga hospital provides a dedicated lymphoedema service which was modelled on the Földi clinic in Germany.⁽⁴⁸⁷⁾ The author led the filming of the S&TS video series when working as the Lymphoedema Team Leader at Mt Wilga hospital, more than a decade ago.

The S&TS is sold by the ALA as a DVD and is also hosted YouTube.⁽⁴⁸⁸⁻⁴⁹⁰⁾ Below is the YouTube cover of the video, where the author is featured delivering MLD to her own body. As of the time of writing this video had garnered over 59,000 views over the preceding 11 years (Figure 137).

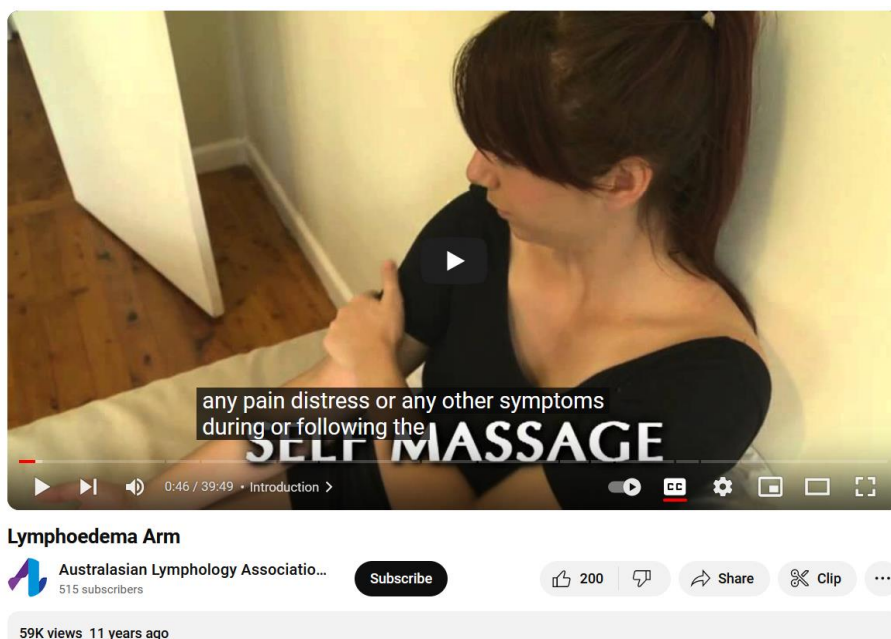


Figure 137 - 59,000 views on the Survive and Thrive upper limb YouTube video posted 11 years ago

Some of the public comments on this video are interesting (Figure 138). Several of the comments congratulate the content by thanking the providers for the resource. One criticises the content for not mentioning the importance of nutrition, “No one talked about proper nutrition which is a key to heal lymphoedema. Dr. Roberr [sic] Morse has many talks about the subject.” Another also criticises the content for not focussing on the prevention aspect, “Why not enough PR & focus on CURING the very painful crippling condition lymphoedema attached to breast cancer where, by the way, we no longer want to just 'prolong death' but having been CURED for good. Now. We don't have time.”

- L** @luzvimindasuficiencia4804 2 years ago
Awesome video, thanks for sharing your wonderful video. Stay safe everyone.
👍 🗨️ Reply
- 🌸** @charlottemarx3 10 years ago
What a great video!! Thank u so much now i have more ways to treat my lymphedema and manage it.
👍 1 🗨️ Reply
- 🌿** @truckndyke 10 years ago
Thank you, what a wonderful video.
👍 1 🗨️ Reply
- 👤** @zavangalia 10 years ago
This has been very interesting I will be watching it again soon
👍 1 🗨️ Reply
- M** @margiescott383 8 years ago
Thank you found it very interesting. New I had it last year But the cancer breast clinic said my breast was fine Now I have it in my breast and my arm has swollen just a little I will do everything my Physiotherapist starting tomorrow Do all the exercises Next time I will be more assertive to the doctor in the breast clinics So thank you And thank to my wonderful JP
👍 1 🗨️ Reply
- M** @Benstephan123 6 years ago
No one talked about proper nutrition which is a key to heal Lymphedema Dr. Roberr Morse has many talks about the subject
👍 1 🗨️ Reply
- J** @janicepperson7511 7 years ago
Thank you. This video has been so helpful. I did the massage and found to be such a relief I will make the massage and exercise part of my daily routine. Thank you again. 😊
👍 1 🗨️ Reply
1 reply
- 👤** @sallyholden7220 7 years ago
I have just found out iv got this and no one told me.
👍 2 🗨️ Reply
- 🌈** @maskent-ol3jy 6 years ago
Why not enough PR & focus on CURING the very painful crippling condition Lymphedema attached to breast cancer where, by the way, we no longer want to just 'prolong death' but having been CURED for good. Now. We don't have time.
👍 🗨️ Reply

Figure 138 - Public YouTube comments on the upper limb Survive and Thrive video

The lower limb video has less views, 10,000 views over the last eleven years (Figure 139).

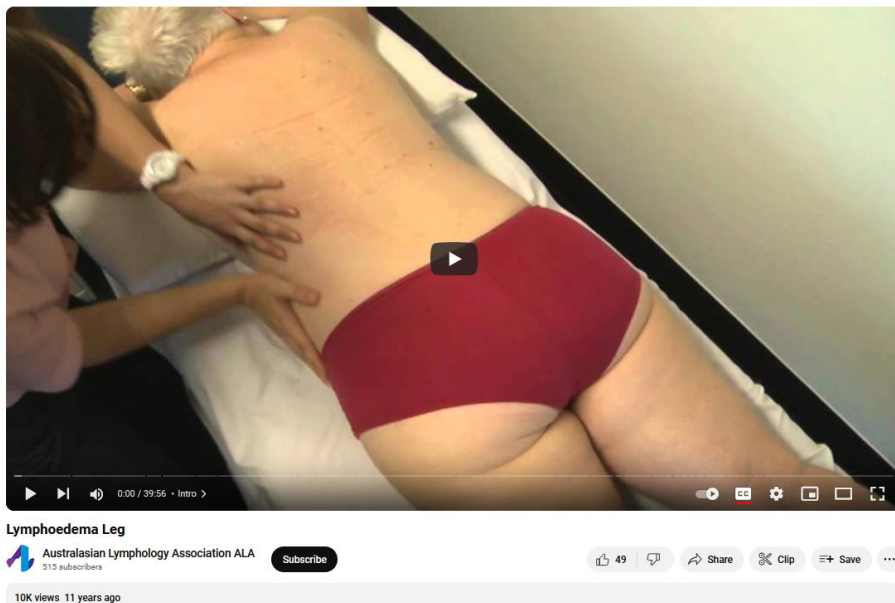


Figure 139 - 10,000 views on the Survive and Thrive lower limb YouTube video posted 11 years ago

The publicly available comments for the lower limb video are below (Figure 140). One example of positive feedback is, “Thank you I needed this advice. My leg's increasing rapidly, and I've obviously been doing the exercises or it's wrong or not enough. I felt better just listening and watching. I'll do it. Where can I buy it? Lurline.”

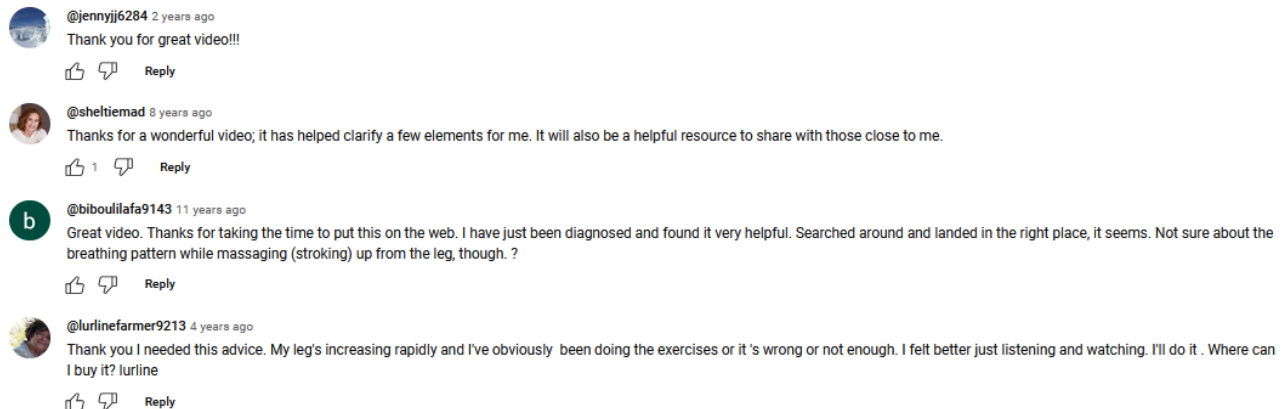


Figure 140 - Public YouTube comments on the lower limb Survive and Thrive video

The S&TS was developed after Mt Wilga Hospital received a significant bequest from a patient, specifically intended for the funds to be put towards resources which provided free patient lymphoedema education. The ALA also provided funding and assumed ownership and hosting responsibilities for the video. A professional videography crew was hired to produce the filming, which also included the engagement of a professional presenter.

To understand the equivalent budget in 2024, the total funds were ~\$80,000 AUD in 2009 which is equivalent in purchasing power to about \$117,154.62 today, an increase of \$37,154.62 over 15 years. The dollar had an average inflation rate of 2.58% per year between 2009 and today, producing a cumulative price increase of 46.44%.⁽⁴⁹¹⁾ Production costs however have also considerably increased, with most videographers quoting for minutes of filming time as opposed to hours. It took days to film all the content featured in these videos, with the author's estimation being that an equivalent product would cost upwards of \$300,000 (AUD) to produce today. Staff labour hours would also need to be funded as well as presenter fees. Patients would need to be reimbursed for their time, unless a volunteer model was organised. A large grant would therefore need to be sourced to fund such a project.

Without any research funding, it was unknown if a course could be developed on lymphoedema and what the development considerations would be.

Method

An online course was developed to facilitate learning during its creation and to produce a research prototype. The course aimed to educate patients about the early intervention of lymphoedema.

The Australian Institute of Lymphoedema provided funding of software licencing fees and allowed for the creation of the customised educational resources for this thesis.

The brand “HELP Online – Health Education on Lymphoedema for Patients” was created by the author, for the purpose of research, to support education products designed to support patients living with lymphoedema. A custom avatar was created of a woman with lymphoedema in her right arm. A custom introduction video showing her swollen arm was created (Figure 141). The introduction video concluded with the avatar hugging the logo to reflect receiving support for her lymphoedema (Figure 142).

“CANdetect” as the course name was also created by the author. It was a term that combined “CAN” from cancer treatment and “detect” from lymphoedema. It was designed to proactively encourage the early detection of lymphoedema in patients who have undergone cancer treatment, emphasising the importance of timely intervention.



Figure 141 - HELP introduction video with custom avatar with lymphoedema



Figure 142 - HELP introduction video with custom avatar hugging the HELP logo

Signed consent forms were obtained from two patients who featured in the content and shared their story of living with lymphoedema. The intended use of the content was behind a password protected learning management system.

Results

A prototype online course was successfully developed.

Structure of the course

The course included 15 sections (Figure 143 and Figure 144). Each section was designed to be consumed quickly, with short entertaining videos, text and downloadable PDFs. The topics in each section are presented in Table 26.

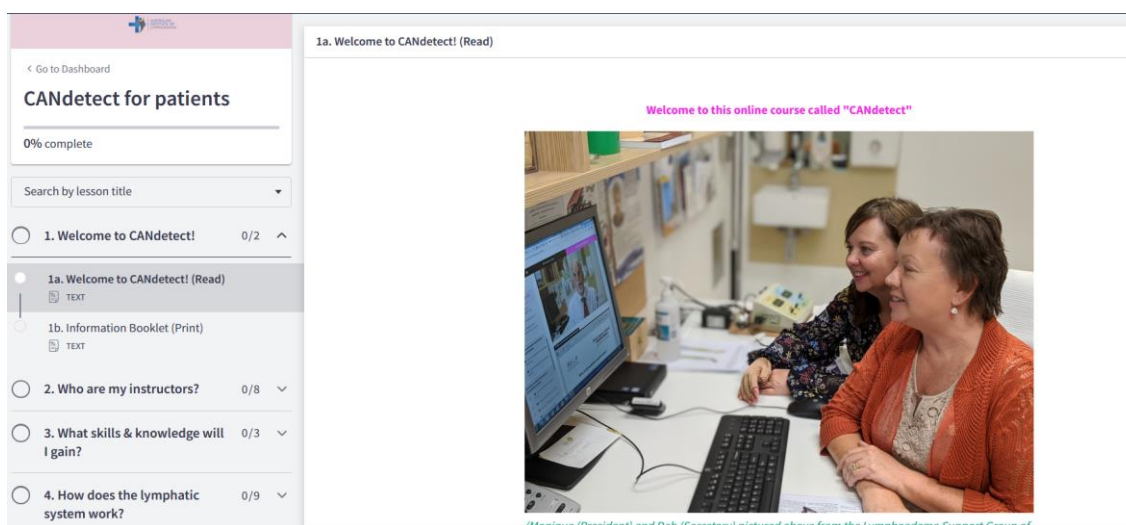


Figure 143 - CANdetect course sections 1 to 4

[Pictured is Monique Bareham and Deb Hart who were both instrumental in helping with the success of the course. Monique provided her perspective on living with lymphoedema and Deb Hart reviewed the content.]

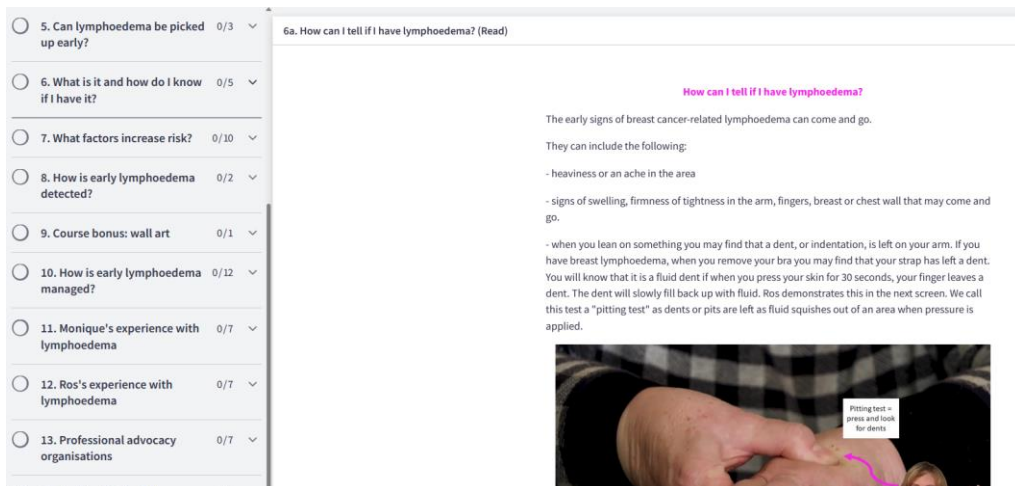


Figure 144 - CANdetect course sections 5 to 13

Ensuring motivation

The learner was encouraged to stay motivated with learning through digital “gifts” being embedded in the content. Digital artwork was available as downloadable PDFs. The gift at the halfway point is pictured below (Figure 145 and Figure 146). The text read, “You have made it half-way through this course! To celebrate we wanted to give you a gift. Too often we forget to remind ourselves how beautiful we are and how much our amazing lymphatic system does for us without our conscious control. We designed this artwork for you so you can print it out and walk by every morning with a smile saying to yourself, "Why hello beautiful!"

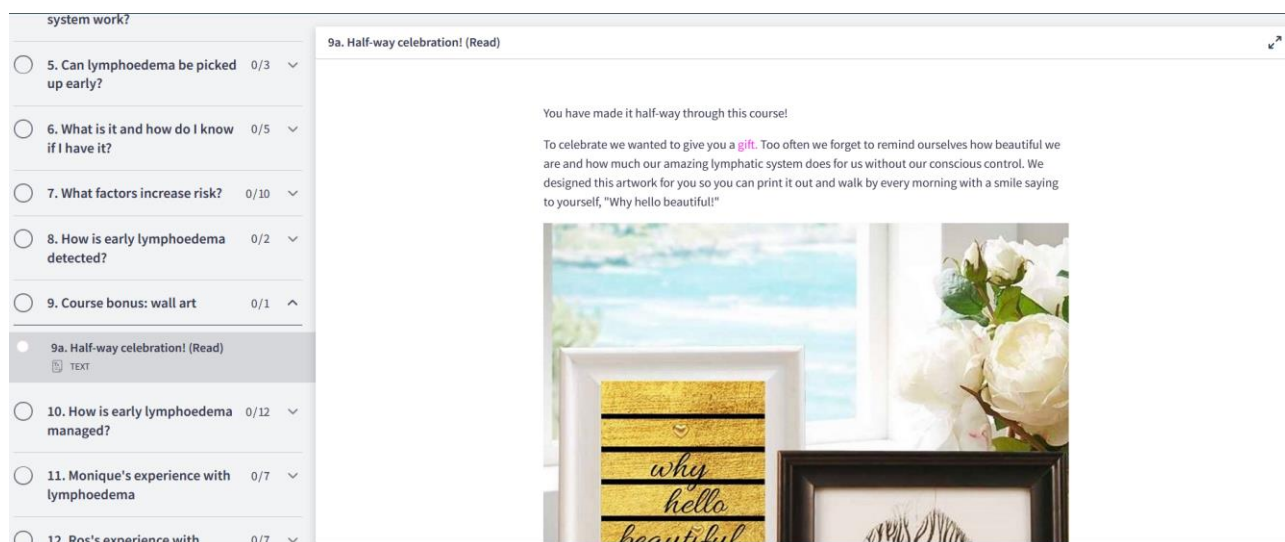


Figure 145 - Digital gift at halfway point



Figure 146 - Gift contextualised to the home environment

At the end of the course, another digital gift became unlocked (Figure 147). The text read, "Congratulations! You have completed this course! To celebrate we wanted to give you a little gift that was suggested by Monique. Monique said to Andrea that, "We can sometimes forget that life is a gift. It cannot be exchanged. It cannot be returned, and we cannot borrow it for a certain period of time. As you look at this artwork hopefully it will help remind you of how strong you are, and that each day is an opportunity to be the best version of yourself."



Figure 147 - Final course digital gift contextualised to the home environment

Accessibility

Each video within the online course was followed with a transcript to improve digital accessibility (Figure 148). Pictured in the transcript is the start of Professor Piller's introduction, "My professional title, here at the moment, is Director of the lymphoedema clinical research unit. I absolutely love the lymphatic system because way back in about 1969, I was introduced to lymphatic diseases through one of my lecturers and Professors, Professor John Casley-Smith. Way back then, just one thing he showed me, one picture of a lymphoedematous leg, made a difference. That got me started with respect to my enthusiasm for lymphoedema and lymphatics. One picture!"

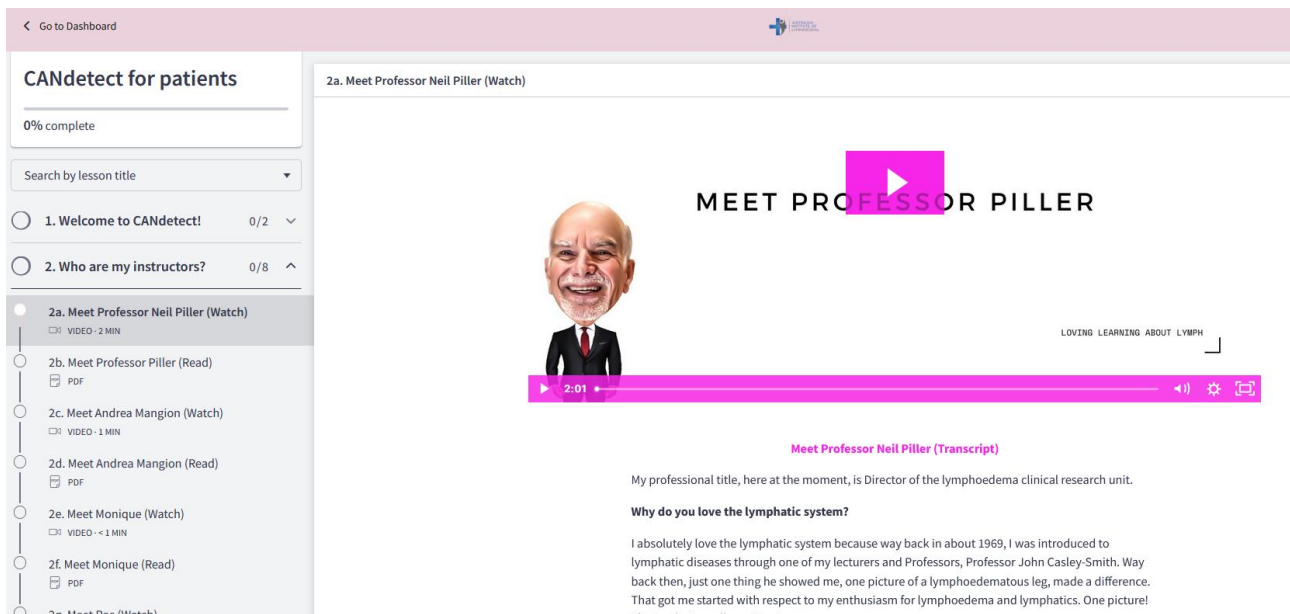


Figure 148 - Example of a transcript

Entertainment and fun

Entertainment and fun was built in with a bloopers section (Figure 149 and Figure 150) and “big head” characters (Figure 151) and cartoons. Over 50 cartoons were professionally illustrated on the lymphatic system (Figure 152 and Figure 153) as well as cartoons to represent the hero (cardiovascular system Figure 154 and Figure 155) and unsung hero (lymphatic system - Figure 156 and Figure 157).

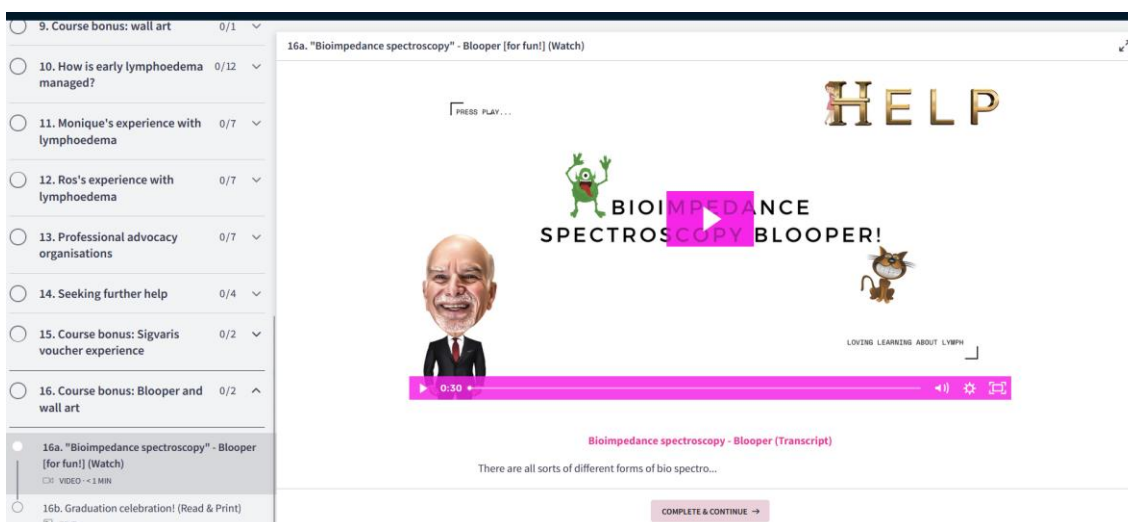


Figure 149 - Example of bioimpedance spectroscopy blooper front screen

16a. "Bioimpedance spectroscopy" - Blooper [for fun!] (Watch)



Bioimpedance spectroscopy - Blooper (Transcript)

There are all sorts of different forms of bio spectro...
There are many forms of bioimpedance spectroscopy
There are many forms of bioimpedance spectroscopy
I got it right and then I laughed!

Figure 150 - Blooper mid-way of bioimpedance spectroscopy demonstrating Professor Piller smiling!

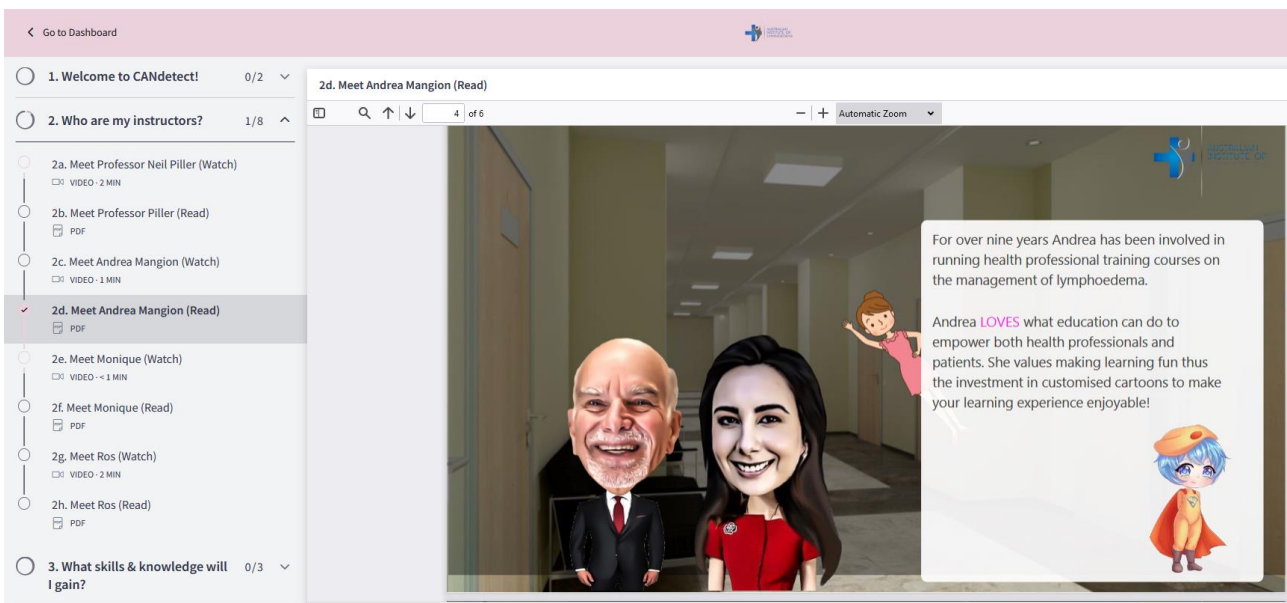


Figure 151 - Example of big head characters and cartoons

[Big head characters of Professor Piller (far left), Andrea Mangion (left), little lady (on the diagonal) and unsung hero (right)].

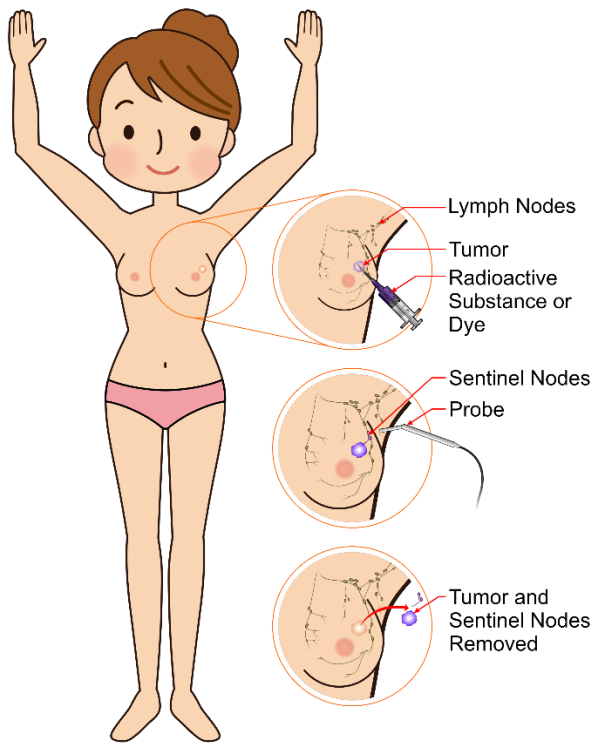


Figure 152 - Example of a cartoon to educate about sentinel lymph node biopsies

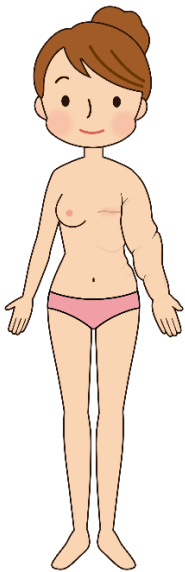


Figure 153 - Example of a cartoon to educate on lymphoedema after a breast cancer treatment

Everyone has heard of the cardiovascular system...



Figure 154 - Cartoon of the "hero" the cardiovascular system



Figure 155 - Cartoon of the "hero" the cardiovascular system without clothes

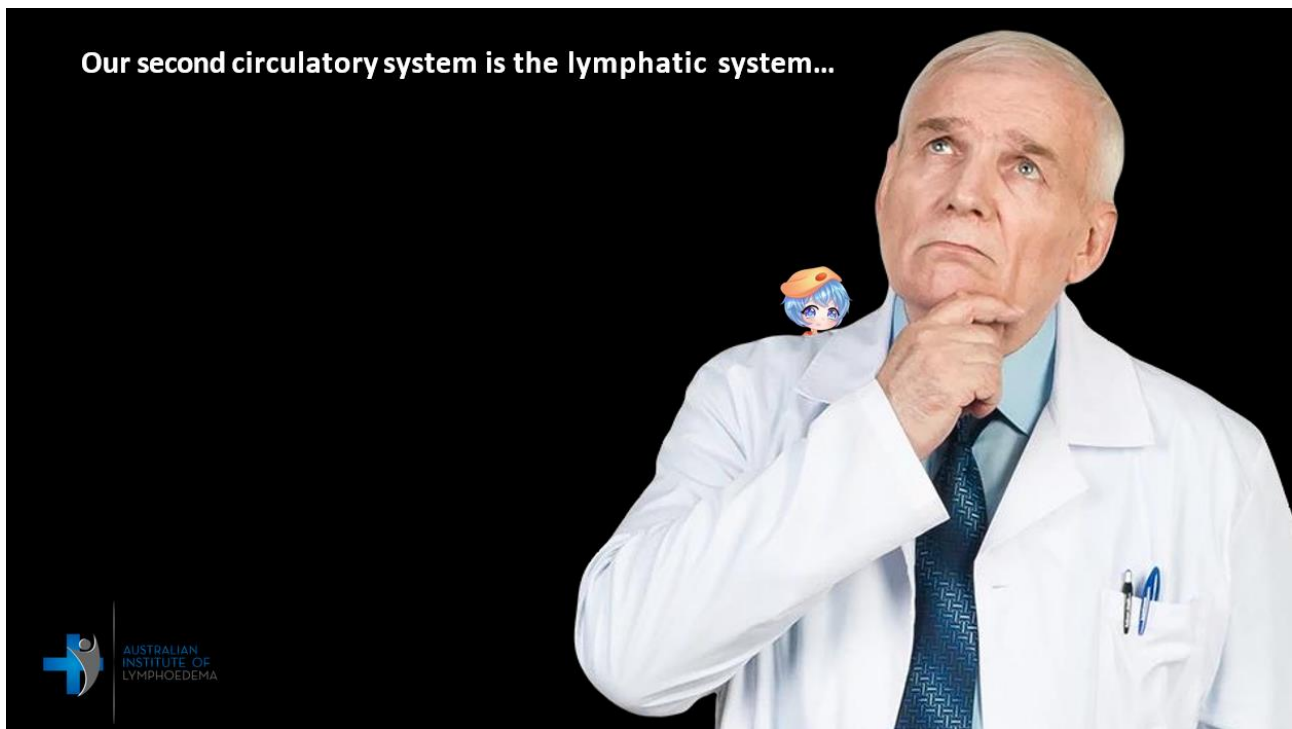


Figure 156 - Cartoon of the “unsung hero” the lymphatic system



Figure 157 - Cartoon of the “unsung hero” the lymphatic system without clothes

Empowerment of the learner with evidence-based information

The learner was encouraged to be in the driver’s seat of their learning experience. Professional marketing software (Canva) was used to outline what the learning experience would be in the course information booklet, provided in section one of the course (examples of content provided in Figure 158 and Figure 159).⁽⁴⁹²⁾

HELP

WELCOME!

CANDETECT

CANdetect was designed to empower anyone that is undergoing, or has undergone, breast cancer treatment to understand breast cancer-related lymphoedema.

This course aims to teach you:-

- How the lymphatic system works and what breast cancer-related lymphoedema is
- How early detection & diagnosis can occur and what stage zero lymphoedema is
- The factors that increase lymphoedema risk, things to avoid and the early warning signs
- How early lymphoedema is treated
- What it is like living with breast cancer-related lymphoedema. You will hear the story of two women living with lymphoedema, Monique & Ros, so you can learn from their first-hand experiences.
- The right questions to ask your breast surgeon & breast care nurse about breast cancer-related lymphoedema and questions to ask a lymphoedema therapist before booking your first appointment.

Education is the first step in empowering yourself to seek the care that you need.



Figure 158 - Information in the course instructions booklet on what to expect from the course

HELP

WHAT IS BREAST CANCER-RELATED LYMPHOEDEMA?

Breast cancer related-lymphoedema is a medical condition, as opposed to a disease, that may occur as a side effect of breast cancer treatment/s. The condition occurs when the lymphatic system becomes damaged and fails to function adequately. This results in lymph fluid building up in the tissues of the arm, breast and/or trunk.

Lymphoedema can be considered an "inflammatory condition" involving long term tissue swelling and inflammation. If the condition is not treated well, over a period of time, lymphoedema can also involve the tissues becoming hard (known as fibrotic tissue) and fatty tissue building up in the areas that are swollen.

Does everyone treated for breast cancer develop lymphoedema?

No! Being scared of lymphoedema is not helpful. It is important to remember that anyone treated for breast cancer has a greater chance of not developing breast cancer-related lymphoedema than that of developing the condition!

Current scientific evidence suggests that around one in five patients develop the condition with the risk varying based on "individual" and "treatment-related" risk factors.

Examples of treatment-related risk factors are: lymph node surgery, breast surgery (such as a mastectomy or lumpectomy) and other cancer associated treatments (such as chemotherapy and radiotherapy) or complications (such as a seroma, infection or cording). Examples of individual risk factors are: being overweight, having high blood pressure, low activity levels or poor kidney and/or heart function). These factors may impact the ability of the lymphatic system to drain lymph fluid.



Figure 159 - Details in the course instruction booklet explaining breast cancer-related lymphoedema

Discussion

The research question of, “What factors need consideration in the building of an online course for patients with lymphoedema?” was answered through the process of building this prototype. Several factors were considered in the development of the course, including course structure, strategies to ensure learner motivation, accessibility, entertainment, and engagement, as well as the empowerment of the learner through the provision of evidence-based information. The course structure was designed to ensure clarity and logical progression, while motivational strategies were incorporated to encourage learner persistence and completion. Accessibility was prioritised to ensure that all learners, regardless of their needs, could fully engage with the material. The inclusion of engaging and interactive elements was intended to maintain interest and make learning enjoyable. Additionally, the course aimed to empower learners by providing them with accurate, evidence-based information.

Lessons learned

Several lessons were garnered in this process of prototype development:

- **Consent and patient case studies:** Consent forms need to be considered when patient case studies are included as part of educational content. Hosting content in the environment of a secure learning management system (LMS) is very different to hosting content on a free streaming service such as YouTube. While a secure LMS incurs fees, it ensures that content is only accessible to a specific audience, offering greater privacy and control.
- **Development costs:** One of the major expenses in eLearning development is videography, especially the editing of content rather than the filming itself. Furthermore, an instructional designer (in this case, the author) must meticulously plan and curate the supplementary content to ensure it effectively complements the videos.
- **Hosting costs:** Significant hosting costs are associated with maintaining an educational course in a secure LMS. These expenses must be budgeted not only for the initial creation of the product but also for the ongoing maintenance throughout the course's lifetime.
- **Development time:** Considerable time must be invested in creating high-quality educational content. This process, separate from instructional design or course development, involves extensive research, content creation, and iterative revisions to ensure both accuracy and educational value.
- **Distinct skill sets:** Creating an educational course demands a broad range of skills. Content development requires expertise in the educational field, usually provided by an Instructional Designer, along with an engaging and knowledgeable presenter. In contrast, course development involves technical skills, such as programming (depending on the authoring platform), user interface design, and software integration.

- **User experience design:** An intuitive and user-friendly experience is essential for the success of an educational course. The design process must prioritise ease of navigation, clear instructions, and engaging multimedia elements to enhance user engagement and adherence. Concepts such as motivation, entertainment and fun should be considered in online course development.
- **Digital accessibility:** Ensuring that the educational content is accessible to a diverse audience is crucial. This includes using video transcripts, plain language, and incorporating features that cater to individuals with varying levels of digital literacy and different learning preferences.

Implications for future research

This prototype garnered several insights relevant for those wishing to build educational courses for empowering patients to understand their own lymphoedema. Each of the lessons, including the importance of obtaining consent and incorporating patient case studies, understanding development and hosting costs, recognising the distinct skill sets required in the development of an online course, and the need to prioritise user experience design and accessibility, should be considered in future research.

Table 26 - Topics in the online course CANdetect

Topic	Lessons	Topic heading and approximate duration
Welcome to CANdetect!	2	1a. Welcome to CANdetect! (Read) Text 1b. Information Booklet (Print) Text
Who are my instructors?	8	2a. Meet Professor Neil Piller (Watch) Video · 2 min 2b. Meet Professor Piller (Read) PDF 2c. Meet Andrea Mangion (Watch) Video · 1 min 2d. Meet Andrea Mangion (Read) PDF 2e. Meet Monique (Watch) Video · < 1 min 2f. Meet Monique (Read) PDF 2g. Meet Ros (Watch) Video · 2 min 2h. Meet Ros (Read) PDF
What skills & knowledge will I gain?	3	3a. Why do little things make a big difference? (Watch) Video · 2 min 3b. What will I gain? (Watch) Video · < 1 min 3c. Our why (Watch) Video · < 1 min
How does the lymphatic system work?	9	4a. How does the lymphatic system protect against disease? (Watch) Video · 1 min 4b. What are the components of the lymphatic system? (Watch) Video · < 1 min 4c. What vessels move lymph fluid? (Watch) Video · 2 min 4d. What are lymph nodes? (Watch) Video · < 1 min 4e. How do lymph nodes fight disease? (Watch) Video · 4 min 4f. How do lymph nodes drain fluid? (Watch) Video · < 1 min 4g. What are sentinel lymph nodes? (Watch) Video · 1 min 4h. What are normal patterns in lymph flow? (Watch) Video · 1 min 4i. How does the body compensate after cancer treatment?
Can lymphoedema be picked up early?	3	5a. Can lymphoedema be detected early? (Watch) Video · 1 min 5b. What does early detection mean? (Read) Text 5c. What can I show my Doctor on this topic? (Watch) Video · < 1 min
What is it and how do I know if I have it?	5	6a. How can I tell if I have lymphoedema? (Read) Text 6b. How do I assess my lymphoedema? [by Ros] (Watch) Video · 1 min 6c. What does Stage One lymphoedema look like?(Read) Text 6d. What does Stage One lymphoedema look like? (Watch) Video · 4 min 6e. When am I most at risk? (Read) Text

Topic	Lessons	Topic heading and approximate duration
What factors increase risk?	10	7a. Why is a sentinel lymph node biopsy performed? (Watch) Video · < 1 min 7b. Is lymph node removal a risk factor? (Watch) Video · 3 min 7c. Are radiation and chemotherapy risk factors? (Watch) Video · 3 min 7d. Is infection a risk factor? (Watch) Video · < 1 min 7e. What is a seroma? (Watch) Video · 1 min 7f. What is cording? (Watch) Video · 3 min 7g. Is obesity and a lack of movement a risk factor? (Watch) Video · 1 min 7h. Is high blood pressure a risk factor? (Watch) Video · < 1 min 7i. What about injections and other risk factors? (Watch) Video · 5 min 7j. Is flying a risk factor? (Watch) Video · 2 min
How is early lymphoedema detected?	2	8a. What is bioimpedance spectroscopy? (Watch) Video · 3 min 8b. How can I self monitor? (Read) Text
Course bonus: wall art	1	9a. Half-way celebration! (Read) Text
How is early lymphoedema managed?	12	10a. How is lymphoedema treated? (Watch) Video · 3 min 10b. How do I care for my skin? (Watch) Video · 2 min 10c. How can I do some self-scar massage? (Watch) Video · < 1 min 10d. What is manual lymphatic drainage? (Watch) Video · 5 min 10e. How firm should the massage be? (Watch) Video · 2 min 10f. How do I do self massage? (Print) Text 10g. How can I do a diaphragmatic lymphatic breath? (Watch) Video · < 1 min 10h. What are compression garments? (Watch) Video · 3 min 10i. What should I look for with chest compression? (Read) Text 10j. What should I look out for with arm compression? (Read) Text 10k. How important is exercise? (Watch) Video · 2 min 10l. What are some decongestive arm exercises? (Watch) Video · 1 min
Monique's experience with lymphoedema	7	11a. Meet Monique (Watch) Video · 5 min 11b. How severe was my lymphoedema? (Watch) Video · 4 min 11c. What did I learn from the "green" dye? (Watch) Video · 3 min 11d. What does my lymphatic drainage look like? Video · 1 min 11e. How do I manage my lymphoedema? (Watch) Video · 5 min 11f. Am I perfect? (Watch) Video · 1 min 11g. What advice would I give to others? (Watch) Video · 3 min
Ros's experience with lymphoedema	7	12a. Meet Ros? (Watch) Video · 2 min 12b. When did my right arm start to swell? (Watch) Video · 3 min 12c. What were the early signs of swelling? (Watch) Video · 1 min 12d. Have I had cellulitis? (Watch) Video · 4 min 12e. What did I learn from the "green" dye? (Watch) Video · 2 min 12f. How do I manage my lymphoedema? (Watch) Video · 4 min 12g. What advice would I give others? (Watch)

Topic	Lessons	Topic heading and approximate duration
Professional advocacy organisations	7	13a. Australian Government Funded Programs Including Garment Subsidy Programs (Read) Text 13b. Australasian Lymphology Association (Read & Print) Text 13c. National Lymphoedema Network (Read & Print) Text 13d. Breast Cancer Network of Australia (Read & Print) Text 13e. Cancer Council (Read & Print) Text 13f. Westmead Breast Cancer Institute (Read & Print) Text 13g. Encore (Read) Text
Seeking further help	4	14a. Where can I find a qualified therapist? (Watch) Video · < 1 min 14b. Where can I find a support group? (Watch) Video · 1 min 14c. Where can I learn more? (Watch) Video · < 1 min 14d. Acknowledgements (Watch) Video · < 1 min
Course bonus: Blooper and wall art	2	15a. "Bioimpedance spectroscopy" - Blooper [for fun!] (Watch) Video · < 1 min 15b. Graduation celebration! (Read & Print) Text

Twenty(iii) - Prototype development – educational app

Highlights

The key highlights of this research include:

- A prototype of an education app on lymphoedema was successfully developed
- Developing an effective education app can be a complex process. There are modern software tools however which simplify the process
- The prototype development demonstrated the feasibility of creating a digital education app to help patients learn about the early intervention of lymphoedema
- Before this tool could be made available it would need to undergo thorough testing, necessitating research funding. The cost of funding app development and hosting needs to be carefully considered.
- The design of educational content requires significant consideration. Keeping videos short and to the point required a skilled presenter. Artificial Intelligence (AI) can also be used for video curation.

Aim

The objective of this research was to develop a prototype of a patient app designed to provide education on the early intervention of lymphoedema and to learn from this process.

The systematic review discussed in Chapter Nine of the thesis highlighted that patient adherence to lymphoedema treatment via digital health interventions can be negatively affected by overly lengthy or overly instructive online content. To address this, the prototype was designed to incorporate short and concise videos, each lasting no more than a few minutes.

The questions the author wanted to answer were: “Can a simple patient education app be designed?” and “What factors should be considered for an effective app to be built?”

Background

Mobile health (mHealth) apps are increasingly sought after as educational tools for patients due to their accessibility and ease of use. These apps offer readily available, evidence-based information that can be accessed anytime and anywhere, making them particularly useful for patient education. They empower patients to take a more active role in managing their health by providing tailored content, interactive features, and real-time updates. Additionally, mHealth apps support healthcare systems by addressing barriers to access, such as geographic distance and limited healthcare resources, ultimately enhancing patient engagement and self-management.

Method

A prototype of a digital education app was developed to facilitate learning during its creation and to produce a research prototype. Educational content, apart from AI curated videos specifically designed for the app, were sourced from the online course mentioned earlier in this thesis (called CANdetect) which the author had developed.

The app software which was selected after product comparison analysis was Passion.io.⁽⁴⁹³⁾ The Passion.io platform requires the user to define the app's primary objectives and target audience. Next, the user can choose from various customizable templates, which are designed to suit different educational themes and structures. These templates help streamline the design process and ensure a professional appearance for the app. Users can then populate the templates with their own content, including videos, text, quizzes, and interactive elements, leveraging drag-and-drop functionality to easily arrange and format the material.

Multimedia content was embedded to enhance engagement and learning outcomes. Passion.io supports the inclusion of high-quality video lessons, downloadable resources, and interactive exercises. Additionally, Passion.io allows for the app to be published on Google and Apple app stores.⁽⁴⁹⁴⁾

Results

A prototype of an educational app was successfully developed. The app featured four main sections (Figure 160):

- Learn
- Community
- Tracking
- User Profile

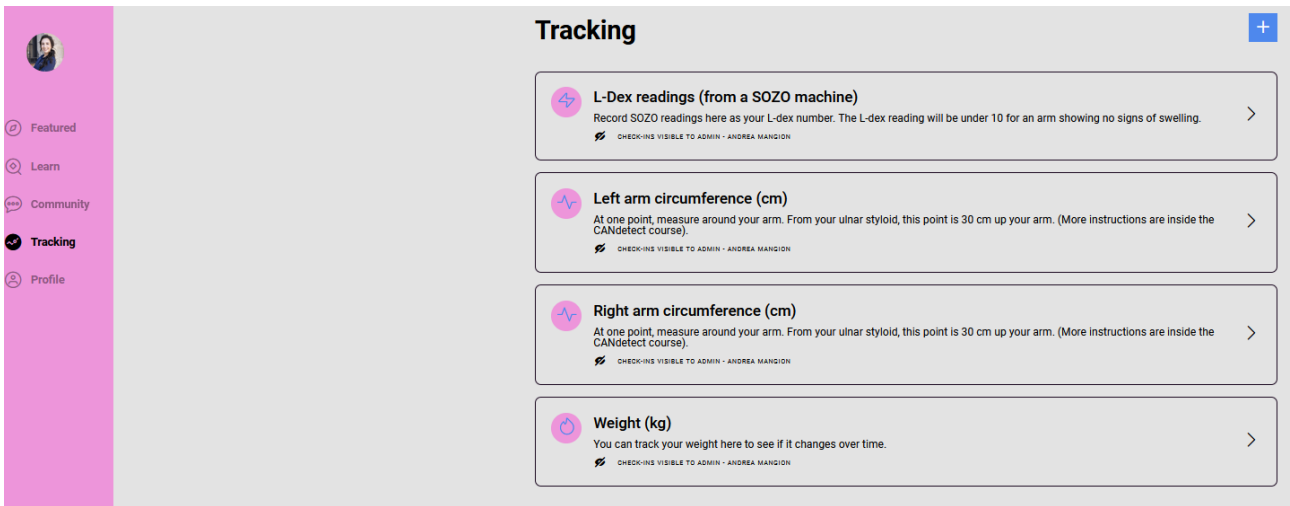


Figure 160 - App screen showing four side-bar menu options and hovering over tracking screen

In the learn section, the app hosted an educational course designed to teach patients about the early detection of lymphoedema. Videos created with AI were embedded. An avatar called Josie was created (Figure 161).

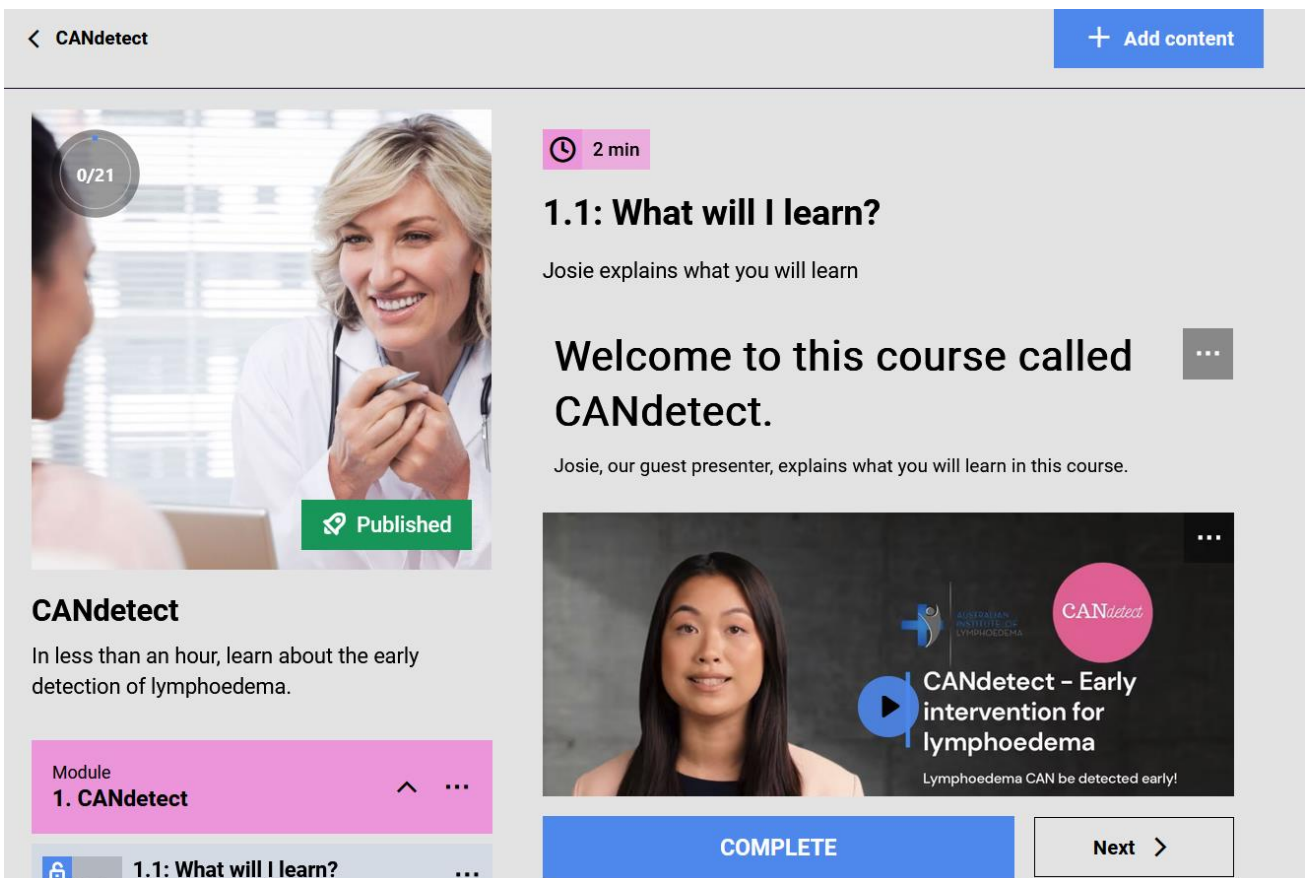


Figure 161 - Josie welcoming the learner

Educational videos which featured Professor Neil Piller were also embedded (Figure 162).

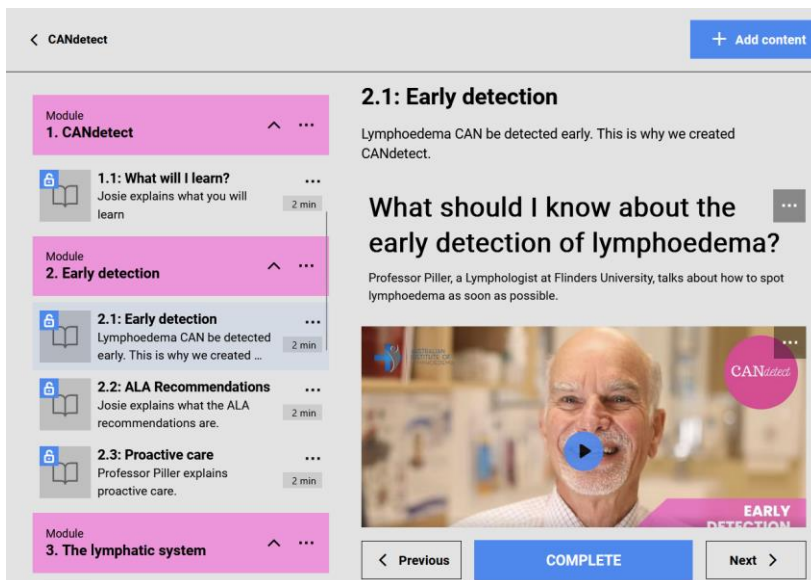


Figure 162 - Professor Piller teaching about the early intervention of lymphoedema

Educational content was evidence-based and aligned to current industry standard recommendations, such as the Australasian Lymphology Association’s (ALA) guide on the early detection of breast cancer related lymphoedema.⁽⁴⁹⁵⁾ A picture demonstrating educational content teaching about the ALA guidelines is below (Figure 163).

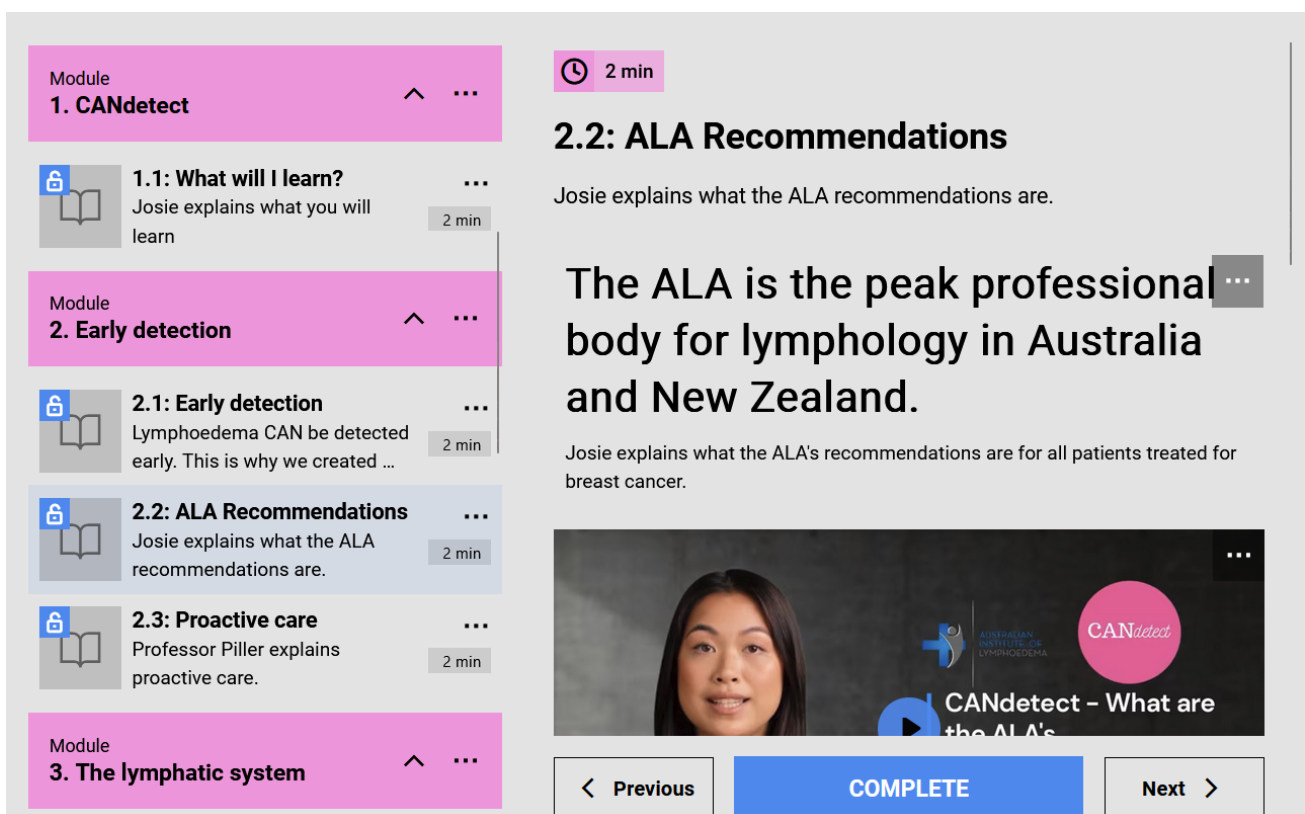


Figure 163 - Australasian Lymphology Association (ALA) guidelines within the app

Plain language was employed in the educational content, facilitated by the expertise of Professor Piller. His expert presentation skills and deliberate avoidance of technical jargon ensured that the material was accessible to a broad audience, enhancing comprehension and engagement. An example of this concept is below where Professor Piller explains what “proactive care” means in simple, easy to understand language (Figure 164).

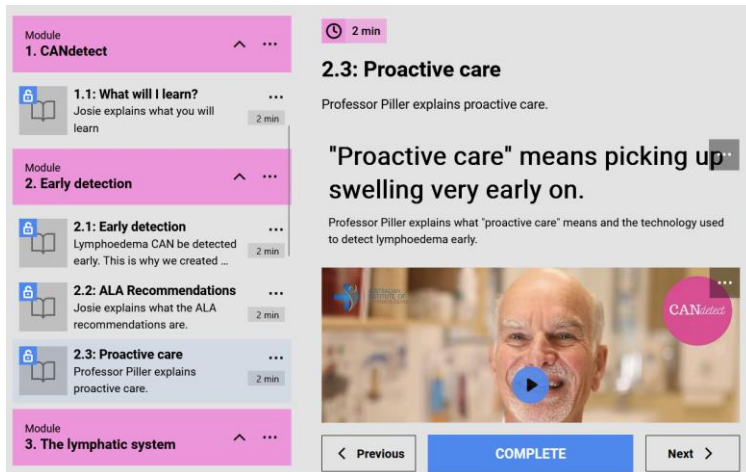


Figure 164 - Example of keeping educational content simple

The design of each section included an instructional video followed by a transcript. A picture of the editable transcript section appears below (Figure 165).

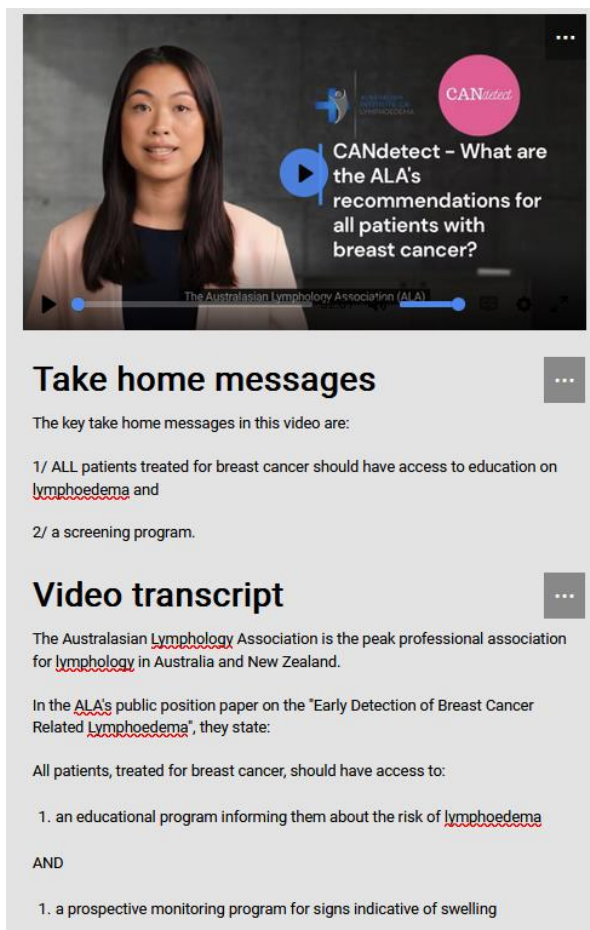


Figure 165 - Editable transcript section within the app

An example of a video transcript featuring Josie is included below.

“The Australasian Lymphology Association (ALA) is the peak professional association for lymphology in Australia and New Zealand. In the ALA's public position paper on the "Early Detection of Breast Cancer Related Lymphoedema", they state:

All patients, treated for breast cancer, should have access to:

- i. an educational program informing them about the risk of lymphoedema
- AND
- ii. a prospective monitoring program for signs indicative of swelling

We developed CANdetect to fulfil the ALA's first recommendation. For ALL patients treated for breast cancer, to have access, to an educational program informing them about the risk of lymphoedema.

The ALA's second recommendation is "a prospective monitoring program". It's important you understand what it might mean for you. "Prospective" means to do something in anticipation of something else occurring. In the context of lymphoedema prevention, this refers to screening for signs of swelling very early on. In the past, people didn't find out about lymphoedema until they had swelling, at which point, it was too late to prevent life-long lymphoedema. The second ALA point basically means: don't wait until swelling appears. Get screening very early on, and continue with screening on an ongoing basis so that lymphoedema can't be a surprise.

The types of technology used for screening and its importance for early detection is covered in later modules. For now, we want to emphasize the importance of you discussing your options for screening with your medical team. Should your centre not cater for screening in their approach, you can always find a qualified therapist that does offer screening services through directories of qualified lymphoedema therapists. Links to such services are provided at the end of the course.”

Symptom tracking

The app also featured a section designed to empower patients to track their own symptoms (Figure 166).

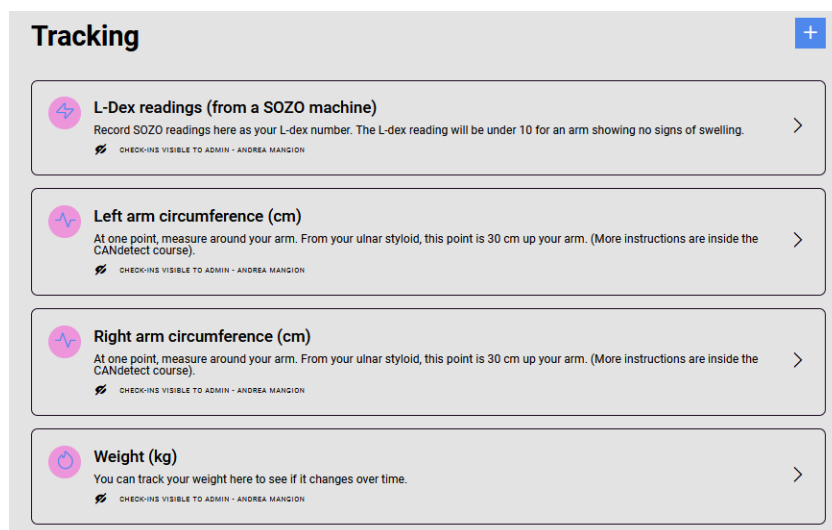


Figure 166 - Within app symptom tracking

The instructions for self-measurement included research by Hidding et al (2019) which found a circumference difference between arms of 4% measured at 30 cm proximal to the styloid process could be used as a surveillance site for monitoring of patients at risk for lymphoedema.⁽⁴⁹⁶⁾

Research by Dylke et al (2012) was also included to explain normative arm size differences.⁽⁴⁹⁷⁾

The instructions read:

“At home you will not have access to bioimpedance spectroscopy. You can instead use a tape measure.

Try to use a tape measure with a locking mechanism. It is very difficult to use a retractable tape measure whilst measuring yourself correctly.

The steps are:

1/ Find the little bone on your wrist (known as the ulnar styloid)

2/ Measure the length 30cm upwards from this bone. This spot is normally just over your elbow.

3/ Measure your arm at this point

4/ Compare to your other side

This little bone is the ulnar styloid.
Mark here then measure 30cm up
your arm from this.

The point of measuring varies
depending on the length of your
forearm. The measurement point is
normally just above the elbow.



5/ Do the maths

The formula = (treated limb - non-treated limb) / non-treated limb x 100

6/ See your doctor or lymphoedema therapist if there is greater than 4% difference between sides.⁽¹⁾

Example

Mary was treated for breast cancer 4 years ago and is self-monitoring at home.

Mary's left breast has not been treated for breast cancer and her arm measures 31cm at the measurement point.

Mary's right breast was treated for breast cancer and her arm measures 34cm.

34 minus 31cm is 3cm. Then $3/31 \times 100 = 9.68\%$

Alongside feelings of heaviness, discomfort or swelling a measure of 9.68% would warrant Mary booking in with her doctor or lymphoedema therapist.

Do we normally have a difference in arm size?

Yes. It is normal to have one arm that is slightly bigger than the other arm based on whether this arm is the dominant arm (meaning that you use it more often).⁽²⁾ This is why if you are monitoring yourself you should do so with the care of a lymphoedema therapist so they can help you interpret any differences in the size of your arm.

References:

1. Hidding JT, Beurskens CHG, De Vries MT, Nijhuis-van der Sanden MWG, van Laarhoven HWM, van der Wees PJ. Accuracy of a single measurement site for self-monitoring of patients with breast cancer at risk for lymphedema. *Physiotherapy Theory Practice*. 2019 Dec;35(12):1322-27.

2. Dylke ES, Yee J, Ward LC, Foroughi N, Kilbreath SL. Normative volume difference between the dominant and nondominant upper limbs in healthy older women. *Lymphatic Research and Biology*. 2012 Dec 1;10(4):182-8."

The inclusion of references was to demonstrate to patients that the content was evidence-based.

Discussion

Both research questions were answered in the process of building this prototype. The first question of, "Can a simple patient education app be designed?" was answered through the design of a simple patient education app. The second question of, "What factors should be considered for an effective app to be built?", was answered through each phase of the build process.

The app was designed with several key features that made it a suitable educational tool for lymphoedema patients. The "Learn" feature provided access to evidence-based information, being designed to empower patients with comprehensive resources to better understand and manage their condition. The "Community" feature aimed to foster peer support by allowing users to connect with others facing similar challenges, thereby enhancing social engagement and reducing feelings of isolation. The "Tracking" feature was designed enable patients to monitor their symptoms, treatment adherence, and progress over time, promoting self-management and facilitating more informed discussions with healthcare providers. Finally, the "User Profile" feature allowed for personalisation of the learner profile to possibly increase feelings of a tailored educational experience.

Creating educational videos is a time-consuming process, requiring careful planning and content curation to ensure the material is both accurate and engaging. Each video must be meticulously scripted, recorded, and edited to effectively communicate key concepts, which can be resource-intensive. To streamline this process an AI-powered video creation tool was employed to save time and customise the content for the app. AI allowed for the rapid production of high-quality, tailored videos without the need for traditional filming. However, several considerations were essential when utilising this technology, including ensuring the accuracy of AI-generated content, maintaining the Australian accent, tone and clarity of the educational material, and addressing the potential lack of human nuance in video delivery through purposefully adding pauses and time for the learner to reflect in the video scripts.

Lessons learned

Several lessons were garnered in this process of prototype development:

- **Developing educational content:** Educational content needs to be carefully considered. Videos which are short and to the point requires a skilled presenter who can quickly and concisely convey complex concepts without technical jargon. AI can also be used for video curation when a face-to-face presenter is not available and to reduce development time.
- **Range of features:** There is value in producing an app which includes a range of features in addition to education alone. Apps which allow for communities to be developed, for example, may allow for peer support. Apps which allow for tracking of symptoms, may help with translating some of the educational material into actional steps which patient can take to monitor their lymphoedema.

- **Data and privacy concerns:** The hosting of this app via a provider such as Passion.io involves the user giving consent to their privacy agreement. The privacy of patient data being entered into apps would need to be carefully considered especially if confidential health information through the tracking section was being entered.
- **Hosting costs:** There are substantial hosting costs associated with maintaining an educational app. This needs to be budgeted for not only for the product to be created, but considered for the lifetime of the app. In this prototype development case, development efforts will be lost once the subscription expires as the content and app will be deleted.
- **Development time:** There needs to be considerable time invested into building high-quality educational content. This process is distinct from app development itself and involves thorough research, content creation, and iterative revisions to ensure accuracy and educational value.
- **Distinct skill sets:** Developing an educational app requires a diverse skill set. Content creation demands expertise in the specific educational field, typically provided by an Instructional Designer, along with an engaging and knowledgeable presenter. Meanwhile, app development requires technical skills, including programming (depending on the authoring platform), user interface design, and software integration.
- **User experience design:** An intuitive and user-friendly experience is essential for the success of an educational app. The design process must prioritise ease of navigation, clear instructions, and engaging multimedia elements to enhance user engagement and learning outcomes. Using Passion.io assisted in this process as the templates were easy to use.
- **Digital accessibility:** Ensuring that the educational content is accessible to a diverse audience is crucial. This includes using plain language, avoiding technical jargon, and incorporating features that cater to individuals with varying levels of digital literacy and different learning preferences.

Implications for future research

This prototype garnered several insights relevant for those wishing to build educational apps for empowering patients to understand their own lymphoedema. Future research should consider lessons learned from this project, including the importance of carefully developing customised educational content and building an app with diverse features beyond education, such as symptom tracking and a community section. Additionally, data and privacy concerns, understanding development and hosting costs, recognising the distinct skill sets required for developing an app, and prioritising user experience design and accessibility are factors that must be considered in order to create an effective app.

CHAPTER TWENTY-ONE: DEVELOPMENT OF A DIGITAL ASSESSMENT TOOL FOR LYMPHOEDEMA

Chapter overview

This chapter explores the development of a prototype of a digital assessment tool for lymphoedema. This research was inspired by Fu et al's (2018) research of artificial intelligence (AI) and real-time symptom report to help diagnose lymphoedema.⁽⁴⁹⁸⁾ They found their online assessment tool could detect lymphoedema and the detection accuracy was "...significantly higher than that achievable by current and often used clinical methods such as bioimpedance analysis." Given the potential for improved accuracy, accessibility, and early detection of lymphoedema, this research was deemed relevant to advancing digital tools which can enhance diagnostic capabilities.

Highlights

The key highlights of this research include:

- A prototype of a digital assessment tool was successfully built
- This research revealed the process of developing a digital questionnaire tool is complex, involving several nuances and intricacies. Word choice within a digital survey, for example, requires significant consideration.
- The prototype development demonstrated the feasibility of creating a simple digital assessment tool to help patients determine if their symptoms could be likely to reflect lymphoedema.
- Before this digital assessment tool could be made available to patients it would need to undergo thorough testing. Several considerations for further research were garnered.

Prototype development – digital assessment tool

Aim

The objective of this research was to develop a prototype of a straightforward and free digital assessment tool for patients and learn from this process. The digital assessment tool, through an online questionnaire, was designed to be able to indicate whether patients' symptoms were likely to reflect lymphoedema.

The questions the research aimed to answer were: "Can a simple digital assessment tool be designed?" and "Once the prototype is developed, what factors would need to be considered for such a tool to be researched?"

Background

There is no set period following cancer treatment after which the risk of lymphoedema no longer applies to survivors.⁽⁴⁹⁹⁾ Consequently, ongoing self-assessment tools would be valuable in empowering patients to continuously monitor their condition.

Previous research has shown that there are significant associations between symptom features and lymphoedema status.^(364, 500, 501) Armer et al (2003) demonstrated the validity of predicting breast cancer related lymphoedema (BCRL) by self-reported symptoms using a questionnaire. “Heaviness in the past year” and “swelling now” were predictive of lymphoedema.⁽⁵⁰¹⁾ The findings of Armer et al's research suggested that changes in sensations may be indicators of early lymphoedema.

Fu et al (2015) in later research found that the count of lymphoedema symptoms was able to differentiate healthy adults from breast cancer survivors with lymphoedema and those at risk for lymphoedema.⁽⁵⁰⁰⁾ A diagnostic cutoff of three symptoms discriminated breast cancer survivors with lymphoedema from healthy women with a sensitivity of 94% and a specificity of 97%. Quoting from the paper, “Count of lymphoedema symptoms was able to differentiate healthy adults from breast cancer survivors with lymphoedema and those at risk for lymphoedema. A diagnostic cutoff of three symptoms discriminated breast cancer survivors with lymphoedema from healthy women with a sensitivity of 94% and a specificity of 97% (area under the curve =0.98). A diagnostic cutoff of nine symptoms discriminated at-risk survivors from survivors with lymphoedema with a sensitivity of 64% and a specificity of 80% (area under the curve =0.72).” Research suggests therefore that questionnaires can effectively link symptoms to the likelihood of disease manifestation in patients. Such questionnaires could be a tool to aid in patient empowerment given research has shown that self-assessment tools may empower individuals with chronic health conditions.⁽⁵⁰²⁾

Method

A prototype of a digital assessment tool, via a digital survey, aimed to be developed to test if the concept was feasible. Research by Fu et al (2015) formed the basis of the digital survey questions.⁽⁵⁰⁰⁾ In their research, three symptoms were correlated with high risk of lymphoedema including arm swelling, arm heaviness and arm firmness (Table 27).

Table 27 - Bivariate association between each symptom and lymphoedema

Do you have now:	Fu showed bivariate association between each symptom and lymphoedema (odds ratio)	Most predictive risk factors
1. Arm swelling	561.00	High risk factor
2. Arm heaviness	17.46	High risk factor
3. Arm firmness	10.33	High risk factor
4. Increased arm temperature	9.07	
5. A Seroma (a collection of fluid that requires drainage with a drain)	8.61	
6. Arm tightness	7.78	
7. Limited arm movement	5.86	
8. Tingling in affected arm	5.54	
9. Arm aching	5.14	
10. Limited fingers movement	4.56	
11. Limited elbow movement	4.39	
12. Limited wrist movement	4.23	
13. Limited shoulder movement	3.84	
14. Stiffness in the affected arm	3.55	
15. Burning in the affected arm	2.86	
16. Arm redness	2.47	
17. Numbness in the affected arm	2.40	
18. Stabbing in the affected arm	2.12	
19. Tenderness in the affected arm	2.07	
20. Pain in the affected arm	1.99	

The logic for the identification of high, medium high, medium or low likelihood of lymphoedema is represented in Table 28. In diagrammatic form, as a decision tree, the logic is represented in Figure 167.

Table 28 - Logic of risk calculations from high to low

High = Greater than or equal to nine symptoms or all 3 of major risks (Q1 and Q2 and Q3)
Medium high = Great than or equal to 3 of any three or (Q1 and (either Q2 or Q3))
Medium = Q1 OR (if count is greater than or equal to 2)
Low risk = Less than any 2 symptoms

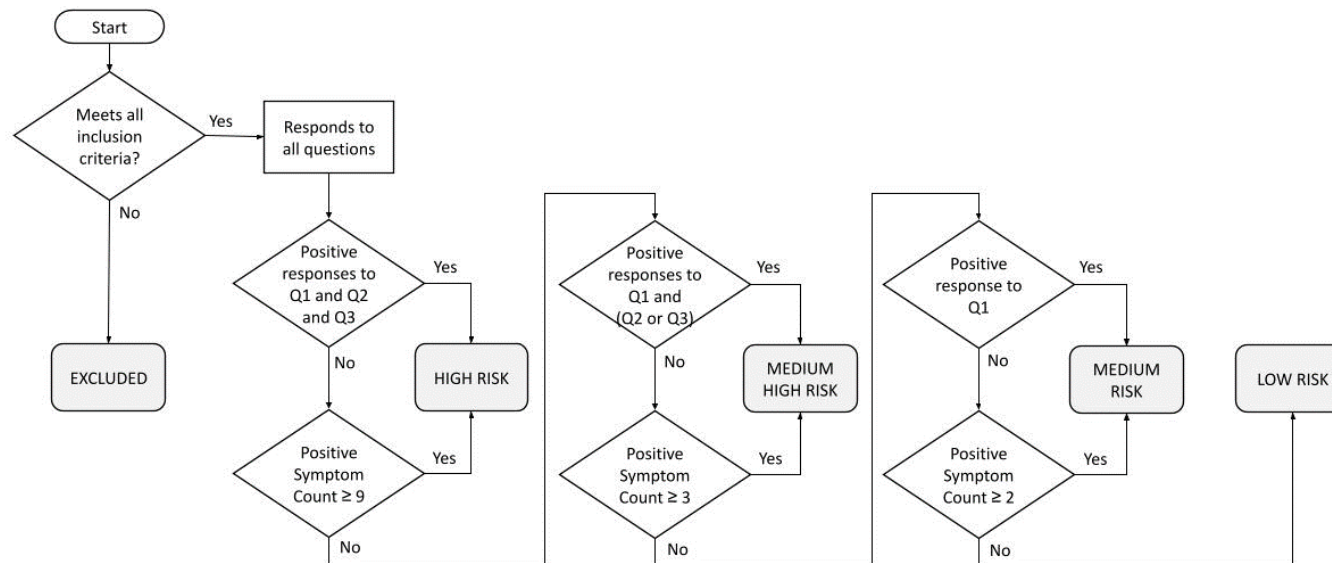


Figure 167 - Decision tree

The rationale behind each survey question was carefully considered and aligned with the differential diagnosis process of which a lymphoedema practitioner would undertake based on patient responses (Figure 168).

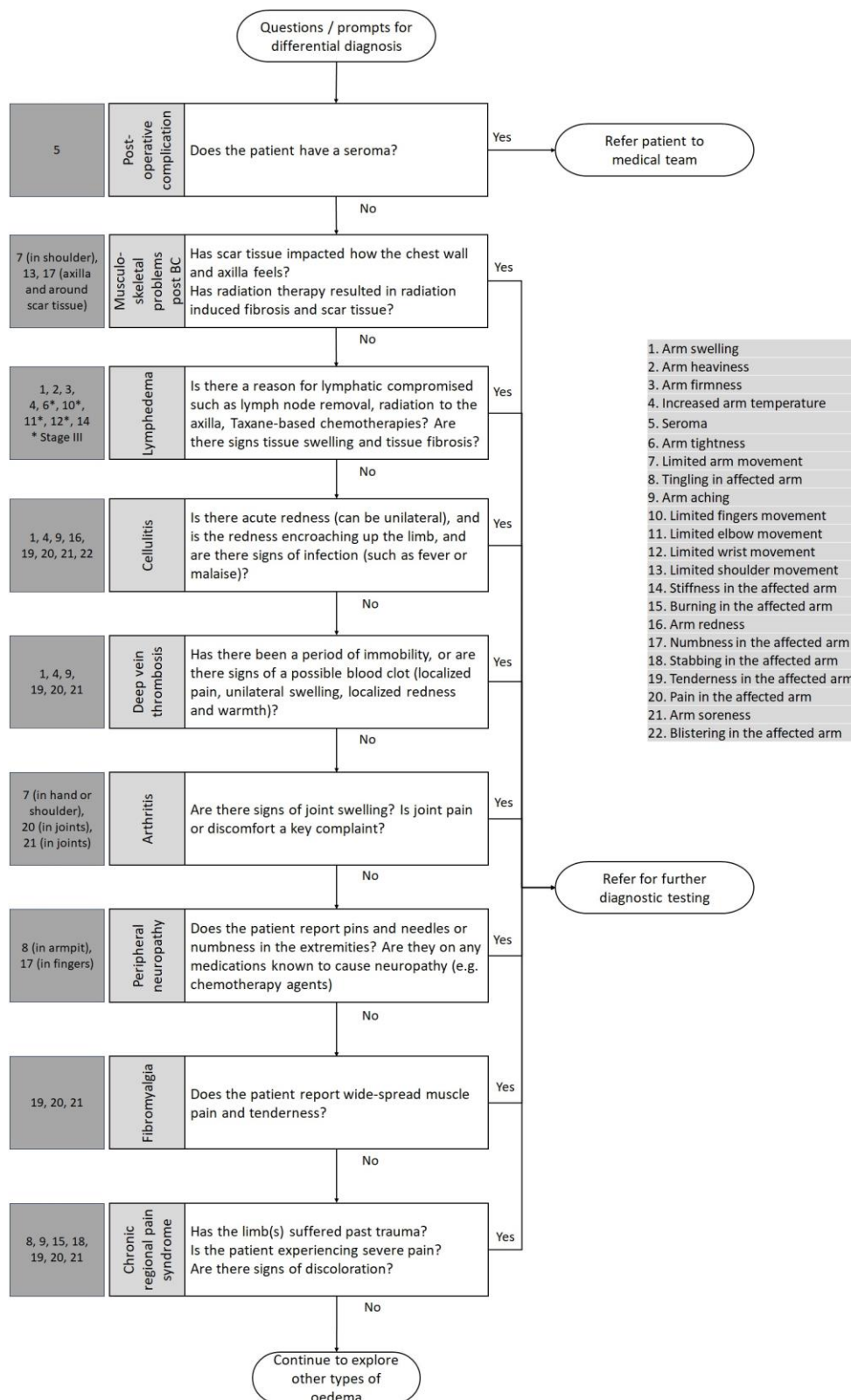


Figure 168 - Differential diagnosis being linked to each question in the survey

Software

Qualtrics provides a user-friendly interface that simplifies the creation and deployment of questionnaires, ensuring a streamlined and effective data collection process.⁽²⁶⁹⁾ This software was chosen for hosting and authoring the digital questionnaire due to its mobile-friendly and user-friendly interface, as well as the absence of additional hosting costs, which were covered by funding from Flinders University. The responsive design is illustrated below (Figure 169).

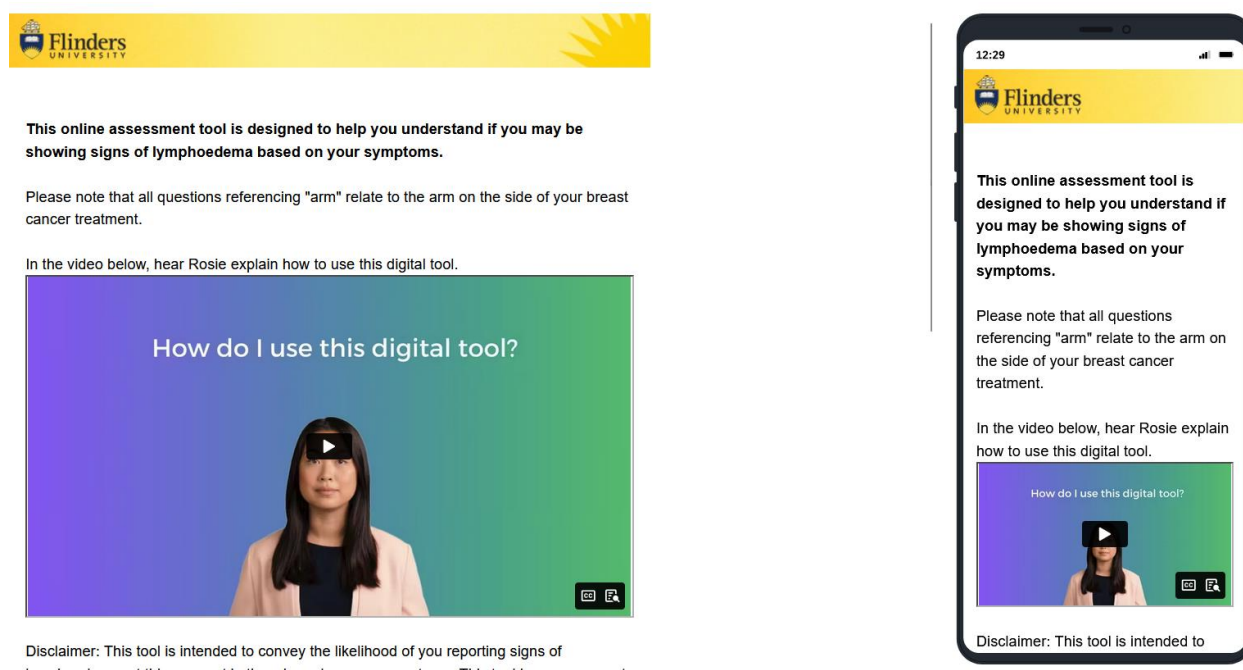


Figure 169 - Responsive design for mHealth applicability

Embedding educational content

The prototype was not only meant to be an assessment tool, but also a form of Instructive Online Information. To achieve this, educational videos were embedded at the end of the survey. Content included a digital avatar created by AI as well as educational videos by Professor Piller sourced from the online course discussed in Chapter Twenty. Videos were embedded via Html through Qualtrics and hosted on Vimeo.⁽⁵⁰³⁾

Branching and survey flow

Considerable time was invested into planning the flow of the survey to ensure an enjoyable experience for the patient as well as retrieval of the suitable response. If any of the screening questions indicated that the patient was not a suitable candidate for the digital tool, the survey ended (Figure 170).

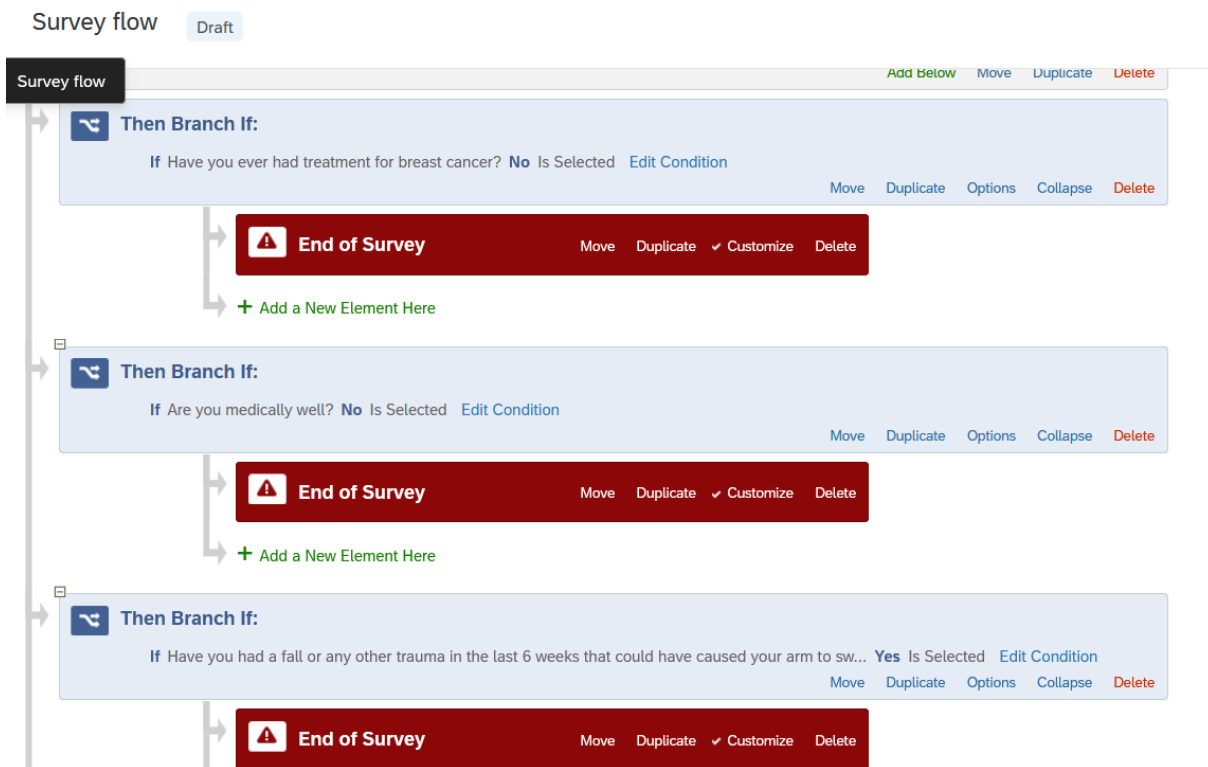


Figure 170 - Branching for the survey to end based on qualification questions

If the patient entered 3 responses demonstrating high risk, the survey took them to the high-risk response screen (Figure 171).

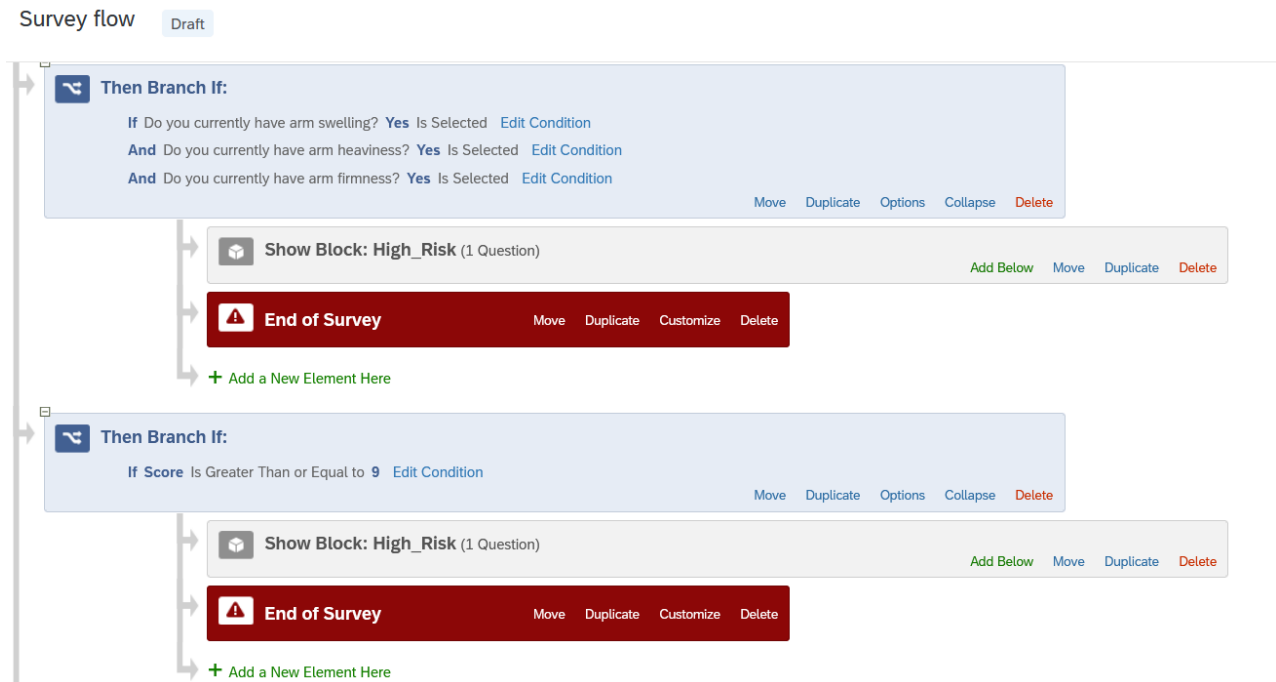


Figure 171 - High risk response survey flow

If the patient entered 3 responses demonstrating medium-high risk, the survey took them to the medium-high-risk response screen (Figure 172).

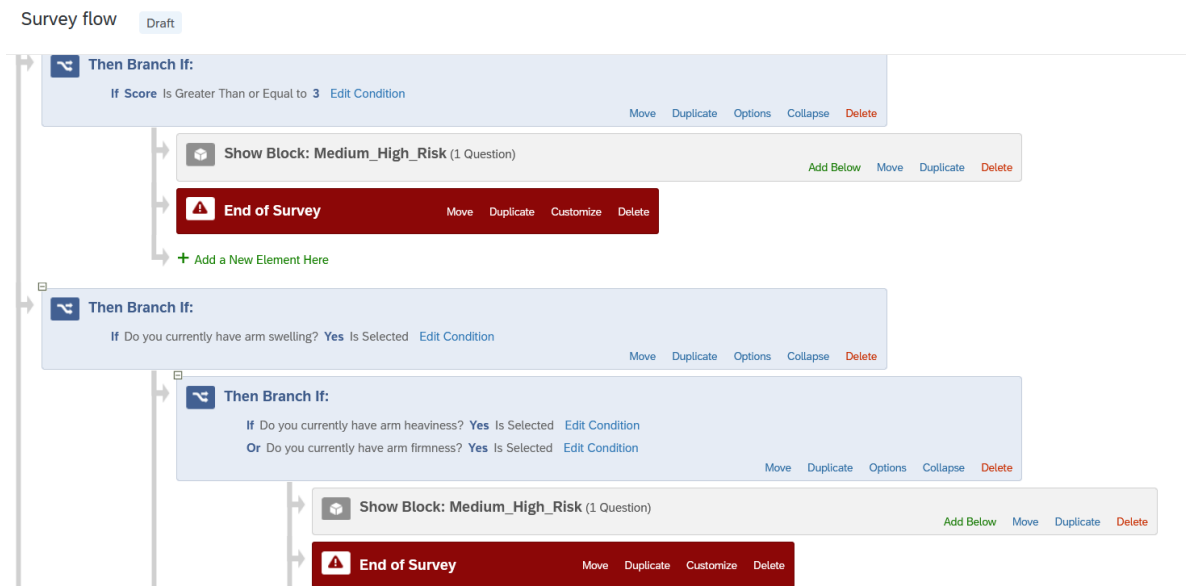


Figure 172 - Medium high risk survey flow

If the patient entered responses demonstrating medium risk, the survey took them to the medium-risk response screen (Figure 171).

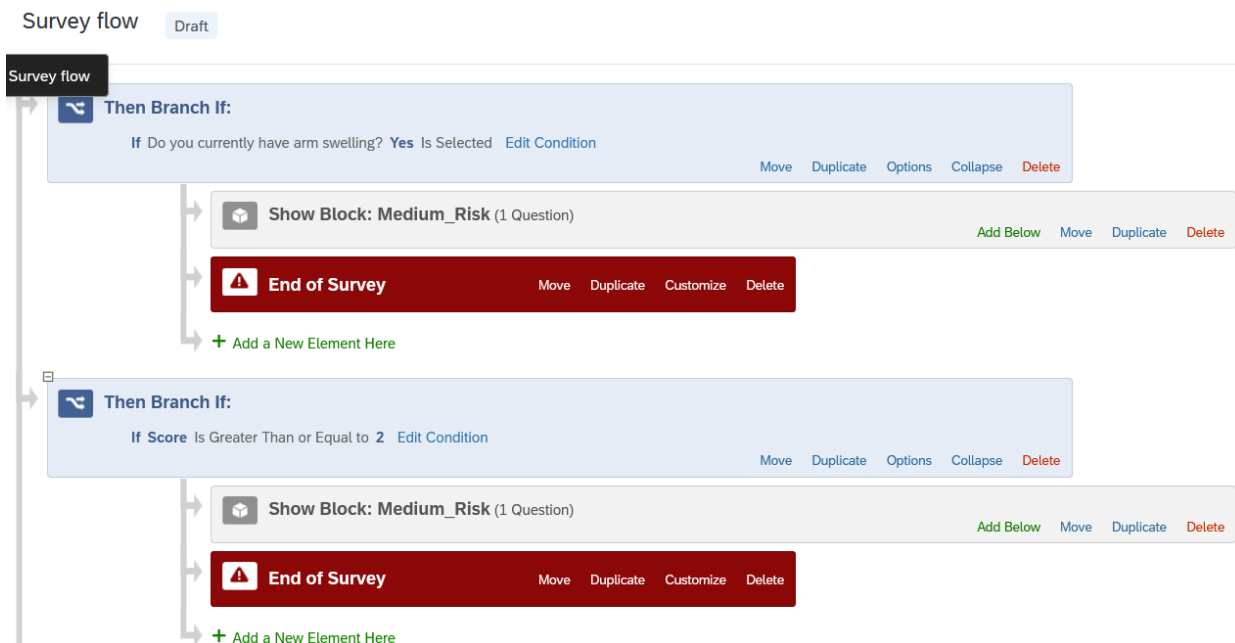


Figure 173 - Medium risk survey flow

If the patient entered responses demonstrating low risk, the survey took them to the low-risk response screen (Figure 174

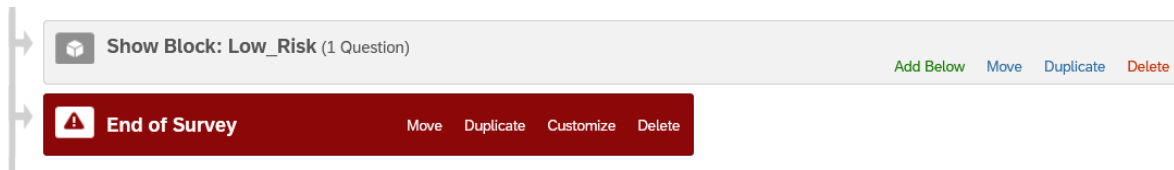


Figure 174 - Low risk survey flow

Results

The digital survey tool included 3 sections:

i/ **Section 1 - Screening and instructions for use**

ii/ **Section 2 -Symptoms questions:** 20 questions related to different lymphoedema symptoms

iii/ **Section 3 - Likelihood of lymphoedema rating:** Based on how many symptoms were selected, the survey tool produced a likelihood of high, medium-high, medium or low risk.

i) **Section 1 – Screening and instructions for use**

Instructions on how to use the tool appeared at the start of the survey. A customised video was generated with AI to describe how to use the tool. The digital avatar was named Rosie.

Pre-qualification questions were also asked at the start to ascertain if the patient was at risk of breast cancer-related lymphoedema and to exclude acute oedema (Have you ever had treatment for breast cancer? Are you medically well? Have you had a fall or any other trauma in the last 6 weeks that could have caused your arm to swell?)

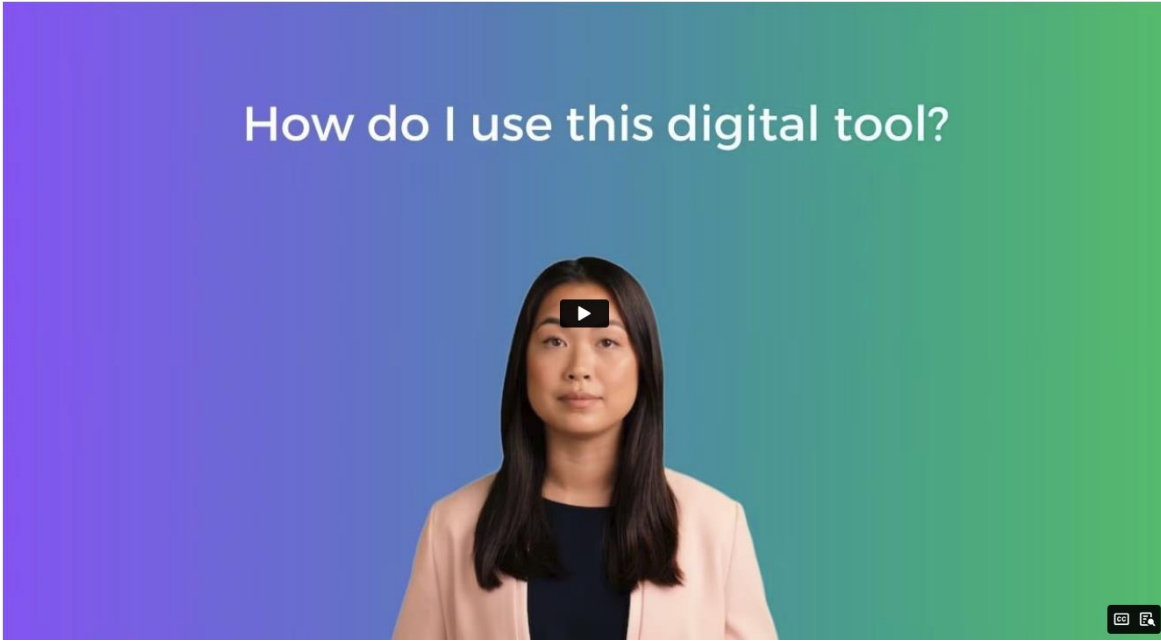
The instructions read:

“This online assessment tool is designed to help you understand if you may be showing signs of lymphoedema based on your symptoms.

Please note that all questions referencing "arm" relate to the arm on the side of your breast cancer treatment.

In the video below, hear Rosie explain how to use this digital tool.”

How do I use this digital tool?



Disclaimer: This tool is intended to convey the likelihood of you reporting signs of lymphoedema, at this moment in time, based on your symptoms. This tool however cannot diagnose lymphoedema on its own. You are encouraged to discuss the results with your Doctor or qualified Lymphoedema Practitioner.

ii) Section 2 – Symptoms questions through Yes or No responses

Do you currently have:

- arm swelling?
- arm heaviness?
- arm firmness?
- increased arm temperature?

Did you have a seroma on the same side of your breast cancer surgery?

[A seroma is the abnormal accumulation of fluid under the arm. A seroma usually requires drainage via a chest drain.]

Do you currently have:

- arm tightness?
- limited arm movement?
- tingling in your arm?
- an ache in your arm?
- limited movement of your fingers?
- limited movement of your elbow?
- limited movement of your wrist?
- limited movement of your shoulder?

Do you:

- feel stiffness in your arm?
- feel a burning sensation in your arm?
- have redness on your arm?
- have numbness in your arm?
- have a stabbing sensation in your arm?
- have tenderness in your arm?
- have pain in your arm?

iii. Section 3 – Likelihood of lymphoedema rating

The text from each section is included below.

I. High

“The signs you have indicated have evidence supporting their association with lymphoedema. Based on the number of signs you have indicated, the risk level of you having lymphoedema is **HIGH**.

You should see a qualified Lymphoedema Practitioner for screening and to confirm whether or not your arm fluid levels are outside of normal limits.

Disclaimer: This tool is intended to convey the likelihood of you having lymphoedema at this moment in time. This tool however cannot diagnose lymphoedema on its own. You are encouraged to discuss the results with your health practitioner.

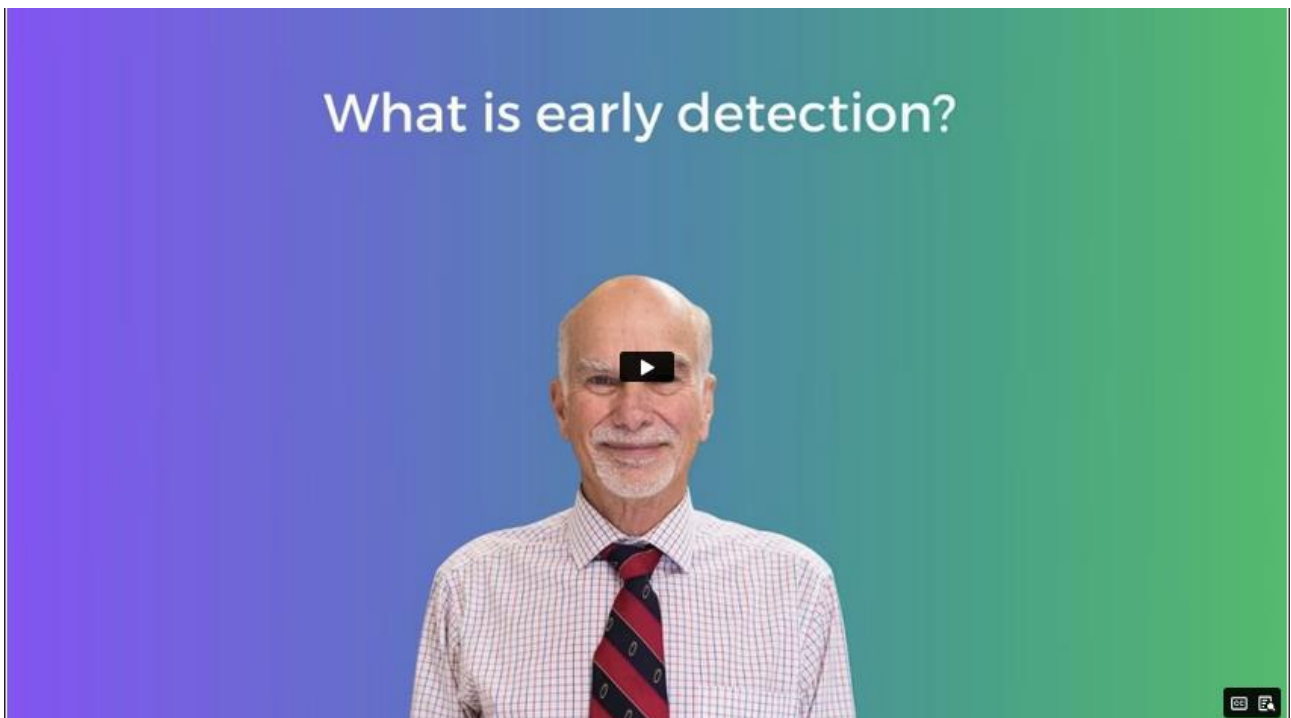
If you are not currently seeing a qualified lymphoedema practitioner you can search for one [here](#).
(This was linked to the Australasian Lymphology Association National Lymphoedema Practitioners Website.)⁽¹⁷⁶⁾

[LEARN MORE](#)

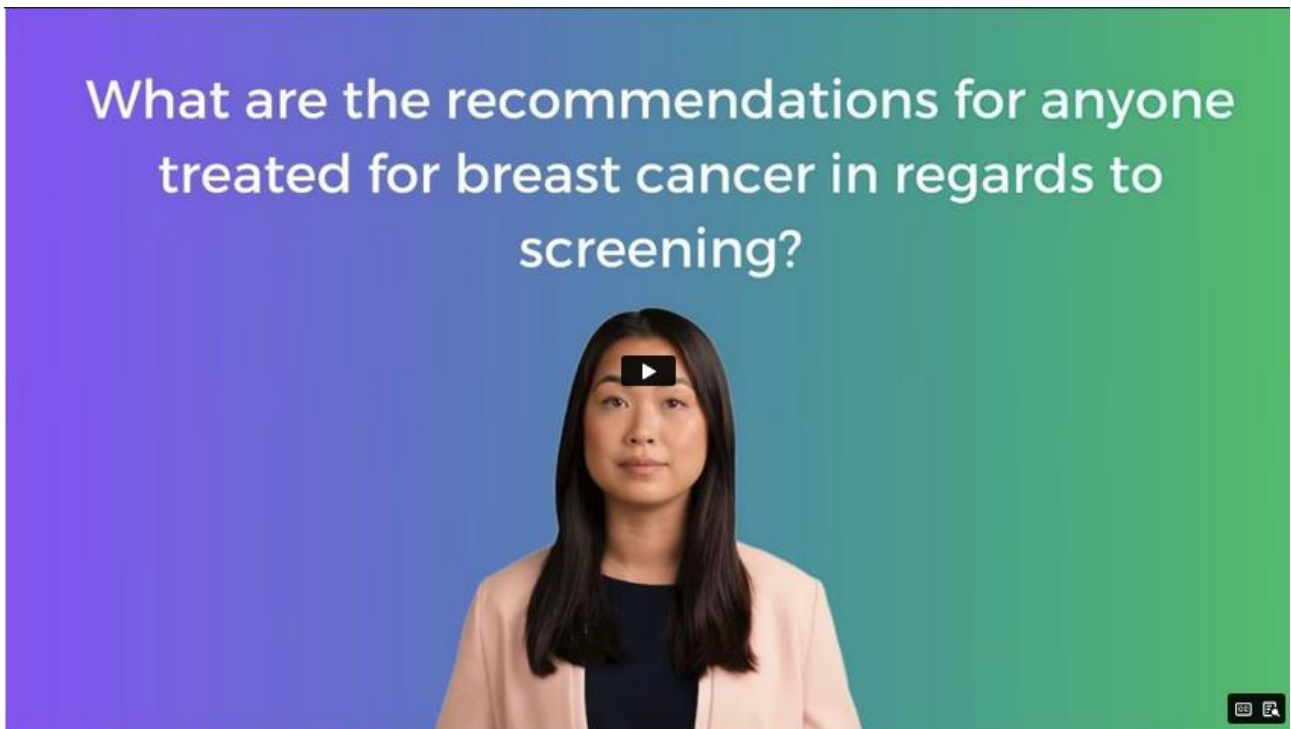
Hear Rosie talk about what the terms "risk" and "likelihood" of lymphoedema mean.



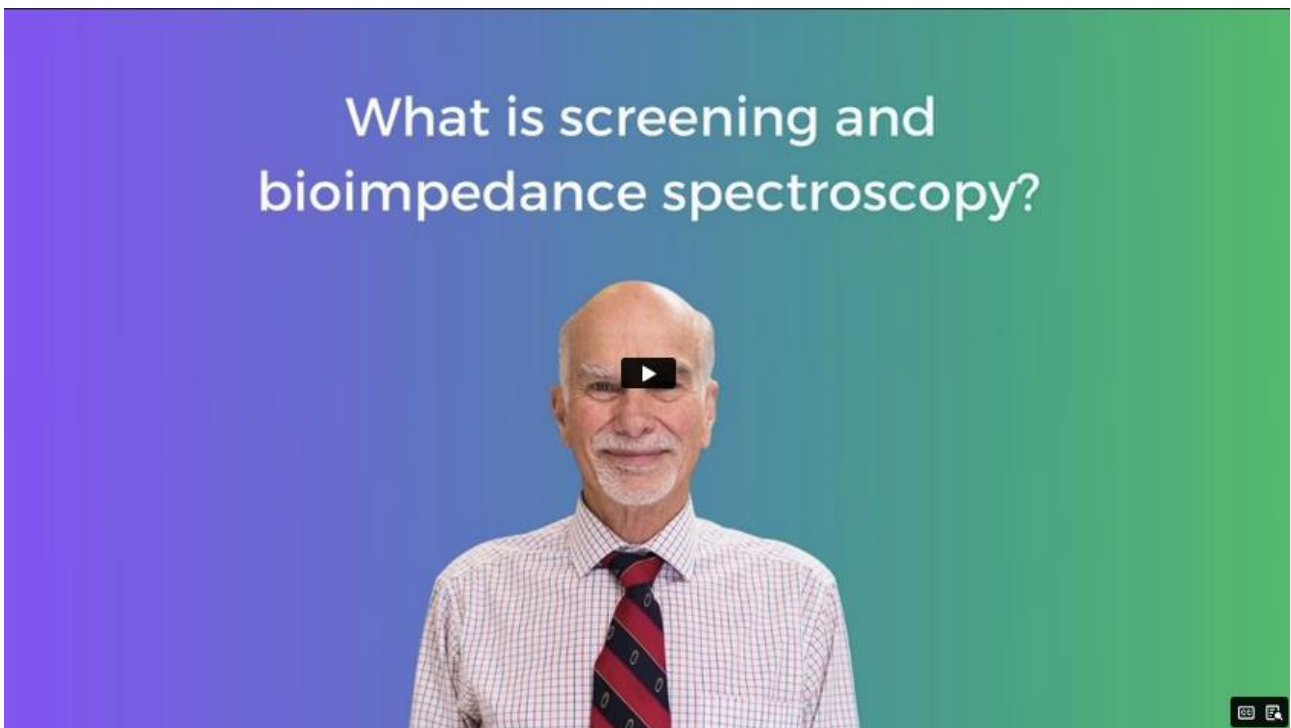
Hear Professor Piller talk about what early detection means.



Hear Rosie talk about the recommendations for anyone treated for breast cancer in regards to screening.



Hear Professor Piller talk about what screening and bioimpedance spectroscopy involves.”



II. Medium high

“The signs you have indicated have evidence supporting their association with lymphoedema. Based on the number of signs you have indicated, the risk level of you having lymphoedema is **MEDIUM-HIGH**.

You should see a qualified Lymphoedema Practitioner for screening and to confirm whether or not your arm fluid levels are outside of normal limits.

Learn more, disclaimer and link to see a therapist is the same as previous.

III. Medium

“The signs you have indicated have evidence supporting their association with lymphoedema. Based on the number of signs you have indicated, the risk level of you having lymphoedema is **MEDIUM**.

You should see a qualified Lymphoedema Practitioner for screening and to confirm whether or not your arm fluid levels are outside of normal limits.”

Learn more, disclaimer and link to see a therapist is the same as previous.

IV. Low

“The signs you have indicated have evidence supporting their association with lymphoedema. Based on the number of signs you have indicated, the risk level of you having lymphoedema is **LOW**.

You should see a qualified Lymphoedema Practitioner for screening and confirmation that your arm fluid levels are within normal levels.”

Learn more, disclaimer and link to see a therapist is the same as previous.

Discussion

Both research questions were answered through the process of building this prototype. The initial research question, “Can a simple digital assessment tool be designed?” was addressed through the development of a prototype, which provided valuable insights. The second question, “Once the prototype is developed, what factors would need to be considered for such a tool to be researched?” was also explored during the development phase. Consultation with a statistician provided guidance on the careful use of terminology (such as likelihood of having lymphoedema not being the same as indicative of lymphoedema and terms such as agreement and correlation being vastly different outcome measures). There was discussion of the recommended minimum sample size for different types of investigations and the overall outcomes of future research.

Future research would need to clarify the specific aspects of the digital assessment tool to be examined. Qualitative methods, for example, could explore whether digital tools foster a sense of empowerment by providing accessible, evidence-based information to users. Quantitative analysis, for example, could focus on assessing the agreement between the tool's outputs and traditional assessment measures. The agreement between standard clinical assessments such as bioimpedance spectroscopy and perometry, would be of value in researching. A hypothesis for possible agreement between the survey tool, bioimpedance spectroscopy and perometry is provided to assist if further research is undertaken (Table 29).

Table 29 - Possible agreement hypothesis between the survey tool ratings, bioimpedance spectroscopy and perometry

Digital survey tool	Bioimpedance (in clinic measure)	Perometry (in clinic measure)
High = Greater than or equal to nine symptoms or all 3 of major risks (Q1 and Q2 and Q3)	>10L-dex points on SOZO or 200ml on Inbody. Expect to see signs of swelling.	>200ml difference in arms
Medium high = Great than or equal to 3 of any three or (Q1 and (either Q2 or Q3))	>10L-dex points on SOZO or 200ml on Inbody. Expect to see signs of swelling.	>200ml difference in arms
Medium = Q1 OR (if count is greater than or equal to 2)	>10L-dex points on SOZO or 200ml on Inbody	>200ml difference in arms
Low risk = Less than any 2 symptoms	Under 10	Less than 200ml difference in arms

Ethical considerations for investigating such a tool highlighted concerns about potential patient distress if a high or medium risk score was provided, emphasising the need for the research protocols to allow for provision of traditional patient assessment methods alongside the tool.

For the tool to undergo research, it would require ethical review and several stages of testing. The most appropriate initial step would involve pilot testing with health professionals to gather their expert feedback, followed by testing with a small sample of patients before expanding to a larger patient group. Testing with real patients would require researchers capable of comparing this method to traditional assessments, providing face-to-face screening and bioimpedance spectroscopy as needed.

Lessons learned

Several valuable lessons emerged during prototype development. Creating a digital assessment tool through a questionnaire, while seemingly straightforward, proved to be a complex and time-intensive process. Each question required careful consideration of its wording, rationale, and presentation. Additionally, the branching scenarios needed meticulous planning to ensure coherent and valid results.

Formulating questions and interpreting terminology presented significant challenges. Previous research involving the author identified substantial variability in lymphoedema terminology among experienced practitioners. For example, what one therapist identified as Stage 2 lymphoedema might be classified by another as Stage 3.⁽⁵⁰⁴⁾ Words appearing on a digital questionnaire form can therefore mean different things to different people.

Implications for future research

This prototype, in the author's knowledge, is the first Australian digital tool aimed at empowering patients to understand their own lymphoedema symptoms. Further research is needed to extend on the careful considerations that went into this prototype. If further research is undertaken, there should be a dedicated research team involved and adequate research funding to support such a project. Ethical considerations, such as patient's experiencing distress if they received a high-risk score, would need to be carefully considered in the approach to conducting testing. Telehealth consultations for follow up with patients after they completed the digital survey would be appropriate as well as the availability of in-person sessions for a lymphoedema assessment, allowing for the confirming or exclusion of a diagnosis of lymphoedema.

CHAPTER TWENTY-TWO: CONCLUSION

Chapter overview

This chapter presents a comprehensive discussion of the research findings, outlines implications for future research, and addresses the limitations, strengths, and overall impact of the research within this thesis. The discussion section summarises the total number of eHealth modalities examined within this thesis, remarks on contemporary issues, evaluates the extent to which the thesis objectives have been met, and analyses the original thesis hypotheses in light of the research findings. The chapter ends with a final conclusion of the thesis.

Discussion

Quantification of the types of eHealth modalities

In the prevention of lymphoedema, digital health was found to be being used in a variety of ways with six types of eHealth modalities being used. One of the most advanced methods described in this thesis involved the use of robotics to enhance the accuracy of lymphadenectomy, thereby reducing the likelihood of patients developing lymphoedema following cancer surgery. Other means included instructive online information including the use of eLearning, targeted client communication through email, eRecords, ePrescribing of garments, and health knowledge management.

In the diagnosis of lymphoedema, digital health was also found to be being used in a variety of ways with seven types of eHealth modalities being used. The most advanced method described in this thesis was inveillance where artificial intelligence (AI) identified population groups at risk of living with filarial-related lymphoedema. Another was the application of AI where a digital survey tool could detect breast cancer related lymphoedema simply by asking the respondent a few online questions. Other means included eRecords, eResults, instructive online information through eLearning, clinical decision support and health knowledge management.

In the context of diagnosis, the author also tested generative AI for the purpose of instructive online information and clinical decision support.

In the assessment of lymphoedema, four types of eHealth modalities were being used. AI was being used for the assessment of limb volume and fibrosis. Remote data collection and exploratory data analysis were ways in which eRecords were being leveraged to benefit the assessment of lymphoedema. Smart wearable devices were also being used for condition tracking. Telehealth assessments were also used.

In the treatment of lymphoedema, thirteen types of eHealth modalities were being used. Digital health was being used through robotics to improve traditional surgical and treatment outcomes. Robotics was also being used through a novel wearable device prototype designed to provide lymphatic drainage. Instructive online information was being delivered for remote education of both patients and practitioners through eLearning, online sources of information as well as video streaming platforms (such as YouTube). Remote service provision through telehealth provided care, education and supported psychological wellbeing.

Other means of digital health being used included computer/web-based interventions, smart wearable devices, ePrescribing of garments, eRecords, eReferrals, mHealth including health apps and healthcare information systems. Social media platforms (including Facebook, Instagram, and LinkedIn), digital gaming, and health knowledge management through a digital community of practice (such as those facilitated through Google Groups) were found to be utilised in the treatment of lymphoedema to either benefit patients or practitioners. Some of these eHealth modalities served multiple roles, such as providing patient care, educational content, facilitating peer support, and enabling professional development.

Overall, eighteen different types of eHealth modalities were reported (Figure 175). Ubiquitous health (uHealth) technologies were not reported in lymphoedema care, despite their growing presence in other areas of healthcare. This gap indicates a need for further research to explore the potential of uHealth in enhancing lymphoedema treatment and management.

Using the World Health Organizations (WHO) classification framework (2.0) of digital health interventions (DHI) thirty-five types of DHIs were reported in this thesis (Table 30).⁽¹⁰⁴⁾ Where a DHI had not been explicitly mentioned in this thesis, it was not included in the count of 35, even if that DHI is commonly known. The best example of this is the use of social media for peer support (1.3.1 Peer group for individuals within the WHO classification framework), which was not included because no specific DHI had been described for this purpose. Instead, research within this thesis found examples of social media being used for instructional online information as well as patient advocacy.

Exploration of contemporary issues

This thesis addressed several contemporary issues in digital health, including accessibility, appropriateness and the applicability of various eHealth modalities.

i) Accessibility - What accessibility factors can stop digital health being used?

This research emphasises the critical importance of accessibility in digital health both online and in clinical scenarios. If digital content is not accessible it can stop people with disabilities from accessing instructional online information and from using lymphoedema-related technology such as perometry. Digital health tools must be able to cater to diverse user needs, ensuring that all users, regardless of their abilities, can benefit from technological advancements in healthcare.

In Chapter Eleven the perspective of Kate, a blind health professional, offered crucial insights into the real barriers faced when digital health solutions lack accessibility. Despite a significant capital investment of funds in specialised medical equipment, Kate's ability to effectively use the equipment was compromised due to the manufacturer's failure to prioritise digital accessibility. This outcome is not only disappointing but also has serious implications for the comprehensiveness of care she can provide and the sustainability of her professional practice. Since the case studies were written, Kate has been forced to limit her services to manual lymphatic drainage, as other key aspects of Complex Physical Therapy—such as limb volume measurement and garment prescription—are hindered by accessibility challenges. Further research, education, and advocacy are needed in this area as accessibility in lymphoedema care presents both challenges and opportunities for improvement.

ii) Appropriateness - Can AI-driven chatbots deliver suitable responses contextualised to lymphoedema care?

Testing of generative AI-driven chatbots revealed several key insights into their potential and limitations. While the chatbots were not able to outperform an experienced lymphoedema practitioner in differential diagnoses, they did provide knowledge comparable to that found on reputable health websites and could therefore provide contextualised information for lymphoedema care. Furthermore, the development of the chatbot prototype demonstrated that specific patient queries could be effectively addressed, and that an entire website's content could be integrated into the chatbot to create a comprehensive knowledge base. This capability indicates that chatbots could serve as valuable tools for patient education and initial information gathering, streamlining the process for patients and potentially reducing the burden on healthcare providers.

Researching the chatbots highlighted the importance of thoroughly testing AI tools, particularly if patients will be entering clinical queries. Currently, information derived from chatbots needs to be considered with caution as some of the information derived was incorrect. The chatbots platforms themselves, provide warnings as to this effect.

Even when the responses are not factually wrong, they may still be inappropriate. An example of this is in Chapter Twelve where a “patient” who was complaining of lymphorrhoea and having a wet leg was told to “keep their wound moist.” Confusion may arise if the chatbots deliver information without the full medical context of the information. In this case, the concept of “moist wound healing” may be well-known to wound care practitioners but not typically understood by patients.

The research conducted in this thesis was based on early versions of AI models, specifically OpenAI's ChatGPT (3.0) and Google's Bard (2.0.1).^(346, 366) Since then, both platforms have advanced to more sophisticated versions with enhanced capabilities. As AI technology continues to develop rapidly, ongoing research is crucial to evaluate the appropriateness, reliability, accuracy, and safety of AI-driven health advice in real-world settings, presenting significant opportunities for future inquiry.

Applicability – Social media

The case study in Chapter Thirteen on the use of social media in patient advocacy highlighted how digital technology can be utilised to amplify patients' voices. Few will ever achieve the honour of being named Australian of the Year, a testament to the level of advocacy, effort, and energy Monique has dedicated to supporting lymphoedema patients.

A publication by Ezeilo et al (2023) provided practical tips on the use of social media for health advocacy.⁽⁵⁰⁵⁾ They found successful practices on one platform alone (X) included “...personable, picture-based tweets; using a series of posts on a particular topic rather than an isolated post; leveraging team members' and partners' collaborations in shared posts; incorporating hashtags in tweets; using a balanced mix of texts and graphics in posts; using inclusive (non-stigmatising) languages in tweeted posts; and use of polls to share tweets.” To understand what this statement means, the language of social media—such as hashtags, tweets, and analytics—needs to be understood. The utilisation of social media could therefore be explored in much greater detail including an examination of the methodologies involved in its use, the empowerment of practitioners to effectively engage with platforms, and the continued amplification of patient voices to drive positive change in lymphoedema care.

iii) Applicability – Digital communities of practice

The case study on the digital community of practice (CoP), in Chapter Fourteen, demonstrated that Google Groups can be an effective digital platform for connecting professionals and fostering collaboration. This platform facilitated knowledge sharing and peer support, highlighting its potential as a valuable resource for building and sustaining digital communities.

To fully understand the benefits and challenges of digital CoPs, further research is needed. Future studies could explore the long-term impact of digital CoPs on professional development, the dynamics of online interactions, and potential barriers to participation.

iv) Applicability – Instructive online information

The case studies in Chapters Fifteen and Sixteen explored the training of staff, patients, and practitioners through instructional online information. The effective use of video technology as a teaching tool was demonstrated.

In Chapter Fifteen, the Encouragement, Normalcy, Counselling, Opportunity, Reaching Out, Energies Revived (ENCORE) program, used online videos to provide a practical and accessible method for making staff training widely available, ensuring that all personnel could receive consistent and high-quality instruction regardless of their location. In Chapter Sixteen, YouTube was effectively utilised to disseminate specific product training for the Fast'n Go™ lymphoedema product.

The prototype development of the serious game, online course, and patient education app incorporated short instructional videos into their content. These examples underscore the effectiveness of videos as an educational tool. Videos are particularly impactful because they can visually demonstrate complex concepts, engage learners, and cater to different learning styles, making them a powerful medium for conveying information clearly and concisely. Further research and training would be beneficial for lymphoedema practitioners in understanding the most effective methods for producing instructional videos, their optimal use, and the advantages of different digital platforms.

i) Applicability – Telehealth

The perspective piece, in Chapter Seventeen, on the use of telehealth services to deliver virtual wound and lymphoedema services showcased the success of delivering virtual lymphoedema care. Catherine, an experienced NSW Health wound care nurse, summarised key considerations for running a telehealth program with the following statement, “The running of a successful virtual service involves many complexities, including not only the technical aspects of telehealth but also the human elements, such as building trust with patients and fostering a culture of collaboration among healthcare providers. The service must be agile, responsive to feedback, and committed to ongoing education and support for both staff and patients.” Catherine’s mention of “complexities” aligns with the findings in Chapter Eight, where telehealth was found to be limited in lymphoedema care due to practitioners facing challenges in conducting certain assessments remotely. Further research is required on the technical and human aspects of providing telehealth services.

Achievement of the thesis objectives

This thesis addressed the research question of "How is digital health being utilised in the prevention, diagnosis, assessment, and treatment of lymphoedema?" This thesis quantified the types of eHealth modalities being used in lymphoedema care and included an exploration of contemporary issues of accessibility, appropriateness and applicability. The overarching aim, along with the primary and secondary research objectives, were accomplished through sixteen publications. This thesis also explored the development of digital prototypes to translate insights from previous research activities into five research products, including a chatbot, serious game, educational app, online course and digital assessment tool.

Hypotheses

The research hypotheses were, firstly, that the number of eHealth modalities used in lymphoedema care is limited, and secondly, that digital health may not have reached its full potential. The determination of whether the use was "limited" was based on the reported number of eHealth modalities currently in use. The results revealed that these hypotheses were only partly true, with the number of eHealth modalities not being limited to only a few modalities. Digital health was applied across a wider range of eHealth modalities than expected, with 18 different types reported. This was an unexpected finding, especially given the specialised nature of lymphoedema, where research is typically lacking. As Moffatt et al (2023) note, "The evidence base on the management of lymphoedema is currently weak and further work is required to assess the best practice and cost-effectiveness of different management regimens."⁽⁵⁰⁶⁾

However, the utilisation of digital health in lymphoedema care seems to have yet to reach its full potential, with research appearing to be in an early growth phase. For instance, lymphoedema practitioners continue to report barriers to using telehealth, despite it being the most widely accepted eHealth modality since the COVID-19 pandemic. This finding was anticipated, as other fields have also recognised that telehealth was underutilised and understudied before the pandemic, with further research still being needed to optimise the use of this eHealth modality.⁽⁵⁰⁷⁾

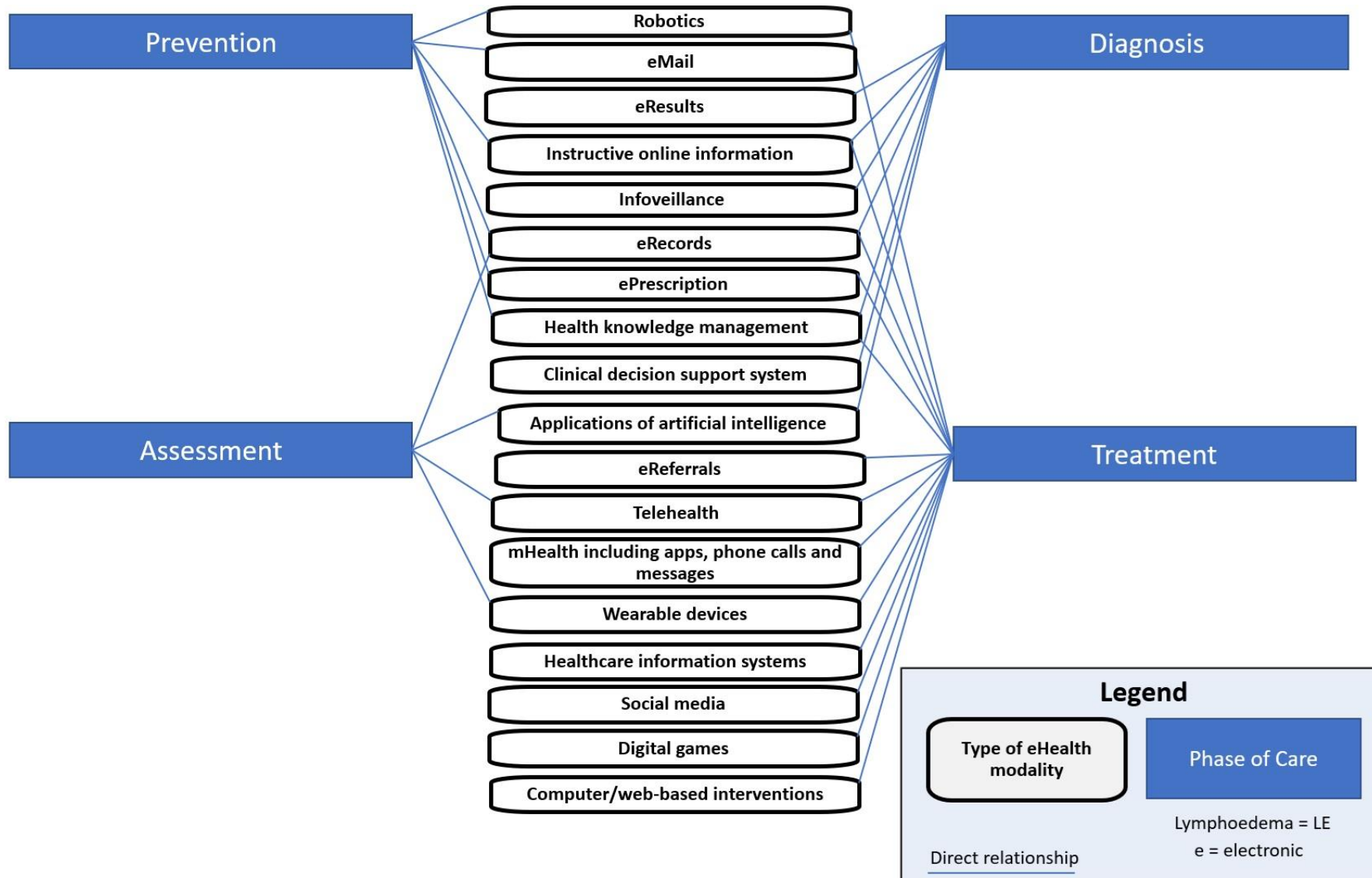


Figure 175 - eHealth modalities used across the prevention, diagnosis, assessment and treatment of lymphoedema

Future research

In addition to future research discussed above, this thesis has garnered several further considerations for future research.

i) Emerging research

Future research should focus on the continual assessment of digital health in lymphoedema care as new technologies and publications emerge. The systematic review in Chapter Nine excluded nineteen papers because they did not meet the standard of randomised controlled trials. Anticipated significant research developments in the coming years are expected to yield more robust data and insights.

ii) Utilising classification frameworks

In future research, it would be helpful if researchers applied the Population, Intervention, Comparator, Outcome, Timing, Setting, Communication, Technology, and Context (PICOTS-ComTeC) framework for describing DHIs.⁽⁸⁶⁾ This framework offers a transparent means of understanding what the DHIs are within research. Further to this, the WHO classification system (currently at Version 2.0) could be used when researchers describe which end user the DHI is impacting.⁽¹⁰⁴⁾

iii) Improvements in standard lymphatic treatments

Research from the systematic review on a novel wearable device prototype for lymphatic drainage offers promising potential to enhance lymphatic drainage massage in the future.⁽¹⁹⁸⁾ A systematic review by Yang et al (2024) on robotic technology for massage found, "All studies provided evidence that robotic massage interventions can enhance health and well-being, indicating a promising future for the integration of robotics in the field of massage therapy."⁽⁵⁰⁸⁾ While the use of robotics in lymphatic surgery is well-regarded and logical for enhancing surgical capabilities, further research is needed to explore the application of robotic technology in improving standard lymphatic treatments.⁽⁵⁰⁹⁾

Khogali and Mekid (2023) state “It has become standard practise for scientists to conduct in-depth evaluations of the impact of robotics, automation, and AI on future working conditions and job trends, as well as detailed analyses of the influencing variables behind the acceptance of modern technology.”⁽⁵¹⁰⁾ It seems that lymphoedema care is a long way from robotics and automation having an impact on job trends. In the short term, it is hoped that future research will focus on technologies that enhance patient care. As noted by a lymphoedema practitioner in Chapter Eight, there is a desire for "...more innovative solutions that improve patients' quality of life and improve practitioners' efficiency."

iv) Digital assessment tools

Digital tools for the assessment of lymphoedema could offer cost effective means of detecting the condition. Data collection on the prevalence of lymphoedema may be able to be improved if a nationally available digital diagnostic tool was developed. This would be a step towards overcoming the problems highlighted in the Research Imperative section of Chapter Two.⁽⁷³⁾

Machine learning was investigated by Fu et al (2018) to determine if cancer-related lymphoedema could be detected based on real-time symptom reporting. In their web-based study real-time reporting of symptoms was captured using a mHealth system.⁽⁴⁹⁸⁾ Prompted by this research, the digital assessment tool prototype demonstrated the feasibility of creating a cost-effective and simple digital tool that could assist patients in determining whether their symptoms might be indicative of lymphoedema. However, before this digital assessment tool could be made widely available, it would need to undergo thorough testing and validation. This process would require research funding and collaboration with lymphoedema professionals to ensure that the tool was accurate, reliable, and safe. Additionally, it would be crucial that testing was supported by the availability of lymphoedema professionals who could provide clinical care, particularly for patients who received a high or medium-high score, which could indicate the presence of lymphoedema. This approach would help to minimise patient distress and ensure proactive planning of ethical considerations in this research.

v) Barriers and enablers to digital health utilisation

Future research could also explore the barriers to digital health implementation reported by lymphoedema practitioners. These barriers included the difficulty in providing lymphoedema-specific assessments online, concerns about data security, insufficient time for training, deficiency in skills, lack of available solutions, lack of awareness, patient acceptance, and the challenge of overcoming the field being in early phases of implementation.

Future research could involve collaboration with digital health leaders around the globe. Clinical frameworks could be developed based on lymphoedema practitioners sharing insights on how they managed to successfully leverage DHIs. If clinical frameworks could be developed, practitioners could learn how to overcome barriers to conducting lymphoedema assessments and treatments successfully online. This thesis has identified certain groups around the world which have published on their remote (mHealth or telehealth) lymphoedema care programs such as in the UK, Australia, Qatar, Chile, America, Iran, China and Japan.^(1, 173, 196, 252, 253, 299, 300, 303-305, 511) Such research groups could be consulted if collaborative, international research was undertaken.

Concerns about data security in digital health are warranted. The increasing use of digital platforms for health interventions raises significant issues related to the protection of sensitive patient information. Ensuring the confidentiality, integrity, and availability of health data is paramount, as breaches can lead to severe consequences, including loss of patient trust, legal repercussions, and potential harm to patients. The narrative review mentioned research by Na et al (2018) who were able to reidentify nearly all (94.9%) individual adults from the National Health and Nutrition Examination Survey using machine learning techniques.⁽⁵¹²⁾ A study by She et al (2020) found that hacking incidents were the most prevalent forms of attack behind healthcare data breaches, followed by unauthorised internal disclosures.⁽⁵¹³⁾ Research into both security protocols and well as staff training on how to use health information is therefore required.

The topic of “insufficient time for training” ties in with “deficiency in skills.” While it may seem intuitive, the skills needed to be a skilled lymphoedema practitioner are quite different from those required to develop effective digital health solutions, yet there is often a lack of training to bridge this gap. Monique’s case study on her strategic use of social media, demonstrated that she had developed her strategic use of the technology over time. This came through years of persistent use of various social media tools and therefore the growth of her skills, confidence and digital network over time. Research looking into the skills associated with telehealth use alone found that a combination of technical knowledge, management abilities, soft skills, and communication skills are required.⁽⁵¹⁴⁾ Further research needs to outline all of the various competencies required for each different type of digital health technology.

The need for comprehensive education in both lymphology and digital health technologies is becoming increasingly apparent. Just as it has been highlighted that lymphoedema education requires improvement, with calls for greater exposure to lymphology embedded within tertiary education programs, there is a parallel need to ensure that all undergraduate healthcare programs include substantial coverage of how to leverage DHIs.^(515, 516) The rapid evolution of these technologies and their growing integration into healthcare practices suggests that practitioners emerging from undergraduate programs should be proficient in their use.

In particular, the ability to effectively utilise social media and AI is becoming a critical skill for healthcare professionals. This thesis has emphasised that patients are increasingly turning to social media as a first source of information before consulting their doctor.^(74, 75) This trend underscores the importance of healthcare professionals being knowledgeable about the digital platforms their patients are using, so they can guide them towards reliable information sources as well as integrate digital tools into patient care strategies.

Incorporating this knowledge into educational programs is essential for preparing the next generation of healthcare professionals to meet the demands of a rapidly changing landscape. By doing so, we can ensure that lymphoedema practitioners are not only competent in traditional lymphoedema knowledge but are also adept at utilising modern digital tools to improve patient care and outcomes.

Limitations

Several limitations are recognised in this thesis. It is acknowledged firstly that this thesis could have been made more robust through the digital prototypes advancing to feasibility testing. The prototypes within this thesis are presented as research products, which require further testing in order to be fully understood.⁽⁵¹⁷⁾ Further research was hindered by a lack of research funding. To test the digital assessment tool, for example, without funding of a small team to ensure patient welfare through offering face to face or telehealth appointments, was deemed to be unethical. Nevertheless, prototyping is recognised as an essential part of product development and research to assist with learning and informed decision-making.^(518, 519)

Secondly, it is recognised that the mixed-methods research, in Chapters Eight and Ten, involved a small sample size. Despite this the results offered helpful insights on the use of digital health in lymphoedema care. If the results had significantly differed from that discovered in previous research, a larger sample would have been sought. The financial implications of lymphoedema, for example, have been reported as an issue impacting lymphoedema patients.⁽⁵²⁰⁾ The mixed-methods research corroborated these findings, with cost being identified as the primary health system challenge reportedly faced by patients. As a second example, Australian research previously published had discussed barriers faced in delivering lymphoedema assessments remotely.⁽⁵²¹⁾ The mixed-methods research also corroborated these findings with the most common theme of challenges in using eHealth for lymphoedema care being difficulties in delivering lymphoedema assessments remotely.

Thirdly, the quality of research on accessibility, appropriateness, and applicability could have been improved by using objective frameworks for assessment. Guidelines such as the Web Content Accessibility Guidelines (WCAG) 2.1 provide a comprehensive set of recommendations for making web content more accessible.⁽³²⁸⁾ However, accessibility challenges are multifaceted; for example, someone may not have an internet connection or even access to a computer, as evidenced by research mentioned in Chapter Eight from Noble et al (2019) where 25% of participants lacked access to a device with an internet connection with a camera and speakers.⁽²⁷³⁾

In the case studies of Kate in Chapter Eleven, as a blind remedial health practitioner, Kate managed to overcome barriers in lymphoedema training by finding an education provider who ensured the eLearning and face to face training experience were accessible. Despite this, Kate faced ongoing accessibility issues in clinical practice. Her case studies highlight the complexity of researching accessibility as many factors must be considered and there are elements of subjectivity.

Applicability is also subjective. Researchers have previously stated that, "...the published literature offers little guidance on how to define or assess acceptability."⁽¹⁷⁾

For appropriateness, the criterion of achievement is technical or social.⁽¹⁵⁾ As an example of a technical criterion, the AI-driven chatbot responses were assessed as either right or wrong. For example, to state that lipoedema is unilateral is wrong. Having said this, some aspects of using the chatbots were appropriate, and some were not making a statement of overall appropriateness impossible.

Fourthly, an independent researcher could have been engaged to test the AI-driven chatbots, but this was not possible due to insufficient funding and access to other research volunteers. The approach of involving an independent researcher may have been beneficial to exclude the authors overall bias towards conducting this research. If the author had been strongly opposed to the use of AI-driven chatbots, for example, the research testing appropriateness might not have occurred or might have focused on different aspects, such as the ethics of their use.

Strengths

One of the key strengths of this thesis lies in the author's journey of discovery and growth. Initially, the author did not have a deep understanding of accessibility prior to undertaking this candidature. However, through engagement with Kate's experience, the author developed a profound and genuine passion for advocating for accessibility. This personal evolution not only enriched the research process but also added a layer of authenticity and commitment to sharing the results of the publications at relevant industry conferences and contributing to advocacy efforts.

Another strength of this thesis is its pioneering nature, which builds upon the strengths of previous research while introducing original findings and practical resources which aim to help lymphoedema practitioners. The checklist developed in Chapter Seventeen, for example, draws from NSW Health's key doctrine to empower lymphoedema practitioners with a helpful resource that can guide the establishment of their own telehealth services.

Another strength of this thesis is its documentation of the early versions of Bard and ChatGPT, capturing a significant moment in the evolution of AI. By documenting these early chatbot iterations, the research not only contributes to the understanding of their development but also marks an important part of technological history.

Furthermore, the thesis stands out for its broad scope in addressing the field of digital health. The author has successfully established a solid foundation for future research. The guidance provided for future research activities is both specific and actionable, offering clear direction that should empower and inspire future researchers.

Impact

This thesis makes a significant and original contribution to the field of lymphoedema care by providing a comprehensive description of how digital health is being used in lymphoedema care. Through sixteen publications and the development of innovative research prototypes, this research addresses critical gaps in the current literature and offers practical insights for improving patient outcomes through leveraging digital health in lymphoedema care.

Beyond its specific focus on lymphoedema care, it is hoped that the impact of this thesis reaches a broader audience within the digital health sphere. By clearly defining digital health and exploring its application in a clinical context, this research offers valuable guidance for healthcare practitioners, researchers, and policymakers across various disciplines. The publication that emerged from this work defining digital health, may serve as a foundational resource for those seeking to understand and navigate the complexities of terminology in this field. In addition, the work assessing the ability of chatbots to differentially diagnose health conditions, could be replicated across many other health conditions.

This thesis also suggests future research directions that could advance both lymphoedema care and the broader field of digital health. The insights provided on the chatbot prototype, for example, could be applied to anyone working in digital health or anyone with a website who wants to deploy a chatbot for the purpose of improving the user experience.

Conclusion

Eighteen different types of eHealth modalities were being utilised across the various stages of lymphoedema care including prevention, diagnosis, assessment, and treatment. These modalities encompassed a wide range of DHIs, with thirty-five distinct types identified. Issues related to accessibility, appropriateness, and applicability of digital health in lymphoedema care presented both challenges and opportunities. The utilisation of digital health in lymphoedema care has yet to reach its full potential, highlighting a clear need for future research to fully harness the capabilities of digital health in this field.

Table 30 - Digital health interventions reported in this thesis

Category		Digital Health Interventions	Reported or researched in this thesis	One example from research reported within this thesis
1.1	Targeted communication to Persons	1.1.1 Transmit health event alerts to specific population group(s)		
		1.1.2 Transmit targeted health information to person(s) based on health status or demographics		
		1.1.3 Transmit targeted alerts and reminders to person(s)		Chapter 8 - Use of mobile phone messages reported by LP
		1.1.4 Transmit diagnostics result, or availability of result, to person(s)		
1.2	Untargeted communication to Persons	1.2.1 Transmit untargeted health information to an undefined population		Chapter 13 - Social media targeted a broad audience in Monique's case study
		1.2.2 Transmit untargeted health event alerts to undefined group.		
1.3	Person to Person communication	1.3.1 Peer group for individuals		
1.4	Personal health tracking	1.4.1 Access by the individual to own medical or summary health records		Chapter 10 – My Health Record mentioned by LP
		1.4.2 Self-monitoring of health or diagnostic data by the individual		Chapter 20 – LymphTrack™ as a example of an app for tracking of LE symptoms
		1.4.3 Active data capture/documentation by an individual		Chapter 6 – Singh et al (2022) and activity trackers
		1.4.4 Access by the individual to verifiable documentation of a health event or health status		
1.5	Person based reporting	1.5.1 Reporting of health system feedback by persons		
		1.5.2 Reporting of public health events by persons		
1.6	On demand communication with persons	1.6.1 Look-up of information on health and health services by individuals		Chapter 12 -Reputable LE websites providing information on breast cancer-related LE
		1.6.2 Simulated human-like conversations with individual(s)		Chapter 12 -Chatbots explored in the generative AI publications
1.7	Person-centred financial transactions	1.7.1 Transmit or manage out-of-pocket payments by individuals		
		1.7.2 Transmit or manage vouchers to individuals for health services		

Category		Digital Health Interventions	Reported or researched in this thesis	One example from research reported within this thesis
		1.7.3 Transmit or manage incentives to individuals for health services		
1.8	Person-centred consent management	1.8.1 Manage provision and withdrawal of consent by individual(s)		
2.1	Identification and registration of persons	2.1.1 Verify a person's unique identity		
		2.1.2 Enrol person(s) for health services/clinical care plan		
2.2	Person-centred health records	2.2.1 Longitudinal tracking of person's health status and services		
		2.2.2 Manage person-centred structured clinical records		Chapter 8 - Use of eRecords reported by LP
		2.2.3 Manage person-centred unstructured clinical records (e.g. notes, images, documents)		Chapter 8 - Use of mobile phone images reported by LP
		2.2.4 Routine health indicator data collection and management		
2.3	Healthcare provider decision support	2.3.1 Provide prompts and alerts based according to protocol		
		2.3.2 Provide checklist according to protocol		
		2.3.3 Screen persons by risk or other health status		Chapter 7 - Fu et al (2022) – Machine learning to detect LE
2.4	Telemedicine	2.4.1 Consultations between remote person and healthcare provider		Chapter 8 - Use of telehealth reported by LP
		2.4.2 Remote monitoring of person's health or diagnostic data by provider		
		2.4.3 Transmission of medical data (e.g. images, notes, and videos) to healthcare provider		Chapter 8 - Use of mobile phone reported by LP
		2.4.4 Consultations for case management between healthcare providers		
2.5	Healthcare provider communication	2.5.1 Communication from healthcare provider to supervisor(s)		Chapter 7 - Kalinga et al (2022) - Text messages simplified the exchange of information between lower and higher levels of management
		2.5.2 Communication and performance feedback to healthcare provider(s)		
		2.5.3 Transmit routine news and workflow notifications to healthcare provider(s)		

Category		Digital Health Interventions	Reported or researched in this thesis	One example from research reported within this thesis
		2.5.4 Transmit non-routine health event alerts to healthcare provider(s)		
		2.5.5 Peer group for healthcare providers		Chapter 14 -Digital CoP
		2.5.6 Generative AI for tailored content creation		Chapter 12 -Generative AI publications
2.6	Referral coordination	2.6.1 Coordinate emergency response and transport		
		2.6.2 Manage referrals between points of service within health sector		Chapter 8 -eReferrals reported by LP
		2.6.3 Manage referrals between health and other sectors (social services, police, justice, economic support schemes)		
2.7	Scheduling and activity planning for healthcare providers	2.7.1 Identify persons in need of services		
		2.7.2 Schedule healthcare provider's activities		
2.8	Healthcare provider training	2.8.1 Provide training content to healthcare provider(s)		Chapter 16 -YouTube reported in the case study of Fast'n Go™
		2.8.2 Assess capacity of healthcare provider(s)		
2.9	Prescription and medication management	2.9.1 Transmit or track prescription orders		Chapter 8 -ePrescription of garments reported by LP
		2.9.2 Track individual's medication consumption		
		2.9.3 Report adverse drug effects		
2.10	Laboratory and diagnostics imaging management	2.10.1 Transmit person's diagnostic result to healthcare provider		Chapter 8 -eReferrals reported by LP
		2.10.2 Transmit and track diagnostic orders		
		2.10.3 Capture diagnostic results from digital devices		Chapter 7 – Kalinga et al (2022) Community Health Workers used text messages to report lymphatic filariasis
		2.10.4 Track biological specimens		
2.11	Healthcare provider financial transactions	2.11.1 Verify individual's health coverage and financing scheme membership		
		2.11.2 Receive payments from individuals		
3.1	Human resource management	3.1.1 List health workforce cadres and related identification information		

Category		Digital Health Interventions	Reported or researched in this thesis	One example from research reported within this thesis
		3.1.2 Monitor performance of healthcare provider(s)		
		3.1.3 Manage registration/certification of healthcare provider(s)		Chapter 6 - ALA website and the NLPR register
		3.1.4 Record training credentials of healthcare provider(s)		
		3.1.5 Manage health workforce activities		
3.2	Supply chain management	3.2.1 Manage inventory and distribution of health commodities		
		3.2.2 Notify stock levels of health commodities		
		3.2.3 Monitor cold-chain sensitive commodities		
		3.2.4 Register licensed drugs and health commodities		
		3.2.5 Manage procurement of commodities		Chapter 8 - ePrescribing of garments reported by LP
		3.2.6 Report counterfeit or substandard drugs by persons		
3.3	Public health event notification	3.3.1 Notification of public health events from point of diagnosis		
3.4	Civil Registration and Vital Statistics (CRVS)	3.4.1 Notify, register and certify birth event		
		3.4.2 Notify, register and certify death event		
3.5	Health system financial management	3.5.1 Register and verify health coverage scheme membership of persons		
		3.5.2 Track and manage insurance billing and claims processes		
		3.5.3 Transmit and manage payments to health facilities		
		3.5.4 Transmit and manage routine payroll payment to healthcare provider(s)		
		3.5.5 Transmit or manage financial incentives to healthcare provider(s)		
		3.5.6 Manage and plan budget allocations, revenue and expenditures		
		3.5.7 Determine level of subsidies for health coverage schemes		
		3.5.8 Collect health insurance contributions		
3.6	Equipment and asset management	3.6.1 Monitor status and maintenance of health equipment		
		3.6.2 Track regulation and licensing of medical equipment		
3.7	Facility management	3.7.1 List health facilities and related information		Chapter 6 - ALA website and the NLPR register

Category		Digital Health Interventions	Reported or researched in this thesis	One example from research reported within this thesis
		3.7.2 Assess health facilities		
3.8	Person-centred health certificate management	3.8.1 Register and store current health certificate information		Chapter 10 -My Health Record mentioned by LP
		3.8.2 Retrieve and validate current health certificate information		
		3.8.3 Revoke and update health certificate		
4.1	Data Management	4.1.1 Form creation for data acquisition		
		4.1.2 Data storage and aggregation		Chapter 8 -eRecords reported by LP
		4.1.3 Data synthesis and visualizations		Chapter 7- Tidhar et al (2023) descriptive analysis of an EHR database
		4.1.4 Automated analysis of data to generate new information or predictions on future events		
4.2	Data coding	4.2.1 Parse unstructured data into structured data		
		4.2.2 Merge, de-duplicate and curate coded datasets or terminologies		
		4.2.3 Classify disease codes or cause of mortality		
4.3	Geo spatial information management	4.3.1 Map location of health facilities/structures and households		Chapter 6 - Locations of bioimpedance spectroscopy devices
		4.3.2 Map location of health event		Chapter 6 - AI for filariasis mapping
		4.3.3 Map location of persons and settlements		
		4.3.4 Map location of healthcare provider(s)		Chapter 6 - ALA website and the NLPR register
		4.3.5 Map health and health indicator data to geographic data		Chapter 6 - Kondeti et al (2019) machine learning to predict filariasis using socio-economic factors
4.4	Data exchange and Interoperability	4.4.1 Point-to-point data integration		
		4.4.2 Standards-compliant interoperability		
		4.4.3 Message routing		
4.5	Data governance compliance	4.5.1 Authentication and authorisation		
		4.5.2 Data privacy protection		

Category	Digital Health Interventions	Reported or researched in this thesis	One example from research reported within this thesis
	4.5.3 Data consent and provenance		
	4.5.4 Trust architecture		

LP = lymphoedema practitioner

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