Exploring design and implementation of technologies with rural mental health consumers and professionals

Simone Kate Orlowski

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School of Medicine

Faculty of Medicine, Nursing and Health Sciences

Flinders University

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SUMMARY

Young people (aged 16-24) are most at risk of developing mental illness; yet they under-utilise mental health services. Greater use of new and existing technologies is projected to play a significant role in the Australian mental health system into the future, with the aim of improving engagement in care and care systems. This research program has investigated the question: What are the scope and roles of technologies within rural, community-based youth mental health services? The research privileged end user perspectives and applied and investigated participatory design-based (PD) methods for their capacity to improve technology design and implementation to this context. Of principal interest were technologies used by mental health professionals and young people that assist with improving consumer *engagement* and *support*, along with *navigation* of the mental health system (ESN technologies).

In the first instance, a systematic review was conducted to investigate ways in which participatory methodologies have been applied to develop technology-based youth mental health and well-being interventions. Results indicated that participatory methodologies are not well understood within this area of research, with impacts on intervention effectiveness unknown and lack of implementation following piloting. The review confirmed that consumer participation was predominantly consultative and consumerist in nature. Hence, the current research further explored the potential role of user-focussed, design-based methods in the design and implementation of technologies in mental health contexts.

Building on the review, a detailed case study was conducted in one rural region in South Australia. Initially, a two-part scoping study was conducted to obtain in-depth end user perspectives (i.e. those of mental health professionals and consumers) around the role of ESN technologies in facilitating traditional mental health care. For a range of reasons, mental health professionals and youth consumers were ambivalent around use of technology to facilitate that care.

End users, along with organisational and systematic factors were then investigated via an observational study. The results of that study positioned mental health work in rural community-based settings as contested, multifaceted and underpinned by an individualised and empowerment care focus. The participating services were conceptualised as operating within the larger, complex mental health system; this conceptualisation highlighted widespread and multilayered considerations and consequences for the design and implementation of any technology.

Finally, a series of participatory workshops were conducted with mental health professionals and young people; they aimed to define domain criteria associated with mental health care. Through this research, self-directed and potentially narrative-redefining technologies were found to be philosophically aligned with community-based youth mental health service provision.

Overall, this research outlined positive contributions that technology could make to the experience of current and future mental health help-seeking and service provision. It also outlined a range of consumer and workforce barriers that continue to influence the limited uptake of technologies to facilitate youth mental health care. This research has demonstrated application of PD to the investigation of the conditions and conflicts that characterise the context of technology use as opposed to the design of products within the context of youth mental health care.

DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text

Simone Orlowski

LIST OF ORIGINAL PUBLICATIONS

Orlowski, SK, Lawn, S, Venning, A, Winsall, M, Jones, GM, Wyld, K, Damarell, RA, Antezana, G, Schrader, G, Smith, D, Collin, P & Bidargaddi, N 2015, 'Participatory research as one piece of the puzzle: A systematic review of consumer involvement in design of technology-based youth mental health and well-being interventions', *Journal of Medical Internet Research Human Factors*, vol. 2, no. 2, p. e12.

Orlowski, SK, Matthews, B, Bidargaddi, N, Jones, G, Lawn, S, Venning, A & Collin, P 2016, 'Mental health technologies: Designing with consumers', *Journal of Medical Internet Research Human Factors*, vol. 3, no. 1, p. e4

Orlowski, SK, Lawn, S, Matthews, B, Venning, A, Wyld, K, Jones, G, Winsall, M, Antezana, G, Schrader, G & Bidargaddi, N in revision, 'The promise and the reality: A mental health workforce perspective on technology-enhanced youth mental health service delivery', *BMC Health Services Research*, vol. 0, no. 0.

Orlowski, SK, Lawn, S, Antezana, G, Venning, A, Winsall, M, Bidargaddi, N & Matthews, B 2016, 'A rural youth consumer perspective of technology to enhance face-to-face mental health services', *Journal of Child and Family Studies*, pp. 1-10.

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Orlowski, SK, Matthews, B, Lawn, S, Jones, G, Bidargaddi, N & Venning, A submitted, 'Designing for practice: Understanding technology use in rural community-based youth mental health contexts'.

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ABBREVIATIONS

Australian National Health and Medical Research Council	NHMRC
Cognitive Behavioural Therapy interventions	iCBT's
Community-based participatory research	CBPR
Country Health SA Local Health Network	CHSALHN
Cooperative Research Centre	CRC
Design thinking	DT
Experience-based Design	EBD
eMental Health in Practice	eMH Prac
Technologies which facilitate engagement, support and navigation through the mental health system	ESN Technologies
Frontline Mental Health	FMH
General Practitioner	GP
Human Computer Interaction	HCI
Information and communications technology	ICT
Interactive socio-emotional toolkit	iSET
Internet-based Cognitive Behavioural Therapy	iCBT
Journal of Internet Medical Research	JMIR
Men who have sex with men	MSM
Mindfulness awareness training and education	MATE
Mental Health Emergency Care – Rural Access Program	MHEC-RAP
National Health and Medical Research Council	NHMRC
Nurse Knowledge Exchange	NKE
Online health-promoting community	OHPC

Participatory action research	PAR
Personally Controlled Electronic Health Record	PCEHR
Participatory design	PD
Primary Health Network	PHN
Randomized controlled trial	RCT
Same sex attracted young people	SSAY
Short Message Service	SMS
South Australian	SA
Technology Acceptance Model	TAM
University of California Davis	UC Davis
User-centred design	UCD
Victorian Health Promotion Foundation	VicHealth
Web-based support system	WBSS
West Australian Aids Council	WAAC
West Sacramento Youth Resource Coalition	WSYRC
Youth Mental Health System	YHMS
Youth Voices for Change	YVC

OVERVIEW

OUTLINE OF THESIS

This qualitative program of research is intended to provide an in-depth understanding of whether technologies can facilitate traditional mental health care, and how this can be implemented. To achieve this, a detailed case study of mental health consumers and providers, i.e., those proposed to use the technology, was undertaken in one rural South Australian region. Rural, community-based youth mental health services were the context of focus for the research. Within this project, the complexity associated with the design process of new technology and its implementation in the workplace is investigated, as is the potential contribution of participatory design-based methods to understanding the role of technology in face-to-face youth mental health contexts. At its core, the current research program explores alternative paradigms around help-seeking and health research in young people, and the ways in which alternate thinking can contribute to building a more consumer-centred youth mental health system.

For the purposes of the current project, 'youth' is defined as young people aged 16-24 years, in accordance with definition set out in the National Survey of Mental Health and Wellbeing (Slade et al. 2009). This particular age range also aligns with the newly implemented state-wide South Australian Youth Mental Health System of Care, the context within which this research program was informed and conducted. The term 'technology', in the context of this research program, assumes a broad definition, one of an "agent of change" (Fett 2000) within the current Australian mental health system. Practically, this definition refers to any technology capable of altering the traditional ways in which young people *engage* with, are *supported* within and *navigate* the mental health system, and are referred to as ESN technologies for the purposes of this thesis. References to the facilitation of 'traditional mental health care' throughout this thesis pertain to those mental health services provided within a face-to-face service model.

Four independent, but interrelated, studies form the basis of the research program and are outlined in six journal articles. Three of which have been published, two of which are in review and one which has been submitted.

- Chapter One outlines the problem statement for the current research program, the gaps in the literature, and the aims for the thesis.
- Chapter Two is an exegesis for each of the four studies undertaken. The methodological approaches for the studies are outlined, the assumptions embedded in the research, and the specific rationale for each study is laid out in the context of the broader research goals. Information that was outside of scope of the published papers is also provided with respect to both the individual studies and the wider research focus.
- Chapter Three provides a targeted review of the literature which outlines the broader field of study. It draws together the major threads of the research focus: youth mental health services as an implementation context, the call for greater attention to user perspectives in the design and delivery of mental health

services and interventions, and the application of user-focussed, design-based approaches in mental health technology design.

- Chapters Four to Seven present the six journal articles. Each of these chapters begins with a preamble which outlines the rationale for the article(s) and how it is positioned within the broader research, and ends with a summary of the major results emerging from the research. Chapter Four contains a systematic review article and a viewpoint article, and Chapter Five contains two sub-studies / articles that underpin a larger scoping study. Chapters Six and Seven each contain one journal article.

- Chapter Eight provides a summary and discussion of results. Informed by the results of this program of research, a number of key recommendations to inform design and implementation of technologies in clinical youth mental health settings (and mental health settings more broadly) are then presented. Limitations of the work, future directions and a concluding statement complete this chapter.

CONTEXT OF THE CANDIDATURE

The current program of research was carried out within the context of a larger project, Young and Well Towns (2011), which was principally funded by the Young and Well Cooperative Research Centre (Young and Well CRC) and supported by Flinders University and Country Health South Australia Local Health Network (CHSALHN). The research was conducted while the researcher was working as a project officer within this larger project. The Young and Well CRC envisions "a digitally connected world where technologies are used to support young people to feel safe, healthy and resilient" (Young and Well Cooperative Research Centre 2011), and the Young and Well Towns project, a major project within the CRC, is specifically focussed on technology-based promotion of wellbeing and increased engagement with mental health services in young people through innovative technological solutions in rural South Australia. The majority of the empirical data was collected in one rural South Australian region. The nature and scope the research was made possible through the participation of a number of mental health services within the Young and Well Towns project.

Given the author's dual role as a doctoral candidate and project officer, it was important that the research resulted in a publishable body of work which allowed rapid dissemination and peer review of the studies through submission to journals. With this in mind, the current research within the wider context of the project was designed and led by the author of this thesis. Although each of the studies are separate in nature, each successive study was informed by, and developed upon, the methods and the findings of previous studies. The primary supervisor was not directly employed or involved in the larger Young and Well Towns project, a factor which served to enhance the independence of the PhD study from the project role.

CHAPTER 1: AIMS

STATEMENT OF THE PROBLEM

One in five young Australians qualify for a mental illness each year (Ivancic et al. 2014) and the majority, 60%, report feeling uncomfortable seeking help or advice for mental illness (Ivancic et al. 2014; Kessler et al. 2007). This poor engagement with services makes early intervention to ameliorate or reduce the impact of mental illness a difficult proposition. Many barriers to accessing traditional face-to-face help have been reported. For example, the impact of stigma, along with financial, geographic and disease specific barriers are well established in the literature (Gulliver, Griffiths & Christensen 2010; Lambert & Newcomer 2009; Lawn 2012; Muir-Cochrane 2006), as are those barriers resulting from limited mental health literacy and a preference for self-reliance and/or informal support (Hickie et al. 2007; Rickwood, Deane & Wilson 2007).

Rural young people with their specific contextual and geographical barriers such as increased social visibility and physical distance from specialised health services, arguably stand to gain the most from the rise of communication-enabled technologies. While these technologies demonstrate remarkable promise in facilitating greater, more flexible access to and engagement with mental health services, the extent to which they can facilitate traditional ways of accessing and receiving mental health help remains unknown, with lack of implementation and uptake in existing face-to-face mental health service contexts (Montague, Varcin & Parker 2014). Rural mental health consumer and professional perspectives around use of technology for this purpose is under researched, to the extent that little is known about factors which facilitate implementation and uptake of technologies in face-to-face mental health service delivery contexts. Of particular interest in the current research are technologies which assist with improving consumer *engagement* and *support*, and facilitate *navigation* of the mental health system (ESN technologies).

Most prior research has focussed on implementation of clinician-only (as opposed to clinician-consumer) technologies to treat physical illness in hospital settings (Gagnon et al. 2012; Montague, Varcin & Parker 2014). Given the large economic impact and disease burden associated with mental illness (Council of Australian Governments 2006) a better understanding of key stakeholder perspectives is required. This specifically pertains to the potential value of technology as an agent of change in traditional delivery of mental health services, taking into account the conditions that support successful implementation and uptake of technologies in community-based youth mental health contexts. In part, this understanding may be facilitated by use of participatory research methods which have been repurposed from design and technical disciplines, and which are seeing increasing uptake application in the design of technology-based health and wellbeing tools (Hagen et al. 2012).

GAPS IN THE LITERATURE

A number of gaps in the current literature surrounding this topic exist.

1. **An absence of a review into how participatory methodologies have been employed to develop technology-based youth mental health and well-being interventions.**

End user participation in research projects focussed on mental health technology intervention design is an emerging field of research and thus a dearth of literature exists (Owens et al. 2011). In particular, motivations for inclusion of mental health consumers in technology design projects are not well understood. Design issues, such as the way in which human factors are incorporated into technology-based health interventions (Christensen & Mackinnon 2006; Coyle et al. 2007; Mohr, Cuijpers & Lehman 2011) are postulated to play a role in the poor uptake and adherence currently associated with these devices (Christensen, Griffiths & Farrer 2009; Christensen & Mackinnon 2006; Eysenbach 2005; Kelders et al. 2012; Lillevoll et al. 2014). With this in mind, researchers are increasingly advocating for more formal incorporation of end users into design processes (Coyle & Doherty 2009; Howe et al. 2014; Mohr et al. 2014). Boote, Telford and Cooper (2002) conceptualise motivations underpinning consumer involvement in research in two ways: (1) empowerment (i.e. consumer participation leads to greater consumer autonomy); and (2) consumerism (i.e. consumer participation leads to creation of more efficient, economical and effective products, services or interventions). These fundamentally different motivations have divergent consequences for the chosen methodology and role of the consumer. To fill the gap identified, a systematic review was undertaken with the aim of synthesising previous literature, and generating practical recommendations for mental health technology designers wishing to employ participatory research methods. Key concepts investigated included: (1) the nature of consumer involvement; (2) the nature and outcomes of the design process; and (3) the relationship between participatory research and the implementation of research.

2. **An absence of in-depth investigations of rural, youth mental health consumer and workforce perspectives around the role of ESN technologies to support frontline community-based mental health services.**

The successful implementation and integration of ESN technologies into rural, community-based youth mental health services requires an in-depth appreciation of current workforce and consumer perspectives and experiences. To date, previous research into the willingness and readiness of the youth mental health workforce to utilise technology has been quantitative in nature (Blanchard et al. 2012) and has not captured systemic perspectives associated with the different tiers of the mental health system (Blanchard et al. 2012; Montague, Varcin & Parker 2014; Sinclair et al. 2013). To fill the gap identified, a series of focus groups and interviews were carried out with the major youth mental health services in one rural South Australian region. The participating organisations were chosen as they represented the major youth mental health services in the region and thus the various tiers of the mental health system. These perspectives were supplemented by the views of key youth workers employed outside of the mental health area in the region. Individual, organisational and systemic

perspectives were sought on the role of existing technology to support face-to-face mental health service delivery in community-based settings.

In addition to the perspective of mental health workers, the perspectives of typical youth consumers - those actively seeking mental health help - have not been sufficiently investigated (Montague, Varcin & Parker 2014), and the views of rural young mental health consumers have not been represented at all. Consequently, to fill the gap identified, an in-depth qualitative, interview-based study exploring the perspectives of current rural youth mental health consumers was conducted. Its purpose was to investigate rural youth consumers' personal experiences of struggling with mental health concerns, of help-seeking in a rural context and their experiences of the mental health system. These two sub-studies formed the basis of an overall scoping study aimed at uncovering what role, if any, existing technology has in augmenting youth, community-based mental health service provision and associated help-seeking.

3. **An absence of observational studies of rural, community-based youth mental health work to inform design and implementation of ESN technologies in this context.**

Various human centred methods have been employed within the field of mental health technology design (Coyle et al. 2007; Hagen et al. 2012). Observing frontline mental health service provision in real time, however, has not been utilised extensively for studying user experience. This is primarily the case because negotiating access and consent to observe face-to-face mental health sessions between professionals and consumers remains a sensitive and difficult proposition. That said, some first-hand observational accounts of mental health work do exist (Brinkman et al. 2010; Frost & Houben 2014; Lederman et al. 2014; Thieme et al. 2013; Thieme et al. 2015), along with a body of literature around the observation of collaboration, communication and decision making within multidisciplinary team meetings in medical contexts, which inform the design of technologies aimed at enhancing this work (Kane, Groth & Randall 2011). However, to deepen current understanding of frontline mental health service provision, particularly with respect to work culture and practice, a two-week observational study was carried out at two of the services involved in the earlier scoping study. These services represented different tiers of the South Australian Youth Mental Health System, and worked with different consumer groups with respect to case complexity and severity. The focus of the observational study was to investigate from the frontline mental health workers' viewpoint perspectives on the nature of their role, examining also the nuance, complexity and interconnectedness of the mental health system. Young people's interactions with, and trajectory through, the mental health system were also under consideration. Overall this study aimed to add to the literature outlined above, and inform the design of technologies intended to improve young people's experiences within the mental health system.

4. Adapted use of Participatory Design methods to inform understanding of the potential role of technology in rural, community-based youth mental health contexts.

Participatory Design (PD) is a research method that was developed by Scandinavian system designers and computer scientists in the 1980's (Ehn 1988). Early PD research projects, carried out with unions and workers as research partners, aimed to support workers in their quest to retain autonomy as a result of changes to work organisation from the introduction of technology (Clement & Van den Besselaar 1993; Ehn 1988). Since that time, the application of PD has diversified and is now conceptualised by some as a "collection of tools and techniques, a set of methods *and* a mindset" (Sanders 2013 p. 61). PD has been utilised in diverse ways in various disciplines to develop technology-based solutions (Spinuzzi 2002), and over the last 20 years, interest in the design of mental health technologies has increased. To that end, a framework outlining adaptation of PD in youth mental health contexts has been developed by Hagen et al. (2012) for application of PD by health researchers. PD methods are generally used to inform design of individual technologies, to generate a rich understanding of end users' needs and, in some cases, to promote collaborative decision making. These methods, however, are not commonly used to systematically investigate the implementation context. To fill the gap identified, a series of future-inspired workshops (Kensing & Madsen 1992) were carried out with mental health consumers and professionals. The intention of these workshops was to (1) gain greater understanding of models and structures as they relate to current rural, community-based youth mental health work; and (2) generate future visions and design proposals for technologies to be used in the context of face-to-face youth mental health care. The overall aim of the workshops was to build on earlier studies of the project by investigating how and why technologies could be utilised by frontline mental health professionals and consumers.

AIMS AND OBJECTIVES

The overall aims of the research project were to:

(1) Investigate design processes that engage end users and the potential contribution of these processes in facilitating the effective implementation and uptake of ESN technologies in rural, community-based youth mental health services

(2) Explore the perspectives of the individuals working in, and consumers of, mental health services around technology to facilitate traditional mental health care.

(3) Examine the complexities of the design and implementation of ESN technologies in and for rural, community-based youth mental health organisational contexts, with an overall view to developing practical recommendation strategies to inform the design and implementation of best practice in this context.

CHAPTER 2: EXEGESIS

PREAMBLE

The original intention of this research was to utilise Participatory Design (PD), the methodology of choice for the larger project funder (the Young and Well CRC), in order to develop an eMental health model aimed at increasing rural youth engagement with mental health services. As the PhD progressed, however, a number of insights and learnings led to a natural reframing of the focus and structure of the PhD. Firstly, in the process of researching and reflecting on how a rural eMental health model may be incorporated into existing face-to-face community-based mental health service delivery, the perspectives of consumers and the workforce were noted to be missing from the literature. The original project was built on the untested assumption that technology-based solutions can assist in improving young people's low rates of help-seeking with face-to-face services. As a result of deeper reflection and engagement with the literature it was deemed important to unpack this embedded assumption via in-depth engagement with mental health consumers and professionals before developing potentially unnecessary or inappropriate models of rural eMental health. Privileging a rural perspective in this research made it possible to investigate the assumption, often-repeated, but little interrogated, that technology-based solutions can provide greater accessibility and flexibility around the ways in which rural consumers access mental health services. Put simply, in-depth investigation into the case for technologies to support face-to-face mental health services, as seen through the eyes of the end users – youth mental health professionals and consumers - was identified as a gap in the literature. Moreover, the low implementation rates of technologies in mental health service contexts could not be ignored (Blanchard et al. 2012; Montague, Varcin & Parker 2014).

Despite their wide availability and efficacy, current mental health technologies are not routinely used by mental health professionals (Meurk et al. 2016; Montague, Varcin & Parker 2014). Research aimed at understanding the complexity of designing and implementing these technologies in and for youth mental health services is not common, particularly systemic-focused, immersive research capable of investigating the interconnections, interdependencies and relationships present in the mental health sector that influence technology implementation and uptake. With this in mind, further investigation of the organisational, systemic and cultural barriers to technology implementation and uptake was needed.

Early findings in the research project – specifically those arising from the systematic review of participatory research as applied to design of mental health and wellbeing technologies (Chapter Four) – demonstrated that empirical support for use of PD methodology in this context was limited. Having been supplanted from its original context – that is, use by computer scientists and systems designers to democratise the introduction of technology into workplaces in the 1980's (Ehn 1988)– PD is now employed by researchers and practitioners of many different backgrounds working in many different fields (Sanders 2013). Co-opting a methodology in this manner, particularly for use in an extremely sensitive context such as youth mental health, has potentially significant and as yet unexplored implications for its use. With this in mind, greater understanding around how

and why this methodology and associated methods may be relevant and useful in design of mental health technologies was required.

The larger research project (Young and Well Towns), and this PhD research, was conducted in collaboration with Country Health South Australia Local Health Network (CHSALHN). The project coincided with the implementation of the new South Australian Youth Mental Health System (YHMS) of Care, which services young South Australians 16-24 years of age. The YMHS of Care framework was developed and endorsed in 2012 and services rolled out in a stepwise fashion state-wide across late 2014 and throughout 2015. The impetus for, and intention behind, the system is South Australian agencies working together to provide age appropriate best practice characterised by an accessible, flexible and responsive service for young people and those that care about them. CHSALHN in particular was considering how the system might integrate more technology into its services. This context helped to facilitate the participatory nature of the current research project.

The following sections will discuss the underlying assumptions of the research project and then go on to establish the context for each paper presented.

RESEARCH DESIGN AND UNDERLYING ASSUMPTIONS

This program of research was pragmatic and practical in nature. The research was less focussed on purity of methodological quality and instead intended to be judged by the way in which it demonstrated situational responsiveness to the research focus (Patton 2002). Whilst at its broadest conceptualisation the research project is an in-depth qualitative study, the research design represents an attempt at breadth both in terms of giving voice to a number of individuals with underrepresented perspectives, and in engaging with these individuals via a number of different methods. These decisions were underpinned by the fact that the researcher assumed that mental health implementation contexts are not homogenous, and thus attempted to design a series of studies which enabled the various perspectives of individuals within one rural South Australian mental health region to be represented as far as practically possible. The research was designed to generate deeper understanding, through the eyes of mental health professionals and consumers, around whether and how technology can support and/or improve current face-to-face mental health service delivery. Overall this research aimed to generate "practical and useful knowledge for action in the tradition of reflective practice" (Patton 2002 p. 78) and as such improve real world technology design and implementation.

A ground-up qualitative approach to research, moving from specific observations to broader generalisation was required as workforce and consumer perceptions, experiences and motivations around technology use in face-to-face mental health services needed to be understood at the most basic level. A detailed, immersive and contextualised understanding of the various dimensions of mental health work and help-seeking and their relationship to technology-based support was sought. In order to achieve this, the research project was underpinned by emergent design flexibility (Patton 2002), and characterised by openness to following where the natural progression of the data and associated increasing depth of understanding led. Each methods' choice was

dictated by the learnings and new research questions generated by the prior studies (within the above mentioned constraints) and a sensitivity to the most appropriate way in which to study the possibilities of technology within a multifaceted work setting, while providing services to complex consumer groups. Furthermore, the design of this project aimed to make transparent the complexities of designing and implementing technology within and for mental health services, and the system more broadly, and as such allowed space for the uncovering of the important elements of successful design and implementation rather than pre-defining them for the purposes of measurement.

The use of interviews and focus groups, along with observational and workshop-based methods allowed investigation of individual, organisational and systemic perspectives. Inductive thematic analysis of the resultant qualitative data was carried out, which facilitated answering the research question in a holistic, iterative and reflexive manner. As far as practical, this investigation was conducted in a manner that ceded researcher and environmental control in order to collect real world and context sensitive data. This meant researching within already existing structures which manifested in the ways in which mental health consumers were recruited into the project, the ways in which the data was collected within the scoping study and the general nature and execution of the fieldwork and participatory workshops. This naturalistic approach to the research will be elaborated on in the outline of the rationale and context for each study.

Finally, the researcher acknowledges her own unique perspective that informs this PhD thesis. Having grown up in one of the earliest cohorts of generation Y, my socialisation has included the emergence of the ubiquity of home and then personal computing devices, followed by saturation of internet access, mobile phones and social networking/media. Being socialised across this digital divide has afforded me, and those of my particular cohort, a distinctive perspective with respect to life (just!) before and after the age of the networked society. In addition, my own middle class, half rural, half urban upbringing influenced my understanding of the research context and positioning of the research project through an equity lens.

Informed by a strong understanding of the prior literature, the study investigated what mental health professionals and consumers *say*, what they *do* and what they *make* (Sanders 2002) in pursuit of a holistic understanding of whether and how ESN technologies (those technologies that assist with improving consumer *engagement* and *support*, along with *navigation* of the mental health system) may facilitate traditional mental health care. Consequently, the findings of each successive study were triangulated by the investigation of the same phenomena via different but complementary qualitative research methods that moved the investigation from exploration through to confirmation. In this way an increasing depth of understanding was developed.

Pansiri's (2009) suggestion that "problem statement, purpose, significance, research questions and methodology are not static" (p. 84) was borne out in the process of conducting this PhD research. The pragmatic approach to the research meant that various theoretical positions - such as a complex systems approach and sociotechnical theory - were drawn on to inform and explain both research design and the outputs of the discrete but

interrelated studies comprising this body of work. These theories reflected the developmental and dynamic perspectives that were brought to the research (Patton 2002) and the reality that this field of research in particular – eMental health - is in a state of constant change and rapid growth. In this case the emphasis was on applying explanations and methods which were seen to best produce the desired outcomes with respect to the broader research aims irrespective of their epistemological leanings.

The results of this qualitative, utilisation-focussed study are intended for those engaged in design and implementation of technologies within existing face-to-face mental health services. This includes those directly involved such as health intervention and technology design researchers, technology developers and those responsible for organisational implementation. At a broader level, it also includes those who influence, develop and enact health policy, associated service delivery models and financial decision making. At the broadest level, the results of this program of research are likely to be important for encouraging dialogue between health, eHealth and human computer interaction research fields which traditionally have tended to operate in discipline-specific silos.

This researcher assumes that technology-based additions to face-to-face mental health care requires a substantial change to practice that is embedded in long established work structures and culture. In line with common humanistic values and principles that underpin qualitative inquiry, this research recognises that "change processes (and research) should be negotiated, agreed to, and mutually understood – not imposed, forced or required" (Patton 2002 p. 177). Moreover, that "change processes should be person centred, [and] attentive to the effects on real people as individuals with their own unique needs and interests" (Patton 2002 p. 177). For these reasons, methods were chosen that privilege the voice of those most affected by technological additions to care - mental health consumers and professionals. A priority was placed on engaging these intended technology users actively in the research process where possible within the personnel, time and resource constraints. This empowerment-focussed approach recognised that within many technology design projects, mental health professionals and consumers are often represented by research-interested professionals and consumer advocates who may not be reflective of typical mental health providers and help-seekers.

With this in mind, embedded in this research is an assumption that participatory or co-design processes play an important role in effective design and implementation of technologies within a face-to-face metal health service delivery context. The influence of PD methodology is made explicit throughout this research. Not only is its value for mental health technology design investigated, its methods (specified use of future-inspired workshops) and theoretical underpinnings (privileging the voice and experience of the end user) have been utilised to inform, justify and guide the research. At its core, a PD orientation to research ideally positions those intended to use the technology or research output as research partners with expert and tacit knowledge that should be accessed and honoured. Where possible this research attempted to remain true to core PD principles, particularly with respect to giving voice to the end users of technology in a meaningful and sensitive way. That said, the research design

and implementation were researcher-led. This decision was made for pragmatic reasons as the time pressures and resources associated with the larger research project did not allow a fully participatory process.

SYSTEMATIC REVIEW AND VIEWPOINT PAPER

As little was known about how participatory methods have previously been employed to develop technology-based youth mental health and well-being interventions, the decision was made to conduct a review that was broad in focus and systematic in its approach to evaluation. A multidimensional qualitative evaluation framework was created for use in this review, informed by prior literature and the needs of the broad research question. The review was ambitious in its attempt to summarise and draw together learnings from prior participatory research with respect to project context and focus, the nature of end user involvement, participatory and design processes, and process outcomes which included intervention efficacy and implementation. In addition, the review aimed to learn from a broad range of studies which developed technologies that were promotional through to treatment-focussed in nature; standalone or adjunct tools were both considered. Immersion within the design literature to inform this systematic review led to investigation of broader debates around the increasing influence of human centred approaches to health intervention design. In particular, Design Thinking (DT) was identified as a process which, like PD, has been adapted from its original context for use in healthcare research and delivery. This led to a comparative review of PD and DT underpinned by two case studies.

SCOPING STUDY

The scoping study was made up of two complementary sub-studies designed to access the views of the two major groups affected by potential technological changes to traditional mental healthcare: mental health professionals and consumers. One South Australian rural region was principally sampled for this study which enabled a range of perspectives to be investigated within the time and resource constraints of the project.

The first sub-study used maximum variation sampling to access the views of the range of mental health professionals engaged in frontline delivery of services. Therefore, the three major community-based services working with youth in the chosen region were identified and invited to participate in this study; all accepted. In line with the naturalistic design of the project, the focus groups were conducted with pre-existing teams and scheduled to take place in designated professional development and team meeting periods, as these meetings also acted as opportunities for learning and reflection. Focus groups were chosen as they provided a group level perspective and dialogue around what was considered a topical and timely issue facing the mental health profession. An additional focus group was carried out with key youth workers employed outside of the mental health area in the region to broaden the perspective of the data collected. Major themes that emerged from the initial four focus groups were then validated against individual perspectives accessed via a series of eight semi-structured confirmatory interviews with individuals also able to provide organisational and systemic viewpoints. These individuals were recruited from one of the services represented in earlier focus groups. The data generated from this sub-study was also validated at a participatory workshop in which the participants were

invited to engage with the researcher to extract key themes to produce their own thematic maps. This workshop took place in the region in which the data was collected.

The second stub-study originally intended to sample young people who were disengaged but could from mental health services. After finding difficulties recruiting these young people through their current workers, the sampling strategy was altered to recruit those young people who were well engaged with services, who were generally lower risk and regularly attending appointments. In this way the interviews could seek to explore current positive and prior negative experiences of help seeking. These young people were recruited through their clinicians who, in turn, were employed by two of the three services which participated in the focus groups of the first sub-study. A relatively small number of participants were recruited into this sub-study; this decision was made in order to create space in the analysis to honour the complexity and multidimensionality of their individual experiences and perspectives, whilst still extracting and learning from the major common themes present in their stories. The study's naturalistic design allowed the young people to be interviewed when and where they felt comfortable - in some cases this included having family members or their clinician present.

In order to generate data capable of providing a holistic perspective, the interview and focus group questions in both sub-studies were wide ranging in their focus. The focus, therefore, was not restricted to the use of technology in mental health work and help-seeking but sought to understand the broader experience of providing and seeking help in this rural South Australian region. Furthermore, all data generated in this scoping study were analysed inductively in order to allow the data to direct the focus of further investigation.

OBSERVATIONAL FIELDWORK STUDY

This fieldwork-based observational study was conceptualised after immersion in the research field and the literature, along with engagement with the study's major stakeholders led, to recognition that although many mental health technologies are designed in consultation with mental health professionals and consumers, observation of work practices and culture is not common. The rationale for this immersive field-based study was also strengthened by the many systemic, organisational and contextual barriers to technology implementation and uptake in community-based face-to-face mental health services identified in the scoping study.

This study investigated the importance of the setting, and the interdependencies and complexities between the various parts of the newly established YMHS. More specifically, the study investigated the nature and culture of community-based frontline mental health service provision and mental health help-seeking, as they relate to technology design and implementation. In order to curtail the investigation to a manageable, yet in-depth design, two of the three services which participated in the scoping study focus groups were approached to participate. Involvement consisted of a one-week observation of their site. The specific services were approached because: (1). they were working directly with the age group under investigation more so than the third service which had a mandate to work with children and early adolescents; and (2). they represented different, but interconnected,

tiers of the South Australian YMHS. This design allowed for investigation of organisational and systemic perspectives.

The field study was approached in different ways at the two different services. For instance, in one service, which works with clients aged 16 and above, the primary method of observation involved shadowing one staff member who had a largely youth-specific portfolio. The other service was a youth-specific service and thus observation of a range of staff and their clients was undertaken. At both services observation of client group activities, team and service-related meetings was conducted.

PARTICIPATORY DESIGN WORKSHOPS

Drawing from Sanders' (2002) *say-do-make* framework, the learnings and research outputs generated in the earlier phases of the project were used to inform a series of future workshop-inspired participatory design workshops. These workshops were intended to act as a space in which *"negotiation, shared construction and collective discovery"* (Muller & Druin 2012 p. 15) could occur between mental health professionals and consumers with respect to investigating use of technologies to support mental health help-seeking and provision. In particular, the workshops were used as a method by which: (1) understanding of models and structures of mental health service provision and help-seeking generated in earlier phases of the research could be further developed; and (2) co-creation of future visions and design proposals could take place. In this study, PD-based methods were employed, not to design technologies as in their common application, but instead to investigate the design domain in a manner which goes beyond the type of data which emerges from talk and observation-based methods. Furthermore, the use of participatory workshops in this study served the broader purpose of validating research outputs from earlier phases of the project which were used to inform and conduct the workshops. Participants, both mental health professionals and consumers, from the scoping and field work phases of the research were invited to participate in the workshops. The workshops were conducted in the same South Australian rural region as previous phases of the research. A series of three workshops were designed to work within the busy schedules of the participating mental health professionals. The youth participants, who were originally intended to participate in their own series of workshops, were instead invited to participate in the third and final workshop with the mental health professionals. In line with the pragmatic nature of the research, this decision was made to limit undue burden on participants, given that no actual technologies were developed and in response to a restricted timeframe. Each of these separate but interrelated studies worked to develop key recommendations for the design and implementation of technologies within, and for, face-to-face clinical mental health contexts.

FURTHER NOTES ON THE RESEARCH AND RESULTANT PAPERS

The focus of the research project was on the design and implementation of ESN technologies within government funded mental health services and organisations, as distinct from privately run services comprised of one or multiple mental health professionals. More specifically, it is envisaged that the research will inform the design

and implementation of ESN technologies to increase help-seeking in young people with psychological distress through increased engagement with existing services, principally through greater continuity and empowerment with respect to care. Additionally, given the interdisciplinary nature of the current research, it is acknowledged from the outset that the framing in terms of the respective research disciplines which inform the research including psychology, psychiatry, public health and design are targeted, even potentially narrow, in focus. As an additional consequence, given that the thesis is primarily underpinned by published work in a number of discipline-specific journals, various terms were used interchangeably, specifically clinician/worker/mental health professional/practitioner; mental health consumer/client; young people/youth; technology enhanced or supported/eMental health as dictated by the audience for the journal article. Throughout this thesis technologies have also variously been referred to as products, interventions and devices depending on the context of use. With respect to published papers, journal spelling and numeric conventions were retained.

CHAPTER THREE: TARGETED LITERATURE REVIEW

Given the nature and structure of the research project, which is underpinned by four separate but interrelated studies resulting in six journal articles with their respective literature reviews, a targeted literature review is presented here. The literature review aims to situate the program of research within the wider field of knowledge and will discuss the three broad areas that underpin its focus: (1.) Community-based youth mental health services as a potential *engagement*, *support* and *navigation* technology (ESN technology) implementation context; (2.) The call for greater attention to user perspectives in the design and delivery of mental health services; and (3.) The application of user-focussed, design-based approaches in mental health technology design. This literature review, and the research project more broadly, are positioned within the Australian mental health system.

1: YOUTH MENTAL HEALTH SERVICES AS A TECHNOLOGY IMPLEMENTATION CONTEXT

Mental Health

As defined by the World Health Organisation "mental health is a state of well-being in which an individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (World Health Organisation 2014).

Mental Illness

"A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behavior (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above." (American Psychiatric Association 2013 p.20).

Australian mental health policy context

In 2011 the Australian government commissioned a national review of mental health programs and services, which was conducted by the National Mental Health Commission and released in April 2015 (National Mental Health Commission 2014). The report identified a number of key areas of concern, which included a disproportionate funding focus on acute services, system-wide fragmentation, gaps in services for rural and remote areas which contributed towards a broadly inefficient system that fails to maximise social or economic

outcomes. The Commission recommended a system redesign underpinned by person-centred design principles, in which the system is designed around the needs of its consumers rather than the needs of providers. This user-centred approach was to be achieved through implementation of a stepped care model of service delivery with a range of interconnected care options matched to level of need, integrated and individualised care packages for those with severe or complex needs and more flexible delivery of services for those with mild to moderate needs.

In line with the Commission's recommendations, the Australian government's response, to be rolled out over a three-year period ending in 2019, includes a refocussing of the system such that services will be planned and commissioned at the local level, with a flexible funding model which facilitates a regional approach to mental health services suited to local needs (Department of Health 2015). This service delivery model aims to support innovative approaches to clinical care coordination, particularly for people with severe and complex mental illness, and targeted services for rural and remote areas and vulnerable or at risk populations. The Government's response also included a focus on greater integration of and equity around youth mental health services, along with a renewed commitment to early intervention. With this model providing a framework, the Government aims to develop a flexible, integrated and accessible system, in part, through the optimisation of eMental health resources and implementation of a new Digital Mental Health Gateway which will mediate access to mental health services. To this end, eMental health, and person centred design principles more broadly, are at the forefront of Australian mental health service planning and delivery.

Australian eMental Health Policy context

Computer and internet supported therapies and tools show significant potential to augment existing face-to-face mental health service delivery as their potential for flexibility, anonymity and cheap, mass delivery is significant (Griffiths & Christensen 2007). Australia has been an international leader in eMental health research, development and delivery (Teesson et al. 2014), particularly for the treatment of mild to moderate high prevalence mood and anxiety disorders (Meurk et al. 2016). eMental health can be defined as

> "the delivery of services targeting common mental health problems through online and mobile phone interactive websites, apps, sensor-based monitoring devices and computers. The term also extends to telephone crisis lines and online crisis support services. eMental health services are delivered in real-time through multiple settings, including the home, the workplace, schools, and through clinicians' workplaces. Some services offer fully automated self-help programmes, while others involve guidance from clinicians, crisis workers, teachers, administrators or peers" (Teesson et al. 2014 p.5).

Five separate but interrelated types of eMental health programmes can be outlined, which include: (1.) Health/wellness promotion and psychoeducation; (2.) Prevention and early intervention; (3.) Crisis intervention and suicide prevention; (4.) Treatment; and (5.) Recovery and peer support (Teesson et al. 2014). Currently these components are not integrated with one another or the Australian mental health system. eMental health defined and compartmentalised in this way represents a system perspective of the role of technology in mental

healthcare; the system has therefore decided the ways in which technology can and should assist consumers in their help-seeking and pursuit of good health.

Significant federal investment in eMental health was initiated in 2006, when a number of projects under the Telephone Counselling, Self Help and Web-based Support Programme were funded (Department of Health 2014). Since that time, eMental health initiatives have been piloted by universities, and the non-government and private sectors (Department of Health 2014). Late 2010 saw another major investment of the Australian government ($466.7 million) into eHealth initiatives, the highest profile of which was the personally controlled electronic health records (PCEHR). The federal government promised that using the PCHER, "Australians will be able to check their medical history online…….. which will boost patient safety, improve health care delivery, and cut waste and duplication" (Department of Health 2014).

In 2012 the Australian government rolled out its eMental Health Strategy in an attempt to improve access to mental health services while reducing inherent costs. Treating mental illness is estimated to cost AUD 20 billion (Council of Australian Governments 2006). The eMental health strategy represented a transition from the piloting of a number of small key projects to a national agenda driving the research and development of a legitimate technology-based arm of the current mental health system (Department of Health 2014) . Australia's current eMental health strategy is built around three core components: (1.) An e-Mental Health Portal (mindhealthconnect); (2.) e-Mental Health Training and Support – eMental Health in Practice (eMH Prac); and (3.) A virtual clinic comprised of online and telephone-based mental health assessment and treatment (The MindSpot Clinic). These three strategies aim to provide accessible, acceptable, effective, scalable and efficient mental health services.

The eMental health portal *Mindhealthconnect,* is operated by Heatlthdirect Australia and was launched in July (mindhealthconnect). It combines mental health information and content and promotes links to eMental health services. Its guided search tool supports users to access relevant and industry endorsed support, resources, tools and content. The virtual clinic *Mindspot* provides screening assessments and therapist guided treatment (MindSpot). Assessment is possible over the phone or online, with clients able to self-refer or be referred via a health professional. It was launched by the federal government in mid-2013 and is led by Macquarie University. The virtual clinic offers four online treatment courses; their materials can be accessed online, via email or in hard copy through the post. The treatment courses consist of two Wellbeing courses (for 18-60 years and 60+ years) which help clients improve stress, worry, social anxiety, depression, low mood and panic. The two other programs are specialised treatments for obsessive compulsive and post-traumatic stress disorders. The programs consist of four to six sessions over eight weeks with follow ups at three and six months. To date MindSpot has serviced over 35,000 Australians. Of those who enrolled in a course (2,049 people), over 70% completed it (1,471 people) and experienced symptom reduction of an average of 50%. These improvements were sustained at 3-month follow-up. The treatment programs were primarily used by females aged under 55

years. Although the majority of people who initially sought help were from major Australian cities, those that completed the programs were an even mix of metropolitan and rural residents (Titov et al. 2015).

eMH Prac, the eMental health workforce training and support initiative, was launched by the federal government in mid-2014 and is led by Queensland University of Technology (eMHPrac). Its training and support initiatives aim to embed eMental health in routine service delivery via the training of general practitioners, allied health professionals and those services working with Aboriginal and Torres Strait Islander people. eMH Prac aims to increase literacy and awareness around eMental health, to train and support the mental health workforce in eMental health implementation and uptake, and to establish effective referral pathways into eMental health resources, support and treatment. Beyond these major eMental health initiatives, the federal government's Department of Industry also provided $27.5 million toward the establishment of the Young and Well CRC. The government contribution was supported by an extra $8.3 million in case and over $80 million of in-kind contributions from other partners. The cooperative had a mandate to investigate the role of technology in helping to promote and maintain youth mental health (Young and Well Cooperative Research Centre). Young and Well CRC commenced operations in July 2011 and the funding term ended on June 30th 2016. Collectively these initiatives represent a tangible, significant and ongoing commitment from the Australian federal government to the role of eMental Health in promoting and maintaining the nation's health.

Promoting uptake into routine practice: Training the workforce

Despite the proliferation of eMental health research, exemplified by the emergence of a new Journal of Internet Medical Research (JMIR) affiliate JMIR Mental Health, and fertile national policy positions as outlined above, integration of technologies into routine mental health care has been limited (Blanchard et al. 2012; East & Havard 2015; Mohr et al. 2014; Montague, Varcin & Parker 2014; Reynolds et al. 2015). That said, the rapid development and expansion of eMental as a translational research discipline has ensured that diffusion of technologies and uptake into routine practice is gathering momentum. Initiatives such as the Australian government's eMH Prac have produced emerging clinical models for blended approaches, combining traditional and technology-based approaches to care. These clinical practice models are intended for use in primary mental health care which is traditionally provided by professionals such as general medical practitioners, allied, community and indigenous health professionals, psychologists, primary care and mental health nurses, social workers and peer support workers. The clinical practice models include: health promotion, case management, coaching, and technology integrated into symptom-focussed or comprehensive therapy. Each of these requires greater integration of technologies into, and subsequent changes to, current practice. Greater awareness, knowledge, familiarity and skill with mental health technologies would also be required by workers. Evaluation of effectiveness, safety and efficacy of these clinical models is yet to be determined with each of them at various stages of implementation. Currently only anecdotal evidence is available, except for in the case of the coaching model which is the most researched and shows great promise. The case management model is also well supported and promoted in Australia (Reynolds et al. 2015).

Supports for the workforce are also emerging through tools which assess consumer fit for blended care (Wentzel et al. 2016). Wentzel et al's (2016) instrument assists the professional and consumer to assess the practical necessities, along with possible barriers and facilitators to successful implementation of blended care with a specific consumer. The instrument's design positions the possible use of blended care as a negotiation between the mental health professional and the consumer. It assesses factors such as availability of appropriate eMental health tools, the client's current clinical presentation and level of need, and their access to technology and the appropriate environment in which to use it. Also considered are consumer cognitive and physical capacity, presence of comorbid conditions, relevant psychosocial factors, current therapeutic alliance, level of motivation, and personal preferences around help-seeking style. As such, the instrument highlights the number and complexity of factors a professional must consider when attempting a blended care model of practice, and thus the relative difficulties inherent in transitioning into this way of working.

Furthermore, tertiary education programs are slowly responding to the call to equip future mental health professionals with the clinical and technical skills and competencies necessary for integrated use of technology in their practice. One such example includes training in the use of telepsychology such as videoconferencing facilities, for provision of counselling-based psychological services (McCord et al. 2015; Simpson, Richardson & Pelling 2015). Recent literature has also called for incentivising healthcare providers to integrate technologies into their work (East & Havard 2015; Teesson et al. 2014), along with support from accreditation bodies with respect to standards that reflect the shift toward consumer centred care through technology (East & Havard 2015). International associations have created aspirational guidelines for use of telepsychology but development of training standards has lagged behind.

Crucially, a recent systematic review of use of eMental health for treating depression and anxiety has highlighted the state of the current evidence (Meurk et al. 2016). Whilst good evidence exists for the efficacy of internet-based, self-help Cognitive Behavioural programs (iCBTs) for treating mild to moderate mood and anxiety disorders, there exists a dearth of research and empirical evidence to support the financing, governance and implementation models necessary to facilitate routine uptake of eMental health in existing face-to-face eMental health services (Meurk et al. 2016).

The case for technology in rural Australian: Telehealth as an exemplar

As previously stated, Australia has been an international leader in the use eMental health and development of e-platforms and internet based prevention and early intervention tools (Christensen & Hickie 2010b; Mucic & Hilty 2016). Telemental health, specifically the delivery of mental health treatment and support via videoconferencing facilities remains the best implemented example of the power of technology to augment and expand traditional ways of providing mental health services, particularly to rural and remote populations. Telepsychiatric networks for delivery of psychiatric services via videoconferencing facilities have been rolled out in South Australia, Victoria and New South Wales (Moffatt & Eley 2010). The South Australian Digital Telehealth Network, which

involves the use of digital telehealth, video and telecommunications technologies to provide remote delivery of health services, was initiated by Country Health South Australia Local Health Network. This digital network has now expanded in scope and is comprised of 80 videoconferencing units throughout metropolitan and rural South Australia. It facilitates provision of many specialist services such as burns, cancer, cardiac, rehabilitation and renal. Across 2013-14, the digital telehealth network was used to conduct approximately 10,000 teleconferences and approximately 4,000 clinical consultations (SA Health). Furthermore, since 2008 the Mental Health Emergency Care – Rural Access Program (MHEC-RAP) has allowed provision of specialist emergency mental healthcare to rural and remote residents in western New South Wales via telepsychiatry (Saurman et al. 2014). Digital networks such as these allow timely access to specialists and quality care for consumers, along with decision support and supervision for health professionals, advanced clinical collaboration and ongoing training and education of staff.

Delivery of psychologist-led cognitive behavioural therapy via videoconferencing has proven feasible in public mental health services in rural Australia (Griffiths, Blignault & Yellowlees 2006) and found to be acceptable to both consumers and case managers who supported their clients in accessing the treatment. Overall research has shown that telehealth can lead to improved access to and quality of healthcare for Australians living in rural and remote areas (Moffatt & Eley 2010). Recent research has indicated that 54 telehealth services across metropolitan and rural Australia are in use by a range of health services including medical, surgical, nursing and allied health (Wade, Eliott & Hiller 2014). Wade et al.'s (2014) research has indicated that the key factor necessary for telehealth sustainability is clinician acceptance. Other necessary factors are the workforce's availability to provide this type of service, adequate resourcing and technology to deliver it, and clinician demand for the service. Wade and Eliott's research has also highlighted the critical role for champions in moving the telehealth initiatives from a pilot project status to an ongoing service (Wade & Eliott 2012). These lessons from the telehealth literature highlight the importance of understanding and designing for end users' needs and desires and the human impact on successful uptake and implementation of technology. They also provide a strong rationale for greater utilisation of research methods and service design approaches which privilege end user perspectives.

2. THE CALL FOR GREATER ATTENTION TO USER PERSPECTIVES AND NEEDS IN THE DESIGN AND DELIVERY OF HEALTH SERVICES

Participation in mental health

Participation in mental health can manifest in a number of different ways. It is often thought of as consumers participating at the service and system level as advocates and staff members within service planning and delivery. Treatment engagement in the first place, along with approaches to care that foster shared decision making, are also forms of mental health consumer participation (Lawn 2015). Formal consumer participation in mental health services rose to prominence in Australia in the late 1990s following earlier national reviews of the

mental health system which reflected unfavourably on the delivery of services and the system more broadly (Lammers & Happell 2003; Tobin, Chen & Leathley 2002). Subsequent federal government policy directives outlined in the National Mental Health Strategy and the Second National Mental Health Plan (Australian Health Ministers 1992, 1998; Lammers & Happell 2003; Tobin, Chen & Leathley 2002), brought the consumer participation debate out of the theoretical and into the policy making sphere. Lammers and Happell (2003) situate the trajectory towards more empowered consumers within the wider history of mental health services in Australia. This history progressed through four main stages which involved the establishment of mental asylums, the establishment of early treatment facilities (deinstitutionalisation), through to the expansion of treatment offerings (including drug treatments) and types of consumers able to receive them such as treatment for a wider range of non-psychotic disorders. Greater opportunities for consumer participation represented the beginnings of a major cultural shift in the nature of the service provider-consumer relationship, away from older paternalistic and service-oriented conceptions and towards a growing realisation that mental health consumers, by their lived experience, possess hard won and valid forms of contextualised personal and systemic knowledge and expertise (Lammers & Happell 2003). In the early stages of the consumer participation movement, the academic literature questioned the nature, extent and value of consumer participation in services (Lammers & Happell 2003; Tobin, Chen & Leathley 2002). Sadly, over a decade later similar questions still remain (Lawn 2015).

The delivery of mental health services via technology represents the latest trend toward greater service and treatment choice and thus more empowered consumers. Empowerment, defined as the right and opportunity to make one's own decisions, is often put forward as a major principle which underpins consumer participation in mental health service design and delivery (Salzer 1997). The notion of empowerment is closely linked to consumer self-determination and control, and the upholding of one's personal dignity and integrity in a historical context of disenfranchisement, oppression and powerlessness (McLean 1995; Nelson, Lord & Ochocka 2001a). Empowerment is central to understanding consumer participation in mental health service planning, delivery and research, especially given the ongoing and inherent tension present in this area of healthcare where people are detained against their will and treatment choice is imposed upon them as 'care' (Lawn 2015). In addition to the depersonalising, coercive and medicalised history of mental health service provision, there exists an ongoing battle for opportunities to exert authentic autonomy and decision making power within a context of variable personal capacity, compliance and a culture of psychiatric risk management (Lawn 2015; Nelson, Lord & Ochocka 2001a; Sawyer 2005). Along with the opportunity to exert choice and control, consumer empowerment has also been linked to opportunities to access valued resources along with community integration, which together, facilitate establishment of identity, social roles and participation in community life (Nelson, Lord & Ochocka 2001a).

Youth-based participation in mental health service development and delivery

The development of youth participation in mental health service planning and delivery has progressed more slowly than the adult movement (James 2007). In 1989 the UN convention on the Rights of the Child highlighted

the need for youth participation and a voice in issues that directly affect them (United Nations 1989). The National Mental Health Plan 2003-2008 outlined different approaches to participation for different consumer groups, including age groups. Youth service participation is still a work in progress, however, with few models of youth participation implemented in practice (Coates & Howe 2015; James 2007). Opportunities for youth participation are, however, increasing in recognition of the fact that young people are best placed to know and communicate their health and service needs (Burns & Birrell 2014; James 2007) . A number of youth participation best practice models exist in Australia. They were developed within of a range of government and non-government organisations like *beyondblue* (beyondblue), ReachOut.Com (ReachOut.com 2016), ORYGEN (Orygen Youth Health), headspace (headspace), and previously in South Australia, Headroom. Each of these services promote and create opportunities for meaningful youth participation in different ways. The models generally involve, however, public speaking, development and editing of mental health-related materials and involvement with various committees or in staff hiring. Some models of participation also facilitate various levels of commitment and increasing responsibility, along with the possibility of transitioning volunteers into paid staff members over time. When opportunities are scaffolded which allow young people to participate how and when they feel comfortable, positive outcomes such as skills, knowledge and network building can result (Jacquez, Vaughn & Wagner 2013; Jardine & James 2012). Youth service participation programs often face the not insignificant challenges of negotiation and setting of realistic expectations, representation of diversity and the development of flexible work practices that fit within the wider organisational structure (Coates & Howe 2015; James 2007).

Youth participation in research

With respect to youth participation in research, less progress has been made despite much academic literature focussed on youth (Jacquez, Vaughn & Wagner 2013; Langhout & Thomas 2010). Youth participation in health research projects has most commonly occurred in the context of Community Based Participatory Research (CBPR) which has a rich history of partnering communities of interest in health focussed research projects. This partnership-based approach to research offers practical strategies for generating community of interest buy-in and opportunities for meaningful participation. Despite this, it is often difficult to ascertain levels of involvement, particularly because reporting standards and journal requirements often don't allow for detailed accounts of youth, or any other end user participation. This difficulty is further compounded by a lack of consensus around what constitutes youth participation and author choices around framing particular research projects. Even work self-described as CBPR with youth is widely variable in nature, and in a minority of cases actually involves partnering with youth to conduct research. The inherent complexity and additional ethical layers associated with working alongside youth makes this type of research more difficult, as researchers must account for vulnerabilities, particularly with underage young people and scaffold the process to promote autonomy and competence (Jardine & James 2012). It is encouraging that where youth involvement does occur, it often

includes participation in research planning and designing. Youth perspectives of participation in research remain difficult to ascertain as they are not routinely assessed or reported (Jacquez, Vaughn & Wagner 2013).

Within this context, the Photovoice research method, in which individuals are trained in taking photographs around an issue of interest and then given opportunities to discuss their meaning to encourage learning and change, has proven an effective way to actively involve disenfranchised young people in research projects (Jacquez, Vaughn & Wagner 2013; Jardine & James 2012). In Australia, the Young and Well CRC is at the forefront of creating opportunities for large scale youth participation in research (Zelenko et al. 2012). Facilitating the conditions in which young people are able to make significant and tangible changes to their environment or context remains an ongoing battle, with respect to participation in research and service delivery (Coates & Howe 2015; Vaughan 2014).

Consumer participation in health research

The lack of progress in youth participation in research may be associated with consumer participation in research more generally. A gap exists between researcher knowledge and awareness of the value of consumer participation and actual methodological choices involving consumer participation. Despite a self-confessed keen awareness of the importance of consumer involvement in research particularly for translation of outputs and results, widespread uptake of meaningful consumer participation beyond consultation has not been reported (Brett et al. 2014b; Lawn 2016). The range of benefits of consumer participation at all stages of the research process is clear; these benefits extend beyond added value to the research process as they also involve the researchers and the consumers. Broadly they can be characterised as increased quality and relevance of the research, greater researcher connection with the community of interest, opportunities for consumer empowerment, and greater dissemination and implementation of research outputs (Bath & Wakerman 2015; Lawn 2016; Saunders & Girgis 2010; Williamson 2010). Despite this, barriers to greater consumer participation have included researcher concerns around scientific rigor (including concerns around bias), associated challenges to the power status quo and difficulties sustaining consumer participation (Brett et al. 2014b; Buck et al. 2014; Hewlett et al. 2006; Kenny et al. 2015). A widespread lack of consumer participation in health research provides the backdrop for the historical expert-led approach to intervention design.

3. THE APPLICATION OF USER-FOCUSSED, DESIGN-BASED APPROACHES IN MENTAL HEALTH TECHNOLOGY DESIGN.

Traditional complex intervention design in health

In 2000 the Medical Research Council in the UK published a widely influential framework for the development of complex health interventions (Campbell et al. 2000). This framework advocated for the design of complex health interventions, such as the development of mental health technologies based on a number of sequential phases.

The phases consisted of: preclinical (exploring the role of theory to inform the intervention, hypothesis generation), Phase 1 modelling (identification of the major intervention components and how they interact to effect change), Phase 2 exploratory trial (feasibility studies), Phase 3 randomised controlled trial (to demonstrate efficacy) and Phase 4 long term implementation (effectiveness of the intervention in real world settings) (Campbell et al. 2000).

These early guidelines were criticised for being too closely aligned with the linear process of drug development and were subsequently revised (Craig et al. 2008).The new guidelines attempted to better account for the role of context and human factors in the design and development of complex interventions and provide further guidance on the front end stage of intervention design. They also advocated for end user involvement at all stages of the project cycle, particularly in community-based projects, primarily for methodological purposes such as improved recruitment and retention, along with increased intervention relevance and promotion of implementation (Craig et al. 2008). The shift in mainstream health intervention research towards greater public and consumer participation coincided with wider application of user focussed methods outside of design. While these updates and advancements are welcome, traditional health intervention design and evaluation is still largely focussed on optimising researcher-led processes to prove effects, causation and outcomes (Pagliari 2007).

User focussed design-based methods in health research

The term User Centered (or Human Centered) Design (UCD) (Kelly & Matthews 2014), emerged initially in the 1970s, as a broad term which encompasses a focus on, and the involvement of, the user, historically in the development of technologies. In earlier and more traditional UCD the user is passively studied through techniques such as interviews and observations which then feed into creation of design concepts and ideas. UCD is considered both a philosophy and a broad range of methods (Abras, Maloney-Krichmar & Preece 2004; Moody 2014; Nielsen 1993). A focus on the user, however, is now associated with a range of terms including;

> "Participatory Design (PD), interactive or interaction design, empathetic design, human-centred design (and its sub specialism 'human computer interaction' HCI), usability engineering, high interactivity design, co-design, co-creation, co-operative interaction, co-operative design, participatory action research, people-centred design, user-based design, interactive design, user centric/centred design, user experience design and experience based design" (Bate & Robert 2007).

The myriad of terms highlights the diverse applications of processes which prioritise a focus on the needs and desires of the end user and have increasingly positioned users as experts in understanding their own ways of living and working, rather than as individuals to be studied and designed for (Sanders 2002, 2013).

The currently ubiquitous and probably overused, umbrella term 'co-design' (liberally applied in the US and increasingly so in Australia), describes the idea that designers (as experts) collaborate with non-design professionals (the domain experts) who are usually the recipients of the designed product or artefact. Co-design has been attributed to the early PD movement which co-originated in Scandinavia and the United Kingdom

(Sanders & Stappers 2008). This specialised form of PD, in which system designers and computer scientists combined with employees and their unions to preserve workplace democracy around the introduction of technologies in industrial workplaces, was quickly adopted and repurposed in a range of ways to develop software and products throughout North America (Muller, Wildman & White 1993). Altering what was traditionally thought of as design, social scientists and designers were increasingly collaborating to create products, systems, and services that met the needs of the intended user (Sanders 2002). At the turn of the twenty first century Sanders (2002), a social scientist by trade, was writing about the move from user-centred to PD and applying it across the various domains of design, not just to development software or technologies. By the mid-2000s the broad application of co-design outside of design was evident (Gage & Kolari 2006; Sanders & Stappers 2008).

Co-design as it is practised today takes on all manner of forms, "depending upon the expertise and mindsets of its practitioners" (Sanders & Stappers 2008); it is however, generally characterised as a process in which the end user is supported with tools for ideation in a role as expert by experience. That said, innovation via co-design within and between organisations and their customers, in wider communities and in the design of products and services (be they consumer, industrial or medical in nature) outline some of the many ways in which PD mindsets, methods and techniques are now applied (Sanders 2013). At its core, co-design involves ceding an expert mindset and instead embracing the knowledge, experience and perspectives of consumers; it is underpinned by the belief that all people have the capacity to be creative (Gage & Kolari 2006). Increasingly user studies and experience are viewed as way to be creative and gain a competitive edge, particularly as qualitative leaps forward in technology become increasingly harder to achieve. Furthermore a shift between passive consumption of products and services to more active, experience-based engagement with organisations and companies has pushed the co-design agenda forward (Sanders & Stappers 2008).

Service design as one of the many manifestations of a greater focus on designing for purpose and not products, emerged as a broad discipline around the mid-2000s. It made its way into healthcare (Sanders & Stappers 2008) in the form of experienced-based design (EBD) (Bate & Robert 2006), which had its roots in traditional design (Bate & Robert 2007; Norman 2005, 2013). Referred to as a "quiet revolution in design", experience design was born out of the realisation that designing in and for domains such as the Internet requires sensitivity to an individual's subjective experience and latent needs, as opposed to a more narrow focus on visual appearance (Carton 2001; Norman 2005, 2013). As such, service design in healthcare was directly informed by, and adapted from, experience/interaction design of technologies (Bate & Robert 2007). As previously noted, this trajectory of co-design of health services and adaptation of design methods to health research was foregrounded by greater consumer participation in health, and more specifically mental health described above (see for e.g. Institute for Family-Centred Care (2008)). Healthcare service design involved explicit discussion of the move away from the patient as a passive recipient of care, towards consumers as active and vital participants in shaping, planning and delivery of services. Service design relating to EBD advocated for partnership between patients and healthcare staff in design of care, to unlock tacit and experiential knowledge which can be utilised for effective and responsive service design. Bates and Robert (2007) also characterised the process as expert-led. EBD was

a clear attempt at balancing the traditional focus on process, performance and governance and that of the human experience, with "the desired end result [being] a positive connection and interaction between the person and the service" (Bate & Robert 2007 p. 309). EBD privileged the power of storytelling and use of other traditional UCD techniques to uncover key touch points in which a patient's subjective experience of the service is shaped.

More recently, there have been renewed calls for the application of design methods in health research. In particular, the use of UCD methods, particularly within the field of Human Computer Interaction (HCI) have been seen as a way to increase the acceptance and adoption of health technologies (Poole 2013). To this end, the integration of the heath and design disciplines has recently been referred to as *Health Design* – an emerging and interdisciplinary field of research (Moody 2014; Yoxall & Christer 2013). With respect to mental health technology design – user centred methods have been applied in a rage of ways to develop a diverse range of technologies that are health promoting through to treatment-based in focus. Use of PD in design of metal health technologies (Hagen et al. 2012) and interventions is thus the latest chapter in the story of the intersection between health and design, and a desire to both access the needs of the user and also empower them. Hagen et al's (2012) guide to PD of online youth mental health and wellbeing interventions adopts similar phases to traditional design of complex interventions but values additional types of evidence in uncovering the necessary answers at each stage. This intervention design approach derives research questions from the population of interest, as well as with from epidemiological data, professional experts or current policy. The framework also utilises qualitative, interactive and inclusive methods to define, position, conceptualise and create interventions. The similarities and differences between traditional and user-centred intervention design, and integration of the two, is outlined by Hagen et al. (2012) and reproduced below in Figure 1.

IDENTIFY

Top questions: What do young people see as a problem?

Methods: Focus Groups, Interviews, Discussion Groups, FB Polling

Blue methods: Epidemiological data analysis; Consultation with services and experts; National, state and local policies & strategies

Blue questions: What is the problem? How does the burden of the problem compare to other health priorities? Who and how many young people are affected? What are the likely future trends if no action is taken?

DEFINE

Top questions: How do young people relate to the issue? How does the issue manifest in young people's everyday lives?

Methods: Surveys, Mobile Diaries, Focus Groups, Codesign Workshops (Discovery), Interviews, Discussions

Blue methods: Further epidemiological data analysis; Literature reviews; Social, market and environmental assessment

Blue questions: What are the key determinants and factors contributing to the problem? How modifiable are these factors? What else is being done? Should a population, community or individual approach be taken?

POSITION

Top questions: What defines a successful outcome from the perspective of young people? How does this problem or topic need to be framed or communicated in order to be meaningful or relevant young people?

Methods: Focus Groups, Crowdsourcing, Brand Testing

Blue methods: Review evaluations of previous interventions; Assess potential tools and strategies; Apply behavioural theories

Blue questions: Which tools and strategies can make the most impact on the contributing factors? What are the expected health outcomes and impacts and amongst who? What behavioural theories are most relevant? What has / has not worked well in the past?

CONCEPT

Top questions: What does it need to do in order for young people to be motivated to use it? What do young people see as the benefits of using/doing this?

Methods: Codesign Workshops (Design), Brand Testing

Blue methods: Concept testing, stakeholder mapping & consultation; Build logic models; Develop evaluation framework

Blue questions: How do the proposed strategies relate to the impacts & health outcomes? What type of evaluation is needed and who will use the findings? What questions should be asked? Which process, impact and outcome indicators?

CREATE

Top questions: Do young people want to use it? Can they use it? How should it / could it be improved?

Methods: Codesign Workshops (Prototyping), Mobile Diaries, Usability Testing, Pilot/Beta Testing, Card Sorting

Blue methods: Pre-experimental, experimental, mixed methods designs; Develop protocols, build & test data collection tools

Blue questions: What study design(s) and data collection and analysis methods are most suitable? Are the evaluation tools valid and reliable? What are the ethical considerations and risks? How do we ensure safety during implementation?

USE

Top questions: What is the impact or outcome for young people? Is the outcome successful from the perspective of young people?

Methods: Alpha/Beta Testing, Pilots, Surveys, Focus Groups, Mobile Diaries, Interviews, Usability Testing

Blue methods: Monitor and evaluate process, impact & outcome indicators: Analytics, Surveys, Interviews, Focus Groups

Blue questions: Was the intervention implemented as planned? Who participated and what was their experience like? Were the desired impacts and health outcomes achieved? Any unexpected results? Was it more effective for some groups of young people than others?

Between-stage labels: PERSONAS, PROPOSITION, DESIGN GUIDELINES, USER JOURNEYS, MOCKUPS, SCENARIOS, USER GOALS, PROTOTYPES, LIVE

Figure 1 Framework for integrating Participatory Design with traditional intervention design

Interdisciplinary considerations

As alluded to above, the design of effective, useful and usable technologies requires extensive interdisciplinary collaboration. The broad field of eHealth has many stakeholders, disciplinary contributors, objectives and a range of technical applications foci (Pagliari 2007). For the sake of brevity and simplicity, two different major disciplinary contributors can be identified, each with their own individual foci. On the one hand, software developers, despite a wide range of discipline-specific influencers, have had a traditional focus on product development and fitness for purpose. On the other hand, health services researchers who themselves hail from a diverse collection of sub-fields, are focussed on the scientific endeavour of hypothesis generation, proving impact and informing policy (Pagliari 2007). These differences have consequences for the way in which a researcher approaches project scoping, sampling, data collection and analysis. Natural tensions exist between an innovation mindset and one more oriented toward perceived methodological rigor. This culture clash manifests in a number of different ways (Pagliari 2007). For example, ongoing debate exists around HCI's contribution to health and wellbeing technologies (Smith et al. 2014). Smith et al. (2014) favour an unbounded view of HCI contribution, a perspective which supports HCI consideration of the distal effects or outcomes of technologies along with more HCI-specific strategies such as interaction and patterns of use. Others argue for a more restricted HCI focus (Brynjarsdottir et al. 2012; Siek et al. 2014). This debate speaks to the difficulties in merging the historically separate research fields in the pursuit of translational and effective technologies. Discussion above around which research goals are privileged, by whom, and at which stage of the development process has implications for the types of collaborations and outputs possible. Doherty, Coyle and Matthews (2010) have advocated for the

development of project goals which meet the need of both technical discipline aspects like usability, user experience, and those of the health disciplines like the impact of therapeutic outcomes. These in turn can assist with establishing holistic design rationales and measures of success (Doherty, Coyle & Matthews 2010).

Moreover, significant language barriers between contributing stakeholders and disciplines can result in misunderstandings throughout projects (Egbert & Matthews 2012; Gammon, Strand & Eng 2014). Different standards for reporting have made it difficult to jointly evaluate research regarding specific interventions arising out of the different disciplines. Related to this is the issue of method of dissemination, in which the time-intensive nature of publishing in peer reviewed journals in health gives way to the peer reviewed conference paper in design and engineering disciplines (Poole 2013). More broadly, expectations around appropriate timelines regarding development and evaluation can differ markedly (Egbert & Matthews 2012; Pagliari 2007). Associated with this are the types of projects that are likely to be funded within each discipline and what counts as evidence and methodological rigor, for example health projects that have a focus on controlled studies are more likely to get funded (Pagliari 2007). Further still, the degree of knowledge each discipline needs to have about the other in order to foster effective collaboration remains an open question (Egbert & Matthews 2012). Despite these differences, parallels have been drawn with iterative nature of software lifecycle models and development of complex health interventions, and between methods-based similarities, for example qualitative, talk and field-based methods and broadly convergent rationales for their use (Pagliari 2007).

Application of Participatory Design-based methods in mental health: Rationale and Opportunities

In the context of increased participation of consumers in the design and evaluation of mental health services, PD has been advocated for particularly in the design of youth mental health technologies (Hagen et al. 2012). The term PD has been used to refer to a range of participatory processes in the design of technologies for a mental health context. For example, in some cases the intervention or product ideas are generated by the researchers alone; end users are then engaged in field testing and consulting throughout a collaborative and iterative design process (Hodge et al. 2015; Matthews & Doherty 2011). In other cases, the end users are seminally involved in project and intervention design right from the outset (Gammon, Strand & Eng 2014; Gordon et al. 2016; Wadley et al. 2013).

The use of technology as an adjunct to face-to-face treatment for mental health problems is a growing research area (Montague, Varcin & Parker 2014). Design processes which aim to actively involve mental health consumers present a range of ethical and practical challenges however (Coyle et al. 2007; Matthews et al. 2015). Ethical considerations involve conducting research in what might be considered extreme contexts such as forensic correctional and inpatient mental health facilities, and with extremely vulnerable populations such as active mental health consumers and young people. As such, developing strong working relationships with mental health professionals is an important way in which researchers are able to operationalise reflexive research protocols that are sensitive to collaborating with mental health consumers (Thieme et al. 2014). Negotiating

informed consent is also more difficult and requires an appreciation of the cognitive impairments that can be associated with mental-ill health (Thieme et al. 2014). In some contexts, the physical safety of the researcher and the participants has also been an important consideration (Hodge et al. 2015; Thieme et al. 2014). Consequently, appropriately preparing for and undertaking this type of research can be time intensive (Thieme et al. 2014).

These collaborative design practices and research processes have, however, facilitated design with the most vulnerable and difficult to access and engage mental health populations (Frost & Houben 2014; Gordon et al. 2016; Hodge et al. 2015; Thieme et al. 2014; Wadley et al. 2013). Projects have included design of: self-management systems for assisting in bipolar treatment (Frost & Houben 2014; Matthews et al. 2015), interactive artefacts for women situated in an inpatient facility with a joint diagnosis of Borderline Personality Disorder and a learning disorder (Thieme et al. 2014), a range of eMental health tools for women from vulnerable populations who are susceptible to perinatal depression (Gordon et al. 2016) and a game to support rehabilitation and facilitation of discharge of mental health services users who have been detained in forensic correctional facilities (Hodge et al. 2015).

Examples of youth-focussed tools include an electronic psychosocial assessment tool for use in community-based mental health services (Bradford & Rickwood 2015), a screening tool for use in general practice settings (Webb et al. 2015), apps for addressing alcohol misuse and mood management online treatment for psychosis (Wadley et al. 2013), a mood diary (Matthews & Doherty 2011), and a university virtual clinic (Zelenko et al. 2012). Taken together, this body of literature suggests that despite concerns around access to consumers and settings (Coyle et al. 2007), active and meaningful mental health consumer participation in technology design is possible.

The above mentioned body of work has revealed significant workforce apprehension around use of technologies in the context of face-to-face mental health service provision. Commonly reported concerns include adverse impacts on help seeking such as potential disengagement from face-to-face treatment and damage to therapeutic rapport (Wadley et al. 2013). Mental health professionals have also raised concerns around increases to workload, difficulties assessing risk, access to appropriate training and threats to their own personal privacy (Frost & Houben 2014; Matthews & Doherty 2011; Wadley et al. 2013). Availability of appropriate resourcing for consumers along with the appropriateness of certain technologies for specific diagnoses have also been raised as potential barriers (Wadley et al. 2013). Furthermore, consumers themselves have expressed concerns around use of technologies to support their face-to-face help seeking. For example, threats to personal privacy, unintended consequences of particular technological components/functions at various stages of illness, and the potential for various types of feedback to reinforce or highlight lack of progress with respect to treatment goals and overall health (Frost & Houben 2014; Matthews & Doherty 2011; Wadley et al. 2013; Webb et al. 2015).

The above workforce and consumer concerns provide a strong rationale for obtaining contextually and ecologically valid data to support the front end design process (Doherty, Coyle & Matthews 2010; Frost & Houben 2014; Hodge et al. 2015; Løventoft, Nørregaard & Frøkjær 2012; Matthews & Doherty 2011; Matthews et al. 2015; Wadley et al. 2013). In the past, methods such as focus groups and role plays have been used to gain feedback. Workshops have been used to great effect in defining project scope and the types of interventions that may be useful in a particular context. In some cases, a small number of workshops are conducted over a short period of time (Hodge et al. 2015; Wadley et al. 2013; Webb et al. 2015) and in others many workshops are carried out over an extended period (Gordon et al. 2016). Matthews et al. (2015) described their recent approach as in situ design where a priori design ideas were put into the field to be tested and iteratively developed over time. This process recognises the complexity embedded in the lived experience of mental illness and the consequences for design of mental health technologies, which include variations in wellness over time and associated unforeseen safety risks and consequences of the technology (Wadley et al. 2013).

This brief review of participatory mental health technology projects highlights the traditional manner in which PD has been used to inform product design. As will become apparent throughout this thesis, PD methods will be used not to design products, but instead to investigate domain specific criteria required to implement technology as an agent of change within the traditional mental health system. In summary, both the methodological and content focus of the current research challenge existing power structures in healthcare and in research. The research challenges the role of mental healthcare professionals as experts in the delivery of health services, along with the role of the traditional mental health system more broadly. It also questions the role of researcher as expert in knowledge generation, by investigating what counts as knowledge and whose knowledge is valued. It does so with the aim of better understanding the role of technologies within rural, community-based youth mental health services.

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CHAPTER FOUR PREAMBLE

Chapter Four consists of two papers: *Participatory research as one piece of the puzzle: A systematic review of consumer involvement in design of technology-based youth mental health and well-being interventions* and *Mental health technologies: Designing with consumers.* The first paper presented in this chapter is a systematic review of research that has applied participatory methodologies to the development of technology-based youth mental health and wellbeing interventions. It addresses a significant gap in the literature as, to the author's knowledge, it is the first review of its kind pertaining to this subject. The second is a viewpoint paper that was informed by the review and underpinned by two case studies.

The systematic review was inspired by increasing interest in the application of participatory and human-centred design-based methods to the design and development of mental health and wellbeing technologies (Hagen et al. 2012; Poole 2013). It is thought that these approaches may provide greater insight into the human factors that are often associated with lack of engagement with, and successful implementation of, technologies in health contexts (Gagnon et al. 2012). In particular, youth-focussed technologies are seen to hold significant and unrealised potential to engage a population of consumers disengaged with traditional mental health services but most in need of them (Ivancic et al. 2014; Kessler et al. 2007; McGorry et al. 2011).

In contrast to traditional, expert-led design of complex interventions, participatory research positions the community of interest (or the intervention end users) as key contributors to the research process owing to their lived experience and tacit knowledge of the research phenomena (Ehn 1988, 1993; Liamputtong 2012; Wallerstein & Duran 2008). Reviews of health-focussed participatory research have revealed a range of benefits which include a research process that asks more user-focussed questions, collects better quality data and produces research outputs that are more valued and efficacious (Bath & Wakerman 2015; Brett et al. 2014b; Saunders & Girgis 2010; Williamson 2010). Participatory research in health (e.g. Community Based Participatory Research, CBPR) and design (e.g. Participatory Design, PD) has largely been rationalised through an empowerment lens which situates the research process as the vehicle by which non-dominant groups are supported to effectively have a voice in issues that directly affect them (Ehn 1988, 1993; Liamputtong 2012; Wallerstein & Duran 2008). By contrast, use of participatory research methods to create youth mental health technologies is under researched; it is not known whether or precisely how these methods might lead to better outcomes than expert-led design approaches. Furthermore, the motivation which underpins these research projects has not been systematically investigated.

Given the exploratory nature of the review, a multidimensional framework was developed for the analysis. The framework adopted processes outlined by Lorenc et al. (2008); Oliver et al. (2008) wherein immersion in the literature was important for developing the criteria to populate the final analytic instrument. Background information such as the research context, methodology employed, type of intervention and intended user group

were extracted. From the outset, the review was particularly focussed on gaining an in-depth insight into the nature of youth participation in order to better understand how participatory processes have been adapted and interpreted for mental health technology design. Therefore, the framework was heavily skewed toward the inclusion of consumer involvement and participatory process constructs. A simplified version (Blackstock, Kelly & Horsey 2007; Cornwall & Jewkes 1995) of Arnstein's ladder of citizen participation (Arnstein 1969) was utilised to evaluate the nature of consumer involvement (levels of involvement included: *contractual, consultative, collaborative and collegiate*). The framework also utilised multiple concepts from the Blackstock, Kelly and Horsey (2007) framework developed to evaluate participatory research in sustainability (e.g. representation, development of shared vision and goals, influence on the process, transparency and quality of decision making, capacity building and learning for participants, and accountability and legitimacy of the process and outcomes).

The investigation also examined the nature and outcomes of the research process, including the theoretical underpinnings of the research (i.e. did the research utilise any specific theoretical frameworks to inform the intervention content and/or the technical design?) and whether there was any relationship between the participatory research project and the overall efficacy of the intervention. Finally, the review also explored the relationship between participatory design processes and implementation of the outputs. That is specifically, the review was particularly interested in the translational power of participatory research in the design of youth mental health and wellbeing interventions.

The second paper presented in this chapter embodies a continuation of the discussion around the potential contribution of design-based methods to the development of technology-based mental health and wellbeing interventions. In conducting the systematic review, the borrowing and attempted integration of design-based methods in health research was found to be an emerging area of research and anticipative source of innovation, with PD (Ehn 1993; Hagen et al. 2012) and Design Thinking (DT; Brown 2009; Brown 2013; Schmidt 2009) being the foremost design methods in this developing trend. A gap in the literature with respect to articulating and rationalising this design-based trend in health research was, however, evident. With this in mind, similarities and differences in mindset, process, outcome and emphasis of PD and DT were explored via two case studies to assess the applicability of these methods to mental health technology design. This viewpoint paper was particularly written for researchers from applied health disciplines unfamiliar with participatory and design approaches who may be looking for guidance as to how, why or whether particular design-based research methods and techniques may be of benefit to their research. It was intended that the paper might encourage careful reflection on mindset informing choice of methods, subsequent consequences for key stakeholders (particularly the research participants) and consideration of how the methods align with the philosophical underpinnings and overall aims of the work.

CHAPTER FOUR: PAPER ONE - PUBLISHED

Participatory research as one piece of the puzzle: A systematic review of consumer involvement in design of technology-based youth mental health and well-being interventions

Authorship Declaration: SO conceived and designed the study, carried out data collection, analysed and interpreted the data, and drafted the manuscript. NB, SL, AV contributed to the design of the study, analysis and interpretation of the data, as well as the drafting of the manuscript. RD designed the systematic search strategy and contributed to the drafting of the manuscript. KW, MW, GA, GJ, PC, DS, GS contributed to the analysis and interpretation of the data, as well as the drafting of the manuscript. All authors read and approved the final manuscript. All authors give permission for the paper to be included in this thesis.
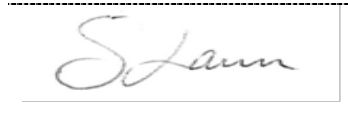
Simone Orlowski		Raechel Damarell	
Sharon Lawn		Gaston Antezana	
Anthony Venning		Geoffrey Schrader	
Megan Winsall		David Smith	
Gabrielle Jones		Philippa Collin	
Kaisha Wyld		Niranjan Bidargaddi	
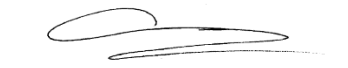
ABSTRACT

Background: Despite the potential of technology-based mental health interventions for young people, limited uptake and/or adherence is a significant challenge. It is thought that involving young people in the development and delivery of services designed for them leads to better engagement. Further research is required to understand the role of participatory approaches in design of technology-based mental health and well-being interventions for youth.

Objective: To investigate consumer involvement processes and associated outcomes from studies using participatory methods in development of technology-based mental health and well-being interventions for youth.

Methods: Fifteen electronic databases, using both resource-specific subject headings and text words, were searched describing 2 broad concepts-participatory research and mental health/illness. Grey literature was accessed via Google Advanced search, and relevant conference Web sites and reference lists were also searched. A first screening of titles/abstracts eliminated irrelevant citations and documents. The remaining citations were screened by a second reviewer. Full text articles were double screened. All projects employing participatory research processes in development and/or design of (ICT/digital) technology-based youth mental health and well-being interventions were included. No date restrictions were applied; English language only. Data on consumer involvement, research and design process, and outcomes were extracted via framework analysis.

Results: A total of 6210 studies were reviewed, 38 full articles retrieved, and 17 included in this study. It was found that consumer participation was predominantly consultative and consumerist in nature and involved design specification and intervention development, and usability/pilot testing. Sustainable participation was difficult to achieve. Projects reported clear dichotomies around designer/researcher and consumer assumptions of effective and acceptable interventions. It was not possible to determine the impact of participatory research on intervention effectiveness due to lack of outcome data. Planning for or having pre-existing implementation sites assisted implementation. The review also revealed a lack of theory-based design and process evaluation.

Conclusions: Consumer consultations helped shape intervention design. However, with little evidence of outcomes and a lack of implementation following piloting, the value of participatory research remains unclear.

INTRODUCTION

Technology and Youth Mental Health

More than a quarter of young Australians aged 16-24 years old will experience a mental illness in a 12-month period, with anxiety, substance abuse, and mood disorders the most common (Slade et al. 2009). Alarmingly, 3 quarters of first episode mental illness occurs before the age of 25 years (Kessler et al. 2007), and it has been reported that only 30% of these younger people are accessing the professional help that would benefit them (Burns et al. 2010; Slade et al. 2009). With that in mind, technology-based mental health resources and interventions, part of Australia's e-mental health strategy (Department of Health 2014), may offer an opportunity to engage the other 70%. The potential of technology, therefore, to increase youth engagement with formal mental health services, particularly in rural and remote contexts where service options can be limited, is yet to be fully realized.

Technology-based mental health care interventions are often cited as methods for providing greater access to and engagement with services (Clemensen et al. 2007; Coyle & Doherty 2009; Coyle et al. 2007). A recent review, however, identified only 2 studies that investigated the use of technology to increase engagement with clinical youth mental health services, and a further 3 explored the role of technology as an adjunct to face-to-face therapy (Montague, Varcin & Parker 2014). This review detailed promising results and possibilities for the role of technology in creating and augmenting developmentally appropriate and responsive youth mental health services. However, the research included lacked rigor and the dearth of studies highlight the need for more research and development in the field that is guided by an evidence base (Montague, Varcin & Parker 2014).

Technology-based health interventions commonly suffer from limited uptake and/or adherence (Christensen, Griffiths & Farrer 2009; Christensen & Mackinnon 2006; Eysenbach 2005; Kelders et al. 2012; Mohr, Cuijpers & Lehman 2011), which may be dependent on methodological issues such as design, particularly how human factors are incorporated (Christensen & Mackinnon 2006; Coyle et al. 2007; Mohr, Cuijpers & Lehman 2011). For example, failing to obtain an in-depth insight into intended consumer behavior and their environments, which is crucial for good design (Institute of Design 2014). Guidelines for technology-based mental health design increasingly emphasize the need for formal incorporation of consumer participation into intervention design (Coyle et al. 2007; Doherty, Coyle & Matthews 2010; Hagen et al. 2012; Mohr et al. 2013). Therefore, engaging young people and their support communities at all stages of development is likely to be crucial in enhancing uptake and adherence of technology-based interventions, particularly those from rural, remote, and disadvantaged communities (Anderson & Lowen 2010a; Howe et al. 2014).

Participatory Research

There is a rich history of participatory research with children and young people in the social sciences (Boeck & Collin 2012; Chen, Poland & Skinner 2007; Ollner 2010; Powers & Tiffany 2006). Participatory research is

conducted in partnership *with* the individuals or community of interest and not *on* them, and in this way differs from traditional research. It purports to increase research relevance and usability through improved context appreciation. Other reported benefits of participatory research include greater stakeholder buy-in and improved efficacy and sustainability of research products (or outcomes) (Allen et al. 2011; Chambers, Pringle & Juliano-Bult 2012; Cornwall & Jewkes 1995; Gibbs et al. 2008). When considering the reported average 17-year gap between publication and translation of findings in health care, it is not surprising that participatory methodologies have gained prominence in the field over the last 20 years (Alegría et al. 2011; Clemensen et al. 2007; Cornwall & Jewkes 1995; Szebeko & Tan 2010).

Within mental health design research, common participatory methodologies include community-based participatory research (CBPR), participatory action research (PAR), participatory design (PD), and user-centered design (UCD). PAR aims to develop an egalitarian partnership with a chosen community or group to generate positive, self-identified individual-, group-, and community-level change. While the research goals and associated theories of change may vary, PAR and CBPR are different terms for 1 research methodology underpinned by the same core principles. As such, the terms are used interchangeably in the literature depending on the country of origin (Liamputtong 2012; Wallerstein & Duran 2008). PD—borne out of British, North American, and Scandinavian traditions—employs iterative design cycles in which knowledge production and research output(s) are shared by researchers and end-users (Muller, Wildman & White 1993). Unlike PD, UCD is controlled by the design and research professionals, and participation takes on a strictly consultative role; the project is led, and decisions are made, by "experts" (Sanders & Stappers 2008). At the other end of the participatory continuum sits consumer-led research (i.e., research initiated and/or controlled by consumers), which has recently taken on new life in the context of social media.

Most research has focused on consumer participation in service delivery, with the literature around participation in intervention design via research projects still developing (Owens et al. 2011). It is also less common for the intervention development process to be reported (Owens et al. 2011). Boote, Telford, and Cooper (2002) argue that consumer involvement in research can be rationalized in 2 ways: (1) empowerment—defined as consumer involvement linked to greater autonomy in decision-making for disempowered/marginalized groups; and (2) consumerism—defined as consumer involvement linked to creating outcomes (e.g., products, services or interventions) that generate satisfaction and value-for-money, with consumer input directed at improving efficiency, economy, and effectiveness. Each has different implications for the chosen methodology and role of the consumer.

The Current Review

Given the potential for technology to increase engagement with mental health services, the current review explored the question: "How have participatory methodologies been employed to develop technology-based youth mental health and well-being interventions?"

Youth participation in the development and delivery of mental health services designed to benefit them has received attention and resourcing for some time (James 2007). On- and offline service-wide youth participation models are well documented and demonstrate a recognition that young people are best placed to judge what works for them given their developmental-specific experience of mental illness (James 2007). Online services such as Eheadspace (2015), beyondblue (2016), and ReachOut.com (2015) provide examples of youth participation best practice. This review, however, focuses on participatory development of technology-based interventions by research groups, which may include collaboration with services or other health organizations, as compared to youth participation in an existing service. Project teams involved in production and design of technology-based mental health interventions are interdisciplinary and diverse, and their outputs and findings are distributed across multiple channels and fields depending on the discipline focus of the authors. These factors make a review of this kind a complex undertaking. This review has chosen to focus on work titled, indexed, and stored in databases with a mental health focus and, as such, will not have accessed the body of literature that exists in humanities and social sciences databases (particularly around child, youth and consumer rights and youth participation) that are reflective of multiple stakeholder contributions.

Projects that involved consumers in the design and development of interventions spanning the breadth of the mental health intervention spectrum were included to maximize learning opportunities and to gain a broad understanding of participatory processes in this emerging field of research. The aim was to synthesize previous literature and make practical recommendations for mental health technology designers who wish to employ participatory research methods in a youth context. The major concepts under investigation were: (1) the nature of consumer involvement and the participatory process in intervention development; (2) the nature and outcomes of the design process; and (3) the relationship between participatory research and the implementation of research.

By "technology-based" we refer to information and communications technology-based (ICT-based) digital interventions such as health promotion/prevention Web sites, community-focused health promotion/prevention technologies, treatment-focused Web sites/programs/therapies, and other mental health apps, games, and products. The interventions may act as standalone entities or as an adjunct to existing face-to-face treatment or programs. For inclusion in this review, developers need to have adequately defined and documented (ie, via a project report, journal article, conference paper, or thesis) a participatory development/design project.

METHODS

Search Strategy

A systematic search strategy was used to identify published and unpublished studies that described participatory research mental health projects. Database search strategies employed both resource-specific subject headings (where available) and keywords describing 2 broad concepts—participatory research and mental health/illness (the emphasis on illness terms reflected the focus on treatment-focused interventions). Keywords were often combined using proximity operators in order to increase search sensitivity (generated by SO, RD, SL, and NB).

Comprehensive literature searches were undertaken in the following 15 databases: OvidSP Medline (1946-), PubMed, PsycINFO (1806-), CINAHL, Scopus, Web of Science, Informit (health, social sciences, and science and engineering subsets), arXiv.org, ACM Digital Library, and IEEE Xplore Digital Library. Database searches were limited to studies published in English. The time period for searches was database inception to June 2014. Full search strategies for the OvidSP Medline and PsycINFO databases are provided as Appendix A.

To identify unpublished studies, 3 simplified versions of the search strategy were used in the Google Advanced search engine and results were restricted to PDF documents. Only the first 100 results for each search variant were reviewed for relevance (ie, total n = 300). Web sites of relevant conferences were also checked for additional unpublished papers, including: Participatory Design Conference; Special Interest Group on Computer-Human Interaction; and the Computer-Human Interaction Special Interest Group of the Human Factors and Ergonomics Society of Australia. Reference lists of relevant citations were checked and email contact was made with authors to source additional relevant documentation and current information on the intervention. All searches were conducted in June 2014. EndNote X6 (Thomson Reuters) was used to manage all database citations. A first screening of titles/abstracts by a research assistant (MW) eliminated clearly irrelevant citations/documents based on research method and age group. The remaining citations were screened by a second reviewer (SO). Full text articles were sourced when a decision on relevance could not be made by title or abstract alone.

Inclusion and Exclusion Criteria

All research papers that involved projects judged as having a primary focus on youth mental health and well-being were included in the review, irrespective of whether the mental health focus was related to an existing physical condition. This decision ensured that learnings from the development of interventions spanning the breadth of the health intervention spectrum would inform development of treatment-focused interventions. Specific criteria are outlined below.

Inclusion criteria:

- Mental health or well-being focus (defined in consultation with a multidisciplinary team comprised of clinical mental health, technology and consumer perspectives, and informed by the DSM-V definition of mental disorder) (American Psychiatric Association 2000)
- English language
- Development and/or design of ICT- or digital technology-based intervention
- Youth-based intervention (or include a youth element)
- Inclusion of participatory research processes or elements thereof

Exclusion criteria:

- Commentaries, opinion pieces, or editorials

- Photovoice studies (judged as a distinct research methodology that does not involve design or development of a technology-based intervention).

Data Collection and Analyses

A multidimensional framework analysis, adapted from research conducted by Oliver et al. (2008) and Lorenc et al. (2008), was employed to categorize research. This involved an iterative approach of familiarization with the literature and gradual development of the conceptual framework based on the broad research question. Concepts were drawn from the literature around participatory research and technology-based health intervention design. The outcome criteria were populated by criteria drawn from previous participatory research evaluation and the information needs of the study (Biggs 1989; Blackstock, Kelly & Horsey 2007; Boote, Telford & Cooper 2002; Cornwall & Jewkes 1995). Due to the exploratory nature of the review, all levels of evidence were considered. Refer to Textbox 1 for definitions of concepts used and their relationship to the areas of investigation. Each study was evaluated by 2 members of the research team using the definitions in Textbox 1. Discrepancies were discussed and consensus reached. A third member of the team was consulted if required.

Textbox 1.

Framework analysis.

- Background Information
- Participatory methodology—which participatory methodology underpins the research?
- Project context—who developed the project? Who carried it out? Who funded it?
- Nature of intervention and intended consumers—description of intervention and intended end users.

Nature of Consumer Involvement and the Participatory Process

- Rationale for consumer involvement—empowerment (greater autonomy in decision making for disempowered/marginalized groups) or consumerism (satisfaction and value-for-money, consumer used to improve efficiency, economy and effectiveness) (Boote, Telford & Cooper 2002).
- Mode of consumer participation—*contractual* (people are contracted into the projects of researchers to take part in enquiries or experiments), *consultative* (people are asked for their opinions and consulted by researchers before interventions are made), *collaborative* (researchers and local people work together on projects designed, initiated and managed by researchers), *collegiate* (researchers and local people work together as colleagues with different skills to offer, in a process of mutual learning where people have control) (Biggs 1989). Taken from agricultural research, Bigg's (1989) modes of participation simplify Arnstein's ladder of citizen participation (Arnstein 1969) and were reproduced in Cornwall and Jewkes' paper on participatory research (Cornwall & Jewkes 1995).
- Representation (of intended users)—referring to spread of representation from affected interests; including how legitimate the representation was seen to be; the diversity of views not just representatives (Blackstock, Kelly & Horsey 2007).
- Develop a shared vision and goals—who developed the vision and goals for the project? Did end users have a chance to shape the project in any meaningful way? (Blackstock, Kelly & Horsey 2007).
- Influence on process (opportunities and quality of involvement)—how and where participants participated in the project (ie, at which stages of the process and in what ways) (Blackstock, Kelly & Horsey 2007).
- Transparency and quality of decision-making—referring to both internal whereby participants understand how decisions are made; and external; whereby observers

can audit the process. Can you determine how and why decisions were made in the project? (Blackstock, Kelly & Horsey 2007).

- Capacity building and learning for participants—have the participants developed relationships, skills and learning that enable them to take part in future processes or projects? (Blackstock, Kelly & Horsey 2007).
- Accountability and Legitimacy—referring to whether the representative's core constituencies are satisfied, including expectations. Referring to the outcomes and process are accepted as authoritative and valid (ie, was there any information regarding participant/stakeholder views on participating in the research the research or on the outcome) (Blackstock, Kelly & Horsey 2007).

Nature and Outcomes of the Design Process

- Theories used to support intervention design—did the author(s) report any specific theories that help guide the intervention development or design?
- Intervention (efficacy)—is there any published work on the efficacy of the intervention?
- Emergent knowledge—referring to the outcome of local knowledge (ie, from end users) on outcome of the research (Blackstock, Kelly & Horsey 2007).
- Challenges/limitations plus what worked—limitations and strengths of the process

Relationship Between Participatory Research and Implementation

- Champion/leadership—referring to both the internal leadership for the project and champions for the project (Blackstock, Kelly & Horsey 2007).
- Implementation—was the intended implementation site(s) indicated? Was it integrated into the project?
- Fate of the intervention—was the intervention implemented in practice? (If not, what stage did the project/intervention reach?)

RESULTS

Study Selection

In total, 14,021 citations and Web documents were identified through database searches and open Web searching. Once duplicate citations were removed, 6210 items remained for preliminary assessment of relevance. After title, abstract, and full paper screening, 17 studies were chosen for inclusion in this systematic review (Figure 2 and Table 1). Of these, 1 study reached proposal stage (Carroll et al. 2010), and 1 was designed but not developed (Ekberg et al. 2013).

Table 1.

The 17 projects included in the literature review.

Project authors (publication year)	Participatory methodology	Project context	Nature of intervention and intended consumers	Fate of intervention
Carroll, Burge, Robertson, and Rosson (2010)	PAR	Proposed intervention design developed by researchers at Pennsylvania State University.	Preventive Intervention: an on- and offline community network health intervention for university students and families with children with autism.	Not designed or developed (project reached proposal stage).
Coyle and Doherty (2009)	UCD/ collaborative design	Project driven by human computer interaction researchers at Trinity College, Dublin.	Treatment Intervention: 3D computer game (Personal Investigator) to support therapists working with adolescents in public clinical mental health services.	Personal Investigator has undergone initial clinical evaluation over 6 months at multiple sites (n=8 mental health clinicians; and n=22 youth, aged 10-16, gender not reported). Indicated that more formal evaluations of the game were under way, no further information beyond time of publication.
Ekberg, Timpka, and	CPBR with PD process for	Collaboration between university- and government service-based researchers in	Preventive Intervention: Online health-promoting community (OHPC)	Email correspondence with first author indicated a pilot of the OHPC was carried out; however, no

Angbratt, et al. (2013)	intervention design	Sweden. Grant funded by the Research Council for South-East Sweden.	aimed at addressing factors that prevent obesity, including mental health, targeting young people aged 15-20.	formal evaluation was written up. The lead author wished to obtain sustainable funding before launching the OHPC and this is yet to be secured.
Elf, Rystedt, Lundin, and Krevers (2012)	PD	PhD project of first author, in Sweden. Funded by The Swedish Institute for Health Science, the University of Gothenburg, and Vinnvård.	Preventive Intervention: Web-based support system (WBSS) for young caregivers (aged 16-25) living close to someone with mental illness.	During Web site development phase, after previous attempts to pass the Web site on, the original Web site (Molnhopp.nu) was partially redesigned and rebuilt on a different platform (Livlinan.org, Lifeline) run by SPIV (a suicide prevention organization) and a volunteer-run local mental health service for ongoing management.
				The first author published on the relationship between intended (Molnhopp.nu) and real (Livlinan.org) use of the Web site. Intended and real use were weakly related and dependent on context and the needs/interests of users.
				The original Web site Molnhopp.nu progressed to a randomized controlled trial (RCT) carried out over 8 months (N=241, aged 16-25 years); WBSS (Molnhopp.nu) n = 120 (73% female); folder support (containing information on 24 different kinds of available support services in the community or society) n = 121. The intention to treat for the primary outcome (stress) showed no significant differences between the Web group and the folder support group. Stress decreased significantly in the folder group.
Hallett, Brown, Maycock, and Langdon (2007)	PAR	Project driven by a multi-stakeholder participatory action research committee, led by a project officer of the West Australian Aids Council (WAAC) and funded by Healthway (West Australian	Preventive Intervention: online, peer-based sexual and mental health promotion (CyberReach) for adult men who have sex with men (MSM) and same sex attracted young people	Stated project objectives met (ie, developing sustainable, transferrable protocols and training, and development of transferrable protocols for peer-based Internet outreach).

| | | | (SSAY). No exact age groups stated, likely to be 14-25 for SSAY and 25+ for MSM. | Paper reports that the piloted intervention became 2 separate services offered by the WAAC: (1) Expanded the existing SSAY to include online outreach and chat; and (2) After a more extensive trial, the MSM service eventually became a national program called "Netreach" offered by the AIDS Councils in Queensland, Victoria, Western Australia, and Tasmania. Netreach primarily provides online chat and support for MSM. Program supported by the Australian Federation of AIDS Organisations and by Gaydar.com.au.

No health promotion outcome data available. |
| --- | --- | --- | --- | --- |
| Health Promotion Foundation). | | | | |
| Løventoft, Nørregaard, and Frøkjær (2012), | PD with modified form of classic contextual inquiry | University-based research project in Denmark.

Project supported by Lundbeck A/S, DIKU, Telenor A/S, HTC Denmark A/S, and PROSA. | Treatment Intervention: mobile phone app aimed at supporting people with depression by assisting with their daily lives. No target age explicitly stated. Youth consumers participating in the study aged 17-24. | Small scale 4-week evaluation of the intervention with participants who assisted with the design process—no further information available on intervention after publication. |
| Madsen, el Kaliouby, Eckhardt, Hoque, Goodwin, and Picard (2009) | UCD with PD iterative design sessions | Project carried out by MIT Media Lab. Close links with Groden Center and Things That Think Consortium. Funded by National Science Foundation grant (hardware and software prototypes provided by Google and Samsung). | Treatment Intervention: prototype interactive socio-emotional toolkit (iSET) to assist adolescents with autism to improve social interactions (recognition, understanding, and expression of both the user's and others' facial expressions via software and hardware). | At time of publication, the iSET intervention was still under development, no further information is available beyond this date. |
| Matthews and Doherty (2011) | UCD | Project driven by Human Computer Interaction researchers at Trinity College, Dublin (funding source and trial partners not stated). | Treatment Intervention: a mobile phone and online symptom tracking tool (Mobile Mood Diary) to assist adolescents with depression. | Clinical pilot (n=3 therapist, n=9 clients, mean age = 13.78, SD= 2.63, n=3 males and females, respectively) and n=1 parent, across a range of issues, including depression, mood disorders, self-harm, and anger management. |

				No further information available on intervention after time of publication.
Mazzone, Read, and Beale (2008)	UCD with PD	PhD study of first author who was the design researcher in a multidisciplinary research team. UK university-based project led by researchers in developmental psychology and computing. Overall project, joint collaboration between a team of psychologists, interaction designers, and developers. Funded by the HEFCE's Strategic Development Urban Regeneration Fund, devoted to a consortium of universities in the UK, with additional funding from Esmee Fairburn Foundation.	Treatment Intervention: e-learning product to improve teenagers' emotional intelligence for pupils (aged 12-15 years old) taken out of mainstream schooling due to behavioral issues (participating consumers were recruited from Pupil Referral Units).	Intervention (Uthink) implemented in Flash by a graphic designer. Uthink evaluation: N=84 (youth aged 14-16, n=72 males, n=12 females), no control group. Significant changes in a number of socio-emotional skills, including stress management, adaptability, and the ability to appreciate relationships between environmental cues and emotions. Participants demonstrated experiencing more care and guidance within friendships and less conflict. Reduced delinquent behavior and a desire to be increasingly challenged in school was also demonstrated. Correspondence with project leads indicated that the game is freely available at the Uthink Web site and is currently being used by schools in Lancashire, England, and is recommended by the Lancashire County Council for use in high schools.
Moen and Smørdal (2012)	Action research with PD workshops	University-hospital collaboration in Norway. Funded by Centre for Rare Disorders and the IT department at Oslo University Hospital. Exploratory study.	Preventive Intervention: wiki-like site offering information, strategies, and support for people (and their families) living with anorectal anomaly focused on "living well." Indicated all ages were being targeted, but email correspondence with first author indicated a significant youth component.	Email correspondence with the first author indicates there is no outcome paper for the intervention due to employment changes for key contributors. Piloting was undertaken but was challenging due to technical and interoperability problems and lack of professional and organizational support.
Monshat, Vella-Brodrick,	Participatory	Researcher-led via Orygen Youth Health Research Centre. Funding: K.M.	Preventive Intervention: online mindfulness therapy program	Pilot testing: (n=11 young people, aged 16-24, gender not reported) evaluated the 6-week MATE

Burns, and Herrman (2012)	research	Australian National Health and Medical Research Council (NHMRC) Public Health Postgraduate Scholarship, J.B. Victorian Health Promotion Foundation (VicHealth) Fellowship, and H.H. NHMRC Practitioner Fellowship.	(mindfulness awareness training and education (MATE)) targeted at young people aged 14-25.	program. Focus group (n=7) and interview (n=5) data. No further information available.
Lakey (2014)	Participatory research	Project driven and funded by the National Health Service Greater Glasgow and Clyde as part of their strategic direction for Child and Youth Mental Health. The Greater Glasgow & Clyde NHS, Mental Health Foundation, Snook, and Young Scot were commissioned to carry out project in partnership. Outcome of project is to provide a basis for discussion with stakeholders in the board area to translate findings.	Preventive Intervention: Aimed at exploring the potential of the Internet, social media, and mobile technologies in promoting better mental health and well-being for young people. Multiple planned outputs. Produced digital postcards that act as a guide to staying safe and well online for young people aged 15-21.	Project supported the development of youth-generated ideas for digital interventions to promote youth mental health and well-being. Animated GIFs (youth guide) developed but not available to the public yet. The project also developed other health service/resource design briefs. Work officially launched by Health Board on March 28, 2014. Project opened up connections with innovators across the UK who are willing to collaborate and develop it further. Email correspondence with project lead: project is close to gaining confirmation of funding that will allow development and delivery of recommendations from the project's first phase.
Owens, Farrand, Darvill, Emmens, Hewis, and Aitken (2011)	Participatory research	Collaboration between university and government service researchers and representatives in the UK. Funded by the National Institute for Health Research.	Treatment Intervention: text-messaging intervention to reduce self-harm for all ages.	Exploratory trial in progress at time of publication. No further information available.
Schmidt (2009)	PAR	Source document was author's master's thesis. Youth Voices for Change (YVC) project was a subset of a larger research project (Healthy Youth/Healthy Region) that investigated connections between	Preventive Intervention: Google map (containing youth-produced videos and photos relating the built environment and well-being—eg, favorite, challenge, and adjust places	Media products presented at the planned youth community event. Qualitative data (interviews and surveys) indicated that the media products created for the event were perceived as successful by both the youth and the attendees (in terms of overall

		youth well-being and regional prosperity in the Sacramento, California, region in the US. Participating agencies: The Center for Regional Change at the University of California Davis (UC Davis) in collaboration with other project centers in UC Davis and the West Sacramento Youth Resource Coalition (WSYRC), which led the project. Funding from Sierra Health Foundation and The California Endowment.	in the community) and project Web page (the project produced other outputs but they were not technology-based). The overall aim was to investigate links between the built environment and youth well-being.	satisfaction, learning about the community, inspiring discussion, understanding people in the community and its diversity). At time of writing, the thesis indicates that the videos (and other project outputs) were being used by youth groups involved in the project, the Sactown Heroes, to promote their ideas and profile within the community (no clear idea how). The current utilization status of the Google Map is unknown as it was transferred from the project Web page (which was discontinued) and placed on a community Web site. The WSYRC is using the output and connections made as a result of the YVC project to develop a sustainability plan for the Sactown Heroes group as other funding comes to an end.
Stewart, Riecken, Scott, Tanaka, and Riecken (2008)	PAR, youth participation model	Collaboration between university-based researchers and Canadian indigenous youth.	Preventive Intervention: Canadian indigenous youth developed artistic educational videos to address self-identified health concerns. For use in the local and other communities (aimed at high school and university students). Key research question: how can creating videos contribute to expanding health literacy?	Student videos presented at planned showcase event at the end of the school term to an audience of peers, friends, family, and community members. No information as to whether the videos have been used in other communities/contexts as planned.
Valaitis, O'Mara, and Bezaire	PD	Campus-community partnership between researchers at McMaster University and the local government health unit in	Preventive Intervention: rural youth (aged 14-24) developed a Web site aimed at meeting their specific health	No peer reviewed papers published for this study. Project report: the Web site was evaluated over 8

(2007)		Ontario, Canada (rural context). Funded by Health Canada's Drug Strategy Community Initiatives Fund.	promotion needs (with moderated peer support) with a broad aim to address problematic alcohol use. The project also aimed to provide an opportunity and skills for local youth at-risk to develop and implement the health promotion Web site.	months (2006-2007). No outcome data available on ability of Web site to meet identified health promotion needs.

The Youth Spark Web site was functional and updated until late 2014, when it was converted to a Facebook page. |
| Wadley, Lederman, Gleeson, and Alvarez-Jimenez (2013) | PD | Research project that involved collaboration between universities (from human-computer interaction and clinical backgrounds) and a research supportive youth mental health clinic in Australia. Supported by Victorian Government, University of Melbourne, Telstra Foundation, IBES, the Telematics Trust, and the Helen Macpherson Trust. | Treatment Intervention: online therapy involving psycho-education, peer-to-peer social interaction, advice, and moderation from mental health practitioners for young people with psychosis aged 15-25. | Completed a 4-week safety and acceptability trial (n=20 clients, n=3 clinicians, age and gender not reported).

Results of pilot testing results secured funding for a 4-year RCT.

Email correspondence with first author indicates that the intervention is in the first year of a RCT—no final outcomes available. |

Figure 2. The multiple stages through which studies were selected for inclusion using the PRISMA flow diagram.
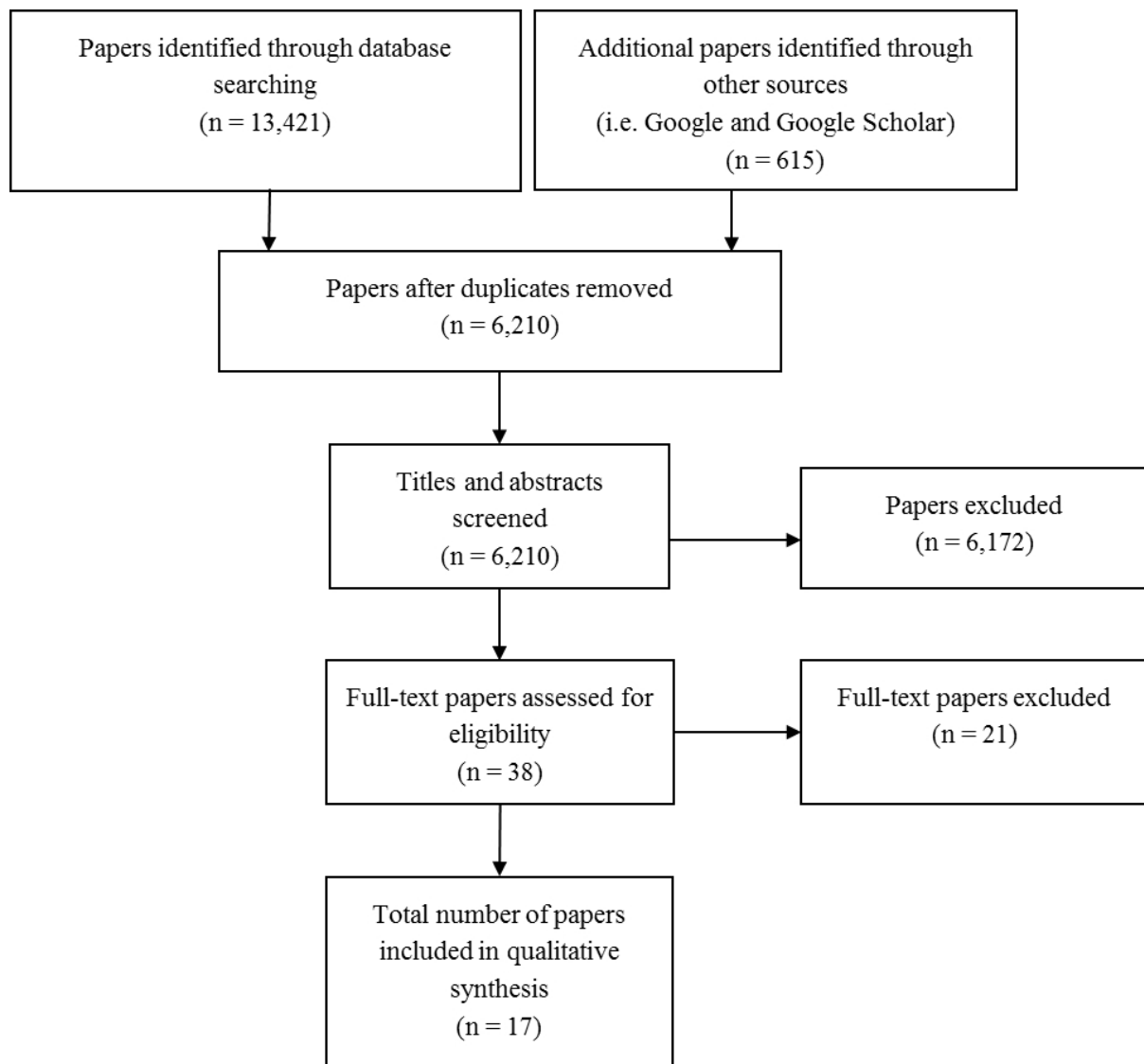
Characteristics of the Included Studies

7 of the 17 projects included in the review, included treatment-focused interventions (Coyle & Doherty 2009; Løventoft, Nørregaard & Frøkjær 2012; Madsen et al. 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Owens et al. 2011; Wadley et al. 2013). The remaining 10 were preventive interventions (Carroll et al. 2010; Ekberg et al. 2013; Elf et al. 2012; Hallett et al. 2007; Lakey 2014; Moen & Smordal 2012; Monshat et al. 2012; Schmidt 2009; Stewart et al. 2008; Valaitis, O'Mara & Bezaire 2007). UCD (Coyle & Doherty 2009; Madsen et al. 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008), PD (Elf et al. 2012; Løventoft, Nørregaard & Frøkjær 2012; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013), and PAR (Carroll et al. 2010; Hallett et al. 2007; Schmidt 2009; Stewart et al. 2008) were the most common methodologies used (4 projects each). PD provided the sub-framework for an iterative design process in a further 4 projects (Ekberg et al. 2013; Elf et al. 2012; Madsen et al. 2009; Moen & Smordal 2012). UCD or PD methodologies tended to scaffold

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development of treatment-focused interventions. Three projects were based in the US and Australia, respectively, and 2 each in Ireland, Sweden, England, and Canada. The final 3 were based in Denmark, Norway, and Scotland. The age range of youth involved was 10-26 years old; 5 studies did not report age, 9 did not report gender. Besides age, no other socio-demographic variables were reported.

Nature of Consumer Involvement and the Participatory Process

Most projects (11 of the 17) involved young people (and other relevant stakeholders) for principally consumerist purposes (Carroll et al. 2010; Coyle & Doherty 2009; Ekberg et al. 2013; Hallett et al. 2007; Lakey 2014; Løventoft, Nørregaard & Frøkjær 2012; Madsen et al. 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Monshat et al. 2012; Wadley et al. 2013); that is, to create usable, effective, and efficient interventions. A further 2 reported elements of both empowerment and consumerism (Elf et al. 2012; Owens et al. 2011). No projects actively involved youth consumers in the project planning stage, with project aims and goals unreflective of their input.

Overall, consumers were involved in a combination of 3 main stages of research: (1) Needs analysis/design specification; (2) Intervention design/prototyping and development; and (3) Usability and pilot testing. Two projects involved consumers in all 3 stages (Løventoft, Nørregaard & Frøkjær 2012; Valaitis, O'Mara & Bezaire 2007). Projects commonly included consumers, who were most often youth and mental health clinicians (rarely family or caregivers), in the needs analysis/design specification stage (Coyle & Doherty 2009; Ekberg et al. 2013; Elf et al. 2012; Lakey 2014; Løventoft, Nørregaard & Frøkjær 2012; Matthews & Doherty 2011; Moen & Smordal 2012; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). Some projects entered this stage with a predetermined intervention in mind (Ekberg et al. 2013; Elf et al. 2012; Løventoft, Nørregaard & Frøkjær 2012; Matthews & Doherty 2011; Valaitis, O'Mara & Bezaire 2007), while others operated with a looser set of intended outcomes (Coyle & Doherty 2009; Lakey 2014; Moen & Smordal 2012; Wadley et al. 2013). Four projects involved consumers in the intervention design/prototyping and development stage (Lakey 2014; Løventoft, Nørregaard & Frøkjær 2012; Owens et al. 2011; Valaitis, O'Mara & Bezaire 2007). In other projects, consumer involvement involved consulting to refine an existing intervention (Hallett et al. 2007; Monshat et al. 2012) or solely usability and pilot testing (Madsen et al. 2009; Mazzone, Read & Beale 2008). The community-based projects of Schmidt (2009) and Stewart et al. (2008) developed community health education tools. They involved consumers at all stages of the project besides initial project planning.

Youth participation was variable, both across and within projects. Overall, 70% of projects reported predominantly consultative consumer involvement (Coyle & Doherty 2009; Ekberg et al. 2013; Elf et al. 2012; Hallett et al. 2007; Løventoft, Nørregaard & Frøkjær 2012; Madsen et al. 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Moen & Smordal 2012; Monshat et al. 2012; Wadley et al. 2013) and the remaining projects were collaborative in nature (Lakey 2014; Owens et al. 2011; Schmidt 2009; Stewart et al. 2008; Valaitis, O'Mara & Bezaire 2007). The projects, therefore, sat in the middle of Biggs' modes of participation

(Biggs 1989). Youth involvement was consultative in 6 of 7 treatment-focused projects (Coyle & Doherty 2009; Løventoft, Nørregaard & Frøkjær 2012; Madsen et al. 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Webb et al. 2015) and 4 of these projects involved mental health clinicians as part of the research team (Coyle & Doherty 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Wadley et al. 2013). Projects that developed treatment-focused interventions generally involved the most limited forms of consumer input. The highest level of youth participation was evident in the prevention-intervention projects (Lakey 2014; Schmidt 2009; Stewart et al. 2008; Valaitis, O'Mara & Bezaire 2007).

Families, caregivers, and intended implementation-site representatives were under-represented in the projects. Of the 16 carried out, 7 projects clearly identified the intended implementation site and included representatives in the design phase (Coyle & Doherty 2009; Ekberg et al. 2013; Hallett et al. 2007; Lakey 2014; Monshat et al. 2012; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). The Stewart et al. (2008) and Schmidt (2009) projects developed community-education focused interventions with local community representatives; however, it was unclear how widely their products were intended for distribution and thus the specific implementation site(s).

Overall, it was difficult to gain insight into consumers' views on their participation in the projects (process evaluation) and their outputs (evaluation of the intervention). Three projects involved consumer evaluation of their experience of research (Schmidt 2009; Stewart et al. 2008; Valaitis, O'Mara & Bezaire 2007). These evaluations suggested a general trend toward perceived legitimacy and accountability of the research process and its outputs, but they also served to highlight the different expectations regarding process and outcomes between project/research leads and consumers. Other projects reported informal and anecdotal consumer support for the research process (Hallett et al. 2007; Mazzone, Read & Beale 2008; Moen & Smordal 2012; Monshat et al. 2012). In some cases, pilot and small-scale clinical evaluation data were reported (Coyle & Doherty 2009; Hallett et al. 2007; Løventoft, Nørregaard & Frøkjær 2012; Matthews & Doherty 2011; Monshat et al. 2012; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013).

In line with the consumerist rationale for most projects, deliberate capacity building and learning for consumers was limited; only 5 projects involved significant opportunities for this (Hallett et al. 2007; Lakey 2014; Schmidt 2009; Stewart et al. 2008; Valaitis, O'Mara & Bezaire 2007). These involved development of preventive interventions.

Consumer involvement was seen as crucial to intervention design and development in most projects; emergent knowledge was evident in all project outputs and each made explicit reference to value of consumer involvement in intervention development. Projects reported clear dichotomies around designer/researcher assumptions of effective and acceptable interventions and those of the intended consumer. These differences were present in intervention premise and content (Elf et al. 2012), and mode of delivery and characteristics/components (Løventoft, Nørregaard & Frøkjær 2012; Moen & Smordal 2012; Wadley et al. 2013). Projects reported compromises between the perspectives, which were evident in the designs. Consumer consultations in the

needs analysis/design specification stage were used to underpin and inform intervention design (Coyle & Doherty 2009; Ekberg et al. 2013; Elf et al. 2012; Lakey 2014; Løventoft, Nørregaard & Frøkjær 2012; Matthews & Doherty 2011; Moen & Smordal 2012; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). Consumers also played a role in tailoring and contextualizing interventions (Coyle & Doherty 2009; Madsen et al. 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008).

Eleven of the 15 completed projects reported challenges with consumer recruitment, capacity, commitment, and reliability (Coyle & Doherty 2009; Elf et al. 2012; Hallett et al. 2007; Lakey 2014; Løventoft, Nørregaard & Frøkjær 2012; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Owens et al. 2011; Schmidt 2009; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). Cited reasons included lack of access to the target consumer group, consumer personal circumstances and/or condition-related factors, and the busy lives of youth. All projects aiming to develop treatment-focused mental health interventions found recruitment and ongoing participation of intended youth consumers difficult to achieve; however, youth consumer attrition during intervention design and development was not specific to development of treatment-focused interventions (Elf et al. 2012; Schmidt 2009; Valaitis, O'Mara & Bezaire 2007).

Nature and Outcomes of the Design Process

Three projects used heuristic guidelines to support intervention design (Coyle & Doherty 2009; Matthews & Doherty 2011; Wadley et al. 2013). Monshat et al. (2012) was guided by constructs of the Technology Acceptance Model (TAM) (Davis 1989). Overall, 4 projects reported use of technology frameworks or theory to guide intervention development (Coyle & Doherty 2009; Matthews & Doherty 2011; Monshat et al. 2012; Wadley et al. 2013). Valaitis, O'Mara and Bezaire (2007) used logic models to support major project decisions, including those specifically related to intervention design, such as the prototyping process, as well as techniques from scenario-based design (Blythe & Wright 2006; Bødker 2000). Ekberg et al. (2013) employed design rationales and design space analysis, which detail reasons for and justification of design decisions, to guide development of their intervention (MacLean, Young & Moran 1989). Eight of 17 studies utilized PD methodology or principles to guide intervention development (Ekberg et al. 2013; Elf et al. 2012; Løventoft, Nørregaard & Frøkjær 2012; Madsen et al. 2009; Mazzone, Read & Beale 2008; Moen & Smordal 2012; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). Ten projects mentioned the broad theories (including psychological, health, education, group, empowerment, and cultural) on which the intervention or project were based (Carroll et al. 2010; Coyle et al. 2007; Hallett et al. 2007; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Moen & Smordal 2012; Owens et al. 2011; Stewart et al. 2008; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013) (the details of 2 were found in project reports provided by the authors, not in the published articles (Hallett et al. 2007; Valaitis, O'Mara & Bezaire 2007).

A structured design process, with activities able to scaffold consumer input through the design stages, was seen to be effective in a third of completed projects (Ekberg et al. 2013; Lakey 2014; Løventoft, Nørregaard & Frøkjær

2012; Mazzone, Read & Beale 2008; Valaitis, O'Mara & Bezaire 2007). Use of scenario-based design—which included techniques such as storyboarding, personas (Blythe & Wright 2006; Bødker 2000), think-aloud techniques (Birru et al. 2004; Hansen et al. 2003), and varied methods for capturing user experience and knowledge—was seen to assist the design process. Inspiration/idea progression and prototyping was facilitated by appropriate planning and resourcing with respect to design activities and the space in which they were conducted.

Project flexibility and responsiveness, including the ability to adapt to changing resources, priorities, work styles/preferences, output standards, and deadlines, was often built into design and was a common thread throughout projects that reported high levels of consumer involvement and influence (Hallett et al. 2007; Owens et al. 2011; Schmidt 2009; Valaitis, O'Mara & Bezaire 2007). Projects led by nontechnical researchers also reported the need for integration of technical expertise at all stages of intervention design and development (Ekberg et al. 2013; Owens et al. 2011; Valaitis, O'Mara & Bezaire 2007). A professional appearance of the final intervention product was also seen as important by youth consumers in a number of projects (Ekberg et al. 2013; Elf et al. 2012; Wadley et al. 2013).

In addition, balancing consumer requirements with what was possible technically, ethically, and practically (ie, time and resource, both financial and human, restrictions) was highlighted in 3 projects (Ekberg et al. 2013; Elf et al. 2012; Moen & Smordal 2012). Of particular concern were social and consumer self-authoring components of interventions, privacy, confidentiality, clinical risk, and authenticity of information. Formal outcome data was available for 2 projects (Elf et al. 2012; Mazzone, Read & Beale 2008).

Relationship Between Participatory Research and Implementation

While leadership was not always clearly defined, most projects were researcher-led. Interdisciplinary project teams were common, including researchers or professionals with various combinations of mental health and technology domain expertise. Often, however, 1 discipline had overall responsibility for the project.

Five projects (Hallett et al. 2007; Lakey 2014; Owens et al. 2011; Schmidt 2009; Valaitis, O'Mara & Bezaire 2007) reported existing relationships with outside champions who were linked to implementation sites or organizations capable of progressing the project beyond the intervention development stage. In 2 projects, Hallett et al. (2007) and Valaitis, O'Mara and Bezaire (2007), project and governance plans were designed such that implementation of the intervention was integrated and a further 4 studies reported established links with intended intervention sites (Lakey 2014; Mazzone, Read & Beale 2008; Monshat et al. 2012; Wadley et al. 2013). Stewart et al. (2008) and Schmidt (2009) integrated community-based dissemination of outputs into their project plans. Many projects were, however, exploratory and involved development of technology-based interventions with a limited evidence base.

With the information available at the time of writing, 5 projects had extended beyond the intervention design, development, and pilot stage (Elf et al. 2012; Hallett et al. 2007; Mazzone, Read & Beale 2008; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). It is unclear the extent to which outputs from the 2 community-based projects (Schmidt 2009; Stewart et al. 2008) were used in a health promotion or prevention capacity beyond the life of the project.

Eleven projects utilized existing relationships and networks to assist with recruitment of target consumers (Ekberg et al. 2013; Elf et al. 2012; Hallett et al. 2007; Lakey 2014; Madsen et al. 2009; Mazzone, Read & Beale 2008; Moen & Smordal 2012; Monshat et al. 2012; Owens et al. 2011; Schmidt 2009; Wadley et al. 2013). The benefits of accessing consumers through existing networks was often noted; in particular, this made a significant difference in recruiting consumers with lived experience of mental illness for studies developing treatment-focused mental health interventions (Madsen et al. 2009; Mazzone, Read & Beale 2008; Owens et al. 2011; Wadley et al. 2013).

DISCUSSION

Nature of Consumer Involvement and the Participatory Process

A strong history of youth participation in mental health research and service development exists, rooted in the empowerment of young people to address service quality and access issues (James 2007). In contrast, the projects included in this review generally involved consumers for consumerist intentions and in a consultative capacity. This represents a departure from the traditional empowerment and emancipatory rationales for participatory research demonstrated in a minority of projects in this review (Elf et al. 2012; Moen & Smordal 2012; Owens et al. 2011; Schmidt 2009; Stewart et al. 2008; Valaitis, O'Mara & Bezaire 2007). These increasingly consumerist underpinnings have implications for why and how consumers are asked to participate in research and the degree of mutual benefit that is possible, desired, and ethical.

Eight of the 17 projects explicitly reported using PD methodology or methods to guide intervention development, and others used PD-related design techniques such as user journeys, personas, and workshops. PD originated in the 1970s from a Scandinavian tradition of empowering workers to exercise control over the role of technology in their workplace (Spinuzzi 2005). Increasingly, however, the application of PD as a methodology or collection of techniques/methods has moved into design underpinned by consumerist principles that emphasize usability, effectiveness, and acceptability of the product (Clemensen et al. 2007; Hagen et al. 2012). This shift was embodied in several projects in this review (Ekberg et al. 2013; Lakey 2014; Løventoft, Nørregaard & Frøkjær 2012; Madsen et al. 2009; Mazzone, Read & Beale 2008; Wadley et al. 2013). Participatory methodologies with consumerist underpinnings tend to seek information and understanding through consultation and, thus, support a more passive role of the consumer in the research.

In attempting to assess perceived accountability and the legitimacy of the research process and outputs in the studies reviewed, it became clear that researchers are not in the practice of evaluating and reporting on the consumers' participation experience. This is not only a missed opportunity for consumers to collect data in order to reflect on and learn from their experience of research, but it represents an invaluable source of data from which other projects wishing to conduct participatory intervention design and development could benefit. Email correspondence with 1 author of the studies reviewed revealed that the intervention did not progress any further from the design stage due to possible consumer dissatisfaction with the design, despite the intervention being designed and developed in collaboration with them. This highlights the need for formal assessment of consumer perceptions of accountability and legitimacy of the intervention. Existing literature notes the value derived by researchers and consumers in building in evaluation/reflection cycles, particularly for promoting the dialogue, critical reflection, and trust that are crucial components of high-quality participatory research (Boeck & Collin 2012).

While it has been reported that participatory research can enhance recruitment rates (Cargo & Mercer 2008; Jagosh et al. 2012), this review highlights the consumer access, recruitment, and participation challenges faced by projects aiming to develop mental health and well-being interventions, particularly those with a treatment focus that target involvement of consumers with lived experience of mental illness. Those individuals who identify as struggling with mental illness still face stigma and privacy concerns, which restrict use of common recruitment methods such as advertising (Wadley et al. 2013). Even projects that reported collaboration with mental health services or access to those with lived experience of mental illness noted ongoing participation difficulties with maintaining consumer participation throughout the intervention design and development process (Owens et al. 2011; Wadley et al. 2013).

Collaborating with existing groups of young people such as schools and youth groups (Ekberg et al. 2013; Lakey 2014; Madsen et al. 2009; Mazzone, Read & Beale 2008; Schmidt 2009; Stewart et al. 2008) or organizations with a strong track record of engagement and outreach with the target consumers (Hallett et al. 2007; Moen & Smordal 2012; Monshat et al. 2012) represented a recruitment starting point for multiple projects. However, they too still reported struggling with ongoing participation difficulties. These recruitment concerns are not surprising considering the move into more consumerist-based projects that tend to be less integrated into communities than traditional participatory research.

Personal capacity, reliability, and attrition of consumers, particularly in the treatment-focused intervention development projects, must also be considered (Elf et al. 2012; Løventoft, Nørregaard & Frøkjær 2012; Mazzone, Read & Beale 2008; Owens et al. 2011; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). Todays' young people contend with a myriad of demands on their time, and projects included in this review experienced this in the form of participant nonattendance, unreliability, and dropout. This effect may be amplified when the youth consumer is currently living with a mental illness. Consumers may also face financial or transport (Wadley et al. 2013) barriers in attending planned project activities that may be related to their age and/or health status.

Broadly speaking, participatory research that involves consumers, particularly those who are members of minority or vulnerable populations, carries with it particular ethical considerations that require careful and sensitive negotiation and practical restrictions (Bengtsson-Tops & Svensson 2010; Dold & Chapman 2012; Kraemer Diaz, Spears Johnson & Arcury 2013; Moltu et al. 2012). This is best exemplified in the Løventoft, Nørregaard and Frøkjær (2012) project, which reported moving from egalitarian principles of PD to a designer-led user-centered approach due to challenges with consumer engagement, retention, and capacity.

The projects with the most extensive youth consumer participation were those in which young people were involved in design and development of health prevention interventions, as exemplified in Stewart et al. (2008), Valaitis, O'Mara and Bezaire (2007), Lakey (2014), and Schmidt (2009). This nonclinical consumer group is far easier to access and does not have the same privacy, stigma, and personal capacity concerns facing the clinical youth consumers.

Despite this, many studies reported successful participatory research with youth consumers from a range of backgrounds. Participation is greatly assisted by links to existing consumer groups. Integration into the community of interest, via sustained partnerships between academic and non-academic partners, is a hallmark of participatory research and has previously been shown to enhance recruitment capacity (Cargo & Mercer 2008; Jagosh et al. 2012). Beyond this, future research projects would be well advised to plan for attrition; both with respect to an ongoing recruitment source and development of materials that can be provided to consumers for seamless integration into the project whenever they choose to engage or reengage. As borne out in this review, participation can and will fluctuate throughout the project and must be planned for and communicated to consumers (Schmidt 2009).

Flexibility and open-mindedness, embodied by a willingness to work with a non-static group of consumers and to renegotiate the time, length, style, and content of planned interactions, was repeatedly noted by the projects included in this review (Hallett et al. 2007; Mazzone, Read & Beale 2008; Owens et al. 2011; Valaitis, O'Mara & Bezaire 2007). Owens et al. (2011) in particular highlights the flexibility required by a project when working in an egalitarian manner with consumers. Their intervention became more complex than planned and required extra time and resources to create. Increased cost in terms of necessary resources, time and expertise associated with participatory research (Gibbs et al. 2008), along with the a need for flexibility in terms of role division, project structure(s), timeframes, and even communication methods have been noted elsewhere (Boeck & Collin 2012).

In working with adolescents with behavioral problems, Mazzone, Read and Beale (2008) recommend small groups and many short activities with simple tasks and objectives. They also endorse building in praise and a sense of ownership when working with all youth consumers (see also Dold and Chapman (2012)). A structured design process that scaffolds consumers throughout was also found to be effective (Ekberg et al. 2013; Lakey 2014; Løventoft, Nørregaard & Frøkjær 2012; Mazzone, Read & Beale 2008; Valaitis, O'Mara & Bezaire 2007). Given the probable lack of technical and design knowledge of the average consumer, scaffolding the design

process appears to be an important consideration for researchers. via techniques like storyboarding, think-aloud techniques, and scenario-based design.

Planning for and understanding consumer expectations of participation in research, along with their self-perceptions as mental health consumers, matters (Dold & Chapman 2012). Given the limited data available regarding consumer experience of research, building reflection and evaluation into research plans should be a focus for future research projects. Ideally, projects wishing to collaborate with youth mental health consumers require committed, youth-supportive research leadership and a process that is well-resourced and supported. Previous research suggests that projects that are age and developmentally appropriate and incorporate meaningful, individualized, empowering, and capacity-building elements improve consumer output and buy-in (Delman 2012; Dold & Chapman 2012; Schmidt 2009), which has obvious implications for improving the current recruitment and participation issues.

Recognizing that issues of power and agency are embedded in participatory research with young people, it is important to achieve best practice (Boeck & Collin 2012). When researchers adopt the mind-set that "young people are creative agents who bring about change" (Boeck & Collin 2012, p. 207), participatory research can represent an important opportunity for young people to be recognized and contribute meaningfully.

Nature and Outcomes of the Design Process

Most studies indicated that consumer participation was integral to good intervention design and development (Coyle & Doherty 2009; Ekberg et al. 2013; Elf et al. 2012; Hallett et al. 2007; Lakey 2014; Madsen et al. 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Moen & Smordal 2012; Owens et al. 2011; Stewart et al. 2008; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). Accessing consumers' implicit domain knowledge was the cornerstone of producing relevant, accessible, and usable interventions and output, which is consistent with prior reviews of participatory research (Jagosh et al. 2012; O'Fallon & Dearry 2002).

Consumer involvement was associated with flexibility, responsiveness, human-centeredness, and adaptability in design. For example, in their online adaptation of peer-based health promotion for adult men who have sex with men and same sex attracted young people, Hallett et al. (2007) engaged peer volunteers to develop and pilot the intervention. This allowed the project to be responsive and to adapt the intervention and its evaluation as needed. The peer volunteers provided important information regarding online etiquette and technical proficiency, and during piloting facilitated access to clients and development of rapport and credibility through use of shared language and cultural understandings.

Consumer collaboration significantly altered Owens et al.'s (2011) text-based self-harm prevention intervention from the original design brief. Researchers originally planned for a replication study in which generic texts were sent at predetermined, high-risk times; the co-design process resulted in a more flexible and human-centered

design involving client self-authored texts accessible on demand. Authors noted that the final form and function of the intervention would not have been possible without consumer input.

Successful outcomes require researchers to balance consumer requirements against those of other stakeholders, such as funders and implementation sites, while managing time, resourcing, and ethical considerations. This difficult task requires careful negotiation along with clear and ongoing communication (Ekberg et al. 2013; Elf et al. 2012; Mazzone, Read & Beale 2008; Moen & Smordal 2012; Owens et al. 2011).

This is best exemplified by analysis of (1) an exit focus group with youth consumers; and (2) youth consumer-designer/researcher email conversations throughout the Elf et al. (2012) project. Analysis revealed that, as the project progressed, the mind-set of the researcher/designers changed from exploration of ideas with consumers to concrete production of output. This shift in priorities was attributed to increasing pressure around resources (e.g., human, financial, time), and delivering technical components on time became the priority over implementing consumer ideas/suggestions.

Theory to Support Intervention Design

Consistent with prior literature, limited application of theory to guide technology development was evident (Mohr et al. 2014). As a result, researchers are not maximizing the potential uptake, efficacy, and impact of their interventions. Three projects (Coyle & Doherty 2009; Matthews & Doherty 2011; Wadley et al. 2013) used heuristic guidelines to support technology-based intervention design and development. The guidelines emphasize design for outcomes, with mental health professionals, within a UCD framework (Coyle et al. 2007; Doherty, Coyle & Matthews 2010). Consideration of clinical validity, therapist and client usability, along with intervention acceptability, access, engagement, adaptability, and sustainability are also highlighted. Monshat et al. (2012) was guided by constructs from TAM (Davis 1989). Beyond this, theory or models with the ability to explain consumer interaction with the technology were absent.

While the literature is still developing, the Behavioral Intervention Technology Model (Mohr et al. 2014) is an example of a model to guide the conceptual and technical architecture of behavior-changing eHealth and mHealth interventions—where eHealth is defined as "use of the internet and other electronic media to disseminate related information and services" (Gustafson & Wyatt 2004, p. 1150) and mHealth as "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, PDAs, and other wireless devices" (Kay 2011, p. 6). The model guides researchers through development of clinical and usage aims, choice of technical elements and characteristics, and development of the intended workflow associated with the intervention. It assists in translating intervention aims into intervention elements and characteristics (Mohr et al. 2014).

eHealth participatory design best practice advocates for intended users as co-designers and partners in *all* phases of research, along with intervention evaluation criteria that balances youth relevance, meaning, and

engagement with existing evidence (Hagen et al. 2012). This type of theoretical integration is sorely needed in a field constrained by issues with uptake, adherence, and engagement (Christensen, Griffiths & Farrer 2009; Christensen & Mackinnon 2006; Eysenbach 2005; Kelders et al. 2012; Lillevoll et al. 2014; Mohr et al. 2014). Furthermore, persuasive features that "reinforce, change, or shape attitudes or behaviors or both without using coercion or deception" (Oinas-Kukkonen & Harjumaa 2008, p. 202) and consumer motivation have had limited application in participatory technology-based mental health intervention design and, therefore, represents a focus of inquiry for future projects (Fogg 2009; Kelders et al. 2012; Mohr, Cuijpers & Lehman 2011; Ryan & Deci 2000).

Planning for uptake and established connections with intervention sites were common to projects that successfully implemented their interventions or secured future funding (Hallett et al. 2007; Lakey 2014; Mazzone, Read & Beale 2008; Valaitis, O'Mara & Bezaire 2007; Wadley et al. 2013). Few projects reported evidence of inclusion of representatives from intended implementation sites in design and development of their interventions, even when accounting for the exploratory nature of some of the projects. A narrow definition of *consumer* may have led to limited representation of intervention site stakeholders in the intervention design phase.

Researchers need to be designing with an implementation site in mind and integrating influential system and organization level representatives into the process. In the case of treatment-focused interventions, mental health teams exist within larger systems that play an important role in acceptance and adoption of new interventions. Intimate knowledge of, and a strong working relationship with, the implementation sites of interest must be a priority of designer-researchers. Wölbling et al. (2012) argues that "ground-breaking ideas that arise within an existing organization that are not consistent with their values, routines, and overall strategy will be more difficult, if not impossible, to implement." (p. 131). This assertion has clear implications for a research team wishing to implement new interventions from the outside. Organizational factors such as workplace ICT culture and policy and availability of resources have shown to be facilitators of uptake of ICT in health care (Montague, Varcin & Parker 2014). Whilst Coyle et al. (2007) and Doherty, Coyle and Matthews (2010) account for individual therapist considerations in their heuristic guidelines, they fail to account for organizational and system level factors that can impact on intervention uptake and impact.

Designing with target consumers is crucial. The most commonly reported barriers to uptake of ICT in health care are design and technology concerns including lack of clinical relevance or impracticality; in addition, lack of clinician time and perceived ICT skills are frequently reported barriers. On the flip side, facilitators of ICT uptake include system usefulness and functionality, clinical relevance and ease of use (Gagnon et al. 2012; Montague, Varcin & Parker 2014). This research indicates a clear role for application of theory to guide design and systematic consideration of human factors.

Limitations

A limitation of this review was the broad inclusion criteria. This is particularly evident with respect to the Schmidt (2009) project, which developed community health education outputs to explore youth conceptions of the relationship between the built environment and well-being. Whether these outputs can be categorized as interventions is debatable given the limited detail reported on the project. Despite the fact that youth participation was identifiable in the Owens et al. (2011) paper, it did not have an exclusive youth focus. It was chosen for inclusion due to the nature of the project and its value in contributing to the aims of the review. In addition, the screening process may have benefited from involvement of a second reviewer to double screen. Evaluation of consumer representation was deemed too complex and broad to explore fully within this review beyond the description provided in the results table (Table 1). Finally, while every reasonable effort was made to find all relevant citations, the broad terminology used to describe the research in question may have resulted in some studies being overlooked, particularly where participatory processes may have been described in the methods sections of papers and not noted in the keywords, title, or abstract. Furthermore, the broad research field means the publication of some studies may not have been amenable to the titles, search terms, and databases that were used to construct this study and answer the research question. Moreover, participatory approaches are used in service settings but not always evaluated with the findings published and as such this work was not represented in the review. This review highlights the need for more research, evaluation, and publication on the use and outcomes of participatory approaches in the design and delivery of technology-based youth mental health services and interventions. The Young and Well Cooperative Research Centre (CRC) (Young and Well Cooperative Research Centre) is an initiative that prioritizes this connection and creates the required space for the corresponding evidence base to be built.

Given the nascent stage of this field of research and the corresponding exploratory aims of this review, the broad nature of the search terms and included studies facilitated a wide-ranging description and analysis of participatory design and development of technology-based youth mental health and well-being interventions. This ensured that insights and learnings from the breadth of the mental health intervention spectrum were incorporated. The heterogeneous nature of the projects included, however, prevented the number of specific comparisons that could be made between similar projects and intervention types. We also wish to acknowledge that analysis and results of this review attempted to define and summarize a diverse and often ill-defined research field, and in doing so may have inadvertently oversimplified the practical application of participatory intervention design. Finally, in a rapidly evolving field, the search cutoff date meant that highly relevant recent projects found in conference abstracts were not included in the review.

CONCLUSION

The current review found limited evidence that consumer consultations lead to routine uptake of interventions in practice; that is, consumer participation does not act as a default implementation or uptake strategy. Overall,

strategies aimed at increasing uptake of technology in health care practice are not well understood or reported. A consumerist rationale, which prioritizes acceptability and usability of the intervention, has characterized most projects in this field. It was clear that consumer involvement shaped intervention design in ways that were reported as beneficial by the designers/researchers. While consumer consultations were associated with flexibility, responsiveness, human-centeredness, and adaptability in design, it was not possible to determine the impact of this on intervention effectiveness due to lack of outcome data. The implications for why and how consumers are asked to participate in this field of research and the degree of mutual benefit that is possible, desired, and ethical requires rigorous examination. Participatory intervention design projects are advised to develop flexible and well-resourced project plans, which integrate theory and implementation within the design and make space for reflection, evaluation, and publication of consumer experience of research.
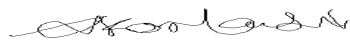
CHAPTER FOUR: PAPER TWO - PUBLISHED

Mental Health Technologies: Designing with consumers.

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Simone Orlowski

Ben Matthews

Niranjan Bidargaddi

Gabrielle Jones

Sharon Lawn

Anthony Venning

Philippa Collin

ABSTRACT

Despite growing interest in the promise of e-mental and well-being interventions, little supporting literature exists to guide their design and the evaluation of their effectiveness. Both participatory design (PD) and design thinking (DT) have emerged as approaches that hold significant potential for supporting design in this space. Each approach is difficult to definitively circumscribe, and as such has been enacted as a process, a mind-set, specific practices/techniques, or a combination thereof. At its core, however, PD is a design research tradition that emphasizes egalitarian partnerships with end users. In contrast, DT is in the process of becoming a management concept tied to innovation with strong roots in business and education. From a health researcher viewpoint, while PD can be reduced to a number of replicable stages that involve particular methods, techniques, and outputs, projects often take vastly different forms and effective PD projects and practice have traditionally required technology-specific (eg, computer science) and domain-specific (eg, an application domain, such as patient support services) knowledge. In contrast, DT offers a practical off-the-shelf toolkit of approaches that at face value have more potential to have a quick impact and be successfully applied by novice practitioners (and those looking to include a more human-centered focus in their work). Via 2 case studies we explore the continuum of similarities and differences between PD and DT in order to provide an initial recommendation for what health researchers might reasonably expect from each in terms of process and outcome in the design of e-mental health interventions. We suggest that the sensibilities that DT shares with PD (ie, deep engagement and collaboration with end users and an inclusive and multidisciplinary practice) are precisely the aspects of DT that must be emphasized in any application to mental health provision and that any technology development process must prioritize empathy and understanding over innovation for the successful uptake of technology in this space.

INTRODUCTION

In light of recent reports that there are almost as many mobile phone subscriptions (6.8 billion) as there are people on Earth (7 billion) (Wang 2013), more humans are connected and have access to a wide range of information and services than ever before. In the context of this "increased access to information" the promise of the Internet and digital technologies is especially powerful in the prevention and treatment of mental health, an area that has been historically impeded by issues of stigma and misinformation as well as disease-specific, geographical, and financial barriers to help-seeking and service engagement (Gulliver, Griffiths & Christensen 2010; Lambert & Newcomer 2009; Lawn 2012; Muir-Cochrane 2006). Despite growing interest in the promise of e-mental health preventive/treatment interventions, little supporting literature exists to guide their design and the evaluation of their effectiveness (Hilgart et al. 2012; Mohr et al. 2014; Orlowski, Lawn, Venning, et al. 2015).

In line with an extensive literature on consumer participation in health care and mental health care more broadly (Boeck & Collin 2012; Boote, Telford & Cooper 2002; Brett et al. 2014a, 2014b; Crawford et al. 2002; Ennis & Wykes 2013; James 2007; NHMRC 2005), human-centered design processes have been identified as a method or set of techniques that assist with good design (Anderson & Lowen 2010b; Coyle et al. 2007; Doherty, Coyle & Matthews 2010; Hagen et al. 2012; Howe et al. 2014; Mohr et al. 2013). Both participatory design (PD) and design thinking (DT) have emerged as approaches that hold significant potential for supporting the design of technology-based youth e-mental health and well-being interventions (Bernstein 2011; Hagen et al. 2012; Johnson et al. 2014; MacFadyen 2014; Orlowski, Lawn, Venning, et al. 2015; Patel et al. 2014). For example, large-scale PD is embedded within Young and Well Cooperative Research Centre (CRC) practice (Hagen et al. 2012; Young and Well Cooperative Research Centre). The CRC combines end-user engagement and youth participation to "explore and understand the role of new and emerging technologies in the lives of young people" (Young and Well Cooperative Research Centre). This paper provides a brief background of the evolution DT and PD, where differences in politics and agenda are explored. We then discuss the applicability of PD and DT to design of e-mental health interventions, particularly in the context of application by novice researcher/practitioners. Finally, we present 2 case studies and highlight similarities and differences in process and outcome, mind-set, and emphasis and draw learnings from each to inform design of e-mental health interventions.

Participatory Design in Brief

PD practice has its earliest roots in Scandinavia where it was employed by computer scientists and systems designers initially in industrial workplaces to preserve the autonomy of employees facing significant changes to the organization of their work due to the introduction of new technologies. In this instance, improved outcomes were achieved due to the context-sensitive and future-oriented approach to the design of technological solutions developed by PD practitioners and the methods they used to involve workers in design (Clemensen et al. 2007; Ehn 1993; Spinuzzi 2005). A fundamental underpinning of Scandinavian PD was democratic participation in

proposed changes to work and skill enhancement for workers (Ehn 1993). One of the reasons PD gained international recognition was that a number of the early and archetypal examples of PD generated far-sighted and innovative solutions. (For example, the graphical user interface that was generated through the UTOPIA project in the early 1980s was clearly ahead of its time.) The methods of end user participation that were developed and shared out of these projects became adopted elsewhere as pathways to innovation—new means of designing successful and user-friendly systems. This gave rise to other more commercial (and less political) forms of PD, particularly in North America, where usability of software and products replaced the focus on workplace democracy (Muller, Wildman & White 1993).

In this Scandinavian context, the practice of PD was characterized by a 3-stage iterative design process aimed at unlocking a users' tacit knowledge: (1) exploration of work; (2) discovery processes; and (3) prototyping. Each of these stages was organized and enacted with users (Spinuzzi 2005). More recently, variations of PD have been used in a range of contexts for a variety of purposes, with each implementation variously drawing on aspects of its practice (e.g. applying PD as a general mind-set for design, or as a method, or adopting individual PD activities as design techniques (Sanders 2013). PD, or "co-design" as it's called in its broad application, is now practiced within local communities, in companies and organizations, and between companies/organizations and their business partners and/or customers to tackle complex problems and promote innovation and user-centered design (Sanders 2013). Increasingly PD has been employed in non-workplace contexts (Wadley et al. 2013) by researchers without specific technical or design training as a means of improving the consumer experience in the design of new health interventions (Hagen et al. 2012). However, there is as yet little evidence as to whether these kinds of consumer participation in the design of new services succeed in improving the efficacy, implementation, and uptake of technology-based interventions (Orlowski, Lawn, Venning, et al. 2015).

Design Thinking in Brief

Broadly speaking, DT is a term that refers to what designers and design researchers know about successful design processes (the first Design Thinking Research Symposium was held in 1991) (Cross 2001; Dorst 2011; Rodgers 2013). In the past decade, however, it has become a term of reference for the mind-set, practices, and methods for generating innovative solutions, taking its starting point from ordinary people's needs. Popularized by prominent design companies such as IDEO, DT has emerged as an articulation of a commercially successful human-centered design process. DT has been defined as "user-centered innovation with a focus on desirability" (Wölbling et al. 2012, p. 124). And, like PD, it emphasizes participation with and empathy toward users. Increasingly DT has influenced health care design, as well as delivery and training of the workforce (Arieff 2009; Brown 2008; Brown 2013; Doss 2014; Ferguson 2012; Spurrier 2015).

DT reinforces the importance of multidisciplinary teams and their ability to generate a diversity of ideas. To harness the best ideas and output, team members are guided by an empathetic mind-set and methods, along with domain-specific knowledge. Naturally, this requires high levels of interpersonal communication. DT's

collaborative mind-set is underpinned by a bias toward action, which reinforces quick-and-dirty prototyping and a fail-early-and-often mentality (Bjögvinsson, Ehn & Hillgren 2012; Brown 2008). DT is marketed for its ability to be successfully applied by novice practitioners using practical off-the-shelf toolkit (Ideo.org 2015; Institute of Design). DT is often associated with innovation as it attempts to uncover unidentified or unknown needs and offers a specific (and more prescriptive) way forward for the development of interventions that move beyond basic translation of paper-based processes and interventions onto a technology-based platform (Bjögvinsson, Ehn & Hillgren 2012; Owens et al. 2011; Sanders 2013). The Stanford d.School Bootcamp Bootleg is one of many available toolkits and is characterized by 5 design modes: empathize, define, ideate, prototype, and test (Institute of Design). Unsurprisingly, these modes neatly overlay the stages, or frameworks, proposed in traditional PD research (Hagen et al. 2012; Spinuzzi 2005). The design-focused methods and mind-set, detailed in a resource such as the d.School Bootcamp Bootleg, provide an explicit and accessible method for health researchers to become exposed to a design mind-set and the possibility to innovate in circumstances that may be characterized as including incomplete or confusing information, which is often the starting point for intervention researchers.

PD and DT in Health Care

If consumer involvement and/or a human-centered process is rightfully considered to be a part of good intervention design, then it is imperative to develop standards for and document cases of best practice. Hagen et al. (2012) suggest a framework and techniques/methods for application of PD in a youth mental health intervention design context. The guide articulates possible ways of integrating PD with more traditional evidence-based health research. The same adaptation work has not yet been done with respect to DT. Currently, the notion of applying a set of management processes developed in a commercial business and consulting context to sensitive fields such as youth mental health remains insufficiently interrogated with respect to benefit, risk, and applicability. For example, DT privileges in situ observation of end users to gain knowledge of subjective experience and insights for design. Privacy, confidentiality, and risk concerns make this type of brief observational engagement (by nonmental-health professionals) difficult to achieve in practice.

While the Hagen et al. (2012) PD framework is practical and accessible, it is unlikely that lay (nontechnical or nondesign) or inexperienced PD researchers would have the specific skill sets necessary to proficiently drive an iterative design process. This skill set in this area of research is particularly important when considering the predominantly consumerist rationale (i.e. creating usable, effective, and efficient interventions) cited for employing participatory processes (Orlowski, Lawn, Venning, et al. 2015). Sanders' research has argued that the application of PD as a mind-set to guide predesign, discovery, and design initiatives "is best executed by very experienced research practitioners or by young, intuitive practitioners" (Sanders 2013, p. 73). This suggests that in the hands of lay and/or inexperienced researchers, PD may risk losing some of its power to create innovative solutions to future problems. This argument suggests a set of learnings and experiences that are tacit in the PD designer-researcher. It is worth emphasizing that while many of the staple PD methods (such as future

workshops) appear easy enough to grasp, organize, and conduct, there is a great deal of skill that is required to successfully facilitate them. There is an important distinction between (1) the kinds of tools, processes, and methods used and (2) the mind-set underlying the approach taken. This raises questions around who is best placed to conduct the research and the kinds of interdisciplinary collaborations necessary for successful application of PD in health research contexts.

In contrast, the DT toolkits actively promote, and are arguably intended for, use by novice practitioners. For example, the method cards of a DT resource such as the Stanford d.School Bootcamp Bootleg (Institute of Design) are deliberately specific in nature and are promoted in such way as to encourage wide dissemination and use. While this may be appealing for inexperienced researchers wishing to adapt design and innovation methods to e-mental health intervention design, it remains unknown just how effective they are in delivering on their promise of scaffolding novice practitioners through a successful design project. The lure of greater innovation in health care, as promised by the DT toolkits, is strong; the requisite skill and practice, however, involved in leading a DT project should not be underestimated, a point clearly highlighted in the following case study.

Case Studies

Beyond the obvious differences in their respective agendas and politics, articulating universal or consistent distinctions between PD and DT practice can be difficult because their similarities are numerous. Both can be categorized under the umbrella term "human-centered design" and are linked to social innovation; collaborative, inclusive, and multidisciplinary practice; and iterative prototyping (Bjögvinsson, Ehn & Hillgren 2012; Brown 2009; Ehn 1993). Moreover, DT and PD employ many of the same methods/techniques; for example, they both draw heavily from ethnographic fieldwork methods in their use of interviewing and observation and from design disciplines such as interaction design with techniques such as personas and scenarios (Institute of Design ; Muller & Druin 2012). Despite these macro similarities, subtle distinctions between the 2 do exist. These distinctions are best made obvious in their practical application; therefore, we present a case study of each to draw these out with the aim of better understanding their applicability to e-mental health and well-being intervention design.

The first case study describes a service design project carried out by an in-house design team at Kaiser Permanente, an American health care provider (Lin et al. 2011). Kaiser Permanente is well known for its commitment to innovation and large-scale organizational application of DT (Carlgren 2013). The current case study describes use of DT in redesign of an initial DT service innovation—the Nurse Knowledge Exchange (NKE). This strategy aimed to improve nursing communication and handover (between shifts) in the organization's hospitals. It did this by moving handovers at shift change from the employee breakroom to the patient bedside—a specific example of the type of innovation possible in application of DT. Five years later, the

design team was tasked with the redesign of the NKE strategy due to incomplete and inconsistent uptake throughout the organization's hospitals.

In their revision of NKE, Lin et al (2011) describe a typical DT cycle—observing and interviewing followed by idea generation/design sessions, prototyping, and field testing. The process, as in most applications of DT, was rapid and expert-led (i.e. controlled from start to finish by the design team), and it called on end users, which included staff from all organizational levels but not patients, for contributions at various stages—particularly during interviewing/observing and field testing. The end result was NKEplus.

The authors described heavy resistance to implementation of the NKEplus strategy outside the pilot site, which they attributed to skepticism in understanding exactly where the solutions that underpinned NKEplus originated. Lin and colleagues believed nurses throughout Kaiser Permanente's hospitals did not see the need for change to their current handover practice and therefore had not bought into the NKEplus strategy. Lin et al. (2011) highlight that, in their organization, DT-based innovations and change are normally coupled with training support and formal changes to work roles and position descriptions. The rest of the case study details re-implementation of NKEplus, a process that resulted in higher uptake and buy-in for NKEplus organizationwide. This (ultimately more successful) re-implementation process shares a number of similarities with the PD case study, thus 2 case studies are described in parallel in the following section.

The second case study investigates adaptation of PD to a health context. Specifically, it concerns design of an eHealth portal to assist patients undergoing treatment for weight loss (Das & Svanæs 2013). In contrast to the designer-led NKE redesign described above, the authors characterize the process as a design partnership with end users (which in this case were health care professionals and their patients). Moreover, as compared to the DT example, the PD design process took place in a research, not service, context that is typical of their respective applications.

As far as can be determined from the article, Das and Svanaes (2013) began the project with a preconceived idea that an eHealth solution could assist patients undergoing weight loss treatment (similar to the DT example in which the overall aim was to improve nursing communication and handovers). Where the process differs from the DT example is that, as per the authors' description, the actual design ideas came from the end users in future workshops that are typical of traditional PD practice. The health care professionals and patients who attended the future design workshops acknowledged the need for support in their treatment via self-help (e.g. educational materials, reminders, asynchronous communication between provider and patient, etc.) and suggested the possibility of an eHealth portal, which informed the prototypes that were presented to end users in subsequent workshops. The authors also investigated the differing priorities for various end users in the eventual design solution. Moreover, when an existing platform was presented to end users as a possible design solution, it was deemed insufficient and the researchers commissioned the custom build of a product that would meet end users'

requirements. This process took a year to complete, which amounts to a much longer timeframe compared to the rapid DT process described above.

In their second attempt to implement the NKEplus strategy, Lin et al. (2011) employed a more participatory version of DT via a "soft start" implementation process that made space for end user customization of the strategy. In contrast to initial implementation, the soft-start implementation was characterized by participation with "everyone on the same level conversing as peers" (p. 79) in the process. It also highlighted the fail-early-and-often mentality of DT, observable in the quick-and-dirty approach to trialing end-user-generated new ideas. Importantly, the authors ceded control over the solutions developed to the participants; for example, when participants raised concerns or criticisms with the proposed changes (or addressed them to the facilitators), the authors responded by asking the other participants to present how they would recommend that the issue be handled. In this respect, there is a clear priority of the process and quality of participation over specific details of the design outcome. The end result, however, was greater buy-in, more compliance, and improved outcomes for their hospitals. Like the PD case study, this process took significantly longer and, arguably, represented a more realistic process for changing long-standing ways of working (see also Carlgren (2013)). The authors note that other teams using DT in their work at Kaiser Permanente had experienced similar disengagement, where the innovations lacked sustainability in sites outside the origin of development. Lin et al. (2011) note the need for the design to arise out of end users' own concerns, which arguably is the central tenant of DT.

While the Das and Svanaes (2013) PD project involved a limited number of end users, there was transparency in the origin of design ideas. The DT and PD teams began with similar processes (eg, interviews, observations) but then diverged, with the PD researchers working with end users in idea generation whereas the DT team did this internally. We are unable, however, to determine whether the more participatory process employed by Das and Svanaes resulted in greater uptake and buy-in by end users with the final implementation; as with much research in PD, the focus of the paper is on how the methods of participation they used elicited valuable insights for design rather than the success of the resulting system in use.

DISCUSSION

The Lin et al. (2011) case study highlights that DT approaches can be employed in ways that limit the participation of non-designers to expert informants of the contexts of use, or evaluators of ideas, that have been generated through the process. This traditional, less participatory application of DT appears more likely to encounter difficulties and/or resistance in a health care context. The case study contains clear lessons for design of e-mental health and well-being interventions, many of which will be implemented in organizational contexts. Design solutions not generated with end users themselves are more likely to fail, a notion that receives support elsewhere in the literature (Gagnon et al. 2012; Wölbling et al. 2012). The manner and method in which design ideas are introduced, discussed, and progressed requires careful consideration for technology design in mental health, a context that is principally composed of highly educated and experienced health professionals who are

afforded considerable autonomy in their daily work. Modern application of PD in health intervention research leverages professional and consumer expertise to collaboratively achieve good design outcomes. Its egalitarian mind-set and process may be better suited to mental health professionals who regularly rely on their clinical judgement and expertise in high risk, complex situations. Drawing from and appreciating this experience through meaningful collaboration, as demonstrated in the Das and Svanaes (2013) PD project and the more inclusive process of the NKEplus redesign, is likely to yield greater uptake and longevity of research outputs in context. This claim is supported by Lin et al who, along with other DT experts in their organization, report experiencing ongoing difficulties with bedding down change initiatives that result from traditional expert-led application of DT methods.

One may ask, in promotion and practice of traditional DT methods, are we unhelpfully replacing one expert-led model in health research with another? The difficulty experienced by the DT teams throughout Kaiser Permanente highlight potential inherent limitations in the DT methods for a health care context and the level of experience required for effective practice (or adaptation) of them. The highly experienced team that led this project reported many problems with generating long-term change as a result of the innovation that came out of their DT cycle(s). Furthermore, in selecting the case study for this paper, DT projects in a health care context were scarce and novice-led DT projects were nonexistent. In light of these findings, the claims of novice user uptake of DT seem optimistic at best.

The Das and Svanaes (2013) project demonstrates the value of PD for buy-in and uptake of interventions; however, the traditional focus on process over outcome in PD research leaves unresolved questions around its utility as a methodology for intervention design, development, and implementation. From a non-design specialist perspective, the Das and Svanaes (2013) paper clearly articulated their methods and techniques, however, the method cards in the DT toolkits more clearly articulate the designer skill set (i.e. the tacit mind-sets and capabilities or what to look for and why). For example, the d.School Bootcamp Bootleg (Institute of Design) articulates mind-sets and behaviors, particularly around empathy and quick-and-dirty prototyping (and show don't tell), which may combine nicely with the participatory, egalitarian elements of PD. In the absence of these designerly mind-sets, it is likely that the early interview and observation work could miss the design perspective and end up an ethnographic study. This is problematic as, while this phase of the design cycle possesses an ethnographic-like quality in that it attempts to better understand existing workflows, circumstances, and people's subjective experience, it should also elicit data around tensions, contradictions, and opportunities for design— crucial design elements that may be overlooked with a purely ethnographic mind-set.

CONCLUSION

The very clear articulation of mind-set (and output expected from a particular method/technique) in the DT toolkits (such as the progression from empathize to point-of-view to ideate in the early stages of a DT project) provide clarity and design direction for the ethnographic and observational components of design projects. Much

can be learned from this approach in health intervention design research and the value of ongoing dialogue and collaboration between health and design research disciplines in this space should not be underestimated. As discussed in the introduction, however, access to mental health workplaces for observation is not an easily negotiated proposition. In comparison to DT, the more integrated nature, and egalitarian purpose, of PD projects supports greater opportunities for meaningful collaboration between research and clinical practice. If the mental health workforce can see the value of the project (because they have played key roles in its origin), research projects stand a greater chance of accessing the individuals and environments they require for intervention design.

We might also note in conclusion that there is a sentiment within the design research community that the notion of design thinking is in danger of being superficially reduced to a toolbox of easy-to-apply methods that appear to offer recipe-like solutions to a vast range of complex problems. This is a serious concern, and it is worth pointing out that the curricula of most studio-based design programs in higher education neither contain nor resemble what has become visible as design thinking. The existence of resources like Stanford's d.School Bootcamp Bootleg, a suite of methods that are freely distributed and packaged in step-by-step instructions is, we believe, a generous gift to the community at large. But their value in application to new and complex spaces (mental health services being our foremost concern in this paper) must be tied to the mind-set in which they are employed. In this domain, such a mind-set ought to draw from both studio-based design disciplines that have given rise to design thinking and from the social and ethical imperatives of participatory design. From design thinking disciplines, such a mind-set incorporates an appreciation of the nature of design as an exploratory, iterative, uncertain, and social form of inquiry (and synthesis) that is never perfect and never quite finished. This understanding of design practice is articulated well in Schön (1983). From participatory design disciplines, the mind-set involves an appreciation that good design emerges from thoughtful and humble facilitation, that participants need to be given the opportunity to take multiple and active roles in all aspects of design, and that shared ownership over proposals for change can be a more valuable form of innovation than technological novelty and disruption. If the design object and/or outcomes require widespread organizational uptake, handing over control of the design process (as in PD) in appreciation of this context can be just as important as the eventual product in generating (and managing) the change.

We in the e-mental health research community must debate and reflect on exactly what we are trying to achieve through the adoption of DT or PD in our work. Do we seek to incorporate new and potentially disruptive ways of working because they are freely available and promise (narrowly defined ideas of) innovation? Or are we in pursuit of methods and interventions that privilege the needs, voice, and contribution of health consumers and professionals? Moreover, from an ethical and moral perspective, egalitarian ways of working such as those exemplified by PD also represent a promising opportunity to redress the legacy of consumer disempowerment in mental health.

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CHAPTER FOUR SUMMARY OF RESULTS

A diverse range of findings emerged from the systematic review. Those of greatest relevance to subsequent studies and the research program more generally, will be summarised here. This includes the findings that pertain to the design of technologies to assist those with an existing mental health condition.

The review highlighted that participatory design and development of youth mental health and wellbeing technologies is an emerging field of research with a small number of studies, 17 in total, meeting the eligibility criteria for inclusion. The interdisciplinary nature of the field of research was emphasised by the range of project foci and disciplines represented in the included studies. That being said, arguably two quite distinct traditions of user-focussed research emerged; from health (Community Based Participatory Research: Schmidt 2009; Stewart et al. 2008) and design (User Centred Design: Madsen et al. 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008). Research that employed a hybrid health and design methods was also represented in the review (e.g. Lakey 2014; Moen & Smordal 2012; Valaitis, O'Mara & Bezaire 2007). The majority of projects that were included, ten in total, focussed on development of promotional and preventative health interventions. Of the seven projects which designed technologies for treating and assisting those with existing mental health conditions, the majority were conceptualised within the design discipline (Coyle & Doherty 2009; Løventoft, Nørregaard & Frøkjær 2012; Madsen et al. 2009; Mazzone, Read & Beale 2008; Wadley et al. 2013). Moreover, these projects involved creation of technologies for specific use cases and treatment populations, for example online therapy for young adults with psychosis.

Beyond the learnings associated with the design and participatory processes that emerged from the review, two important limitations of the field were revealed: (1.) limited consideration of and/or planning for implementation of the technology intervention; and, (2.) negligible prioritisation of process evaluation

Projects which developed technologies that were intended for use in existing mental health settings generally included mental health professionals as part of the research team. These projects also tended to be exploratory in nature (Coyle & Doherty 2009; Matthews & Doherty 2011; Mazzone, Read & Beale 2008; Wadley et al. 2013). As such, the intended implementation site was not always clear and project links to the site were rare. Of all the studies that were included in the review, two projects (which developed health promotion interventions) explicitly planned for intervention implementation via project processes and governance structures and this then had a positive impact on their eventual implementation. A minority of all projects reported existing relationships with outside champions capable of moving the project beyond the developmental stage (5/17), identified the implementation site (7/17) or included representatives from the intended implementation site in the design process. The exploratory nature of the projects overall was highlighted by the fact that only 5/17 had extended beyond the intervention piloting phase. It was impossible to determine the impact of participatory research methods on intervention effectiveness because only 2/17 projects reported formal outcome data resulted in data beyond usability and feasibility trials associated with the intervention.

For the majority of projects included in the review, involving end users were arguably less about ensuring the translation of the research output, and more about eliciting end user needs. As such, inclusion of end users in the design process was associated with consumerist intentions that included creation of more usable, effective and efficient interventions. As a result, largely consultative end user involvement was reported. Furthermore, understanding and learning from end user perspectives of the research process, along with perceived legitimacy of the outputs, was not possible due to a lack of process evaluation mechanisms built into the majority of the project plans (beyond usability and feasibility testing).

For the purposes of this program of research, the crucial result to emerge from the systematic review was that, despite an emerging focus on participatory research methods for the development of youth mental health and wellbeing technologies, implementation of the research output has been given little attention. The lack of implementation of technologies resulting from the projects included in the systematic review is reflective of a wider trend of poor uptake of technologies in mental health services (Gagnon et al. 2012; Montague, Varcin & Parker 2014). Consequently, a dearth of understanding around use of these technologies in routine mental health practice exists. For the most part, the participatory methods in the included research were employed with consumerist intentions, that is, to create better products. While end user consultations were shown to be beneficial through demonstrable flexibility, responsiveness, adaptability and human-centeredness in design, very little is known about the conditions that support technology uptake in mental health services. The value and quality of the research experience for end users also remains an open question with process evaluation not routinely reported in participatory research. With this in mind, how and why end users are asked to participate in this type of research requires deep consideration.

The value of the superficial end user participation evident in the majority of studies included in the systematic review was contested by the findings associated with the second paper presented in this chapter, *Mental health technologies: Designing with consumers.* Through insights and learnings taken from two case-studies associated with Design Thinking and Participatory Design research, this paper highlighted the difficulty associated with creating meaningful counter-cultural change in healthcare contexts, and moreover, the definitive importance of mindset in application of seemingly similar design methods and techniques. The case studies advocated for the prioritisation of empathy and understanding over innovation, along with deep engagement and collaboration with end users when developing interventions. Clear understanding and representation in the intervention, of the needs and priorities of those working in the implementation context, and ownership of the change process, were seen to be important for workforce buy-in and uptake. This is particularly apparent in relation to healthcare contexts where the workforce is afforded considerable role autonomy.

Combined, these two publications shaped the focus of the research project going forward as they indicated that greater scoping work was required with respect to understanding mental health services as implementation contexts (specifically, in the case of the current research, rural community-based youth mental health services),

particularly through eyes of those intended to use the technology. With this in mind, the next chapter presents an in-depth study of end user perspectives – those of young help-seekers and of the mental health workforce.

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CHAPTER FIVE PREAMBLE

The scoping study presented in this chapter is made up of two sub-studies which yielded two papers: *The promise and the reality: A mental health workforce perspective on technology-enhanced youth mental health service delivery* and *Technology to enhance face-to-face mental health services: A rural youth consumer perspective.* Given the rhetoric around the potential of technology to reach the unreachable, the disenfranchised and the disengaged (Griffiths & Christensen 2007), the current study, and the research program more generally, was grounded in a rural perspective generated from one rural South Australian region. The rural region was chosen for its availability and representation of the major organisational stakeholders of the newly established state-wide youth mental health system. The region's services were considered reflective of similar services across South Australia's other rural areas. The scoping study aimed to investigate youth mental health professional and consumer perspectives around the use of technology to facilitate mental health care in its traditional form.

An extant of literature exists about the potential for technology to revolutionise mental health help-seeking and service provision (Blanchard, Hosie & Burns 2013; Burns et al. 2010; Burns, Liacos & Freen 2014; Department of Health 2015). It is suggested technology will play a significant role in increasing access to, along with flexible and personalised delivery of, Australian mental health services (Department of Health 2015). More specifically, technology, as a youth friendly communication platform, is seen to have much potential to firstly engage young people in services and then to improve their difficult journey through services and the system. In the first instance, young people are inexperienced help-seekers and thus may have low symptom recognition and service awareness. They are also known to have a preference for self-reliance and informal sources of help (Hickie et al. 2007; Rickwood, Deane & Wilson 2007) which may be related to fear of gossip, stigma and social exclusion – particularly in smaller rural towns. Other practical barriers such as transport, opening hours and availability of specialists impact on young people's ability to seek timely help (Aisbett et al. 2007; Boyd et al. 2007). Furthermore, when young people have managed to access health help, they have expressed difficultly in negotiating the mental health system (Webster & Harrison 2008). With this in mind, prior research with young people has advocated for the use of technology in existing services at the young person's discretion and level of preference (Montague, Varcin & Parker 2014).

Similarly, from a workforce perspective, previous research has positioned technology in an adjunct role to current youth and mental health practice (Blanchard et al. 2012; Montague, Varcin & Parker 2014; Sinclair et al. 2013). Both young people and mental health professionals have reported a preference for face-to-face service delivery (Montague, Varcin & Parker 2014). Research with registered cognitive behavioural therapists and youth workers has demonstrated low use of internet-based Cognitive Behavioural Therapy (iCBT) programs (Fleming & Merry 2013; Whitfield & Williams 2004), a finding which is supported by research with rural health professionals (predominantly working in mental health roles) which demonstrated low technology use with consumers (Sinclair

et al. 2013). Furthermore, quantitative research with the youth health workforce (which included a high proportion of mental health workers) has demonstrated that technology is used primarily for administrative or referral purposes (Blanchard et al. 2012). The overall low use of technology has been linked to workforce concerns around ease of use, access to appropriate professional development, time associated with adapting to new work practices and potential increases to workload (Blanchard et al. 2012; Sinclair et al. 2013). Low awareness of available technology-related options, lack of policy direction and appropriate resourcing have also been reported (Blanchard et al. 2012; Cloutier et al. 2008; Montague, Varcin & Parker 2014). Concerns have also been raised about youth safety online, personal privacy and security of information, impact on the therapeutic relationship and potential marginalisation of specific groups of young people (Blanchard et al. 2012; Sinclair et al. 2013). At the same time, positive attitudes toward technology and a role for information communication technology in early identification and treatment of young people's mental health have also been reported (Blanchard et al. 2012; Montague, Varcin & Parker 2014).

With respect to the role of technology in existing youth mental health services, prior workforce research has been quantitative in nature (Blanchard et al. 2012; Whitfield & Williams 2004) and involved selected samples of youth mental health workers likely to be more supportive of technology in their work (Montague, Varcin & Parker 2014). Rural mental health perspectives have been represented by the selected views of private providers (Sinclair et al. 2013). As such, the first sub-study presented in this chapter contributed to the literature by prioritising an in-depth and holistic rural youth mental health workforce perspective, in order to minimise selection bias. Furthermore, previous research with young people has involved sampling youth reference group members with little experience of mental health help-seeking, who were unlikely to be representative of typical youth mental health consumers (Montague, Varcin & Parker 2014). With this in mind, the second sub-study extended the knowledge base by investigating the perspectives of current rural youth mental health consumers by exploring their experiences of a rural upbringing, the mental health system and their views on the role of technology in their health and help-seeking.
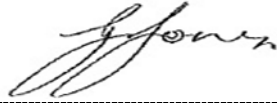
A particular emphasis was placed on discussing the results in the context of learnings around the design and implementation of technology in existing youth mental health contexts.

CHAPTER FIVE: PAPER THREE – IN REVISION

The promise and the reality: A mental health workforce perspective on technology-enhanced youth mental health service delivery

Authorship Declaration: SO conceived and designed the study, carried out data collection, analysed and interpreted the data, and drafted the manuscript. SL contributed to the design of the study, analysis and interpretation of the data, as well as the drafting of the manuscript. KW contributed to the analysis and interpretation of the data, as well as the drafting of the manuscript. NB, BM, AV, GS, GJ, MW, GA contributed to the design of the study and performed the critical revision of the intellectual content. All authors read and approved the final manuscript. All authors read and approved the final manuscript.

Simone Orlowski		Gabrielle Jones	
Sharon Lawn		Megan Winsall	
Ben Matthews		Gaston Antezana	
Anthony Venning		Geoffrey Schrader	
Kaisha Wyld		Niranjan Bidargaddi	

ABSTRACT

Digital technologies show promise for reversing poor engagement of youth (16-24 years) with mental health services. In particular, mobile and internet based applications with communication capabilities can augment face-to-face mental health service provision. The literature in this field, however, fails to adequately capture the perspectives of the youth mental health workforce regarding utility and acceptability of technology for this purpose. This paper describes results of in-depth qualitative data drawn from various stakeholders involved in provision of youth mental health services in one Australian rural region. Data were obtained using focus groups and semi-structured interviews with regional youth mental health clinicians, youth workers and support/management staff (n= 4 focus groups; n= 8 interviews) and analysed via inductive thematic analysis. Results question the acceptability of technology to engage clients within youth mental health services. Six main themes were identified: *young people in a digital age, personal connection, power and vulnerability, professional identity, individual factors* and *organisational legitimacy.* These findings deepen the understanding of risks and challenges faced when adopting new technologies in mental healthcare. Recommendations for technology design and implementation in mental health services are made.

INTRODUCTION

Mental health-related problems account for a significant proportion of the disease burden in young Australians (McGorry et al. 2011). It is reported that over 20% of young Australians (15-19 years) meet the criteria for having a probable mental illness, and 60% of these report to be *uncomfortable* in seeking help or advice for mental illness (Ivancic et al. 2014). Accordingly, it could be said that the individuals who would most benefit from formal mental health assistance do not access it. This failure to engage with mental health services has been attributed to many well-established barriers which include stigma and negative attitudes toward help-seeking, a preference for self-reliance and/or informal sources of help (e.g. friends and family), along with limited mental health literacy and emotional competence (Clement et al. 2015; Rickwood, Deane & Wilson 2007). Additionally, geographic and financial barriers can further amplify difficulties associated with help-seeking (e.g., adolescents in small rural communities with limited financial flexibility and availability of transport). With this in mind, a growing body of literature champions the introduction of more affordable, accessible and acceptable health services and support for Australians via technology-related solutions (Burns & Birrell 2014; Christensen & Hickie 2010b; Department of Health 2014; Eysenbach 2001; Griffiths & Christensen 2007).

Technology solutions widely studied for mental health provision mostly include internet based self-help programs, like internet based Cognitive Behavioural Therapy interventions (iCBT's) for treating mild to moderate mental health problems (e.g. depression and anxiety) or mobile apps for self-management and treatment which require limited or no interaction with health professionals. The evidence for iCBTs to address mild to moderate mental disorders is compelling (Meurk et al. 2016), and, as such, they are now recognised by national review bodies e.g. National Registry of Evidence-Based Programs and Practices in the USA and NICE UK (Reynolds et al. 2015). Telepscyhiatry (i.e. mental health service provision via video-conference) is also well established (Hilty et al. 2013), an approach particularly well suited to the more severe spectrum of disorders which require specialist professional input.

In contrast, relatively little is known about how and which of various technologies can augment traditional face-to-face mental health services, particularly to improve young people's engagement with and navigation of the broader mental health system (Montague, Varcin & Parker 2014; Reynolds et al. 2015). For example, mobile and internet based communication permeate lives of young adults (Australian Bureau of Statistics 2016) but traditional mental health service provision is face-to-face based. The limited number of prior studies situated in a mental health context suggest factors such as a lack of organisational buy-in and readiness have negatively affected uptake of technology (e.g., no strategic planning, limited leadership, and inappropriate funding) (Al-Qirim 2003; Koivunen, Hätönen & Välimäki 2008; Sadasivam et al. 2011; Whitten & Kuwahara 2004). Moreover, human factors such as clinician concerns around lack of clinical utility, suitability of consumers, technical skills, and links to current workflow and practices were reported as barriers to routine uptake in practice (Koivunen, Hätönen & Välimäki 2008; Whitten & Kuwahara 2004). Similar results have been reported in pre-implementation studies in youth mental health service contexts (Blanchard et al. 2012; Montague, Varcin & Parker 2014). This

body of literature suggests an unbalanced focus on the technical components of design over human and organisational factors. Evidence from the telehealth literature has demonstrated that clinician acceptance, along with workforce demand and availability, adequate technology resourcing and project champions are key factors in establishment of sustainable telehealth services (Wade & Eliott 2012; Wade, Eliott & Hiller 2014).

Despite some willingness to incorporate technology in mental health practice, its use with consumers is not widespread (Blanchard et al. 2012; Montague, Varcin & Parker 2014) and arguably underused by specialised mental health professionals (McMinn et al. 2011; Simms, Gibson & O'Donnell 2011). Moreover, technology adoption in professional mental health settings has not kept pace with the rate of non-professional use, presumably because clinicians have reported a lack of awareness of the options available (Boydell, Greenberg & Volpe 2004; Cloutier et al. 2008). Taken together, this evidence suggests that use of technology to engage consumers is, by and large, considered outside standard practice by youth mental health service providers (Blanchard et al. 2012; Montague, Varcin & Parker 2014). In fact, low rates technology use has been reported in CBT therapists, youth workers and rural health practitioners (Reynolds et al. 2015). Recent research with rural healthcare providers (which included psychologists, psychiatrists, clinical social workers and general practitioners) has suggested an adjunct role for technology in service provision. Factors such as ease of use, time required, access to appropriate professional development and impact on therapeutic relationships have been reported as factors affecting uptake of technology-based tools (Sinclair et al. 2013).

With the above in mind, a more nuanced appreciation of mental health work culture is required. For example, individuals currently providing mental health services are primarily tasked with ongoing risk identification, assessment, management and reduction of mental illness symptoms, with allocation of resources and training reflective of the significant priority placed on these endeavours (Ryan et al. 2010; Sawyer 2005). The structure and nature of the mental health system is primarily shaped "by risk and the imperative to manage it (Rose 1998, p. 184). While some innovative examples of use of technology to assist practice exist (Furber et al. 2011; Gardner et al. 2010; Mailey et al. 2010; Reid et al. 2013; Sethi, Campbell & Ellis 2010), the reported clinician preference for face-to-face service provision over technology-based interaction may be reflective, in part, of the risk-focussed culture in which they work (Blanchard et al. 2012; Montague, Varcin & Parker 2014).

An increasingly technology-focussed style of mental health service provision is also at odds with the traditional power distribution and hierarchy in healthcare (Searl, Borgi & Chemali 2010), and more specifically mental healthcare, which has a history of positioning consumers as disempowered participants (Lord & Dufort 1996; Matthews & Heinemann 2009; Mullaney et al. 2012; Nelson, Kloos & Ornelas 2014; Nelson, Lord & Ochocka 2001b). In contrast to this, a technology-based style of engagement implies a shift in power away from the clinician toward the consumer, and a focus on their needs and preferences. A further complicating factor with respect to technology implementation in face-to-face mental health services is the heterogeneous nature of youth mental health service provision in Australia. The different organisations that deliver youth mental health services generally work within distinctly different models of practice. In turn, these differences then impact on the

individual clinician's mindset. For example, interactions with young people can be primarily therapeutic or alternatively case management in nature. Additionally, some organisations run a dedicated youth service, whereas others deliver a serve spanning multiple age groups. Services can also differ with respect to whether they implement an illness or strengths based service model, and whether their primary focus is clinical or psychosocial in nature.

The current study

Previous research around the role of technology in face-to-face youth mental health services has been quantitative in nature, driven by selected samples at an organisational level (Blanchard et al. 2012), or involving a convenience sample of clinicians who were likely early adopters of technology in clinical practice (Montague, Varcin & Parker 2014). Furthermore, research with rural mental healthcare providers has focused on the individual perspectives of private care providers (Sinclair et al. 2013). Thus, the literature in this field fails to adequately capture perspectives of the broader youth mental health workforce regarding their receptiveness and readiness toward use of mobile and online-based technologies in their work with young people, particularly to improve their engagement with and navigation of the broader mental health system. The current study, therefore, aimed to contribute to the literature via an in-depth, holistic and systemic research approach. To achieve this, it sought the perspectives of existing government-based frontline teams servicing different tiers of the youth mental health system. Their perspectives were balanced by the views of individuals working in middle and upper level management roles and in more general youth-based services.

METHODS

Study Setting

Technology used by clinicians when working with consumers is influenced by the type of mental health services available as well as integration between them (Garland, Plemmons & Koontz 2006). The Australian mental health system is comprised of three tiers. Tier one: Primary care - often the first point of reference for help seeking consisting of those individuals/services and informal supports with no formal mental health training. Tier two: Specialist care with mental health expertise; these individuals/services tend to see clients with moderate to severe mental health disorders or those at risk of developing one. Tier three: Specialist mental health services; these services are multidisciplinary in nature; they provide varying levels crisis response and assertive outreach (and inpatient services) to clients who may present as difficult to engage and/or have complex needs (Government of South Australia 2012). Each of the tiers of the system were represented in this study.

Participants

Data were collected from general and mental health youth workers from one rural South Australian region. More than three quarters (77%) of the 1.65 million people living in South Australia reside in the greater Adelaide area and the remainder are widely dispersed throughout the non-metropolitan landscape measuring 982,380km^2

(Australian Bureau of Statistics 2015). Geographical pressures are, therefore, part of providing mental health services in the state. The region sampled in the current study was chosen because the availability and distribution of its major stakeholders in youth mental services reflected that of similar services across South Australia's other rural areas. Participants were recruited to four focus groups (n=40 participants) and semi-structured interviews (n=8 participants). Refer to Tables 2 and 3 for a description of focus group participants. Interview participants were comprised of three youth mental health clinicians (one female): two were social workers and one mental health nurse (two of which were aged 18-40 years and the third 40+ years); and five support and managerial/executive staff (three female): two were executive level management, one middle level management, and two project officers (20% aged 18-40 years and 80% 40+ years). The study received clearance from the South Australian Department of Health Human Research Ethics Committee (HREC/14/SAH/34).

Table 2

Focus group demographic information

Number	Type	Composition	Number of participants	Gender	Age
1	mental health service 1	existing team	14	70% female	18-29 (33%) 40+ (67%)
2	mental health service 2	existing team	7	86% female	18-39 (71%) 40+ (29%)
3	mental health service 3	existing team	13	62% female	18-39 (8%) 40+ (92%)
4	Youth service workers	various	6	50% female	18-39 (50%) 40+ (50%)

Procedure

Focus Groups

Focus groups were chosen as the primary data collection method because they enabled group-level discussion, to unpack and debate personal and professional beliefs and understandings of technology in their work. The focus groups lasted between 1.5-2 hours in length and were audio recorded. Three of the four focus groups were

composed of staff from pre-existing mental health teams working with youth in the region, therefore participants were known to and had working relationships with each other. Focus groups were arranged by emailing the team leader of the service, with composition dependent on staff availability and willingness to participate, and aligning with times designated for team meetings or professional development. Focus groups 1-3 were carried out at the participating service. This approach allowed analysis of both individual and service-level experiences. In order to gain a wide variety of youth sector perspectives, staff in other youth-related services (e.g. education, local government, psychosocial support) were also recruited and participated in one focus group which was carried out at workplace of one of the participants. A preamble at the outset of the focus groups outlined that by technology we were referring to mobile and web-based tools which are usable by the clinician in collaboration with the consumer. Examples of questions included: *How comfortable do you feel using technology in your professional practice? (both philosophically and practically); How could your current comfort level with technology be improved?; In which ways are you currently using technology in your professional practice?; and What are the barriers to your use of technology in your professional practice?* (See Appendix C for full list of focus group questions).

Table 3

Profession of focus group participants

Profession	Percentage
Social worker	17%
Mental health nurse	19%
Psychologist	7%
Psychiatrist	2%
Occupational therapist	5%
Counsellor	10%
Youth worker	21%
Management	10%
Other (Aboriginal health, community health, youth project officer)	10%

*note totals do not add to 100% as some workers identified with more than one profession

Semi-structured interviews

Participants were approached via email regarding their participation in the interviews. The semi-structured interviews lasted between 1-1.5 hours in length and were audio recorded. The interviews were carried out with youth mental health clinicians working in three different South Australian rural regions (*n*=3) and managerial/support staff working in one of the mental health services represented in the initial focus groups (*n*=5). The interviews sought to explore themes and issues identified in the focus groups in greater detail. The data from the focus groups was then triangulated with data extracted from semi-structured interviews. The interviews were carried out until data saturation was reached and were predominantly at participants' workplaces (except two; one of which was conducted at a café and the other at the researchers' workplace).

All focus groups and interviews were conducted by the first author.

Member checking workshop

To increase validity of the findings, member checking was also carried out via a participatory workshop (Creswell & Miller 2000). Individuals who participated in the original focus groups/interviews were invited to attend the workshop and 14 of the original 48 study participants chose to. During the workshop, draft researcher-determined themes and sub-themes were provided as a starting point and, in groups of 4-5, participants produced their own thematic maps. This involved adding, deleting and repositioning themes where participants deemed it appropriate.

Sampling frame

In order to gain an in-depth insight from a diversity of workers' views, participants were recruited using a maximum variation sampling approach (Grbich 1998). This approach involved sampling views from a small number of cases that represent the diversity relevant to the role of technology in youth mental health services (Grbich 1998). Sample size was determined when saturation of ideas was reached, as determined by the research team during data analysis discussions (Rennie, Phillips & Quartaro 1988).

Data analysis

Focus groups and interviews were professionally transcribed (and checked for accuracy by the first author). Transcripts were then analysed using inductive thematic analysis (Braun & Clarke 2006) using NVivo software (QSR International Pty Ltd. 2012) to manage the data . The analytic process described by (Braun & Clarke 2006) was adapted for the current purpose. Initially, this involved: (1.) Reading and re-reading of transcripts; (2.) Generation of initial codes; (3.) Searching for themes; and (4.) Reviewing themes and production of a thematic map. To increase the validity of the results, steps 1-4 were independently carried out by first and fifth authors. The resultant thematic maps were then compared for consistency and an overall map was produced. These themes were then member checked at a participatory workshop (as described above). The first author then

carried out Step 5. Defining and naming themes – the final themes aimed to represent the various interpretations of the data. The second author then provided a logic check regarding finalisation and parsimony of the themes.

RESULTS

Six major themes emerged from the data. direct quotes from participants (see Table 4) are used to demonstrate each theme. Together, they represent: an overall picture of the digital world in which young service consumers now live (theme one); the enablers and challenges this is perceived to create for delivery of mental health care and the therapeutic relationship with consumers (theme two); how technology potentially changes and challenges traditional health professional expertise and interactions with consumers, shifting the power base (theme three); how workers then variously respond to and cope with these challenges (theme four); workers' underlying technology literacy that shapes their response to these challenges (theme five); and, the role of the organisation in addressing these challenges (theme six).

Young people in a digital age

Perceptions of the preferences, motivations and reality of young people's lives were central to discussion of the role of technology in youth mental health services. Participants saw technology as a central part of young people's lives. This was perceived to have implications for the way consumers engage with the clinician and the service and the types of therapeutic conversations that occur between consumer and clinician. There was the general sense that young people are *born into* technology. Some workers suggested that technology could have a positive impact on young people, such as promoting opportunities for connection, belonging and support. Overall, however, there was a strong feeling that reliance on technology could have both direct and indirect effects on youth health and wellbeing via cyberbullying, addiction to technology and increasingly limited face-to-face communication. It created a new and complex world in which to provide mental health care, with advantages and disadvantages, and an unclear sense of how to control for these within their role. Participants' comments highlighted generational differences that they perceive can exist between a clinician and consumer, with clinical best practice involving the ability to appreciate and work within these differences. Participants also spoke about the fine balance between being relatable as a clinician and appearing too eager to appear on a young person's level.

Personal connection

Discussions around the role of technology in youth mental health services highlighted the centrality of human interaction and connection in the provision of effective mental health services. Technology was seen to simultaneously enhance and restrict this central component of service provision, with a complex series of implications and consequences. There was general consensus among participants that technology-based interaction filters communication in a way that does not assist clinical practice because the latter relies heavily on non-verbal consumer cues and the ability to develop a strong therapeutic rapport via personal connection. For

this reason, participants viewed technology as an adjunct only to face-to-face practice. This was also linked to the notion that therapy offers an opportunity for young people to extract themselves from technology and to develop skills required for in-person communication, and active promotion of technology in clinical work may hinder this.

Despite these reservations, participants perceived value in technology for its ability to promote connection and enhance the vital consumer-clinician relationship in previously impossible ways. Short Message Service (SMS) and email (and rarely Facebook chat/messaging) were reported as currently used to connect with consumers outside of sessions; particularly around appointment organisation or reminders. These practices were linked to consumer preferences and awareness of the limited financial freedom most young people face in making phone calls. In the rural context, this technological value took on particular importance. Despite outreach provided by each of the services, consumers living in more remote locations (i.e. outside of larger rural centres) were seen as particularly vulnerable to experiencing extended wait times between appointments, due to both the regularity of outreach visits and consumers' ability to travel to the clinician. Even in larger rural towns, public transport options were restricted for many consumers. Moreover, participants expressed a desire to engage more readily with consumers' families as this was a seen a current area of weakness in service delivery. Participants acknowledged that many young consumers deal with intergenerational familial problems and, despite often complex relationships, family was perceived to occupy a powerful support role in young peoples' lives. Current /emerging technologies were suggested as a means by which increased information sharing and /or shared use of therapeutic technologies outside of session could occur. The same was also true for schools, counsellors, peers/friends and other services that may be a part of the young person's help seeking experience.

Power and vulnerability

When analysing the role of technology in face-to-face youth mental health services, power and vulnerability underpinned a number of perspectives across the data. The concepts were referenced directly in the suggestion that greater use of technology with consumers questions the historical location of power between clinician as expert and consumer as recipient of care. The digital age was seen to be disrupting more traditional power structures, opening up new vulnerabilities in how people relate to each other, and altering the assumed capacities for each party to exercise control within these environments depending on the extent and form of their engagement with technology. Furthermore, for some youth, it was noted that acknowledgement and demonstration of their digital literacy and skills may provide an opportunity for the young person to occupy a position of power in their family which had not previously existed.

Power and vulnerability were also referenced indirectly in discussions around language and technology. Participants said that their ability to connect and form a strong therapeutic bond with a consumer required them to engage in meaningful conversations around the young person's experience. Language was seen to be crucial in this process. Awareness of popular social media sites/applications and games such as Snapchat was seen as

an important way to promote engagement with young people. Some participants asserted that fluency with current technical language was not necessary; however, a willingness and curiosity to seek clarification and learn from the young person was useful to the relationship. In other instances, participants' perceived mastery of relevant language as linked to clinicians' credibility in the eyes of the young person. This tension between perspectives highlights the professional implications and vulnerabilities inherent in greater technology use in youth mental health services. Moreover, in further exploring some clinician concerns around use of technology (i.e. concerns around increased clinical risk and confidentiality/privacy), non-clinicians noted that some of the perceived resistance to technology may have been masking vulnerabilities around exposure of limited skill and confidence in application of technology in clinical work.

Clinicians generally talked about being familiar with technology (i.e. knowing both *how* and *that* it works and is recommended), which spoke to a personal acceptance of the technology and a need for congruence with their professional practice. In contrast, the non-clinical/management staff talked more specifically about skill and confidence when using technology in front of others such consumers and peers (i.e. overcoming fear of the unknown and impression management). These two views were identified as similar but different ways of talking about control – the ability for the clinician to manage the way in which technology is (or is not) integrated into their practice and equally the extent to which they desire to appear in control of their work.

Professional identity

In a number of different ways, participants explored, questioned and asserted their professional identities when discussing the impact of technology in youth mental health services. The professional identity theme manifested in discussions around when, why and how technology should be used by clinicians and consumers. In-person service provision was foundational to the participants' role identity. Participants described a definite time and place for technology in their work and indicated that technology has a role both in and outside of session and as a bridge between the two. When appropriately resourced (i.e. having a phone, tablet or laptop and internet connection in-session), some participants reported using technology with consumers to increase engagement and develop rapport. Others reported using technology to access websites such as *beyondblue* (Muir-Cochrane 2006) to provide psychoeducation to consumers and their families and, to a lesser extent, recommending client use of mobile apps such as Smiling Mind (Müllert & Jungk 1987) or websites such as MoodGYM (Muller & Druin 2012). Technology was deemed to have significant potential to engage young people by tracking clinically important neuro-vegetative markers, such as sleep, diet, mood, energy, concentration. Other novel uses of technology included social media genograms and systematically assessing a young person's technology use - one clinician broadly termed this a "Media Diet" and used systematic questioning around online and general media consumption to determine its impact on mental health and wellbeing.

Furthermore, workers described a distinct set of conditions that would facilitate their use of technology in professional practice. This included personal familiarity with the technology in question, accessibility to resources

in-session such as hardware and an internet connection, and a desire for a clear evidence base and recommendation by reputable individuals and/or services. However, keeping up with the myriad of options available and the break-neck pace of technological innovation was seen as a barrier to uptake in clinical practice. Ultimately, workers reported that they needed more time to feel comfortable and prepared in use of technology-based applications and systems as an adjunct to their clinical practice. This included the need for: (1.) Reliable internet access - which can be limited in terms of connection and cost for some rural youth consumers; and (2.) Consumer interest and willingness to engage with technology as part of their engagement with the service.

Professional identity, expressed through face-to-face service provision, was also tied to discussions of risk. In particular, asynchronous technology-mediated communication was associated with risks in inaccurately assessing a consumer's mental state, and an increased possibility of miscommunication or misinterpretation. Clinicians were very clear on the implications of their professional and legal responsibility to accurately assess consumers' level of risk. This was linked to the importance of non-verbal cues derived from face-to-face engagement with consumers. Dealing with risk was identified as a major focus of training for mental health clinicians; introducing technology, as a way of engaging with consumers, was viewed as potentially increasing the risks a clinician must contend with. Furthermore, maintaining confidentiality of consumer data was seen as central to the work of youth mental health services. For example, the use of technology as an adjunct to clinical practice raised concerns around how and where data would be stored and the confidentiality of clinicians' identity (e.g. giving out email addresses or communication over social media). This limitation to technology was perceived as a particular concern in the rural setting in which personal and professional boundaries can and do blur. Concerns were also raised around the utility of some technologies and their applicability in working with some clinical presentations (e.g. concerns around increasing access to clinicians for consumers with a borderline personality disorder diagnosis or the appropriateness of technology when working with consumers with a diagnosis of schizophrenia). There was also a feeling that clinician and service use of technology with consumers might implicitly encourage overuse or reliance on technology.

Individual factors

Individual worker factors such as age, personal attitudes/beliefs, preferences and experiences heavily influenced their perceptions of the role of technology in youth mental health services and society more broadly. For most participants, prior experience with and use of technology in their personal lives translated to an increased willingness to experiment with or use technology in their clinical practice. There were, however, examples of dissenting cases both where personal use did not translate into professional use and limited personal use did not prohibit professional use. Moreover, older age was linked to unfamiliarity and inexperience with technology and a difference between the way in which older generations communicate and view/interact/use digital and ICT-based technologies compared with today's youth. Participants expressed a general belief that ICT and digital technologies are an increasingly important part of modern society – with the ability to make daily activities/routines faster and easier. Personal preferences around face-to-face service provision, however,

seemed to be associated with a belief that technology limits the quantity and quality of face-to-face connection. This belief was linked to observed personal consequences such as reduced social connection, engagement and resilience. These consequences were often linked to the internet and social media and particularly their negative aspects such as obsessive use, cyberbullying and general perpetuation of negative and anti-social behaviours. A minority of participants rejected these views and asserted that technology only reflects the wider social experience. As discussed earlier, technology was generally seen as a way of interacting with young people on their terms.

Organisational legitimacy

Participants discussed a number of organisational factors that, taken together, suggested a need for legitimacy in any technology-related change to youth mental health services. These factors included appropriate organisational priorities, policy, systems and structures to support use of clinically appropriate and useful technologies that are integrated into current practice. Use of technology in practice was not seen as the sole responsibility of individual workers. Technology adoption was linked to organisational budgets, built around organisational priorities and strategic direction, which are largely determined by outcomes and resourcing the organisation values and promotes. It was clear that clinical outcomes and cost savings were important in encouraging large-scale investment in the required resources. The term "culture change" was used in reference to use of technology with consumers. When discussing the role of technology in services some participants pointed to prior negative experiences with technology such as a lack of streamlining between organisational databases. Non-clinical/managerial staff discussed the need to understand current work practice(s) in order to build supportive structures and business systems.

Organisational legitimacy was also reflected in participants' expressed need for clear and detailed organisational policies and procedures to govern and drive use of technology in practice. However, non-clinical/managerial staff generally felt that excessive policy-making might hinder staff innovation and promote prescriptive work practices. These dichotomous perspectives speak to assumptions around risk – both in terms of what is seen as risky and the personal level versus organisational responsibility desired in promotion of innovative practices. In some instances, current policy prevented participants from downloading apps and various programs onto organisational assets which conflicted with a desire by management for innovation.

Use of technology in clinical practice was also linked to use of SMS, email, social media and applications for tracking clinically relevant indicators such as mood and sleep. While the benefits of technology were seen in the ability to more closely track consumers' progress and level of risk, it was also associated with concerns around an implied level of clinician responsivity and possible increases to workload. These concerns included a perceived lack of processing around information communicated via these modes of communication and unclear guidelines around when and how clinicians should respond to potentially risky information, particularly outside of work hours. Some participants discussed guidelines they negotiated with consumers to establish clear

expectations of when and how the clinician would respond. Overall, clinicians reported experiencing only minor abuses of the system.

Table 4

Illustrative quotes for the major themes

Young People In A Digital Age

To match what is, what the next generation is going to do and what, what sort of my generation did ages ago worked for us, but it may not work for the rest and we might have to adjust it dramatically. (Participant 26)

I think that having that understanding that technology is a part of their life, it is a massive part of their life. (Participant 16)

for many of them they haven't known life without it and I think it's only going to grow and increase um and so I think probably, organisations at some point, need to balance the risk with relevancy and them as the centre. (Participant 38)

Technology can be a source of great stress for them um you know with cyber bullying and all that sort of thing so um and it can be a great source um of strength for them. It can be a real um source of social connection um for them um which all impacts the person's wellbeing. (Participant 31)

You know, we're not natives. We're definitely immigrants to this world. (Participant 48)

Personal Connection

You need to be able to respond to somebody so they feel like there is a human being at the other end of – even if it's a little text or something but there's somebody there that cares about me that I can reach out and connect with even if it's just through a few words. (Participant 39)

If you had an interactive online tool that allows you to stay in touch with your client, particularly if they live out country …….. and you know you have a client there who is you know quite wobbly or has risk issues — so that you have an online chat function with a client. (Participant 34)

It would be really ideal for a parent to be involved in the level that they can help the young person with a thought diary or, or you know sit with the young person and do a meditation exercise or you know like but to have them involved on that online platform in some way would help strengthen the support —you know that already existing family and friends support network of a young person

so that they use that support network a bit better with that technology. (Participant 35)

I think one of the difficulties with existence in the modern world is that ah it may actually be hiding a connection - that everyone's connected to everyone else but in the most superficial of ways. And what therapy is, it's almost a step backwards in terms of communication. It allows you to have in-depth, meaningful conversations about what's most important in life or what's most important in relationships or what's most important with children………I feel like that can only really be done in the context of a meaningful, intimate, face-to-face conversation and to try and do that via media, I think is a very risky thing. (Participant 9)

I mean the non-verbals are so vital in our system. (Participant 14)

I was just going to say, technology fundamentally filters the human experience and also humans filter themselves by using technology. (Participant 2)

I feel like it's a real evolution over the past decade that we're all connected ……but relationally, um it's kind of falling apart. So people are kind of more aware of each other's lives than ever but at the same time, not at all. And so I think yeah, not wanting to conclude on a negative note but that's just something we have to be so conscious of that we think young people are connected or we think as individuals are connected but having 500 and something friends on any sort of social media doesn't actually mean you have any sort of relationship or connectedness to those people. (Participant 26)

Power and Vulnerability

I'm really conscious at times that I can sound like I don't know what I'm talking about but I use the wrong language so, so like I notice my clients now talk about in-boxing each other and it took me a while to pick up that that's a private message on Facebook and they use in-box as a verb…………….I have a friend who says that she tags things on Facebook when she actually means she posts them on Facebook and I kind of cringe every time she says it, wanting to correct her and I, and I wonder if our clients do that with us, if they're cringing. (Participant 12)

How do you shift power which is, at the moment, predominantly owned by service providers, into a middle space of a collaborative approach, rather than an external recipient set up (Participant 46)

Like any new technology when you bring that in, people are worried about not, how they're seen by their peers, whether they be good enough at it or whatever um and then a lot of the excuses you get coming up – that's when you get the secondary barriers where people will then put up the stuff around confidentiality, around not enough training, around, "It takes me longer to do it," - (Participant 45)

Professional Identity

Ways technology is incorporated into clinical work

It would be great to have apps and websites where you can start therapeutic work in session. I'm thinking for example, CBT thought diaries, you could, young people could start them online with you in a session and then they could do that work between sessions and you'd have access to that. So you know it removes barriers like people forgetting to bring things to session like if you've got paper worksheets (Participant 35)

I think it can be useful to titrate the social exposure so whilst there can be a way to avoid, it can also be a way – like I've got one client who's very socially anxious sort of to the point of just freezing when you would ask her a direct question so it was useful to take a back step and try and communicate via email. (Participant 11)

Like if we were doing some goal setting, to kind of ignite some passion I might "well let's jump on the internet, let's research what you want to do" (Participant 29)

Smiling Mind I use myself and so therefore I'm quite happy to that share that with clients. (Participant 35)

there's lots of things that you can access through the internet like …… Beyond Blue, there's….. Mind Gym, there's lots that I, I do all the time. (Participant 24)

I've started to include information ah about social networking into genograms with young people. So getting information about who's on there – who's in their family but also who's in their social network, who is on Facebook and within their family, who are they friends with? So often that produces very useful information in terms of quality of relationships, whether a mother has blocked the child, which has happened……. Or vice versa yeah. So sometimes the technology although not directly being used, can be a measure of other things we're interested in, in therapy. (Participant 2)

I send an appointment reminder in the morning um for their appointment and um they'll either reply "yes, I'll be there" "no, I won't" (Participant 40)

Conditions of use

Um one of the ah concerns is around whether they're evidence-based and um whether they're you know, therapeutic and all of those sorts of things. (Participant 43)

I think it's wonderful if in the future things go down so that there's greater access to support through technology but just not forgetting those regional young people who don't have access to it and not basing everything around that when there's some that just can't access it. (Participant 38)

I feel like I only recommend if I know the site really well and I know that page on that site really well (Participant 12)

Your day's filled up with seeing clients, doing case notes, making phone calls um and you know you definitely have enough work for the whole day. ………….. that's the barrier for me is kind of finding that time to sit down and go through it. I'd want to use it myself if I could, if it was an app that I could use. (Participant 35)

Confidentiality

Make sure that there was…..you know, there was secure ways of, of if you were emailing clients so that we are protecting their confidentiality. (Participant 16)

Actually sometimes have issues around confidentiality too about giving other people your email address. Um so I know with the, the youth they can have an app for everything, you know, like what they eat [laughs] you know, how many calories certain foods…. I don't see if, if they can resource it themselves that there's an issue, you know, that's when yeah I'm, I'm sort of a bit more looking into the confidentiality side, what you can give them. (Participant 16)

Risk

If people log into Facebook and leave messages and you don't respond, well then that's very risky so they [management] didn't like the idea. (Participant 6)

Does that outcome, what you write down and document and your interactions and actions………..stand up in a Coroner's court? (Participant 27)

When I scroll back over my texts I've had very intimate and connecting conversations by texts but I have never had that with a client and I don't think I would even attempt to use that same level of intimacy through text um with a client. ……… it's because it's more risky, because I can take risks with my closest friends that they will misinterpret what I say and that together we will make sense of that but I can't take those risks with my clients. (Participant 12)

Perpetuating a problem/promoting over-reliance

As a parent it's scary to see your children so reliant on technology. It centres their whole, their whole world, you know (Participant 16)

There are a lot of young people who are, you know, living in a cyber-world or a gaming world um who are actually, you know, really are making themselves extremely unwell and ah who are not engaging with school or friends and not eating well that is just horrendous. And so um sometimes when we think about like um, you know, gamification – gamification of things, it's always for me, um there's always for me just that little bit of thought and risk about again reinforcing some of those things that are in fact really unhealthy for young people. (Participant 45)

Personal factors for clinician

Personal preference and experiences

Yeah. I really like using technology. I think also like I am that way inclined myself, I feel one step removed, comes more naturally to me. (Participant 11)

Even to remember, oh yeah maybe you could look up an app on that, oh er it just wouldn't occur to me because I don't do it in my own life (Participant 32)

If I think about myself being not particularly IT literate… one thing I find that I use a lot with clients is I use the internet quite a bit with clients when I'm in session with them we might be talking about .. something they've looked up and I'll look it up then and there with them and then it's a useful point for discussion. Um, but I feel like that's a different use of technology, that something that…… deepens the conversation rather than sort of eh shortens the conversation. (Participant 9)

Attitudes/Beliefs

It's a way of life, like you've got to incorporate it or you just, you know, get left behind. (Participant 44)

I went to a Fringe [music festival] event, this is a few weeks ago………. I was the only person there not fiddling with my phone. And they weren't there turning it off, they were all fiddling …….. I just feel that's a very sad reflection on how - how intrusive technology has become and how addicted to it we've become. (Participant 9)

This is a business of relationships and it's a business of narrative, and needing an interpreter to communicate with a person who speaks a different language is, makes it really difficult………. and that interpreter is um, is, is the technology. I'm not saying that's necessarily a good or a bad thing, but, but I think that's the discomfort perhaps that we're feeling about that. (Participant 1)

Age

The workforce in mental health is average around 50 or thereabouts; it is a group of people who are not as accomplished using media as a younger generation would be. (Participant 46)

Organisational Legitimacy

Priorities

So, any sort of cultural change, it needs to come from the top down. (Participant 44)

So the strategy that we're thinking about is that we're trialling it in a, in a semi controlled and reasonable way with the part of our service that makes the most sense – the youth component and that we hope that we can demonstrate something really strongly that gives us a strong business case. (Participant 45)

This whole transforming healthcare imperative that is happening at the moment, there is a recognition that investing in that area may well be worthwhile in terms of improving clinical outcomes and saving costs at the same time. (Participant 46)

Policy

Generally speaking, I think policy papers have much more to do with risk management than with enhancing the – sort of, moving forward in terms of opening up new creative spaces. (Participant 46)

Organisational policies can't keep up with the internet and so people will find different ways in which to, to use the benefits of it really (Participant 6)

We don't want to be overly prescriptive and you can go way too far in terms of um, in terms of prescribing how people do and don't work around things like technology, there does need to be, there does need to be some framework of support around that. That might be things like policy procedure like a worksite instruction…… guidelines. (Participant 45)

Professional implications and expectations

What I've found with a lot of technologies and Facebook and Twitter and all this stuff ……..there could be a risk um if you were receiving that kind of constant feedback information from um that you know where does that leave us around responsibility to respond to what we're seeing. (Participant 30)

Yeah. I really like using technology…... But I always have my Out of Office on and I always make it clear that I can't um respond and at my other job we use text quite a lot but always just make it clear that you can't respond back to this number and um we're only open during these hours. (Participant 11)

Clinical utility and appropriateness

So yeah, if you can be smart about it, you know, how's it actually going to help clinicians in what they have to do, well it will be a winner. (Participant 44)

Talk to teams about the benefit, get teams' feedback because they're the experts on how – what's going to work for them. ……… really involve them in the process, 'cause if they feel like they can have a part of how it's going to work they really start to own it. (Participant 44)

Yeah and you can't always um put a technology in and expect it to just happen itself. We learned that with [e-health initiative] implementation too and so um you can't just put it in and think it's going to work. You need a lot of time to create the business systems, to change the business systems to support the process (Participant 45)

DISCUSSION

The results of the current study demonstrate the multitude of factors that are at play for mental health workers when considering whether, and how, to use technology to engage youth consumers. While some are internal factors, others are not because they concern organisational and discipline-wide issues. Consistent with other studies in the field (Blanchard et al. 2012; Cloutier et al. 2008; McMinn et al. 2011; Montague, Varcin & Parker 2014; Reynolds et al. 2015; Simms, Gibson & O'Donnell 2011; Sinclair et al. 2013), the current results indicate that, while some community-based mental health professionals are using technology to engage consumers, it is not currently standard practice. In general, the workforce positions technology as an adjunct tool to complement standard practice, with face-to-face modes of working occupying a central role in service delivery. The low rates of technology use found in the current sample of community-based youth mental health professionals fits with findings from studies with CBT therapists, youth workers and private rural healthcare practitioners (Reynolds et al. 2015).

The current results demonstrated overall resistance to technology-related changes based on a clear preference for development of a *personal connection* through face-to-face engagement with consumers; clinicians perceived their skillset as tied to this way of working. These results, along with the results of prior studies, resonate with findings from the earliest sociotechnical studies. The idea that every technology participates in, and contributes to the definition of a sociotechnical system has highlighted that no technical change in people's workplace could have only instrumental consequences (such as, for instance, increased efficiency), but also has effects on things like workers' autonomy, morale and professional identities (Rice 2013; Trist & Bamforth 1951; Trist et al. 1963). These early sociotechnical workplace studies, along with the current results, continue to underline the importance of autonomous, adaptable, complex and meaning-driven work for the creation of successful technologically-mediated workplaces. More recent sociotechnical research highlights the importance of degree of fit between technical design and level of local control and flexibility afforded the individuals in working with the system (Eason & Waterson 2013).

Implications for work practice

Individual beliefs, preferences, experiences and work practices were shown to impact on use of technology in community-based mental health practice. Similar to prior research (Sinclair et al. 2013), most participants viewed integration of technology as *extra work* for which they were under-resourced. This took the form of: (1.) Physical resourcing - internet enabled devices and internet connections required to bring the technology where it is needed (i.e. for use with consumers) are generally unavailable; (2.) Time - clinicians have limited time to remain abreast of the technologies available, to familiarise themselves with individual technologies and to be confident regarding their evidence base; and (3.) Skills and training - the majority of clinicians felt undertrained and skilled in the use of technology to engage consumers. With this in mind, recent investment in workforce training and

support, along with redefining clinical practice models, to facilitate technology integration into mental health work is most welcome (Reynolds et al. 2015).

With respect to the proposed technological change to youth mental health services, the *power and vulnerability* theme highlights the implications of, and on, the socio-political landscape. Mental health clinicians have been socialised and trained in an 'expert' role which, in turn, positions consumers as (largely passive) recipients. Whilst there is a definite policy trajectory toward more empowered consumers (Australian Government Department of Health 2013), the day-to-day practice of mental health service provision sits squarely in an expert-recipient model (Lawn 2015). Technology-based engagement with consumers has the potential to actively shift the power away from clinicians toward consumers. The vulnerabilities and uncertainty inherent in this shift are best made visible in the references to language present in the results of the current study. References to lack of clinician fluency with terminologies associated with use of digital applications and social media popular with youth, speak to a gap in knowledge and skills. The mental health workforce would need to work through this gap in order to enact the required practice change. Engaging with consumers via technology creates tensions between traditional ways of working and a growing appreciation for more consumer-centred approaches. These results have been echoed elsewhere with suggestions that "intrinsic judgements of acceptability and the expectations accompanying their socially defined role" impact on a clinician's decision to use and/or refer clients to technology-based tools and supports (Sinclair et al. 2013).

Similarly, participant concerns around confidentiality and legal and professional implications of technology are based in shared disciplinary perceptions of risk and the consequences of challenging longstanding ways of communicating and engaging with consumers in healthcare that are articulated in discipline-specific codes of practice (Australian Government Department of Health 2013). Health service provision is inextricably linked to risk (Rose 1998; Ryan et al. 2010; Sawyer 2005) which is understandable considering the duty of care shouldered by professionals and organisations under legislation. The results of this study, particularly within the *professional identity* theme, are a manifestation of this orientation to risk. The results suggest that use of technology with consumers was linked to a perceived increased risk of: (1.) Inaccurately assessing mental status; (2.) Increased workload as a result of implications of increased responsivity; (3.) Being exposed with limited technological literacy; (4.) Professional consequences linked to technology enhanced work practices; and 5. (in)ability to maintain clinician and consumer confidentiality. More broadly, the clear majority of participants felt that technology-mediated communication filters the human experience and that the rise of social media, in particular, has adversely impacted societal engagement and communication, a phenomena they feared perpetuating through use their work. It is in this context that the preference for face-to-face engagement with consumers should be understood.

CT implementation evaluation studies suggest high failure rates, coupled with incomplete adoption of the technology (Eason 2008). As in the current context, this situation can be exacerbated where technology is not integral to work functions and users have a choice about how and when they use it. It has been suggested that

"by achieving the right balance and designing processes and policies that recognise the interdependency between the social and technical subsystems of an organisation, the performance of an organisation can be optimised" (Westbrook et al. 2007, p. 747). With respect to the current study, the *organisational legitimacy* theme clearly highlights the need for organisational leadership around how: (1.) Technology will be introduced (and why); (2.) The impact on work roles will be negotiated; and (3.) The impact on work roles will be accounted for. Moreover, the conflicting perspectives between workers and management over the role of policy in promoting uptake in practice, present in this study and others, highlight tensions around the level of organisational permission and support necessary for innovation to flourish (Blanchard et al. 2012). While some clinicians, generally those who value and use technology in their private lives, are willing to assume personal responsibility for negotiating safe and appropriate engagement with consumers via technology, others are not. These sentiments have also been raised in the telehealth literature where the notion of legitimacy was important factor in successful implementation and uptake. As such, providing healthcare services via videoconferencing facilities needed to be seen as safe, normal and part of routine practice; this way of working also needed to be supported by established protocols and standards (Wade, Eliott & Hiller 2014). Recent research suggests that, despite a significant body of literature around efficacy of technologies such as iCBT's, routine uptake of these or many other technologies is not supported by appropriate research around appropriate financing, governance and implementation models (Meurk et al. 2016). The reticence toward technology evident in the current study's results appears, in part, to be linked to this lack of sector-wide leadership.

Implications for design and implementation of technology

As the results of this study and others suggest (Blanchard et al. 2012; Montague, Varcin & Parker 2014), technology-based change to work roles and practice needs to be seen as legitimate. Designing with those intending to use and those required to resource and promote the output can help to achieve this. Participatory Design (Ehn 1993) in mental health has been explicitly recommended (Hagen et al. 2012) and the results of this study and others (Blanchard et al. 2012; Montague, Varcin & Parker 2014) provide additional support for this recommendation. Design that is embedded in the workplace is crucial because, as the results of this study indicate, widespread adoption of technology must be championed from the highest levels of an organisation – those responsible for strategic direction and budget allocation. These ideas around legitimacy are exemplified in the current study results which highlight the need to create and change business systems to support change in practice. Beyond participatory design, approaching implementation in a transitional way via localised piloting/soft rollouts of technology can help to work through the complex reality of technology-related change. It can do this by allowing adoptees to make sense of, and gain ownership over, the technology-related change and to suggest necessary changes/improvements (Bar-Lev & Harrison 2006; Eason 2008; Gasson 2003; Venkatesh & Bala 2008). The notion of designing for minimum specification is important for *legitimising* technology in workplaces.

This process can be encouraged by complementing *organisational inquiry* with *problem closure* in design (Gasson 2003). This complementary process seeks to balance designing a solution to 'fix' a pre-defined problem

with seeking to understand, via consultation, what the problem is in the first place (Gasson 2003). When problem definition is predefined by designers and selected stakeholders in *problem closure* only projects (which are common), these projects are susceptible to failing to meaningfully recognise the central role of the sociotechnical system in its eventual success. Organisational inquiry via inclusive and consultative goal setting is crucial. Workplace technology implementation projects often struggle due to different, and often conflicting, goals of the various stakeholders and intended users in any given project, even when they seem aligned from the outset (Cornford & Klecun-Dabrowska 2012; Orlikowski 2000). Therefore a well-defined process that considers and balances all stakeholders' needs, desires and preferences when setting projects goals is suggested (Gasson 2003). These goals need to be regularly revisited throughout the life of the project to ensure fidelity or to gain a consensus for change (Bar-Lev & Harrison 2006; Gasson 2003; Orlikowski 2000).

Limitations

The current study has a number of limitations. Initially, young people's perspectives were not represented in this study. However, the data used in this research represents only one arm of a larger ongoing study in which workshops and semi-structured interviews were also undertaken with rural young people. The decision to conduct focus groups within existing mental health service teams was made in order to approximate naturally occurring discussions, with the benefit of participants being able to connect with one another's stories and experiences and often question each other in ways not possible if participants were unknown to each other (Kitzinger 1994). Conducting focus groups in this way, however, introduces different power dynamics, as hierarchies exist between staff members. These power differences were offset by enabling participants to exclude questions specifically asking them about their workplace, employee relations, and job conditions/satisfaction over and above being asked for general comments about working rurally, so participants were less likely to be censored in their responses. The fact that the dedicated mental health services in the region work largely independently but are keenly aware of one another meant that, even if focus groups were carried out with participants from different services, it is unlikely they would have been unknown to each other given the rural context of the research. With this in mind, this possible limitation could also be considered a major strength of the study as it allowed a variety of perspectives to be sought and debated, which resulted in the rich data set yielded. Despite perspectives being sought from different rural regions, the majority of the data was collected in one region. Whilst this design allowed for in-depth data collection and analysis, the results should be understood in this context. Similarly, the data collected from executive-level management personnel was the result of sampling one mental health service working with youth. Finally, in the interests of curtailing the study to a manageable population, the youth mental health service workforce did not include general practitioners or those working in private practice such as psychologists and psychotherapists.

CONCLUSION
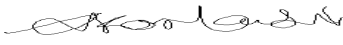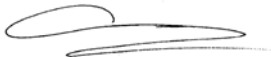
The adoption of technology-based consumer engagement tools by youth mental health clinicians and services involves a major practice change, one that is not currently supported or prioritised by individuals or organisations or the mental health sector more broadly. Nor is it currently likely given the radical cultural transformation that is required to achieve widespread adoption of technology. The culture required to support such a practice change requires a historical appreciation of the challenges of technology adoption that accounts for individual, organisational and discipline-wide perspectives. Technology is revolutionising mental health care. The question with which policy makers, organisations, clinicians, and academics are now faced is both how and whether we will work together to make the most of this.

CHAPTER FIVE: PAPER FOUR – PUBLISHED

A rural youth consumer perspective of technology to enhance face-to-face mental health services

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Simone Orlowski

Sharon Lawn

Gaston Antezana

Ben Matthews

Anthony Venning

Megan Winsall

Niranjan Bidargaddi

ABSTRACT

The imbalance between need and available resources with respect to youth mental ill-health has encouraged a growing body of literature around technology to support existing face-to-face services. However, this literature has not adequately investigated the perspective of youth as consumers and no data exists on the views of rural youth. In response to this gap, in-depth qualitative study investigated the perspectives of rural youth who were currently seeking help at a mental health service. Semi-structured interviews were carried out with a clinical sample of 10 young people (5 female), aged 16-22 years. Participants were recruited from two different mental health services located in two rural South Australian regions. Data were analysed via inductive thematic analysis. Results highlighted a young person's desire for self-determination around their health and help-seeking within a service current environment that systematically subverts it. Overall, participants had long and complex histories of help-seeking associated with a history of isolation, disadvantage and trauma. A strong need for personal connection in the context of help-seeking was evident. Preferences for, and actual use of, the internet for mental healthcare existed on a continuum from no current (or future desire) to use technologies through to active interest in, and current use of, technologies as an adjunct to face-to-face care. Limited financial and infrastructural resourcing made it more difficult to access help online. Understanding and actively seeking out these views in design and implementation of technologies is in line with the current shift toward more consumer-focused and inclusive service design and delivery.

INTRODUCTION

The internet is now viewed as a way of life for young people with the large majority reporting regular access and use. While using the internet to connect with others is the primary reason young people go online (Australian Bureau of Statistics 2011), information seeking is another major use (Cave et al. 2015). Considering the large disease burden mental illness currently presents to young people (aged 16-24 years) (Kessler et al. 2007; Slade et al. 2009) the emergence of technology-supported approaches to mental health care represents a major breakthrough in how services can be delivered. Current technological health applications can be grouped into four main functions: (1) information provision; (2) screening; (3) assessment; and (4) monitoring, with the bulk of these applications aimed at adults suffering anxiety and depression (Lal & Adair 2014). As young people are now seeking health and mental health related information online (Burns et al. 2013; Oh, Jorm & Wright 2009), the internet as a medium through which cost effective, anonymous, accessible and flexible health services can be delivered is now a legitimate reality (Lal & Adair 2014).

Numerous standalone mental health focused technologies exist - such as online Cognitive Behavioural programs for depression and anxiety (Calear et al. 2013) and virtual clinics (Klein et al. 2011; Titov et al. 2015) – along with a growing body of literature around use of technology within existing face-to-face mental health services (Reynolds et al. 2015; Wentzel et al. 2016). With this in mind, it is believed that the judicious use of technologies in the area of mental health support may assist in increasing the historically low youth engagement with mental health services, as they offer an unprecedented opportunity to provide services in a manner congruent with many young peoples' experience of the world (Burns & Birrell 2014; Christensen & Hickie 2010a). Given that increased youth engagement with services has been linked to improved consumer outcomes (Schley et al. 2012) it is crucial that we understand more about how technologies can add value to face-to-face mental health services. For example, the use of technology to support face-to-face mental health practice could deliver more personalised and standardised treatment, and it may help facilitate speedier recovery and prediction and prevention of relapse. This is possible in part, through predictive analytics, increased consumer input and self-management and more inclusive stakeholder communication (Reynolds et al. 2015; Wentzel et al. 2016). Currently, however, the use of technologies to support face-to-face services is under-researched (Montague, Varcin & Parker 2014).

Rural youth are a group of young people who ostensibly stand to benefit the most from technology-supported services. It has been reported that those who live in rural areas experience poorer health, lower life expectancy, greater delays in accessing services and are more likely to engage in negative health behaviours than those living in metropolitan locations (Australian Institute of Health and Welfare 2005; Green, Hunt & Stain 2012). The true impact of rural living on mental health and level of difference between rural and metropolitan mental health service usage, however, remains difficult to determine due to methodological differences and inadequacies in the current literature (Black, Roberts & Li-Leng 2012; Boyd et al. 2000; Boyd et al. 2011; Eckert et al. 2004; Green, Hunt & Stain 2012; Hardy, Kelly & Voaklander 2011; Judd et al. 2001; Newton et al. 2010; Perkins et al. 2013;

Sawyer et al. 2001). In contrast, rural youth perspectives around barriers to mental health help-seeking are well understood. Reported structural barriers include lack of reliable transport, youth mental health specialists, and out-of-hours support, along with perceptions of long wait-lists. Contextual barriers include the social visibility and lack of anonymity that comes with living in rural location and the associated fear of gossip, stigma and social exclusion (Aisbett et al. 2007; Boyd et al. 2007). More broadly, a general preference for informal help (Hickie et al. 2007; Rickwood, Deane & Wilson 2007), a culture of self-reliance (Boyd et al. 2007) and difficulties with symptom recognition and low service awareness (Smith 2012) negatively impact on youth help-seeking.

The fact that young people prefer to seek help from informal sources is not surprising given that previous research has suggested that interaction with the formal mental health system is akin to negotiating a maze (Emmerson et al. 2004). Indeed, Websters' (2008) research with young Australian mental health consumers (aged 18-25 years) describes the process of seeking help as "finding a way" in that getting the right help at the right time is not a straightforward process or a foregone conclusion by any means. As such, information communication technologies are held up as having enormous promise in assisting consumers to better navigate, and/or in redesigning, the currently broken mental health system (National Mental Health Commission 2014).

Whilst the literature is scant around examples of technology as an adjunct to face-to-face mental health service provision, current research suggests that technology can play a crucial role in generating services that better meet consumers' needs. For example, the use of electronic health tools has been shown to assist with increased rates of disclosure of sensitive issues to mental health professionals and time efficiency within a face-to-face therapy context (Bradford & Rickwood 2015). Similarly, the case for using telehealth/psychiatry to deliver specialist services to rural young people who otherwise would not receive them is compelling (Gloff et al. 2015; Wood et al. 2012). This research challenges mental health workforce fears that are commonly associated with technology-supported services such as concerns around privacy, confidentiality, increased workload and possible disengagement from face-to-face therapy (Doherty, Coyle & Matthews 2010; Matthews & Doherty 2011; Wadley et al. 2013)

The rhetoric around technology's perceived ability to enhance services must also be balanced by a consideration of alternative perspectives and experiences. Whilst technology-based tools show promise in a face-to-face service delivery context, the numbers of young people indicating a preference to seek help via the internet is not as high as conventional wisdom would suggest. In response to a self-report questionnaire, the large majority of Australian young people (aged 15-19 years) indicated they would prefer to seek help from face-to-face services or not at all, with only 16% expressing a preference for online treatment (Wetterlin et al. 2014). Moreover, the seemingly ubiquitous nature of information communication technologies and the narrative around youth as 'digital natives' can obscure the fact that many young people do not have access to the internet or related technologies due to unavailability of hardware, connection or download capacity for financial or geographical reasons (Newman, Biedrzycki & Baum 2012). This limited access, be it extent, frequency or quality, is associated

with a cycle that reinforces disadvantage, particularly in the context of the push toward access to services, support and information via information communication technologies (Baum, Newman & Biedrzycki 2014).

While the view of the mental health workforce around technology-supported face-to-face services is well represented in the literature (Blanchard et al. 2012; McMinn et al. 2011; Montague, Varcin & Parker 2014; Orlowski, Lawn, Matthews, Venning, Winsall, et al. in revision), previous research has not adequately investigated youth consumers' perspectives (Montague, Varcin & Parker 2014). No data exists on the views of rural youth while they were experiencing mental health problems. In response to this gap, our in-depth qualitative study investigated the perspectives of rural youth who were currently seeking help at a mental health service. As such it explored a youth's experience of the current mental health system, their personal experiences of mental ill-health and help-seeking in a rural context, and their views around how (and indeed if) technology can assist themselves and other young people to experience better quality help when and where they need it.

METHOD

Participants

Data were collected from a clinical sample of young people who were currently seeking help for a mental health condition. In total, 10 participants (5 female) aged 16-22 years were recruited throughout mid 2014 – early 2015. Participants were recruited from two mental health services located in two inner rural regions in South Australia (refer to Table 5 for reasons support was sought). See Table 5 for further descriptive data around participants. The study received ethical clearance from the South Australian Department of Health Human Research Ethics Committee (HREC/14/SAH/34). Purposive sampling was used in order to equally sample the wide the range of views present in the 16-24 age group and to obtain an equal gender representation. Sample size was determined when saturation of ideas was reached, as determined by the research team during data analysis discussions (Rennie, Phillips & Quartaro 1988).

Procedure

In-depth semi-structured interviews were undertaken. The interviews lasted between 1-1.5 hours in length. Participants were recruited through youth mental health professionals from two different services that had taken part in an earlier stage of the larger research project. Mental health professionals were given a promotional flyer for the project, participant information sheet and consent form, and asked to approach clients to participate in the study. The clients approached were ones who they believed were suitable (i.e. low risk and well-engaged with the service) and interested in discussing their experiences of struggling with a mental health condition, help-seeking and the role of technology within this. Upon a young person's indication of interest, (with the participants' approval) the first author contacted the participant and set up a time and location for the interview. Interviews took place in a location convenient for the participants which was generally in their region of residence. Participants were given the choice as to whether they wished their mental health worker to be present for the

interview; five participants chose to take this offer up. One participant chose to have their grandmother and partner present. At the beginning of interview, participants were informed of the purpose of the study and that it would be audio recorded and transcribed verbatim. All participants signed a consent form. Participants received a $30 voucher for their participation in the study. Please see Appendix E for the interview schedule which was developed iteratively as participant responses necessitated change, either to remove unnecessary questions or add questions where new lines of investigation became apparent.

Table 5

Participant demographic information

Number	Gender	Age	Reason(s) for seeking help
1	F	22	Depression, social anxiety, bi-polar
2	F	18	Trauma, depression, anxiety
3	M	17	Anxiety
4	M	19	Anxiety/depression
5	M	17	Recent trauma (family suicide), anxiety
6	M	22	Anxiety/depression
7	F	16	Anxiety/depression
8	M	17	Anger-related issues
9	F	16	Psychotic symptoms
10	F	22	Depression

Data analysis

Interviews were professionally transcribed (and checked for accuracy by the first author). Transcripts were then analysed using inductive thematic analysis (Braun & Clarke 2006) using NVivo software (QSR International Pty Ltd. 2012). The analytic process described by Braun and Clarke's (2006) was adapted for the current purpose. Initially, the process involved: (1.) Reading and re-reading of transcripts; (2.) Generation of initial codes; (3.) Searching for themes; and (4.) Reviewing themes and production of a thematic map. To increase the validity of the results, steps 1-4 were independently carried out by the first and third author. The resultant thematic maps were then compared for consistency and an overall map was produced. The first author then carried out Step 5. Defining and naming themes – the final themes aimed to represent the various interpretations of the data. The second author then provided a logic check regarding finalisation and parsimony of the themes.

RESULTS

Two major themes emerged from the data with respect to participants' views around the utility of technology as an adjunct to rural face-to-face mental health help-seeking; the themes were *isolation* and *self-determination.* Together they informed participants' help-seeking preferences and interactions with services. Direct quotes from participants are used to demonstrate each theme.

Isolation.

Participants' life experiences to date were characterised by strong themes of isolation and disconnection. This history of disconnection was vital in understanding their attitudes toward technology, their help-seeking journeys and preferences more broadly, and thus the types of technologies likely to be beneficial for, and accepted by, young people in the context of face-to-face help-seeking. The value of connection, however, was equally important for their path into and though services.

Family history of mental illness, dysfunction and early personal trauma were common among the participant group, along with a repeated pattern of transient living. Participants frequently discussed the difficulties associated with repeated attempts to establish a foothold within a new rural community. Participants' generally nomadic lifestyles ultimately left them existing on the fringes of their respective communities and they described prior and current experiences of disconnection and isolation which stemmed from their difficulties in developing a friendship network, accessing entertainment and services, and in gaining employment. Where support networks did exist, participants were reliant on a very small group of individuals that included family, partners and health services. Given that the majority of participants had very complex family relationships, the quality of immediate family support was often questionable and sometimes the responsibility of the extended family.

> Yeah, I've moved around a lot so haven't really…...this town isn't really like the best for me because you know, I haven't really made friends with anyone hardly (participant 9)

A predominantly insular and disconnected existence described by participants was compounded by a lack of reliable internet connection and/or financial restrictions with respect to internet access. Two participants living on farms outside of rural centres were unable to access reliable internet which affected the way in which they were able to access mental health support. For example, during one interview an exchange between a participant and their worker revealed that the worker had unknowingly emailed some out-of-session resources and homework to the young person who was unable to access them. In this situation the worker had made assumptions about the client's level of internet access based on the fact that he lived 10 minutes outside of a major rural centre. The same participant had tried to use an online mental health service for support outside of face-to-face sessions and was unable to as the internet dropped out five minutes after beginning the chat session. In addition, the combination of privacy considerations and restricted internet connection impacted *how* the internet was used.

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Participants also experienced restricted internet access and ability to use health applications due to limited financial stability and their consequent reliance on mobile phone plan data with their and/or free health apps.

> Because most of the time I don't have internet with credit (participant 5)

> To use the internet on the computer it's kind of like Wi-Fi but we don't have Wi-Fi so it's just like a massive satellite dish that's on top of the roof that picks up like the internet signal……but like I use my phone because I get like reception in my room but I get very limited so usually I just sit in my room and like go on Facebook or you know message people (participant 7)

Within this context of isolation, personal connections were important for the way in which participants found their way into services. Knowledge of, and access to, services was primarily facilitated through family, but also schools, community members and partners. Participants also voiced the central role of personal connection in facilitation of successful help-seeking once contact with a service had been established; time and again development of a strong personal bond with a mental health worker was held up as the cornerstone of positive health outcomes. Participants also saw a strong relationship between the physical service environment and the quality of the help-seeking experience. Discussions around unwelcoming and non-youth friendly environments highlighted their recurrent feelings of marginalisation and disconnection from services. Additionally, participants highlighted unwanted interconnections through their numerous examples of inappropriate sharing information by various support workers/organisations, and whilst fear of gossip did not deter participants from seeking help, participants were keenly aware of the risks and impact of it in their rural communities e.g. risks to privacy and confidentiality.

> It's, honestly, no wonder that people don't want to go there for help anywhere, because if – you know, the way it is – like, and I'm telling you these rooms are one of the things that will make a person want to leave and not come back….the environment is, indeed, the most important thing (participant 2).

> Like gossip is a currency. If people hear things and see things then they'll discuss it with someone and eventually it will spread (participant 8)

Self-determination.

The second major theme centred on the different ways in which the young people expressed their desire to make choices about, and have control over, their healthcare. This was despite, for the most part, not being able to make choices in meaningful ways due to systemic (e.g. disjointed service pathways) and structural (e.g. lack of

control over the way in which information is shared) barriers. Participants' stories and experiences of *the system* reinforced the notion that currently it is set up to serve itself rather than the consumer. Most participants were experienced service users in that they had long and complex histories of accessing services from a young age, from which they had gained many hard won lessons around engaging with the *system*.

> Trust me, I've been through a few of them. I've been through teams, I've been through private
>
> counselling, I've been through – you name it, I've (laughter) probably gone through it
>
> (participant 2)

Participants described a mental health system that is difficult to navigate, easy to disengage from and ill-equipped to meet the need of consumers currently battling a mental health condition. Lack of wrap around care and overlap between service boundaries resulted in an inflexible system incapable of meeting the holistic needs of youth.

> More not knowing what services are there for what certain things……..It's just you go to one
>
> place and then oh no we don't cover that here, you know go to this place (participant 4)

> And you have no motivation……..you just, you feel like a zombie, you don't feel like you're
>
> there and you don't want to do anything……….you just want to give up……..you wake up in the
>
> morning, you think about it and like if you have – like with social anxiety and leaving the house
>
> is a bit of an issue you go – all day your brain's just revolved around that one thing, I've got to
>
> leave the house, I've got to leave the house, I've got to go out, and that's all your brain thinks
>
> about all day………. I'll just call up and say that I'm not coming. And so when I did that a
>
> couple of times ….. I'd call up and they'd be like "oh, you know, we'll get them to call you back
>
> and book another appointment". And they never called me back, and I'd call back and they'd
>
> say "oh we'll get them to call back", and they'd never call me back……then next thing I knew,
>
> all of a sudden I didn't have a counsellor anymore, I wasn't seeing anybody, I was just
>
> completely wiped off the book, and I slipped through their fingers. (participant 1)

The large majority of participants talked about the re-traumatising experience of repeating their *story* (i.e. their personal and sensitive reason(s) for seeking help) to new service providers despite a clear preference against it. This repetition commonly occurred when young people moved residence, aged out of a service or when their current worker moved onto alternative employment. Bouncing between federal, state and private funded services meant that information sharing between previous and current service providers was extremely limited and thus

retelling of stories was expected and required. Several young people discussed attempts to maintain consistency and control by remaining with a current worker despite significant geographic barriers.

> You don't want to have to re-live. Like, you've re-lived it once. Re-living it every time brings back the pain you just can't describe it. It's horrible. Like, and the fact that there's more than one person that knows about it is even scarier……knowing that there's someone that you put your entire life into, to just try and bring you back to life, is – is one thing. And, then to have – you know – two or three new counsellors over a few – over a few years is just – ends up destroying you. Honestly. It destroys you. (participant 2)

In addition, negative experiences of help-seeking generally manifested as personal experiences of perceived loss of control or inability to make decisions around their health.

> My experience with [service] was really - I don't know if I'd call it traumatic - but I went there to see a psychiatrist and I didn't get a choice in the matter. They just sent me to hospital, um so that wasn't great. Didn't go back there (participant 10)

In contrast, participants' positive experiences with services were repeatedly peppered with the term 'comfortable' with respect to their interactions with individual workers and services more generally. The repeated used of this term spoke to an inherent desire to feel personally in control of, and at ease with, their help-seeking journey. Participants voiced strong preferences around characteristics (e.g. age and gender) and working styles (e.g. non-judgemental, authentic, maintains privacy, mutual trust and respect, client-centred) of mental health professionals. They also demonstrated a strong willingness to disengage when the criteria were not met. The participants believed that fear of the unknown (i.e. not understanding how services function and what to expect from them) and/or judgement (both from peers and the system itself) contributed to their prior (and peers' current) reluctance to engage with services.

> He's easy to talk to, he's not one of those like judgy people that I don't like (participant 3)

> [with respect to current treatment] there is nothing, I wouldn't change at all because everything that they've done has been run by me first and been okayed by me first and it's all pretty much like, you know, my – they're all my choices and things like that (participant 1)

> There are some people out there that will go above and beyond to help out and then there's just other people will just be like nah……..I'm just here to get paid, I don't really give a shit you know (participant 4)

Participants' historical experiences of disconnection shaped their perceptions of appropriate technology-based services and help-seeking. For example, the majority of participants preferred offline modes of mental health help-seeking. Embedded in this preference was the inherent dignity they believed required honouring when disclosing extremely personal thoughts/feelings/experiences to another person. Some participants also noted concerns around the internet as an untrustworthy medium through which to share personal information.

> Probably the best thing that I've had is the face-to-face kind of interaction because you actually know who you're talking to and yeah, I don't know, it's just – because if you're ringing up other places you don't know who you're talking to, you don't know what they're doing, if they're actually listening or caring (participant 4)

> ….I'm a 'people person' and every time people bring up [online service] ……… I always go 'no I'm not doing it'. 'Cause like if I write it down in some website, they'll be a tracker on it or a cookie and that's going to be saved in my file and who knows where else it's going to be (participant 6)

The use of technology as an adjunct to face-to-face care existed on a continuum of no use, some experimentation, through to use of technologies with their current mental health worker. Interestingly, those participants who saw themselves as anti-technology in relation to their help-seeking did not express anti-technology sentiments across the board, with the majority of participants demonstrating a strong preference for use of the internet for socialisation and secondarily for entertainment. E-mental health applications were cited as examples of the way in which young people could take back control of their health and the manner in which they access help. For example, they were used to form a bridge to face-to-face services. Some participants saw value in use of technology to communicate with their worker between sessions, to track their mood and other mental health-related indicators and to assist in better structuring their face-to-face sessions. In contrast, others discussed the value of simple diagrams used by their workers to explain complex psychological and health-related principles and processes. In some cases, young people were very keen to point out reluctance toward technology replacing face-to-face connection with their worker, but that they were open to technologies that, for example, might assist in sharing information between services to avoid story retelling.

There's like been a few issues that like I can't talk to my psychiatrist about, that I'm too like nervous to talk out loud and so I've gone to e-Headspace to talk about it and like they've been really helpful and they've understood that I don't want to like be face-to-face with someone if I'm so nervous about talking about it and I think it's helpful that there are those sites out there like that can help like if you're really having issues and you don't want to talk about it like person-to-person, just online it's really helpful. And it helps people with like anxiety too that don't want to go out and like too scared and anxious to move out of their house (participant 9)

Within this group prior help-seeking was strongly associated with future help-seeking, and many participants noted the difference accessing this help had made to their lives. The disempowering, isolating and complex experience of struggling with, and help-seeking for, a mental health condition, however, led the majority of participants to discuss their desire to help others in a similar position. The right for all young people to self-determine with respect to their health came through strongly in participants' advocacy for inexperienced consumers. Participants' strong desire to assist these 'inexperienced' young people to access the right information *how*, *when* and *where* they need it spoke volumes with respect to the current help-seeking environment and young people's ability to participate meaningfully within it.

DISCUSSION

The aim of the current study was to investigate rural youth consumers' perspectives of technology-supported face-to-face mental health care. Ten youth from rural South Australia were recruited and two major themes emerged from their semi-structured interviews: *isolation* and *self-determination*. Results indicated that the participants' preferences for and actual use of the internet for (mental) health-related purposes existed on a continuum from no current or future desire to use technologies through to active interest in and current use of technologies as an adjunct to face-to-face care. These results are consistent with prior research that has suggested that while use of technology to support face-to-face services is not considered standard practice by mental health professionals (Blanchard et al. 2012; Montague, Varcin & Parker 2014; Orlowski, Lawn, Matthews, Venning, Winsall, et al. in revision), some young people consider face-to-face services could be enhanced by and are receptive to technology-based support to their care. The consumer-based perspectives and experiences reported in the current study are in line with a growing body of literature which advocates for the applicability of a mix of on and offline mental health support for some consumers (Blanchard et al. 2012; Montague, Varcin & Parker 2014; Reynolds et al. 2015; Wentzel et al. 2016). As such, the term "blended care" (i.e. a combination of online and offline components coordinated in a face-to-face mental health setting) has now entered the literature (Wentzel et al. 2016), with researchers attempting to define this term and use of technology to support face-to-face care more broadly. Given clinical tools, conceptual models and workforce training are now emerging to support this 'blended' way of working (Abbott et al. 2015; ReachOut.com 2016; Reynolds et al. 2015; Wentzel et

al. 2016) this change to service delivery must be balanced by a nuanced understanding of the consumer cohort currently accessing face-to-face mental health services.

It was indicated that, in general, the personal and geographical isolation felt by most participants shaped their help-seeking preferences and experiences, which manifested in a strong need for personal connection with a mental health worker. A participant's desire for personal connection in help-seeking - characterised by acceptance, respect, trust, lack of judgement and authenticity - has been reported elsewhere in the literature (Boyd et al. 2007; Salamone-Violi, Chur-Hansen & Winefield 2015), and as such, these findings suggest learnings for the research, service delivery and policy-based communities with respect to design and implementation of technologies. Information communication technologies that may appear to threaten the personal connection and support that are currently available through services may not be supported by, and/or beneficial to, this group of young people. In contrast, applications that enhance or promote and don't seek to replace the desired personal connection are more likely to be better received and utilised by youth mental health consumers. The range of perspectives participants demonstrated with respect to the value of adjunct clinical technologies are in line with recent evidence on the level of tailoring required for successful technology design (Ranney et al. 2015). In addition, the physical and/or material restrictions around internet access highlighted in the results reinforce the idea that this a group of young people who, at this point, are reliant on a predominantly face-to-face mental health service model. The need for design of inclusive technologies that recognise and accommodate the needs of young people who, along with their mental health (and often comorbid physical health) struggles, are socially and geographically disadvantaged is therefore emphasised. Much can be learnt from the design and implementation of technologies to meet mental health need and develop capacity in underprivileged and war-torn countries such as Afghanistan (Gillis 2015). Low cost and limited internet dependent alternatives should be a focus for future research and design, for example teleconsultations that allow for live and 'store and forward' modes to accommodate those with limited or unreliable internet access (Gillis 2015).

The self-determination theme present in the data has significant implications for the ways in which youth consumers are involved in service planning and delivery. The concept of self-determination is tied strongly to the mental health recovery literature, with its importance in facilitating (and indeed hindering) recovery - a multi-dimensional term encompassing a range of outcomes - well-documented (Anthony 1993). As such, the current participants' experience of systemic disempowerment and lack of self-determination are, unfortunately, not uncommon (Anthony 1993). With the existence of inspiring examples of youth-based participatory research, which demonstrate that it is possible to give meaningful voice to those with lived-experience of mental illness (Lincoln, Borg & Delman 2015), it no longer seems justifiable that these perspectives should not be honoured and included in technology design and implementation processes. These participatory practices that stand to create greater opportunities for consumer self-determination may also benefit the design process. If designed sensitively and inclusively, technology-based additions to care could offer welcome opportunities for young people to participate more meaningfully in their care. For example, flexibility and shared decision-making, two

attributes often linked to technology-based additions to care, have been linked to improved patient satisfaction and overall health outcomes (Clever et al. 2006; Swanson et al. 2007).

The current study has a number of limitations. Perspectives were sought from two different rural regions, and whilst this design allowed for in-depth data collection and analysis, the results should be understood in this context and as such may not be representative of the experiences of different regions. Additionally, it also important to note that nine of the ten participants reside in inner rural regions and thus views and experiences of outer regional and more remote communities were not represented in this study. Whilst the study did sample consumers with a range of mental health conditions, the large majority identified as dealing with depression and anxiety based concerns. These young people were recruited from two mental health services, the extent of issues raised in the data, however, suggests that any potential bias arising from sampling young people with a more positive relationship with their worker was minimal. Finally, the participants were actively engaged in face-to-face mental health services and as such the results may not generalise to all youth in need of mental health services, particularly those who have never accessed, or have disengaged with, face-to-face services.

The results of this study highlight consumers' desire for self-determination around their health and help-seeking within a current service environment that systematically subverts it. The results also reveal important reasons why young people who use offline mental health services may be averse to technological additions to their care. By and large, this was a group of young people with disadvantaged, traumatic backgrounds and corresponding long and complex histories of help-seeking. They have systematic experiences of isolation, and often present for help with complex problems, which shape their need for face-to-face care. In addition, limited the financial and infrastructural resourcing make it more difficult to access help online help. That said, some young people self-identify as interested in engaging with technology-supported models of care. Understanding and actively seeking out these views in design and implementation of technologies is vital for design of useful and usable technologies and, more importantly, is in line with the current shift toward more consumer-focussed and inclusive service design and delivery.

CHAPTER FIVE SUMMARY OF RESULTS

The results of the first sub-study – investigation of rural youth mental health workforce perspectives - resonated with the results of prior research which has found low overall use of technologies by mental health professionals and which positions technology as an adjunct to youth mental health practice (Blanchard et al. 2012; Montague, Varcin & Parker 2014; Sinclair et al. 2013). Despite the acknowledgement that most young people situate technology as an integral part of their everyday lives, use of technology was found to be counter-cultural to longstanding ways of providing mental health services. The types of interactions made possible through and by technology were seen to have significant implications and consequences for mental health work, which was described by participants to operate within a core paradigm of risk prevention and management.

Participants explored professional identity issues through their discussions around use of technology in their work. In particular, the clinician acting in the socially defined, and largely autonomous, role of 'expert' manifested in a number of ways. One such example included debates around language, specifically the degree of familiarity with technological jargon or slang desired and required by a clinician when interacting with a young person.

Participants also discussed their need for demonstrable organisational legitimacy around technology use with their clients. In line with previous research, factors such as physical resourcing, availability of time and appropriate skill level were seen as barriers to changing current work practice (Sinclair et al. 2013). Appropriate policy and organisational leadership around technology introduction and changes to work roles was also seen as important by frontline mental health workers (Blanchard et al. 2012; Montague, Varcin & Parker 2014). This position was debated by staff occupying management level positions who felt that restrictive policy-led approaches may stifle individual creativity and innovation.

Overall, participants felt that a personal connection developed through face-to-face interaction was integral to effective service delivery, a preference that was mirrored by the youth consumers in the second sub-study. This youth preference, along with their predominantly reticent attitude toward technology in help-seeking, was linked to formative experiences of isolation and disconnection. Many young participants described dysfunctional family relationships, itinerant lifestyles and associated difficulties with establishing themselves in a community, finding friends, employment or any type of psychosocial or material stability. Their isolation was further intensified by rural living which was associated with geographical isolation and unreliable internet access.

The majority of participants recounted complex histories of help-seeking and disempowering experiences with the health system, characterised by difficulty accessing the right entry points, repetition of their story to many different service providers and inconsistency in care. Participants' best experiences of help-seeking were described as *comfortable* interactions with non-judgemental, empathetic, authentic and respectful mental health professionals. Many participants defined positive experiences as those in which they felt they had control over their health and help-seeking. On the other hand, negative help-seeking experiences were described as those in

which personal control and choice were absent or impinged upon by services. With this in mind, the participants reported a continuum of experience with, and willingness to try, technology within their face-to-face help-seeking. A number of the young people described mistrust in discussing mental health problems via technology whereas others recounted positive experiences of technology complementing traditional help-seeking.

Taken together, the results of this scoping study indicate that a range of barriers are impeding the uptake of technology in rural youth mental health services. Arguably the most salient of these barriers is the reality that this way of working represents a major shift in current mental health practice and help-seeking. Both mental health professionals and young people in this study demonstrated a desire to establish strong personal connection through face-to-face engagement for a range of reasons. Other barriers were more organisational and systemic in nature, pertaining to factors such as a lack of resourcing, professional skill and appropriate policy. Taken together, these results supported the prevailing narrative of *technology as an adjunct* to practice.

Despite this, the results also reflected a need for a role for technology in traditional mental health service delivery contexts, particularly in helping young people navigate a complex and disempowering system. With this in mind, the next study aimed to further investigate the nature of the mental health system and young people's experiences of it through an observational study of two separate, but interconnected, youth mental health services.

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CHAPTER SIX PREAMBLE

Current research has relegated technology to an *adjunct* role in existing youth mental health services; aside from videoconferencing, use of technology with consumers is at best sporadic. Many barriers to technology uptake have been identified and include a range of workforce and consumer factors, along with organisational and systemic factors. Furthermore, to date the majority of research has focussed on the development of technologies for specific use cases and on pre-implementation self-reports from the workforce. Taken together, this body of evidence is limited in its ability to comprehensively define and explain mental health services as technology implementation contexts. Of particular interest in the current research were technologies that facilitated services in their traditional form; that is those that aren't designed to replace the face-to-face connection but enhance it through increased *engagement*, *support* or improved *navigation* through the mental health system (ESN technologies).

To realise the full potential of technologies in existing mental health services, a more detailed understanding of the system is necessary, as is translation of these findings into design of useful and usable technologies. Observation is a widely applied method for studying user experience. Observation of mental health services and help-seeking, however, is not a commonly used method for informing the design of technologies, particularly due to the complexity involved in negotiating access to contexts and end users (Coyle & Doherty 2009; Coyle et al. 2007). Use of observational research methods becomes even more difficult in the context of working with youth populations. That said, some researchers have conducted firsthand observation in mental health contexts (Brinkman et al. 2010; Frost & Houben 2014; Lederman et al. 2014; Thieme et al. 2013; Thieme et al. 2015). Far more extensive observation has taken place in medical settings, particularly around multidisciplinary team meetings (Kane, Groth & Randall 2011). This body of work has demonstrated how technology can challenge historical ways of working in healthcare contexts (Bhandari, Tiessen & Snowdon 2011; Nilsen 2011).

With this in mind, the current study aimed to investigate the functioning of the mental health system at the level of rural community-based youth mental health services, via the specific example of the newly established state-wide Youth Mental Health System (YMHS). The study involved observation of two key youth mental health services that had participated in the earlier scoping study which represent different but interrelated tiers of the YMHS. This observational study resulted in one paper, *People, process, systems: An observational study of the role of technology in rural youth mental health services*, which is presented in this chapter.

This research aimed to investigate the frontline mental health work role, including the nature of communication, collaboration and work in the system. Additionally, the study explored consumer interaction with and navigation of the system. The research drew on complexity concepts as a means of identifying the interdependencies and interrelationships between the various components of the system, in order to understand the mental health system as a technology design domain. The intention of this research was not to advocate for the prescription

any one technology over another, but instead to provide the field with contextually rich information regarding the design domain, in order to unpack the issues that are likely to impact on design and implementation of technologies in this context.

CHAPTER SIX: PAPER FIVE – IN REVISION

People, process and systems: An observational study of the role of technology in rural youth mental health services

Authorship Declaration: SO conceived and designed the study, carried out data collection, analysed and interpreted the data, and drafted the manuscript. BM, SL, AV contributed to the design of the study, analysis and interpretation of the data, as well as the drafting of the manuscript. MW, GA, GJ, PM contributed to the analysis and interpretation of the data, as well as the drafting of the manuscript. NB contributed to the design of the study and performed the critical revision of the intellectual content. All authors read and approved the final manuscript. All authors give permission for the paper to be included in this thesis.

Simone Orlowski	Megan Winsall
Sharon Lawn	Gaston Antezana
Ben Matthews	Niranjan Bidargaddi
Anthony Venning	Peter Musiat
Gabrielle Jones	

ABSTRACT

The merits of technology-based mental health service reform have been widely debated amongst academics, practitioners, and policy makers. The design of new technologies must first be predicated on a detailed appreciation of how the mental health system works before it can be improved or changed through the introduction of new products and services. Further work is required to better understand the nature of face-to-face mental health work and to translate this knowledge to computer scientists and systems designers responsible for creating technology-based solutions. Intensive observation of day-to-day work within two rural youth mental health services in South Australia was undertaken to understand how technology could be designed and implemented to enhance young people's engagement with services and improve their experience of help-seeking and engagement with services. Data were analysed through a lens of complexity theory. Results highlight the variety of professional roles and services that can comprise the mental health system. The level of *interconnectedness* evident in the system, contrasted with high levels of service *self-organisation* and disjointed information flow. A mental health professional's work was guided by two main constructs - *risk* and *engagement.* Most clients presented with a profile of disability, disadvantage and isolation; so complex client presentations and decision making were core practices. Clients (and frequently their families) engaged with services in a crisis-dependent manner, characterised by multiple disengagements and reengagements over time. Whilst significant opportunities exist to integrate technology into existing youth mental health services, technologies for this space must be usable for a broad range of medical, psychological, cognitive disability and social disadvantage, and accommodate repeat cycles of engagement/disengagement over time.

INTRODUCTION

One in four young Australians (aged 16-24yrs) meet the criteria for a mental illness in a 12 month period (Slade et al. 2009), yet only a minority of these are likely to seek help from formal mental health services (Kessler et al. 2007). Furthermore, following initial help-seeking, those that do engage experience a disempowering system designed to serve itself rather than the consumer (Orlowski, Lawn, Antezana, et al. 2016). New ways of delivering services that tackle poor engagement (Burns & Birrell 2014; Christensen & Hickie 2010b) and stigma-related barriers (Burns, Liacos & Freen 2014; Griffiths & Christensen 2007; Lambert & Newcomer 2009; Lawn 2012; Muir-Cochrane 2006) are therefore necessary. It is in this context that perceived increases in accessibility, flexibility and consumer engagement, along with cost reductions associated with internet technology-based services are championed (Burns, Liacos & Freen 2014; Lal & Adair 2014). Identifying the role of new technologies in models of mental health care, is in part, reliant on the buy-in of those currently responsible for the provision of face-to-face services.

To date, existing e-mental health technologies usually fall within two categories. The first one includes e-mental health interventions developed for the sufferer. These interventions can be standalone or somewhat integrated into care and are primarily delivered through the internet or, more recently, mobile phones (Donker et al. 2013). The plethora of available interventions cover a wide range of disorders, such as depression and anxiety (Pennant et al. 2015), substance user disorders (Hopson, Wodarski & Tang 2015), eating disorders or associated symptoms (Aardoom et al. 2013), and other common mental health conditions in this age group. Interventions across the entire care cycle are available, i.e. primary and secondary prevention programmes, treatment interventions, as well as e-mental health interventions for aftercare. Most, of these intervention are based on Cognitive Behaviour Therapy principles, as it lends itself for self-help interventions (Musiat & Tarrier 2014). E-mental health interventions may include some form of personal support from trained professionals and research suggests that intervention with support show greater efficacy (Andersson & Cuijpers 2009). This group of interventions that, despite reports of limited engagement (Christensen & Hickie 2010b), are well-researched and show strong efficacy for the treatment of mild to moderate mood and anxiety disorders (Meurk et al. 2016).

The second category of e-mental health technologies encompasses solutions to facilitate mental health care in its traditional form. For example, communication tools allow clinicians to provide treatment to and communicate with patients or other carers over large distances (Boydell et al. 2014), communication and information systems to help professionals share case notes and align treatment (Martin et al. 2011) or allow consumer-centred collaborative care (Kurahashi et al. 2016), systems for remote monitoring or collection of data (Bradford & Rickwood 2015; Chinman et al. 2004) or self-management tools which act in an adjunct role to therapy (e.g. Frost & Houben 2014; Gammon, Strand & Eng 2014; Matthews et al. 2015; Thieme et al. 2016). It is the second category of technologies which are of relevance to the current study. With the exception of videoconferencing technologies (Boydell et al. 2014), they are under-researched and implemented in existing youth mental health services (Montague, Varcin & Parker 2014).

With this in mind, further work is required to better understand the complexities of face-to-face mental health work and how they can be translated to inform the design of useful, usable and accepted technology-based solutions. At present, understanding of mental health services as an implementation context is generally restricted to that which is necessary to inform the design of individual products. To better facilitate implementation and uptake of these technologies a more comprehensive and holistic understanding of the mental health system, and its individual components is required. The mental health system is believed by many to be complex and adaptive (Anderson et al. 2005; Chandler et al. 2016; Plsek & Greenhalgh 2001); it is in within this perspective that the current research is positioned. The current study is an observation of the mental health system interpreted through complexity.

Complexity in healthcare is not a new phenomenon (Anderson et al. 2005; Chandler et al. 2016; Leykum et al. 2014; Plsek & Greenhalgh 2001) with a series of publications in the 2000's (Holt 2004; Kernick 2004; Plsek & Greenhalgh 2001; Sweeney & Griffiths 2002) legitimising complexity as an important research focus in healthcare sciences (Fraser & Greenhalgh 2001; Plsek & Greenhalgh 2001; Plsek & Wilson 2001). A complexity way of thinking sits in opposition to reductionist approaches which seek to understand behaviour as a function of the individual and/or its separate components. Complexity theory, defined as "the study of phenomena which emerge from a collection of interacting objects (Johnson 2011, p. 3) has been developed out of, and been applied to, a variety of scientific disciplines (Meyers 2009). Whilst it cannot be considered a unified theory (Johnson 2011), it can be defined as the study of emergent, unpredictable, uncertain, non-linear yet rule-based behaviour of the greater whole via the exchange and relationships that exist between (and beyond) its constituent components.

A thorough appreciation of subtle and complex conditions inherent to the context of use are crucial for designing successful technologies in a complex mental health system. Table 6 provides a brief of overview of core complexity concepts as they relate to the current study.

Table 6

Key complexity theory concepts related to the current study

Interconnection	A complex system is made up of many components. In better understanding the system, the intricate relationships between these components are crucial to appreciate, particularly in the context of understanding and accounting for the organisational dynamics and system properties that may influence introduction of any new stimuli (e.g., technology) (Anderson et al. 2005). Complexity science reminds us that a system such as the mental health system "[is] not constituted merely by the sum of its components, but also by the intricate relationships between these components" (Cilliers & Spurrett 1999, p. 2).
Self-organisation	Complexity theory contends that the autonomy possessed by agents in a complex system results in a series of adjustments in response to changing internal and external stimuli. The result is new behaviours, processes and ways of working specific to various parts of the larger whole (Chandler et al. 2016). This self-organising property creates diversity in work practices, ways of thinking and information systems which are important to identify and understand in order to meaningfully configure resources for communication and information sharing (Balka, Bjorn & Wagner 2008).
Shadow systems	Complex systems are embedded within other *shadow systems;* these are informal and often hidden or less obvious influences, which impact on their functioning (Plsek & Greenhalgh 2001). For instance the role of the family in a consumer's help-seeking journey.
Mental models	Decision-making in healthcare is often governed by mental models or "internalised rule sets" (Plsek & Greenhalgh 2001, p. 625). For example, an orientation to risk management.

From a design perspective, questions such as the following require answers: How does the current system (and embedded sub-systems) function? Who are the typical clients the different services work with? What drives and influences mental health work on a daily basis beyond the well-documented desire for face-to-face service provision and confidentiality/privacy concerns? (Meurk et al. 2016). What characterises a young person's interaction with services? How is communication facilitated? How can help-seeking and engagement be improved? Approaching user experience and design with a complexity sensibility encourages a focus on these social aspects of healthcare that will arguably shape and help define the use of technology in practice.

Observation is one way to understand a complex system (Anderson et al. 2005). While design of technologies for mental health is still a developing field, a number of design methods that value human perspectives and incorporate ethnographic elements have been utilised in this space (Coyle et al. 2007; Hagen et al. 2012;

Orlowski, Lawn, Venning, et al. 2015). Unfortunately, with respect to mental health contexts, observation of help seeking, rapport building and interactions with mental health clients is not a widely applied method for studying user experience, as in-session interaction with health professionals is sensitive and often difficult to negotiate access and obtain consent. However, some researchers have conducted valuable first hand observational work (Brinkman et al. 2010; Frost & Houben 2014; Lederman et al. 2014; Thieme et al. 2013; Thieme et al. 2015). There has also been a rich history of observation in medical contexts to study user experience and design particularly with respect to design of technologies that enhance collaboration, communication and decision-making around patient diagnosis and treatment within multidisciplinary team meetings in various medical contexts (Kane, Groth & Randall 2011). This body of work highlights how technology can challenge historical ways of working (Bhandari, Tiessen & Snowdon 2011; Nilsen 2011).

With this in mind, the current work aims to contribute to the literature via an investigation of the community-based Frontline Mental Health (FMH) role within, and consumers' trajectory through, the mental health system. This area of investigation remains largely uncharted territory from a Human Computer Interaction viewpoint. As such the overall aim was to investigate youth, community-based mental health services as a potential technology implementation context. Practically, this meant, unpacking the complexity and interconnectedness of the design domain (i.e. community based youth mental health services). The specific questions investigated were: *What are the domain requirements of youth community-based mental health services? How do these requirements impact on the design of technologies for young people that assist with the complex reality of mental health help seeking and service engagement?*

MATERIALS AND METHODS

Participants

A convenience sample of staff were recruited from two sites in a rural South Australian region. The sites provided mental health services for young people 16-24 years of age through a newly established South Australian (SA) Youth Mental Health System (YHMS) of Care. Site one was a service designed to be the primary point of help-seeking for youth (12-25yrs) with mental health and related issues via co-location of medical, psychological, drug and alcohol, vocational and allied heath youth health professionals. Site two was a standalone community mental health service. The two sites were selected due to pre-existing relationships as this research formed part of a larger study. The sites represented separate but interrelated parts of the SA YMHS of care and were located in an inner regional town which services a number of surrounding outer regional and remote areas. Please refer to Table 7 for participant information which comprised 12 health professionals working at site one and 10 at site two.

Procedure

Data collection involved the first author shadowing the daily work of employees in the sites where possible (including sitting in on consultations/sessions with clients and team/clinical meetings), non-participant observation (i.e. the researcher was present in the clinical sessions without participating), informal interviews, field noting, and documenting analysis over a two-week period. Where possible debriefing with staff after client sessions or meetings took place to gain further insight into staff perceptions of work. Some audio recordings were made, principally of the staff meetings and informal interviews rather than the client sessions. Brief notes were taken throughout the day and expanded upon during the evenings. Client consent was obtained by the staff who had authority around clients to be approached and excluded (if deemed too risky and/or not adequately engaged with the service). Please refer to Table 7 for further information regarding procedures carried out at both sites. The study received clearance from the South Australian Department of Health Human Research Ethics Committee (HREC/14/SAH/34).

Data Analysis

No analytic framework was prescribed *a priori* for data analysis. However, the applicability of complexity theory concepts to frame and describe the data became increasingly clear as the analysis of specific instances progressed and as diversity of the client population and issues encountered in the mental health service delivery environment emerged. At this point, Chandler et al.'s (2015) explanatory framework derived from complexity theory core concepts and adapted for the social healthcare context was explicitly drawn on as a resource in making sense of the data. Data analysis involved multiple stages: (1) familiarisation with the data which included multiple readings and noting of key observations; (2) construction of a mind map of key observations and ideas to look for patterns; (3) interrogation of the systemic nature of the case study, casting a complexity science lens over the data (Anderson et al. 2005) and compilation and reaching consensus about stories, observations and interactions resonating with key complexity principles (*interconnection, self-organisation* and *mental models)* which represented the key ideas best; and then (4) coding data for sub-themes occurring within and/or between the broad complexity principles. The client vignettes reported are aggregates of typical presentations and as such do not represent individuals.

Table 7

Participant information and procedures undertaken at study sites

Site one participant information	Site two participant information
Staff at site one were employed in a salaried/reimbursement model and consisted of 1 manager, 1 clinical lead and 3 youth workers (0.6-1.0 FTE; 1 psychologist, occupational therapist and social worker and 2 counsellors). All staff carried a caseload, the youth workers were also responsible for intake and health promotion. In addition to the salaried staff, 2 medical and 5 psychological staff were also privately contracted (each 0.2 FTE) in a fee-for-service capacity. Other non-government services (e.g. drug and alcohol and vocation/employment) provided additional in-kind support at the service	The team at site two was made up of salaried staff, 7 mental health nurses and 3 social workers (i.e. 1 team leader with no caseload, 1 clinical lead, and 8 mental health clinicians) (0.8-0.1FTE). In line with state-wide reform of the Youth Mental Health Service (YMHS) of Care, site two (which historically serviced adults) had recently extended its operating parameters to include an integrated youth service in which clients aged 16-24yrs received specialist age appropriate care. Therefore, 2 clinicians carried a 0.5 FTE youth portfolio (0.5 FTE adult) and were supervised by a senior youth mental health clinician who visited weekly. Other portfolios included older adults and prenatal. Given that staff at site two worked with both youth and adult clients, observations at this site were carried out with both client populations.
Site 1 procedure	Site 2 procedure
The first week was spent at site one, with 80 hours of observation conducted in total (40hrs/site). 9 client sessions (which included 2 psychologists, 4 allied health youth worker and 3 GP sessions), one group fitness program and 4 meetings (e.g. weekly team, clinical review, intake, partnership and consortium) were observed. In addition, 12 semi-structured interviews with staff were conducted (which included psychologists, allied health youth workers, administrative support, and centre manager).	The second week was spent at site two. Ten client sessions (all with mental health clinicians and primarily with the same staff member, who was one of two which carried a youth portfolio), one group wellbeing program and 6 staff meetings (which included the daily intake and one clinical review meeting) were observed.

RESULTS

Throughout the study, staff distinguished between physical and mental health, with the latter seen as a *"grey zone"* for decision-making. Staff discussed *"working within significant diagnostic ambiguity"*, a context that was *"very murky"*, and decisions made on a *"case-by-case basis"*. The results should be interpreted with this way of working in mind.

Interconnection

Frontline Mental Health Work

Both observation sites in the study comprised multidisciplinary professional staff in a Frontline Mental Health (FMH) role. Staff from both sites had frequent and regular interactions with youth, but site two staff managed patients with higher risk and complexity. The observations revealed that the mental health professionals employed in this role view their work in different ways. Debates around the nature and purpose of FMH work surfaced, particularly at site two. FMH workers reported diverse beliefs around the exact work and responsibilities attributable to their role. While the multidisciplinary nature of the role is beneficial for tackling complex case presentations, discipline specific ideas around who does what work led to variation in everyday practice. For example, the level of structured psychology-based therapeutic input delivered by FMH workers was highly variable and frequently dependent on professional training and background; with some staff members asserting *"we are not professional counsellors".* The strong influence of professional identity, skill level, role definition and autonomy made visible by the debate was striking. Individuals are afforded considerable latitude in their everyday work which has clear implications for consistency of approach.

Overall, FMH service provision included advocating for and supporting the client (and their family), coordinating care, monitoring mental status and risk and therapeutic input. Staff acted as a constant supportive presence and referred the client to various health professionals and a range of other supports as needed. Young people identified as high risk and/or having complex needs required regular and ongoing interaction with FMH workers which is not possible in the context of working with a psychologist, psychiatrist or GP. These latter professionals do not appear to have the mandate to provide the type of responsive and time intensive support provided by the FMH. To this end, FMH workers were observed juggling their schedules to consult with clients at short notice in an effort to be responsive to fluctuating levels of need and/or risk. This high level of responsivity has implications for the utility of technology-based systems that may allow workers to be available when not able to meet face-to-face. Unlike psychologists who booked back-to-back appointments with clients, FMH staff regularly scheduled a maximum of 3-4 face-to-face sessions with clients daily (approximately 4 hours). The remainder of their time was spent liaising with other services involved with, or on behalf of, the client, communicating with family members, making follow up phone calls to clients and the documentation of all interactions. A need for high level communication and information sharing between many stakeholders was observed.

Information Sharing

Representatives from both sites convened a fortnightly partnership meeting involving other support services to discuss young peoples' pathways into and through services, with the aim of finding the best service match for clients. This particular meeting consisted of the clinical lead from site 1 and three youth clinicians from site 2 (minutes were taken by an administrative support officer from site 1). It was described as a *"big thing"* to achieve because the mental health and supporting services had historically operated in isolation and with reluctance to share information. The services described had limited contact and awareness of one another prior to the rollout of the new YMHS. This recent intentional blurring of the service boundaries was aimed at a more client-centered model of care, but it requires constant negotiation around how the separate, but interrelated, services can provide coordinated care for a client. At one such meeting, the case of a young man 'Sam' was discussed. See Textbox 2 below for a description of Sam's case.

Textbox 2

Sam's case

Sam, aged 19 years, was presenting with mood and anxiety concerns, substance abuse problems and a physical health condition. Recently his care had been shared between sites one and two due to fluctuating levels of risk and a perceived need for more assertive care by site two. Recently Sam's care had involved the following people: a case worker at each of the services, a consultant psychiatrist and a specialist youth worker, a GP, a psychologist (who had recently just resigned thus a new one would need to be assigned) and another non-government agency. During the meeting, it was also indicated that a drug and alcohol worker would come on board. This led one staff member to exclaim there is "*a hell of a lot of a people involved with* [*Sam*]". Staff discussed the need for all individuals/services involved with the client to "*sing from the same song sheet*" in terms of Sam receiving similar/complementary messages around his care.

Bringing together the many stakeholders involved in Sam's fragmented care was clearly necessary. Technology to facilitate multi-stakeholder/organisational/sectorial communication and information sharing is an obvious way in which the work could be better supported. As in Sam's case many examples of care shared across multiple organisations and sectors were observed. Currently face-to-face case conferences and phone calls/email/fax are the primary methods of information sharing available to the different members of a care team. Confidentiality and privacy concerns, along with historically separate record management and data storage systems has resulted in the definitive separation of electronic records between organisations. It was concluded that outdated, incomplete and/or untimely information often results in the client repeating their story over and over again and time spent chasing missing information. For example, throughout the week at site two, one staff member made numerous unsuccessful phone calls to the previous worker of a current client to obtain further insight into the current presentation of the client who was proving complex to manage. Where co-location of professionals working with a particular young person occurred, increased levels of information sharing was observed through many

incidental and brief catch ups. Where colocation did not exist, information sharing was less common. This was highlighted by a staff member who lamented;

> *"we have no idea what they were doing….they work with them for 9 months, they hit a crisis whatever that might look like, we don't know why they hit the crisis or what the work was that brought him to that point and here we are having to pick up the pieces and it's frustrating because they don't tell us what they were doing".*

This comment was made by a staff member from site two in reference to a client in crisis referred into the service by their treating psychologist.

Client Profiles and Help-seeking Experiences

As in Sam's case, many young people that were encountered presented with comorbid conditions which included multiple mental health concerns, physical and/or intellectual disabilities, and physical health and substance abuse problems. Various combinations of unstable or non-existent social support, employment and housing and limited or interrupted education were also common. Many clients also battled poverty. This profile of isolation, disability and disadvantage has implications for how and why technology may be used to support health and engagement with services. Many of the young people encountered, forced into independence from a very young age, spoke of their struggles to afford the basic necessities of life. One staff member remarked "*you tend to have people who move in and out of wellness".* This sentiment summarises the majority of client engagements with the services. Many staff, across both services, described a repeating pattern of client engagement that is often brief in nature and crisis-dependent. Young people, who may be inexperienced help seekers and in the process of developing a mental health disorder, showed reoccurring patterns of engagement, disengagement and then reengagement. This was evident in a number of client sessions observed where the client was re-engaging with the service after a period of disengagement – not always with the same case worker.

Multiple clients failed to attend pre-arranged sessions. A staff member at site one suggested that, in line with adolescent health philosophy, unreliable attendance should not create a perpetual barrier to help-seeking. Many clients also described nomadic lifestyles, often transferring between services in different regions. For site one (where consultations/sessions take place primarily on site) attending a session for some clients meant a four-hour round trip, requiring parents to take a day's leave from work due to business operating hours. Site two provides assertive outreach and as such primarily sees clients in the community (e.g. at their homes), similarly this can result in an entire day dedicated to visiting one client.

Role of shadow systems: the impact of informal and often hidden or less obvious influences on the system

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Textbox 3

Paul's case

'Paul' is 15 years of age and identifies as same-sex attracted. Paul was seeking help to address his social phobia (which affects all of his social interactions, including school attendance) and substance use disorder. He has multiple social media accounts each with many followers, and uses them prolifically to explore and express his sexuality. His parents, with whom he resides, are unaware of his sexual orientation and strong online presence. Paul sees a case worker and a psychologist; he also has a school attendance officer assigned to increase his poor attendance at school. The school attendance officer is very focused on getting Paul to school at all costs; in contrast, the psychologist is working with him on graded exposure therapy around school attendance.

Paul's case (Textbox 3 above) highlights the complexity of presentations facing FMH workers and the need for multiple input at different levels, not only clinical but also contextual including awareness of the virtual world as a legitimate reality for young people. This brings up new challenges in clinical work which include different dynamics, rules and ways of interacting. A number of shadow systems are visible in Paul's case. The influence of Paul's parents is indicative of the role of the family, the importance of which emerged throughout the study. In comparing their work with older adults and youth, one staff member commented, *"they're just so much more complex…because you're not just dealing with that person, you're dealing with the family"*. Many young people (including older youth) chose to have family members accompany them to appointments. The family adds another layer of complexity to the work of FMH clinicians and the role of technology-based interventions within it; complexity that is related to the family's own level of (dys)functioning, beliefs about what constitutes good care and (in)ability to support the young person and related privacy issues.

As in Paul's case, the online world interacted with clinical presentations and health behaviours of a number of young people engaged with the services. This was evident in one staff member's recount of a prior client who had presented at the service on a strict diet/exercise program and having bleached her arm hair. This behaviour was linked to an incident in which, without her consent, a Facebook page calling her fat and hairy was created. Many of her school peers had liked it. Similarly, two young women encountered during the observations discussed histories of sexting; one had naked pictures distributed without her consent and the other had become engaged in daily sexually explicit conversation with a number of male school peers over Facebook. Both talked of the significant impact of the events on them, particularly the shame they experienced.

Self-organisation

Diversity in Organisational Structure and Function

Site one is one of many federally-funded centres throughout Australia which a national body holds the core Commonwealth grant funding for. Funding for each centre is distributed to a local lead agency which is responsible for implementation and operation of the centre in conjunction with a consortium of local service providers. This implementation model aims to ensure local adaptation and context fit of the service, as such everyday operation and practice can vary widely between centres. For example, the lead agency sets the award conditions for the same role that attracts disparate remuneration packages at different centres across the country. Work practices can also vary. For instance, a recent funding-related staff reduction at site one necessitated implementation of a duty system to meet service demand. Accordingly, staff, on a rotating roster, were required to respond to urgent inquires via phone over an allocated two-hour period, this included triaging new clients. Once triaged, an in-person intake session is then booked for a more thorough assessment. In contrast, a centre in a neighbouring region which services a larger geographic area conducts the entire intake assessment process over the phone. These differences demonstrated evidence of need dictating service models and the combination of face-to-face and technology-enhanced service provision to deliver timely care in rural contexts. This need-driven situation represents a departure from the well-established preference for face-to-face service provision and suggests possibilities for design that seek to integrate on and offline service provision. Site two is one of 10 teams comprising a rural state-funded service. Whilst common executive leadership and policy direction govern the service, and a common record management and data storage system is used, each team (directed by a team leader) has developed their own local practices and procedures in response to demands of their context.

The endemic self-organisation of work sites has implications for the large-scale implementation of rigid, inflexible technologies and challenges a one-size-fits-all approach to implementation and uptake. The importance of local knowledge and expertise cannot be underestimated. Many examples of un- or underused technology systems that failed to complement workflow were observed. For example, staff at site two, co-located at a state government health department building, were expected to use an organisation-wide software package to record offsite movements throughout the day to satisfy occupational health and safety requirements. Signs were posted around the office and reminders given in team meetings in an effort to increase very patchy adherence to the system. Staff explained that they had recently moved from a more accessible paper-based system to the software package which failed to integrate with other databases used for daily work. Four major record management and data storage systems exist across the major government-based mental health services located in metropolitan and rural South Australia. Moreover, non-government and individual service providers all use discrete data storage and reporting systems. This legacy of information separation has a disempowering impact on clients who are repeatedly expected to repeat their personal story to many different service providers throughout their help-seeking journey.

Mental models: internalised rule sets which govern decision making and work practice

Risk: consumer-based risk and associated professional risks

Identification, assessment, management and reduction of *risk* is a crucial aspect of mental health service provision and therefore affected many decisions made by staff. This was best highlighted by a set of notes lying on a staff member's desk. The notes, from a professional development seminar titled 'defensive documentation', had been very useful the staff member noted. She then recounted the story of a coronial inquest into a neighbouring mental health service that found evidence of inappropriate risk assessment, failure to refer for psychiatric assessment, and sub-standard case noting. The defensive documentation seminar provided professional development around defending case notes should they be subpoenaed. Case notes are viewed as documentary evidence for an audit trail of clinical decision-making, particularly the way in which risk is addressed / managed and the hierarchy of professional responsibility in decision-making. This anecdote is illustrative of work environment and culture, it speaks to the type of technologies that are likely to be acceptable – particularly technologies that may alter communication between clinician/client, impact on risk assessment/management and necessitate documentation. Designing for a work environment such as this - where risk is embodied - carries important implications for the information communicated through technologies.

Sam's case (Textbox 2) is a good example of not only the interdependencies and overlaps in care, but the constant negotiation around who has final clinical responsibility. His case was raised due to the General Practitioner's (GP) concern "that the medical management sits with her". Sam had previously seen the GP to access medication prescribed by the psychiatrist, however, four months later the GP had not seen Sam (who had failed to attend appointments). Conflicting reports existed around whether he had filled the script and/or commenced the medication. The GP's concern lay in the fact that her name was attached to the case on official records and having "read the level of risk" was left feeling as though she had to carry the case through - though "medically where that [left] her [was] a bit in no man's land". This highlights the responsibility assumed via provision of care and the need for high level and consistent communication and transparency around care between service providers not currently supported by universal or integrated data storage and reporting systems.

Engagement

Throughout the observations it became clear that, behind attention to risk, developing engagement and personal rapport with the client was of utmost importance. One clinician commented "*dealing with youth, you are always dealing with risk……..you can't just do a one off assessment, you have to dig a bit*"; similarly during a clinical supervision session one clinician commented to another "*people engage with the person not the service*" and in doing so aptly highlighted the personal nature of the work and the well-documented rationale for the reluctance to move away from predominantly face-to-face service models which is based on an assumption that technology is not capable of strengthening, or may actively hinder, existing personal connection.

The ability to suspend personal judgement and values is crucial to effective mental health practice. Refer to Textbox 4 below for two ethnographic accounts which illustrate the primacy of engagement in mental health work.

Textbox 4

Primacy of engagement in mental health work

Tori's case

One session observed involved a young woman 'Tori', aged 18, accompanied by her boyfriend (and father of her unborn child) 'Peter'. The young woman had a history of complex trauma and neglect and presented with emotional dysregulation and low distress tolerance. During the session Tori was quite animated and anxious; the majority of the discussion focused on how she felt unsupported by Peter with respect to a contentious share house living arrangement. Throughout the session Peter played games on his mobile phone and did not engage with anyone in the room or look up from his phone. After the session the treating clinician spoke of her reluctance to challenge this behaviour, instead she chose to prioritise engagement and development of rapport with Tori *and* Peter (the latter of which she was meeting for the first time).

Ellen's case

Ellen (16yrs), along with her carers, presented for an intake session. She is one of two children living in a home with multiple adults; exactly who the primary caregiver was difficult to establish, as was their relationships with one another. Ellen's carers suffered from health issues of their own and illicit drug use was a way of life in the home. They had engaged with the service over their concerns around Ellen's self-harming. The staff member described the session as quite intense with the adults dominating the discussion, leaving little room for Ellen to speak when directly addressed. In reflecting on her practice throughout the session, the staff member described adoption of a "curious position" that did "not challenge the worldview of the family" – the intention was to engage the family such that further work could be explored in this very complicated situation. The many other concerns of the staff member took a backseat to the desire to establish and maintain rapport

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Contextual Variables: Age, Gender

SMS-based appointment coordination and reminders were observed to help to develop engagement and rapport. Context, however, played a major role in this practice. For example, one younger female staff member discussed text messages received from young male clients which referred to her by a nickname and suggested conducting

session over coffee at a local café. Whilst conducting sessions outside of the service walls is often encouraged and appropriate, in this instance the implied meaning was related to a perceived personal connection over and above that deemed appropriate. This same staff member described an experience with a client who became a stalker. These stories highlight the fine line staff walk with respect to engaging, and building rapport, with the client to enhance the work but also striving to maintain the requisite professional distance.

DISCUSSION

The current results highlight a myriad of considerations and opportunities with respect to the place of technologies within community-based FMH services and, whilst it is impossible to address all of them, a number of key ideas are discussed. We take pains to note here that the intention of this discussion, and the research more generally, is not to advocate for the design of one specific technology over another, but instead to provide the field with contextually rich information regarding the design domain. Our most urgent concern is to shed further light on kinds of issues which require consideration with respect to the design and implementation of technologies (e.g. multi-user, consumer-centred) that are likely to be relevant for community-based mental health service contexts. We attempt to achieve this through a discussion of existing and emerging mental health technologies.

In the first instance, the analysis of this material through a complexity theory perspective generates distinctive kinds of implications for the design of new technologies. For example, the coordination of the delivery of multiple mental health services is a very real issue for service providers and clients, which might appear to recommend the introduction of a communication platform. Unsurprisingly, therefore, technologies capable of supporting collaborative care via social networking technologies are emerging in both research and industry (Kurahashi et al. 2016). And yet, the introduction of any technology that facilitates communication between clients, service providers and administrators will also necessarily introduce new risks regarding legal and professional accountability for advice and treatments discussed or delivered through such means. This circumstance will (whether intentionally or not) affect the nature and content of the communications (including advice) that service providers will feel comfortable using the system to deliver to clients. Although complexity theory is not a means of predicting specific (negative or positive) consequences of new technologies, it is very useful in sensitising researchers and developers to the subtle interrelations between elements of the systems that are currently in place.

This study's findings highlight two definitive mental models which drive frontline community-based mental health work: risk and engagement. Throughout the study FMH staff were observed balancing the two, for example engaging consumers in order to assess and address risk. Crucially, however, deference to obtaining and maintaining consumer engagement is only possible within predefined system limits. In reality these mental models exist in a hierarchy; engagement is preferred but not required, particularly in the case of site two, where if a consumer is deemed 'risky' enough then detainment against their will is a legitimate possibility. To that end

FMH workers have been described as 'psychiatric risk managers' (Sawyer 2005) and this creates a unique context and culture within mental health service provision (Lawn 2015). Technologies which encompass solutions to facilitate mental health care in its traditional form challenge this hierarchical system, often with negative results.

Take for example early research around the use of email as an adjunct to face-to-face mental health service delivery. Its potential to "change the dynamic of the [worker/consumer] relationship [with] the structure of consultations [becoming] less formal and bounded" as a result of young people being able to more meaningfully engaged with their health and treatment through the writing process was seen to be significant (Martin et al. 2011, p. e.118). Despite this, email as an adjunct to therapy has not been investigated in any meaningful way; existing evidence is methodologically flawed and an overall dearth of literature is apparent (Martin et al. 2011; Montague, Varcin & Parker 2014). This lack of research and widespread adoption in routine mental health service delivery makes sense in the context of the current study's results which highlight FMH workers' orientation to risk and self-protection focus to avoid professional repercussions. As such, a seemingly simple technology-based addition to care such as email is seen to involve changes to "roles, identities and mutual expectations" (Greenhalgh & Stones 2010, p. 1286 p. 1286) that are counter-cultural to current practice and therefore are not readily embraced.

Newer, custom-built, technologies also face the same problem. These technologies designed for adult chronic condition management, e.g. Kurahashi et al. (2016), aim to respond to many of the current study's findings, particularly with respect to disjointed care provision, lack of clarity regarding responsibility and risk management and lack of efficiency in the system to offer comprehensive, responsible, informed care to individuals of high complexity and risk. These clinical collaboration systems are consumer-centred and, as such, exist outside of organisational barriers, web-based systems like Loop (Kurahashi et al. 2016). They, like email-based interventions before them, have the potential to change the nature and frequency of consumer and healthcare provider interactions. Whilst these types of systems provide the platform for consumer empowerment, along with collaborative practice underpinned by better information sharing, their success is reliant, in part, on the willingness and incentivisation of the workforce to share information inter-organisationally and negotiate risk in the context of mental health service provision.

Beyond better integration of the formal (mental) health system, client-centred clinical collaboration systems also have applications for young people in that they offer a tangible way in which to better recognize the role of *shadow* systems highlighted in the current study's results, particularly the family, in the consumer's help seeking journey. Likewise, the interdependencies between the mental health system and others services such as employment, housing, justice, disability, drug and alcohol, education/vocation could be meaningfully addressed by tools such as these whereby key workers from each sector become part of the collaborative ecosystem. The current study's results offer some key points for consideration around the implications for these types of changes for FMH work practice. For example, we have seen evidence of where the family can be a protective and

supportive influence in the lives of young and examples of the opposite. These findings pose difficult questions such as: how does a service working with a tool like Loop support a young person to negotiate and make sense of which members of their support system to include on the system. What about in the case of friends? Everyday FMH professionals working with youth struggle to assist them in the context of very complex family situations. The addition of collaborative communication-based tool may seem extremely helpful but it also carries with it very important and ethically laden issues that become even murkier in the context of working with young people – the notion of vulnerable (both in terms of age and mental health status) consumers making very personal information available for the consumption of others requires serious thought and debate. Furthermore, contextual variables such as gender and age should also be considered by designers and implementers of these systems. The current results beg important questions around the level of engagement required and desired by mental health staff with respect to their clients, and the method by which this is achieved, along with the way in which offline working relationships are translated and facilitated online. Whilst promising opportunities exist to place young people at the centre of their care, e.g. through technologies that allow clients to express themselves *how*, *where* and *when* they feel comfortable and safe, an appreciation of the subtle (and not so subtle) personal dynamics that play out in this space is important for sensitive and ethical design.

The current study's results also outline considerations for the motivational elements of consumer engagement with collaborative, communication-based systems. These types of tools tend to assume high levels of motivation and engagement with health and help-seeking. Our results highlight, however, that young peoples' service journeys tended not to have neat beginnings or endings and their engagements with the system tend to take place in the context of crisis and chaos. Adapting these systems to youth contexts therefore requires sensitivity to the lack of psychosocial stability associated with many potential end users.

At a practical level, design of technology in this space would benefit from a focus on low cost devices and initiatives in consideration of the endemic equity issues associated with those suffering mental health conditions. Physical, cognitive, fiscal, and socioemotional capacity are important considerations, with effective design of technology being much broader than the consideration of a single mental illness. This may seem like generic advice for all technologies, but recent research indicates that current eMental health technologies (particularly internet-based cognitive behavioural self-help interventions) target females who are middle to high income earners and more highly educated (Meurk et al. 2016). These interventions were praised for their potential ability to reach the unreachable and service underserved populations and, as such, offer a timely reminder that designing inclusive technologies is harder to achieve than common wisdom would suggest. This has particular implications for the design of systems that are intended to be consumer centric and are therefore web-based.

In summary, it is evident that there are no easy answers or quick fixes with respect to designing or implementing technologies aimed at enhancing young people's engagement with services and improving their experience of help-seeking. It is clear, however, that innovation is outpacing the cultural changes required to enable the potential of technology in the current mental health system. This reality is supported by recent research which

demonstrates that the necessary financing, governance and implementation models are under-researched (Meurk et al. 2016). The majority of current eMental health solutions are very prescriptive in nature and aim to replace, not enhance, the face-to-face connection (Meurk et al. 2016). At a minimum we require time for the mental system to rationalise the prevailing risk-based paradigm in the context of technology-related changes to information sharing, the nature of inter-organisational collaboration and the role of the consumer in the help-seeking and treatment process. Furthermore, we require real world examples of the use of tools like Loop in routine practice which enable the mental health workforce and system more broadly to grapple with and debate the associated changes, limitations and benefits to their current work.

The results of this study should be considered in light of the fact that they were collected in one inner rural South Australian region. As such, they may not be generalizable to other rural or more remote regions. Additionally, the region was in the midst of system reform with newly established state-wide Youth Mental Health System which may have impacted on nature of collaboration and functioning of the system more generally. Finally, the study's results are based on a relatively short, but highly immersive, observational period.

CONCLUSION

Technologies offer a much-needed opportunity to foster increased engagement, autonomy and choice for young people seeking help and engaging with from mental health services. Whilst significant opportunities exist to improve information sharing in and between the components of the mental health system, this is balanced by a culture of gate keeping and risk aversion. As such, innovation is outpacing the cultural changes required to enable the potential of technology in the current mental health system. That said, consumer-centred collaborative communication systems offer an exciting opportunity to better recognise and incorporate the subsystems such as the family in a young person's care. The ethical and clinical implications of this are, however, yet to be fully debated and rationalised. Technologies developed for this space must be usable for a broad range of medical, psychological, cognitive disability and social disadvantage. It is paramount that they accommodate a range of consumer motivational levels and repeat cycles of engagement/disengagement over time.

CHAPTER SIX SUMMARY OF RESULTS

Intensive observation of everyday work within two rural community-based mental health services was carried out to improve understanding of how technology might enhance young people's engagement with services and their more general experience of help-seeking through increased support and better system navigation. This research positioned mental health work as taking place within the wider mental health system and thus how it impacted on and was defined by core complex systems concepts.

Staff who participated in the study described their work as multifaceted, ambiguous and individualised in its approach to consumer care. Frontline mental health work largely involved risk assessment, management, and care coordination, along with ongoing advocacy and support for young people. Debates around the exact nature of frontline mental health work emerged, and these tensions highlighted the level of professional autonomy associated with the role.

Young people's experiences of a disempowering and difficult to navigate mental health system were evident throughout the observations, as in the earlier scoping study (Chapter Five). This disempowerment manifested through an interconnected but poorly integrated system; one that was not currently equipped, or incentivised, to share information and communicate in ways that promoted consistent and holistic approaches to care, particularly for individuals with high complexity and risk. As such, diversity of structure and function, and localisation of work practice, was apparent and conceptualised via the self-organising property of complex systems (Chandler et al. 2016). This was best exemplified by the range of unintegrated record management and data storage systems used by the various components of the mental health system.

Requirements associated with documentation of worker/consumer interactions served to underline the omnipresent legal and professional implications of frontline mental health work. With this in mind, management and minimisation of risk as a driving force in frontline mental health work was a continued theme in this study, from the earlier scoping study. Understanding of the nature of frontline mental health work was, however, deepened through identification of the hierarchical relationship between risk and engagement. Risk and engagement were identified as core mental models (or internalised rule sets) that govern frontline mental health work. Technologies to facilitate mental health care in its traditional form were seen to challenge this hierarchy and the broader cultural and contextual factors that characterise mental health service provision.

The results also underscored many important factors associated with youth help-seeking relevant to the use of technology in existing mental health services. Irregular appointment attendance and crisis-centric interactions with the system were common and were reflective of ambivalent consumer motivation towards help. Furthermore, interactions with young people were broader than consideration of a single mental illness. Engaging with, and accommodating, other associated life domains such as social support and stability, housing, employment, education and financial stability, along with co-morbid mental health and physical conditions, was

necessary. Additional complexities were associated with related but less obvious system influences, the most notable of which was the role of the family.

The findings of this study offer many points for consideration with respect to implementation of ESN technology in rural, community-based youth mental health services. This was applicable particularly with respect to emerging consumer-centred platforms which encouraged and facilitated collaborative care and other technologies which aimed to alter the nature of communication and interaction in this context.

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CHAPTER SEVEN PREAMBLE

Investigation of rural, community-based youth mental health service provision and help-seeking from individual, organisational and systemic perspectives (Chapters Five and Six), yielded rich insights into relevant personal, contextual, and cultural factors that impact on technology design and implementation. These findings underpin and propose many opportunities for technology design and innovation. Importantly, however, findings from the observational research presented in the preceding chapter position mental health work as contested and multifaceted, undertaken within the complex influences and properties of the wider mental health system. With this in mind, it is argued that these learnings and insights will remain *design opportunities* or ways of *doing technology* that are not fully integrated into mental health work, partly due to the fact that in and of itself, the work is contested by those working in the field. To that end, the research presented in this chapter involved a series of participatory design workshops which aimed to facilitate mental health providers and consumers to further explore the ways in which technologies could support their work and young people's help-seeking (through increased *engagement*, *support* and improved *navigation*, ESN technology) and, in doing so, generate an in-depth understanding of the design domain.

The purpose of this final study, therefore, was to extend the research findings generated by the talk and observation-based research methods utilised in Chapters Five and Six by critically exploring through use Participatory Design (PD) methods appropriate for engaging mental health professionals and consumers in creative visualisation of (technologically-inspired) future possibilities (Xie et al. 2012). The study resulted in one paper, *Designing for practice: Understanding technology use in rural community-based youth mental health contexts*, which is presented in this chapter. Mental health professionals who had participated in earlier phases of the research and represented two different tiers of the mental health system were involved, as were young people with a range of mental health help-seeking experience. Mental health professionals participated in each of the three workshops and young people in the third workshop.
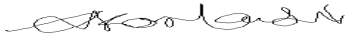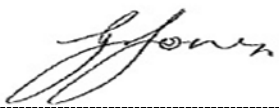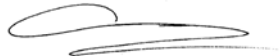
The three workshops were inspired by future workshops (Kensing & Madsen 1992) and informed by the research of Ihlström, Svensson and Åkesson (2005) and McPhail et al. (1998); each workshop had a distinct but integrative focus. Artefacts developed out of the scoping and observational studies were utilised to shape and scaffold the workshop activities. The first workshop was dedicated to the 'Visioning Phase' which aimed to explore, via brainstorming and consensus building techniques, the types of technologies able to support mental health work and help-seeking. The second workshop was the 'Scenario Building Phase' in which personas were provided, and scenarios generated, to encourage mental health professionals to explore the different ways in which particular youth consumers might use, and benefit from, various ESN technologies. The third and final workshop was the 'Mock-up Phase', in which everyday craft-based materials were used to visualise various ESN technologies and design ideas.

CHAPTER SEVEN: PAPER SIX – SUBMITTED FOR PUBLICATION

Designing for practice: Understanding technology use in rural community-based youth mental health contexts

Orlowski, SK, Matthews, B, Lawn, S, Jones, G, Bidargaddi, N & Venning, A submitted, 'Designing for practice: Understanding technology use in rural community-based youth mental health contexts'.

Authorship Declaration: SO conceived and designed the study, carried out data collection, analysed and interpreted the data, and drafted the manuscript. BM, SL, AV, NB contributed to the design of the study, analysis and interpretation of the data, as well as the drafting of the manuscript. GJ contributed to the analysis and interpretation of the data, as well as the drafting of the manuscript. All authors read and approved the final manuscript.

Simone Orlowski

Ben Matthews

Anthony Venning

Sharon Lawn

Gabrielle Jones

Niranjan Bidargaddi

ABSTRACT

The application of emerging social and mobile technologies to community-based, frontline mental health care settings appears to have remarkable scope to address persistent issues of access and quality of care, particularly in remote communities. Their potential, however, has not yet been realised, in part, due to a lack of understanding of mental healthcare settings as technology implementation contexts. With this in mind, the aim of current research was to use design-based methods to better understand domain criteria with respect to the place of technology in rural, community based youth mental health contexts.

Three participatory, adapted future workshops were conducted. The workshops were utilised for their ability to integrate artefacts, and extend knowledge derived from prior interviews and focus groups with, and observations of, mental health professionals and clients. While the workshops utilised recognisable Participatory Design (PD) elements such as personas and scenarios, their principal value was their contribution to generating a contextualised and real world understanding of frontline mental health service provision, and the possible roles of technology within it.

The results of this research demonstrated that adapted use of PD methods were effective for defining domain criteria associated with mental health care rather than simply functioning as a vehicle for informing the design of new products or systems for the context. The use of PD in this way supported community-based youth mental health professionals to articulate the roles of technology in their work beyond the technology as an adjunct rhetoric. The results advocate for alternative ways of thinking about the contribution of technology - beyond technology as quantifying and tracking to the person-centred approach of technology as self-directed and potentially narrative redefining.

INTRODUCTION

A recent review commissioned by the Australian government has advocated for the integration of technology-based tools and support within the mental health system (Department of Health 2015). Technology-enhanced mental health services are, at least in part, seen to be a method by which current gaps and inconsistencies in the system, along with poor engagement with services, can be addressed through the creation of more personalised, flexible and accessible modes of help-seeking (Department of Health 2015). These technology-based solutions are predicted to play such a significant role in the mental health system going forward, that access to services is projected to be mediated through a digital mental health gateway (Department of Health 2015). The ways in which mental health services are provided to young people (aged 16-24 years) are of particular concern since, as a group, they are disproportionately affected by mental illness (McGorry et al. 2011).

Despite the current research and policy push toward technology-related innovation and change, the majority of development and effectiveness research is focussed on standalone, self-help mental health interventions (Meurk et al. 2016; Reynolds et al. 2015). Use of technology to facilitate mental healthcare in its traditional form is comparatively under-researched, and as such, technologies designed for use by mental health professionals and clients largely remain unintegrated into face-to-face service delivery contexts (Montague, Varcin & Parker 2014). The reasons that underpin this are multidimensional. For example, further work is required to develop models capable of informing widespread rollout of blended (i.e. technology-supported) clinical practice (Meurk et al. 2016). In fact, a dearth of research exists around appropriate financing governance and implementation models to facilitate the uptake of technology in existing mental health services. To this end, work in this space is rapidly expanding (Reynolds et al. 2015; Wentzel et al. 2016). Additionally, the adoption rates may have been impacted by the often non-integrated priorities and foci of technology projects separately conducted within the health and technical disciplines (Smith et al. 2014). Finally, a poor fit between technology and current work practices and systems has been reported as a significant factor in lack of adoption of technologies in health settings more generally (Gagnon et al. 2012). With this in mind, design processes that prioritise and privilege tacit knowledge and end users' existing ways of knowing and acting, such as Participatory Design (PD), are increasingly finding traction in this space (Hagen et al. 2012; Orlowski, Lawn, Venning, et al. 2015; Orlowski et al. 2016; Poole 2013). It is this last point around which the current research is framed.

Early Scandinavian PD projects were *"aimed at empowering labour in its struggle with management, particularly in terms of the introduction of new technologies"* (Spinuzzi 2002, p. 209). Since those early projects, which were carried out in strong collaboration with unions (Clement & Van den Besselaar 1993; Ehn 1988), PD research has been reinterpreted in a myriad of different ways and applied in a range of disciplines to develop technology-based solutions (Sanders 2006; Spinuzzi 2002). Over the last two decades some researchers have turned their attention to design of mental health technologies, and recently, there has been increasing interest from the health research community in PD technology projects (Hagen et al. 2012; Orlowski et al. 2016). Hagen et al. (2012) have suggested a framework for integrating traditional design of complex health interventions with PD

sensibilities and methods. The framework is specifically targeted at the creation of youth mental health and wellbeing technologies.

The current study

Hagen et al's (2012) framework, like traditional application of PD, is intended for use in the design and development of individual products and interventions. Currently, however, technology-based innovation challenges longstanding mental health work practices and models of service delivery and, therefore, has outpaced the cultural changes required to support its uptake (Orlowski, Lawn, Matthews, Jones, et al. in revision). With this in mind, the current research aimed to utilise PD methods to generate deeper understanding of community-based, youth mental health services as a design domain and implementation context. This work is in line with more recent theoretical positioning and application of PD which has extended beyond development of individual or networked devices (Björgvinsson, Ehn & Hillgren 2010), to technology design "as entry into the networks of working relations – including both contests and alliances – that make technical systems possible'" (Suchman 2002, p. 92).

The current study has been informed by prior research with young help seekers and professionals in a rural community-based mental health service context (See Figure 3. Orlowski, Lawn, Antezana, et al. (2016); Orlowski, Lawn, Matthews, Jones, et al. (in revision)), which has identified an adjunct role for technology. Principally because help seekers and service providers place fundamental importance on development of personal relationships and human connection and see technology as barrier to achieving this (Orlowski, Lawn, Antezana, et al. 2016; Orlowski, Lawn, Matthews, Venning, Wyld, et al. in revision). Furthermore, mental health practice is defined by a central paradigm of risk: assessing it, managing it and minimising it. Unsurprisingly, therefore, technology-assisted practice is not prioritised by frontline staff or organisations more generally.

From a consumer's perspective, young people seeking help from rural frontline, community-based mental health services tend to have complex needs including co-morbid conditions and their help-seeking patterns are often crisis-centric. Their experience of help-seeking can also be disempowering due to the complexity and fragmentation inherent in the current system. Moreover, some of these young people find it difficult to access technology in a reliable way for a range of reasons (Orlowski, Lawn, Antezana, et al. 2016).

At this point a strong understanding has been established of the individual, organisational, contextual, cultural and systemic factors that impact on rural community-based, youth mental health service provision, help-seeking and thus the role of technology with it. Many opportunities for design can be derived from this research. The problem is, however, that they remain *design opportunities* or ways of *doing technology* that are conspicuous, counter cultural, unessential and/or unintegrated – as such, these design ideas manifest as add-ons to current work. To that end, the current research involved the use of adapted PD workshops to facilitate mental health providers and clients to explore tangible and essential ways in which technology could support their work and help-seeking respectively through an in-depth understanding of the design domain.

Within PD, many types of workshops have been employed to initiate creative thinking and change through exposure of participants to novel practices and unfamiliar contexts, information and activities (Muller & Druin 2012). The workshop format has traditionally been used to encourage multi-stakeholder communication, along with shared goal and outcome setting and strategy development (Muller & Druin 2012). Muller and Druin (2012) describe these workshops as a kind of "third space" in which "negotiation, shared construction and collective discovery" can take place (p. 15). The specific methods and techniques utilised in this research were inspired by Future Workshops; a method that originated in a German civic planning context (Müllert & Jungk 1987) and has subsequently been adopted by participatory systems designers (Kensing & Madsen 1992). McPhail et al. (1998) argues that future workshops in particular assist with: (1) gaining understanding of models and structures as they relate to current work; and (2) generation of future visions and design proposals. In our case, we aimed to investigate the utility of adapted future workshops in achieving these two objectives when conducted in a mental health context and applied to the investigation of community-based youth mental health services as a design domain and implementation context.

Similar to Xie et al. (2012), we aimed to critically explore through use, PD methods appropriate for engaging mental health professionals and clients. The research was influenced by the *tool perspective* which positions design of technologies as design of tools that support a skilled worker by favouring the *work process* as the inspiration for design *not* information flow or data. This theoretical orientation manifests in the creation of tools that complement or enhance the skilled craft (Bodker et al. 1987; Spinuzzi 2002). Previous work has investigated what mental health professionals and clients *say* with respect to technology-based changes to their work and help-seeking (Orlowski, Lawn, Antezana, et al. 2016; Orlowski, Lawn, Matthews, Venning, Wyld, et al. in revision) *and* what they *do* via field observations (Orlowski, Lawn, Matthews, Jones, et al. in revision). In line with Sanders' *say-do-make* strategy, we now aim to learn from what they *make* (see Figure 3) (Sanders 2000, 2006).
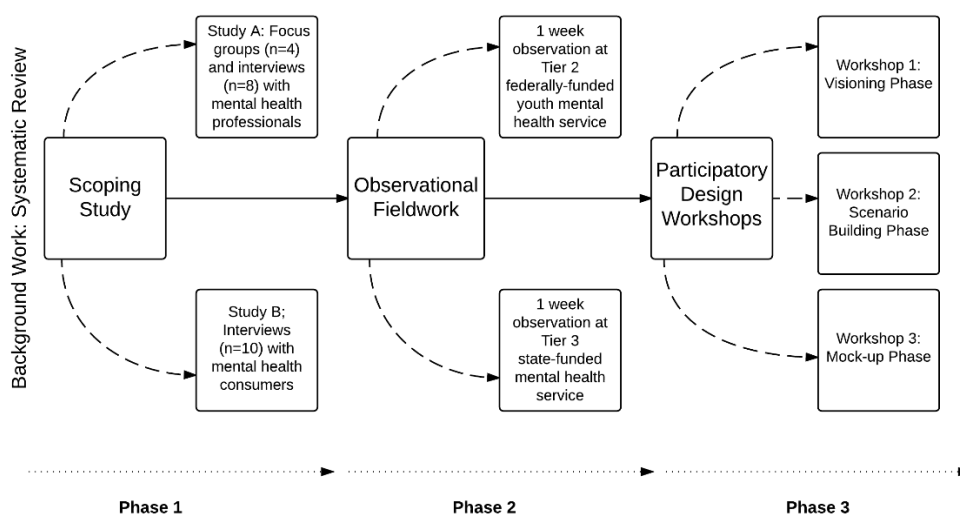

Figure 3 Overview of prior and current research

METHODS

Overview of Workshops

A pragmatic approach to the research was taken, with the current workshops inspired by Kensing and Madsen's (1992) future workshops and informed by those conducted by Ihlström, Svensson and Åkesson (2005) and McPhail et al. (1998). The project was therefore designed to optimise results in a condensed timeframe and required a structure that, whilst each workshop built on the last, was accessible to accommodate participation at any point in the process. Utilisation of artefacts created earlier in the research process was also desired. The focus of the three workshops was as follows: Visioning Phase (an exploration of what may be needed and is possible), Scenario Building Phase (an exploration of *which* types of technologies can be used by *whom* and *why*) and a Mock-up Phase (creative visualisation of possible technologies and designs) (see Figure 3, Phase 3).

Participants

Initially it was decided that a series of three workshops would be carried out with mental health professionals and youth mental health clients separately. Due to time and resource restrictions, however, the first two workshops were carried out with mental health professionals and the third was a combined young person/mental health professional workshop.

As far as practically possible the same group of mental health professionals participated in all three workshops. However, clinical responsibilities were prioritised over participation in workshops which resulted in (1) participants cancelling on the day of the workshop or (2) inability to find a time all participants were available due to pre-existing clinical commitments. Overall, 4/9 participated in all three workshops, one participant was present for two workshops (workshops 1 and 2) and four participants were present for one workshop (three in the first workshop and one in the second). See Table 8 for workshop participant demographic information.

Table 8

Workshop participant demographic information

Workshop 1 Mental health professionals

Number	Gender	Age (years)	Current role/professional background	Employer
1	F	50-59	Youth worker, Management	Federally funded service
2	F	50-59	Mental health nurse	State funded service
3	M	40-49	Psychologist, University Lecturer	University
4	F	40-49	Mental health nurse	State funded service
5	F	50-59	Mental health nurse	State funded service
6	M	50-59	Mental health nurse, Management	State funded service
7	F	40-49	Social worker, Project officer	State funded service
8	F	30-39	Social worker, Project officer	State funded service

Workshop 2 Mental health professionals

1	F	60+	Mental health nurse	State funded service
2	M	50-59	Mental health nurse	State funded service
3	F	50-59	Mental health nurse	State funded service
4	M	50-59	Mental health nurse	State funded service
5	M	40-49	Psychologist, University lecturer	University
6	F	30-39	Social worker, Project officer	State funded service
7	F	50-59	Youth worker, Management	Federally funded service

Workshop 3 Mental health professionals

1	M	50-59	Mental health nurse	State funded service
2	F	50-59	Mental health nurse	State funded service

3	M	40-49	Psychologist, University lecturer	University
4	F	30-39	Social worker, Project officer	State funded service
5	F	50-59	Youth worker, Management	Federally funded service

Youth

Number	Gender	Age (years)	Mental Health Service User	Have you ever sought (1) online or (2) face-to-face help for your mental health?
1	F	17	No	N/A
2	F	16	No	N/A
3	M	19	Yes	(1)No (2)Yes
4	F	21	Yes	(1)No (2)Yes

Procedure

Mental health professionals were recruited from services who had participated in earlier phases of the study. This sample was representative the age and gender profile of Australian mental health professionals. This primarily included a Tier 2 federally-funded youth service (service one) and a Tier 3 state-funded community mental health service (service two), both located in a rural South Australian region. The majority of the participants were employed at Tier 3 state-based specialist mental health service which provides varying levels of care such as crisis response and assertive outreach services to clients who may present as difficult to engage and/or have complex needs. The remainder of participants were experienced at providing Tier 2 services which is designed to cater for clients with mild to moderate mental health disorders or those at risk of developing one.

Youth mental health clients who had participated in earlier phases of the larger study were recontacted and offered an opportunity to participate in the workshops. However, as more than a year had elapsed since their initial participation, none were able to participate. Thus young people were recruited from a youth reference group (comprised of mental health clients and advocates) associated with service one.

Workshops were audio recorded; artefacts and conversation using inductive thematic analysis. The workshops were carried out in the rural South Australian region in which the services were located. The mental health professionals were not financially compensated for their participation, however, youth participants were given a $20 voucher to cover travelling costs for their participation in the final workshop. Each workshop was two hours in length. The paper will now present an overview of the procedure of each workshop.

Workshop 1: Visioning Phase

The intention of workshop 1 was to: (1.) investigate the ways in which mental health professionals see technology as able to support their work and young people's help-seeking; and (2.) discuss the barriers to achieving this. To this end, brainstorming and consensus building techniques were utilised. Individually and then in pairs participants generated a series of technology related opportunities for frontline community-based mental health contexts. The brainstorming was seeded by artefacts produced in earlier phases (see phases 1 and 2, Figure 3) of the research. Artefacts included a current state help-seeking map and client vignettes derived from earlier observational fieldwork, and interviews with youth mental health consumers associated with a larger research project (See phases 1 and 2, Figure 3) (See Appendix I for a more detailed description of the workshop procedure, and Appendix J for examples of the artefacts discussed).

Workshop 2: Scenario Building Phase

Workshop 2 aimed to build on the themes and design ideas generated in workshop 1 by investigating from a mental health professional perspective, both the *circumstances* and the *clients* they saw as applicable to the various technological possibilities discussed so far. To achieve this, participants were assigned to small groups and provided a series of personas generated from earlier phases of the larger research project (see phases 1 and 2, Figure 3). They were then given prompt cards (titled: *Who? What? When? Why? How?)* and assigned a technology-related design opportunity generated in workshop 1. With the resources described, participants were asked to create hypothetical scenarios in which particular clients would use particular technologies. (Please see Appendix I for a more detailed description of the workshop procedure and Appendix L for examples of the personas).

Workshop 3: Mock-up Phase

In the third and final workshop intentional use of 3D arts and crafts materials was employed to create mock-ups. Inspired by the work of Xie et al. (2012), use of existing objects was employed to limit the pressure participants felt to draw. It was intended that workshops provide a chance to be creative while working with existing objects to create new ways of working and interacting. Four scenarios were devised before the workshop (based on the content and output generated in the first two workshops and earlier stages of the larger research project). The scenarios included:

- Scenario 1: Changing service providers
- Scenario 2: Communicating with multiple service providers
- Scenario 3: Tracking various clinical and behavioural indicators e.g. mood, sleep
- Scenario 4: Flexible access to service provider during all states of wellness

(see Appendix M for a full description of the scenarios)

Participants were divided into four groups; two of which were comprised of mental health professionals and the other two of young people with varying degrees of experience of mental health service use. In the first instance each group was assigned a different scenario from the four listed above and asked to mock-up the technology with the objects/materials they deemed appropriate. Next each group was given a second (but related) scenario (scenarios 1 and 2 were linked, as were scenarios 3 and 4) and asked to modify their existing mock-up to accommodate the additional need(s) the new scenario spoke to. Later in the workshop the groups who had received the *same* scenarios (albeit in a *different* order) were combined and asked to integrate the best and most effective parts of each of their designs, with the overall aim of developing one design to meet the needs of the two scenarios they were assigned. In practice, these final groups were a mix of mental health professionals and young people. Participants were also asked to complete an evaluation form and participate in a short interview regarding their experience of the project (See Appendix N for evaluation forms).

RESULTS

Workshop audio recordings and artefacts created during the workshops were inductively analysed for common themes. The results are presented here as a series of major themes extracted from each workshop and are supported by relevant transcript excerpts and images.

Workshop 1: Visioning Phase

Theme 1: Designing for a fractured, self-serving system
Participants highlighted the widespread lack of communication and information sharing which currently defines the mental health system. They advocated for *"systems that talk to one another, because there are multiple systems out there from general practice to [non-government organisations] NGO's, to health, even within health there's three different systems so none of us can communicate with the other unless you've got access"*. This lack of integration across the various layers of mental health care was seen to position the client as a passive receiver of information and participant in their own health. Moreover, participants discussed the potential of technology to disrupt and challenge the current expectation that clients *work within* or *defer to* the system, which often manifests as clients repeatedly retelling their stories and poor information sharing and collaborative practice between service providers. Promotion of client-led service development and delivery and community-based capacity building was discussed as part of a wider narrative around increasing opportunities for client control and ownership.

Theme 2: Engagement and responsivity through technology.
This theme related to existing ways of interacting with young people. That is, *how* and *when* the system interacts with the client, and equally, what the structure/design of existing technologies says about the ways in which the system values (or not) and positions the client. For example, current information sharing processes and devices were seen to be inward facing and controlled by the workers and the larger system and, as such, designed to *"to talk about you not to you"*. This led to discussions around the perceived need for multifunctional and interactional

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tools/systems which are supported by an evidence base and encourage young people to invest in their health through increased engagement. This included better use of existing technologies (e.g. Jabba, FaceTime) to increase access to face-to-face services when distance and/or client capacity make it difficult to attend appointments in person. These ideas were linked to the philosophy that services should be provided in the most appropriate location for the client and that technology could be better utilised to monitor clients remotely. Participants also spoke of their frustration in being unable to access important information when it was most needed – in sessions with clients.

Theme 3: Inferiority complex – what counts as a device???

The service funding restrictions repeatedly discussed in the brainstorming activity positioned technological innovation fairly low down on the organisational strategic planning priority list - *"mental health is not viewed the same…..it is viewed differently in the world of health….different funding model".* This perceived lack of funding and resourcing was tied to an underlying belief that mental health is considered *less than* in comparison to physical health and associated resourcing. It was suggested that technology-based devices to assist with self-management of mental health conditions, unlike those used to manage physical health conditions (e.g. blood glucose monitors for diabetes), are *"not seen as equipment".* Some participants spoke of the need to justify spending to upper management levels – *"is it our core business? is the usual one I get challenged with".*

Workshop 2: Scenario Building Phase

Theme 4: Underlying work structures and models associated with rural, community -based youth mental health work

In this workshop the scenarios created by the participants lacked detail around exactly *what* the technology would be and *how* it would function. Working with scenarios and personas was quite foreign to most of the participants who, for the most part, approached the activities with a *clinician* mindset and thus operated within their own pre-existing ways of reasoning and acting. This provided rich insights into their existing work models and structures. The personas provided a suitable starting point from which to start thinking about how and why technologies may be of benefit to particular clients.

Focussed on the 'why' rather than the 'what' or 'how' of the technology

As the participants engaged with the scenarios and the personas it soon became clear that they were less worried about the exact functions or functioning of the technology and more committed to understanding the clients' current situation and thus why technology may/may not be an appropriate addition to their individual care. In some cases this meant thinking about how the technology could be leveraged to exploit any potential strengths or goals of the client, whereas in others it meant formulating a client case plan (i.e. next steps with respect to services and support for the client) which may/may not have included a technology-based component. Participants' thinking was very much around what was realistically achievable for the client to manage in terms of

their own contextual factors (e.g. living on a rural farm with limited internet access), personal resourcing (e.g. cost of potential technologies) and capacity (e.g. impact of technology on current level of risk and distress).

The participants demonstrated a tendency to think about clients and case formulations in intensely individualised ways, which clearly makes it a difficult context to embed manualised and directed technologies within. Participants also discussed unintended consequences of the tools e.g. not wanting to promote internet-dependent technologies to a client who is pathologically house bound but only has internet access at home, or reinforcing failure if physical activity targets were not met when using a fitness app or wearable device. Participants spent a significant proportion of the time thinking about the client's motivation for engaging with the technology e.g. not just using a device to track sleep because the client is currently sleeping poorly but *instead* using the device because the client is sleeping poorly *and* sleeping better is part of the client's goal to wake up earlier to be able to apply for jobs and attend job interviews.

These discussions provided key insights into the types of technologies likely to flourish in frontline community based mental health contexts such as tools which are person rather than outcome-focussed. By this it is meant that the technology should assist the client to define themselves what is important to track, monitor and focus on rather than the technology making those decisions for them. Throughout the workshop participants repeatedly discussed *whether* and *how* the technology complemented the clients' day-to-day functioning. For example when engaging with a persona, one participant commented: *"I'm looking at the potential gains for Tom, if you are actually able to engage him in a way that could reduce some of that chaos and trauma in his life....I wonder what his goal is around this business management?"* Participants were very aware that at any given time a client's current presentation may mean that they are not motivated and/or capable of engaging meaningfully with the technology. This raised important questions around systematically assessing a client's *readiness* for technology-based enhancements to their care and highlighted the importance of having a good understanding of appropriate *timing* of introduction of technologies into a client's care plan. See Figure 4 for an example a scenario created by one group.
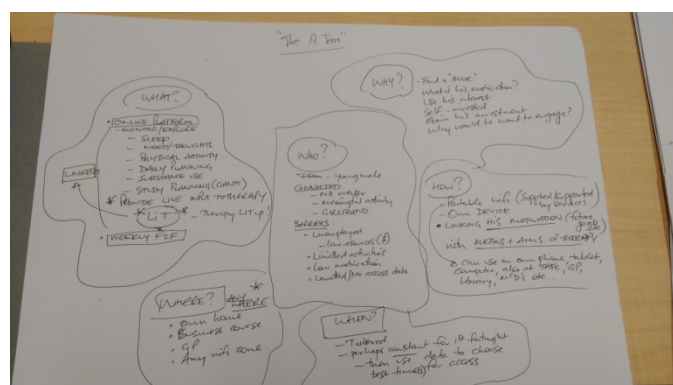

Figure 4. Example of scenario created in workshop 2

Theme 5: Philosophical drivers of frontline community-based mental health workers

Despite being allocated different design ideas around which to build their scenarios, the thematic analysis revealed that, overall, participants saw the technology principally as a way in which they could support their young clients to establish some *control* around their experience of help-seeking. Particularly by increasing their *capacity* to make *choices* around how best to manage and support their health. Participants envisioned technology as facilitating *"the types of conversations we have with [client]) ...... because we know the people with dysregulation, external locus of control...... we know all of that stuff, we also know that the sort of standard model of treating those people doesn't work (agreement), the only way to actually engage with someone like this is to....starts from day one...you are in control here and we're going to help you and walk with you through this process....yes they are going to deregulate........but we have to start thinking about what tools we're using, our own education to keep this moving forward"*

Greater control for clients was linked to having greater control over how information is stored and distributed and, moreover, how young people can be better supported to exercise greater control over *when* and *how* help is accessed. Participants also saw technology as enabling a level of insight, not currently possible, into one's own health and thus encouraging *ownership* over health outcomes. Moreover, technology as a relationship building tool was repeatedly discussed throughout the workshop.

Workshop 3: Mock-up Phase

Theme 6: Learning from different perspectives

Ability to interact with and learn from different perspectives was embraced by participants of workshop 3. From a mental health professional viewpoint *"working with young people was especially valuable........ the process or the result was better because of that.......they have much more of a user insight into how things should work and how they make them feel and whilst we as professionals work to put ourselves in their shoes we can never do that completely accurately...we have much better information from them"* As such, participants found the experience a valuable way in which to interact with others of different professional backgrounds and ages and felt this positively impacted on their own professional learning and development, along with the eventual mock-ups they created.

Theme 7: Using creativity to problem solve

'Making' was extremely valued by participants and enabled creation of design proposals

The exit interviews and workshop evaluation forms suggested that the participants found the mock-up process a worthwhile one. As one participant suggested the mock-up activity *"was not just going back to your work experiences but also your own creative experiences that go beyond work......it was more unrestrained".* One young person indicated that *"the access to craft to further describe our thoughts on paper and physically"* worked well for them. This activity provided an opportunity for participants to express themselves and their ideas in a way that was comfortable for them e.g. writing, creating a model or a mock-up. Overall, this process enabled mental

health professionals to create and communicate design proposals and think about their work in different ways in collaboration with young people.

Theme 8: Ability to generate buy-in

Participants were committed to, and invested in, the designs they created in workshop 3. The participants saw the mock-up activity as *"a creative approach…..a way of addressing a gap at the moment".* Despite being a new and different way of working and interacting, the participants embraced the opportunity, "*I enjoyed them …….. I thought sometimes I was a bit slow to catch onto where we were heading but like five minutes into it was really easy to follow….gave good information and good support…and I think we came up with some GREAT ideas…..some real potential for improving working in this space".* As such, participants expressed pride in their ideas and felt they had developed designs that were worthy of follow-up.

Theme 9: Contribution of technology

Personalising the technology was important for the young people with lived experience of mental ill-health. The group comprised of youth mental health consumers were assigned scenario 1: *changing service providers.* Most important to them in the app they created in response to this scenario was to *"add a photo to know who you're dealing with".* This design feature was aimed at improving the first meeting between a new mental health worker and a client so that when meeting for the first time they would recognise one another in the waiting room. Simple features such as these emphasise the inherent vulnerability associated with seeking help for mental health problems. This was in contrast to the complex tool mocked up by the corresponding group comprised of mental professionals which was more focussed on efficient information sharing as a way to enhance connection between clients and mental health professionals. See Figures 5 and 6 for the individual group and combined mock-ups.
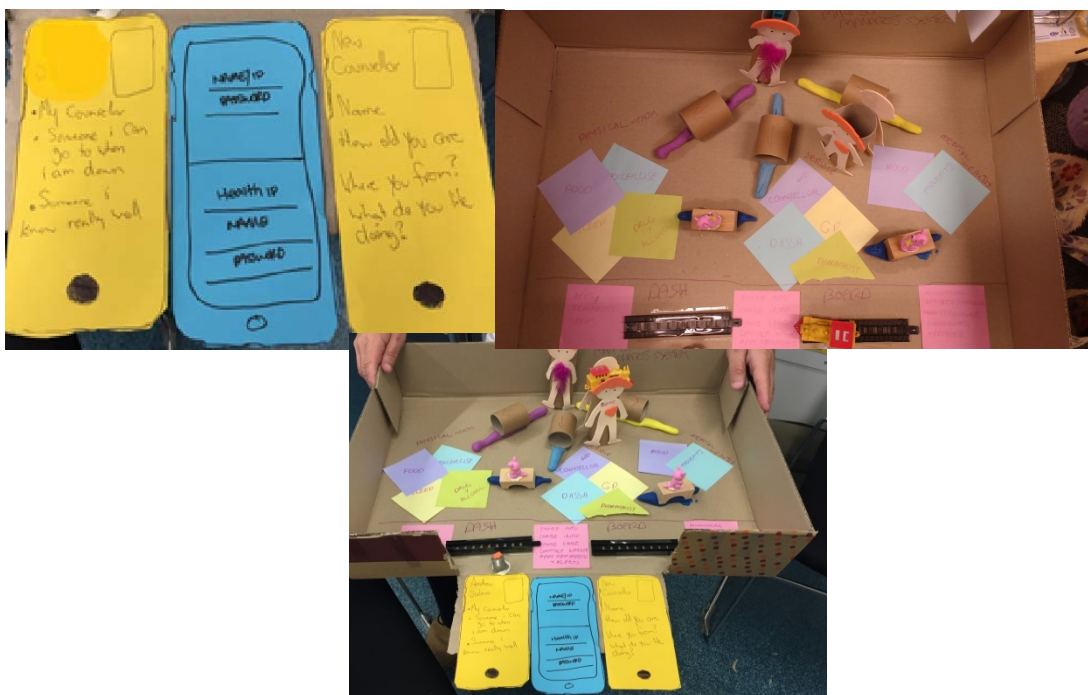

Figure 5 Mock-ups: youth group, mental health professionals group, combined (clockwise) 1
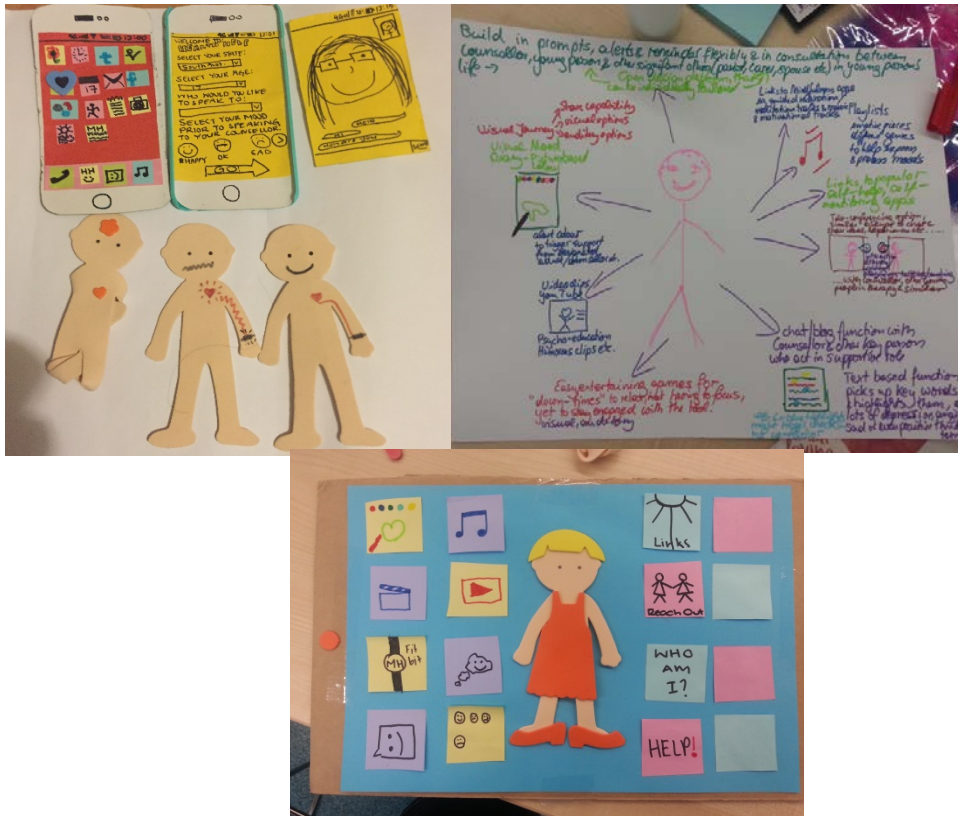
Figure 6 Mock-ups: youth group, mental health professionals group, combined (clockwise) 2

DISCUSSION

The application of emerging social and mobile technologies to rural community-based, mental health care settings appears to have remarkable scope to address persistent issues of access and quality of care, particularly in remote communities (Burns et al. 2010). Their potential, however, has not yet been realised because these mental healthcare settings have proven to be largely impervious and unresponsive to technology-based innovation and implementation (Montague, Varcin & Parker 2014). With this in mind, the current study used an adapted PD process to gain in-depth insight into the ways in which frontline mental health professionals frame technologies within their existing work structures and models. As such, this research utilised design as a vehicle of creativity and collaboration to explore and understand the domain - not to design individual products and interventions. Despite the many insights generated through the workshops in the main the results advocate for specific ways in which the people who inhabit mental health systems can drive technologies, rather than technologies driving people, echoing a sentiment that was reinforced a number of times throughout the three workshops.

Whereas personas and scenarios are generally utilised in a more specialised capacity to understand how an already (or close to) developed product may apply to and be used by particular individuals in specific situations (Carroll 2000; Pruitt & Grudin 2003), in the current study their use in workshop 2 took on a more exploratory and

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hypothetical purpose. The participants' engagement with the personas and scenarios prompted discussions around how and why specific technologies could be useful for particular clients at particular stages of their treatment journey. It also provided an immersive context in which to observe frontline mental health work practice and thought processes as applied to use of technology with clients. Emerging from this workshop were the major themes of: *choice, control* and *ownership,* along with *capacity* and *relationships.* As such, frontline mental health professionals, independent of their organisational affiliation and its relationship to the different tiers of the mental health system, described their role as one which strives to facilitate clients to exercise choice around, and control over, their health, their help-seeking, and their lives more generally. The mental health professionals expressed a desire for their work, technology-assisted or otherwise, to enable clients to build personal capacity and thereby take ownership of their health. Furthermore, engagement and relationship building was also described as a large part of the work with young people.

These findings encourage thinking about the contribution of mental health technologies in alternative ways; ways that move beyond the idea of technology as quantifying and tracking to a person-centred approach of technology as meaning making and narrative redefining. Technology as a conduit for people to visualise themselves as they are and as they would like to be, through a future-oriented lens of empowerment rather than a historical lens of measurement and past performance/compliance. This thinking is in line with recovery-oriented approaches to mental healthcare which have had an increasingly influence in mental health policy (Bird et al. 2014). Recovery-oriented care processes are less focussed on cure, or full amelioration of symptoms, by contrast recovery is conceptualised as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles … a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness" (Anthony 1993, p. 527). Recovery oriented care approaches advocate for an individualised and unique journey through treatment in pursuit of a meaningful and fulfilling life.

The notion of technology as a facilitator of relationships and empowerment was voiced by young service users in workshop 3. Their design proposal to address the well-established problem of service provider change over/inconsistency and subsequent story retelling (Orlowski, Lawn, Antezana, et al. 2016) emphasised a desire for control and the crucial role of personal connection in successful help-seeking. This manifested in one young man voicing his discomfort with sitting in a full service waiting room, nervously anticipating his name to be called by an individual he had never met before. He felt that if technology could facilitate a mutual awareness of who to expect, and thereby avoiding this awkward moment, that this would greatly improve the already traumatic process of parting with a prior worker and beginning with a new one. This example reinforces principles of simplicity of design, of technology in service of people and highlights a potential role for technology to support and maintain dignity and a sense of empowerment for a very vulnerable user group.

The design of open, flexible and end-user driven technologies for use in community-based mental health contexts is supported by Gammon et al's (2014) participatory research. In that case, what started out as a project aiming to adapt an existing an online self-care tool for cancer patients was ultimately abandoned due to an overly

medicalised focus. The final design ended up as *PsyConnect* a tool to "support service users in guiding their lives in the direction they choose, in accordance with their personal values" (Gammon, Strand & Eng 2014, p. 3). This tool, the design of which was heavily influenced by the mental health clients on the project team, is 'non-condition specific', 'person-centred' and able to be adapted for use across the different tiers of the mental health system. The authors report that *PsyConnect* was designed to support clients to develop control over their lives, to recognise their personal knowledge, strengths and values and to improve continuity of care through increased information sharing and collaboration. The final design is strengths-focussed and assists the client to track and record what is of relevance to them.

Taken together this body of work argues for the design and implementation of non-prescriptive technologies that allow people to engage when and how they see appropriate. Put simply, these findings question the utility of rigid technologies which require specific behaviours, responses and levels of engagement by the client in community-based mental health settings. Technology-based systems and tools which direct behaviour, rather than facilitating self-determination can undermine client choice and support the narrative of the system as controlling client behaviour, an issue which has been identified elsewhere (Lawn 2015; Orlowski, Lawn, Antezana, et al. 2016) and again was highlighted by the results of workshop 1. These latter technologies can be seen as technology-based facilitators of the status quo - that is enablers of the traditional mental health system enforcing paternalistic and authoritarian approaches to treatment and service delivery on clients.

This research assists in conceptualising a potential role for technology in rural, community -based youth mental health work. Rural youth mental health professionals embraced the design process, and through it, were able to circumvent the many things that divide them (Orlowski, Lawn, Matthews, Jones, et al. in revision) and to find commonalities and consistencies in their practice. In doing so they imagined future realities that move beyond a primary orientation to risk which relegate technology to an *adjunct* (or in other words unnecessary!) status (Orlowski, Lawn, Matthews, Jones, et al. in revision; Orlowski, Lawn, Matthews, Venning, Wyld, et al. in revision). The open design process, along with the individual techniques employed, created opportunities for the participants, both mental health professionals and young people, to access and communicate understandings and representations of their work and help-seeking and possibilities regarding 'performance' of technology (Ehn 2008) arguably not possible through talk or observational-based research methods.

Limitations

In order to seed participant activity and maintain a well-defined focus throughout the workshops supporting materials and directions were provided (references to these can be found throughout the methods sections of the paper and the accompanying appendices). The results of this study should be interpreted within this context which may have steered thinking and creation down a particular path to the exclusion of others. Whilst there was much value in a health researcher-led process such as the one detailed in this paper, the mock-up workshop in particular was limited by the absence of a workshop facilitator with the technical expertise to comment with

authority on the types of technology which are currently possible. In addition, the participants involved in this study voluntarily agreed to participate and as such may have been more interested in technology design than other mental health professionals.

CONCLUSION

Community-based mental health contexts have proven to be largely impervious to implementation of client centred technologies. In the current research, adapted use of PD methods and techniques have proven to be extremely useful for defining domain criteria in mental healthcare (e.g. individualised and empowerment-focussed care which takes place in a fractured, inward facing and under-resourced system) rather than as a vehicle for informing product design. The results advocate for alternative ways of thinking about the contribution of technology - beyond technology as quantifying and tracking to the person-centred approach of technology as self-directed and potentially narrative redefining.

CHAPTER SEVEN SUMMARY OF RESULTS

This research has demonstrated the utility of Participatory Design (PD) methods and techniques for defining domain criteria and the socio-material context of use, with respect to use of technologies for consumer *engagement*, *support* and *system* navigation (ESN technologies) in rural, community-based youth mental health services. It aligns with contemporary PD research which balances investigation of the context of use with identifying user needs to inform product design (Björgvinsson, Ehn & Hillgren 2010; Ehn 2008).

The results of Workshop 1 reinforced findings of Chapters Five and Six, particularly with respect to the fractured nature of the mental health system, and the associated poor information sharing that serves to disempower the consumer. The results also identified mental health professionals' frustration around their inability to access information when it was most needed (that is, in sessions with clients) and a desire for technology to facilitate positive engagement with young people.

Through adapted use of scenarios and personas in Workshop 2, in-depth insight into ways of thinking about and practising mental health work were obtained. Results of this workshop reinforced and extended those which emerged from the observational study (Chapter Six) by highlighting the individualised nature of care in frontline mental health settings and the need to consider ambivalent consumer motivation and engagement, toward mental health services (and, by default, any technology), over time. The results resonate with previous participatory research in community-based mental health settings (Gammon, Strand & Eng 2014) by advocating for alternative ways of thinking about the contribution of technology in these service contexts that extend beyond technology as quantifying and tracking, to the future-oriented person-centred approach of technology as self-directed and potentially narrative redefining. Central to this are technologies which promote exploration of one's own strengths, life goals, and hopes for the future. These results are in line with a recovery-focussed model of mental health care which aims to facilitate people to define for themselves what constitutes a fulfilling and meaningful life despite the presence of illness or symptomology (Anthony 1993; Borg & Davidson 2008).

The workshops and, in particular, the third workshop, were found to be an acceptable way in which mental health professionals from different organisations and tiers of the mental health system, and young people, were able to collaborate, be creative, learn from one another's perspectives and to imagine new futures in their work and help-seeking, respectively

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CHAPTER EIGHT: SUMMARY OF RESULTS, DISCUSSION AND GENERAL CONCLUSION

OVERVIEW

This program of research was undertaken with the overall aim of improving understanding of the role of technology within rural, community-based youth mental health services and young people with mental illness. The research privileged end user perspectives and investigated, as well as applied, participatory design-based (PD) methods for their capacity to improve technology design and implementation for a mental health context. It is important to note, however, the research aimed to *inform* design and implementation of technology as opposed to being an implementation study in and of itself. Of principal interest in this research were technologies used by mental health professionals and young people that assist with improving consumer *engagement* and *support*, along with *navigation* of the mental health system (ESN technologies).

In the first instance, a systematic review was conducted to investigate the ways in which participatory methodologies have been applied to develop technology-based youth mental health and well-being interventions (see Chapter Four). This was followed by a viewpoint article which further explored the potential role of user-focussed, design-based methods in the design and implementation of technologies in mental health contexts (see Chapter Four). The remainder of the research involved a case study of one rural region in South Australia. Initially, a two-part scoping study was conducted to obtain in-depth end user perspectives (i.e. those of mental health professionals and consumers) around the role of ESN technologies in facilitating traditional mental health care (see Chapter Five). End user, along with organisational and systematic factors were then investigated via an observational study of two community-based youth mental health services (see Chapter Six). Finally, a series of participatory workshops were conducted with mental health professionals and young people. They aimed to further investigate community-based, youth mental health services as an ESN technology design domain and implementation context (see Chapter Seven). The remainder of this chapter will contain an integrated summary and then discussion of the results of this program of research.

SUMMARY OF RESULTS

This section presents a high level integrated summary of these results to identify the overarching contribution of this work and make recommendations around future technology design and implementation. Readers interested in the specific details of the results are directed to the discussions provided at the end of Chapters Four to Seven.

The results of Chapters Five to Seven positioned mental health work in rural community-based settings, as contested, multifaceted and underpinned by an individualised and empowerment care focus. In Chapter Six, rural, community-based youth mental health services were conceptualised as operating within the larger, complex mental health system. This conceptualisation highlighted widespread and multilayered considerations and consequences for the design and implementation of any technology. For example, the self-organising property of complex systems was observed to impact on the level and nature of information sharing and collaboration between various components of the mental health system. Despite a demonstrated need for effective information sharing and collaboration across the mental health system to achieve best outcomes for clients (and beyond to interrelated systems such as education/vocational training, employment, justice, social), individualised work practices, along with fragmentation of documentation and record management systems prevailed. Furthermore, less obvious influences, such as the role of the family, were observed to have a significant (and often polarising) impact on the nature of service access and help-seeking by young people.

The results of Chapters Five and Six in particular highlight that the use of ESN technologies to facilitate mental health care in its traditional form is counter cultural to current practice. Despite a strong focus on consumer engagement to facilitate effective care, the dominant cultural influence was risk-focussed, both with respect to consumer care and professional/legal implications of the work more generally. The new and diverse opportunities for interaction and communication that technology was seen to create challenged this longstanding, risk averse culture. Moreover, personal connection was seen to be a major factor in the provision of successful mental health services by consumers and professionals alike. This preference for personal connection should be understood in the context of young people's interactions and journeys within the mental health system which were found to be non-linear and crisis-centric. Their clinical presentations were multifaceted, cross-systemic and complex. Personal and geographic isolation were common to the experiences of, as were limited psychosocial and financial security, and unreliable internet access. Technology was seen to simultaneously restrict and enhance personal connection through reducing opportunities for face-to-face interaction, but also by increasing flexibility around how services are accessed and the way in which information is stored, accessed, tracked and utilised.

Results from Chapter Five demonstrated that the rural mental health workforce is currently not prepared with respect to training, knowledge or physical resourcing to integrate technology into their work. Additionally, the use of ESN technologies in existing mental health services is not prioritised or supported by individuals or

organisations. Current use of technologies by professionals and consumers within the services was found to be ad hoc and individually driven. The workforce and youth consumers were ambivalent about the use of technology in existing services for a range of interconnected reasons. In part, this ambivalence was underpinned by a central theme of power and control which emerged from the research. Youth experiences of services and the system, more generally, were identified as disempowering, despite an explicit desire for control with respect to health and help-seeking. Technology was seen as both a facilitator and barrier to achieving greater control by youth consumers. Overall, youth consumers expressed a preference for face-to-face mental health care and were ambivalent around use of technology to facilitate their help-seeking and treatment. Some young people felt that technology filtered the human experience of help-seeking and, as such, undermines associated personal dignity and privacy. At the same time, however, young people discussed positive experiences and beliefs around the future potential of technology to facilitate traditional mental health care, particularly with respect to improved flexibility and information sharing. For mental health professionals, use of ESN technology was seen to challenge the location of power in traditional service delivery and, by implication, their skill and knowledge base. This was juxtaposed against stated positives in terms of opportunities for empowerment that technology could potentially offer young people. Overall, given the appropriate training, resourcing, organisational policy and infrastructural support, mental health professionals saw technology as a potentially useful adjunct to their practice.

In Chapter Seven, PD inspired future workshops assisted mental health professionals to creatively explore their work and, in doing so, identify a role for ESN technology with consumers that moves beyond the rhetoric *technology as an adjunct*. Open, flexible and consumer-driven technologies were found to be philosophically aligned with the provision community-based youth mental health services. The results of Chapter Four demonstrated that youth participation in the development of mental health and wellbeing technologies to date has been limited and, arguably, tokenistic. Their participation has been largely consultative and consumerist in nature; that is, centred around a desire to create more usable and useful interventions as opposed to their participation being for democratic or emancipatory purposes. While mental health service providers have been involved as co-investigators or usability/feasibility evaluators in technology development projects, development of technologies predominantly took in the research domain, rather than the service delivery domain. The participatory research reviewed in Chapter Four also found limited resourcing and interest in future implementation of technologies, with few examples of genuine integration between academic and clinical mental health settings found. A dearth of rigorous data was found with respect to consumer self-reported experiences of participation in the design and development of technologies for mental health settings.

DISCUSSION

This program of research addressed the following research aims, which were to:

(1)   Investigate design processes that engage end users and the potential contribution of these processes in facilitating the effective implementation and uptake of ESN technologies in rural, community-based youth mental health services.

(2)   Explore the perspectives of the individuals working in, and consumers of, mental health services around technology to facilitate traditional mental health care.

(3)   Examine the complexities of the design and implementation of ESN technologies in and for rural, community-based youth mental health organisational contexts, with an overall view to develop practical recommendations and strategies to inform the design and implementation of best practice in this context.

In determining the structure of this discussion, a number of factors were considered. In the first instance, it is important to acknowledge that, given the various bodies of literature to which this research relates, there are a variety of ways in which the findings could be positioned. Additionally, many salient discussion points have been addressed both individually and collectively in the journal articles presented in Chapters Four to Seven. Finally, at its core, the current research intended to make a pragmatic contribution to the design and implementation of ESN technologies within rural, community based youth mental health services. With these factors in mind, and considering the interrelated nature of the research aims, the following discussion will address the research aims and findings via an integrated argument which situates the work within the broader context of the Australian mental health system and the use of technologies to facilitate traditional mental health care.

An increasing trend toward co-created research, and use of design methods more broadly, has been identified within health research (Greenhalgh et al. 2016). Research in this space has involved, "increasingly complex intersectoral networks in which university scientists engage with policymakers, civil society, and industry to a far greater extent than in the past" (Greenhalgh et al. 2016, p.397). The core foundation of this approach is knowledge, "generated within its context of application" (Greenhalgh et al. 2016, p.396). In contemporary approaches to health co-creation (Greenhalgh et al. 2016) and PD (Björgvinsson, Ehn & Hillgren 2010; Ehn 2008) research, the motivation and process is less focussed on involving consumers in individual projects that create discrete outputs but instead on applying participatory research in the exploration and design of infrastructures that seek to align research with real world contexts – specifically, in the current case, mental health service development. Where this has relevance to the current research is an identified need for a greater focus on the conditions that support use (or 'performance') of technologies within a specific community of interest. As such, identification of end user needs is increasingly balanced by investigation of processes and contextual influences that either enable or inhibit use of the technology in more recent interpretations of PD (Ehn 2008). These ideas were articulated clearly by Ehn, Nilsson and Topgaard (2014) who stated,

"Whether the designs and innovations concern local services, cultural productions, arenas for public discourse, or technological platforms, the approach is participative, collaborative, and engaging. The starting point is not the search for yet another "killer application," but everyday activities and challenges in people's lives".

The current research was a manifestation of this approach to design, exploring whether and how technology can facilitate traditional mental healthcare in the context of rural, South Australian community-based youth mental health services, by privileging the perspectives of the two key end users of the technology: mental health professionals and youth consumers. In doing so, it found that access to and negotiation of the mental health system by young people in rural South Australia is difficult and disempowering. The research identified a group of young people with complex and extensive histories of help-seeking, and significant personal, psychosocial and geographic disadvantage, attempting to navigate a system that functions to meet its own, and service providers' needs, over those of individuals. As such, the findings of this research align with those of the national review of mental health programs and services commissioned by the Australian government in 2011 (National Mental Health Commission 2014). The subsequent report described fragmentation and inefficiencies of an Australian mental health system that fails to maximise social or economic outcomes (National Mental Health Commission 2014).

The current research also identified that technology-based changes to work are at odds with the day-to-day operation of, and practice within, the mental health system. Mental health professionals are not currently skilled, resourced, organisationally supported or incentivised to utilise existing technologies in their work. These findings are supported by other research (Blanchard et al. 2012; Cloutier et al. 2008; McMinn et al. 2011; Montague, Varcin & Parker 2014; Reynolds et al. 2015; Simms, Gibson & O'Donnell 2011; Sinclair et al. 2013). They are not surprising in the context of recent research which has reported a dearth of evidence around appropriate policy, funding and governance to support the uptake of technologies in mental health care and a primary research focus on technologies to replace (not facilitate) traditional mental health care (Meurk et al. 2016). Misalignment between policy, research and practice is evident in the ad hoc and individually driven manner in which technology is currently used in services by professionals and young people. Taken together, this research suggests that routine use of technologies by mental health professionals is likely not imminent.

The shift toward design of context over products has manifested in PD and innovation, as applied to *matters of concern* (as defined by the community of interest) rather than design of individual products (Björgvinsson, Ehn & Hillgren 2010; Ehn 2008). As such, Ehn (2008) has stressed that the design process should extend to the developmental stages of the life of the project. He describes it as consideration of matters such as,

"how to construct the initial object of design for the project? That is, how to align the participants around a shared, though problematic, object of concern?" (Ehn 2008)

Embedded in this contemporary approach to PD is the explicit assumption that the process of assembling those with claims to and investment in the eventual outcome, and decision processes that determine what are meaningful outcomes to explore in the first place, are of potentially greater importance than (or at least equal to) the outcome itself.

When considering whose perspectives are privileged and why, as part of deciding on *matters of concern* (in this case regarding rural young people's engagement with the mental health system), it is relevant to acknowledge that, currently, the mental health system is engaged in yet another chapter of a multi-decade long struggle to restructure its system with the consumer at its centre (Australian Government Department of Health 2013; Department of Health 2015). As part of this reform agenda, technology is projected to play a significant role in the future. With this in mind, and in the context of the rural youth consumer profile outlined earlier, the results of this program of research argue that, on a conceptual level, technology can improve help-seeking for rural youth consumers by facilitating greater empowerment within this process. For example, it can improve information sharing within a complex system, and the design and implementation of non-prescriptive technologies that allow youth consumers to engage with what they see as important, when and how they deem appropriate. These future technologies align with a recovery-based approach to mental health care, which is underpinned by principles of self-determination and hence, the right to decide what constitutes a meaningful and fulfilling life within an individual's own context (Anthony 1993; Borg & Davidson 2008).

That said, in amongst the reform agenda rhetoric of consumer-centred mental health care, it is entirely plausible that, given the current nation-wide crisis around healthcare affordability, the most salient concern with respect to government priorities is achieving cost and process efficiencies through technology (Dickinson et al. 2016). One example of this is the digital mental health gateway, the federal government's proposed response to calls for improved access to service and system navigation. Like the personally controlled electronic health record (PCEHR), it is a national, government-led response to perceived health consumer needs. Development of the PCEHR involved extensive 'stakeholder consultation' to inform a concept of operations, with design specification development carried out by the National eHealth Transition Authority (Pearce & Bainbridge 2014). Despite significant, repeated, federal financial and infrastructural investment, the PCEHR – which was rolled out in 2012 and designed principally as a document storage and record summary system (Pearce & Bainbridge 2014) – has failed to engage health care providers. Currently used by less than 10% of health care providers (Hossack 2015), consumers and professionals alike have demonstrated limited awareness of its existence, understanding around how it works, and perceive little overall value in its implementation (Lehnbom, Brien & McLachlan 2014; Lehnbom, Douglas & Makeham 2016). Beyond debates around the effect of 'opt-in' versus 'opt-out' approaches to uptake (note the government has recently moved to an opt-out approach with the rebadged My Health Record on the advice of a federally commissioned report (Hossack 2015)), the final design is from which consumers stand to benefit the most (i.e. from an integrated and comprehensive approach to health records and information), and from which general practitioners derive little benefit despite bearing significant workflow costs and changes (Pearce & Bainbridge 2014). With respect to the proposed digital mental health gateway, the

question may be asked: 'Are we poised to repeat the same mistakes in terms of dictating how technology *can* and *should* improve outcomes for mental health consumers?'

A further question which require addressing includes, what exactly is the end goal with respect to use of technologies in existing mental health services, and who has had a say in setting, resourcing and implementing this goal? A fundamental finding of the current research has been that any agenda is likely destined to repeat the mistakes of past reform failures if it is insular or pre-emptive with respect to the voices and perspectives that inform and shape it. As the results of this research have outlined, key stakeholder perspectives, which include mental health consumers and professionals, but also the various other systemic influences (both overt and hidden, social as well as cultural) must be considered. The deeply engrained ways of thinking about mental health work (e.g. risk, personal engagement) that have been associated, in a range of ways, with generally adverse implications for the introduction and use of technologies in mental health services demand consideration.

In fact, the government's response to the National Commission's report reads as a predetermined roadmap for how technology will impact on, and respond to the current deficits within, the mental health system. The closed framing in terms of outlining a digital mental health gateway as *the* solution, to the exclusion of all others, suggests a pre-ordained outcome which could be viewed as transposing current system inefficiencies and fragmentation onto a one-size-fits-all electronic delivery platform. A platform that is potentially exclusionary to a range of mental health consumers, given the geographical and personal disadvantage highlighted by this and other studies (Baum, Newman & Biedrzycki 2014; Newman, Biedrzycki & Baum 2012). In this context, findings from the current research resonate, particularly with respect to the stated preference by mental health consumers and professionals of service delivery models underpinned by personalised access and engagement. An important question, therefore, to ask is, what should we make of these needs in the context of a standardised approach to service access such as a nationalised digital mental health gateway? Furthermore, as highlighted in the current study, this nationalised approach may fail to recognise the self-organising property of complex systems in response to new inputs and, as such, the likely individualised and emergent responses by various components of the system. Such a 'top-down' approach to mental health service design is akin to 'translation' of academic research where the knowledge is generated outside the context for which it has relevance and then translated back *for* the intended audience at a later stage (Greenhalgh et al. 2016). As such, the knowledge requires packaging and processing in a way that is meaningful to the intended audience. In this case, the mental health system is left to make sense (or not, as in the case of the PCEHR) of the new way of working.

The current findings align with a conceptualisation of design and innovation that is inspired by the notion of agonistic democracy which is fuelled by attempts to turn antagonistic interactions into conflicts that drive positive growth and change (Björgvinsson, Ehn & Hillgren 2010). When applied to the results of this project, this approach to design suggests foregrounding the power struggles and conflicting agendas that were found to be at the heart of the research, to enable identification of whose needs are being met by the process and the reasons

for this. The research presented in Chapter Seven describes the processes by which participatory design workshops were used, not to create individual product-based solutions, but instead to begin conversations about what is realistic in terms of technology-based innovation in rural, community-based youth mental health services. In this study, new futures were imagined through a rich understanding of context, and collaborative, mutually beneficial, long-term partnerships. Ehn (2008) positioned design as concerned with "how is the object of design made into a public thing and open to controversies among participants in the project as well as outside?". What follows from this conceptualisation of design and participation is a commitment to long-term collaborative partnerships situated in the messiness and complexity of the socio-material infrastructuring, out of which *the matter of concern* arises and embracing tensions and conflicts as matters to be explored through long-term and malleable co-creation/PD processes.

Key tensions which emerged in this research related to the balancing of risk (primarily in relation to professional and legal accountabilities associated with the work) with engagement of young people as core to frontline mental health work. As such, the ambivalence of service providers toward technology was centred around it simultaneously enhancing consumer engagement and outcomes through increased flexibility, but also restricting or impeding personal connection by fundamentally changing the way in which mental health practice has historically been enacted. Furthermore, this research has demonstrated that many of the salient factors which impact on technology uptake and use in mental health practice extend far beyond the actual process of designing technologies (or the device itself). They also concern historical organisation of the workforce and the system, more broadly. For example, they include the incentivisation of work processes and practices such as inter- and intra-systemic collaboration and information sharing that are likely to underpin useful technologies going forward (Kurahashi et al. 2016). They also pertain to broader issues such as what kind of research is funded, why it is funded and how it is funded. As such, genuine transformational change is likely to come from research (including problems identified, questions asked, methodologies developed and used and outcomes disseminated) that are developed from the inside (in this case within mental health services) rather than being imposed from the outside (i.e. by government or academia) (Lawn 2016).

Beyond complexity thinking and egalitarian considerations related to end user empowerment and self-determination of what constitutes a meaningful outcome from engagement with the mental health system, more concrete design consequences have emerged from the findings of this program of research. Consequences of the implementation of more consumer-centred or self-determined technologies in this space have become possible to anticipate. For example, on account of the fact that there are likely to be misalignments in certain cases between mental health consumers' and service providers' notions of a 'successful' outcome, one can imagine that technologies which are predicated on the principle of consumer control and self-determination have the potential to become an instrument in service of agendas in consultations (and other arenas of consumers' engagement/disengagement with the mental health system). The (design) decision with respect to the degree of access to which service providers will have to clients' interactions with the technology, even and especially if providers have no control over the technology itself or the data, has consequences in this agonistic mode. The

technology and/or data may be likely to become on occasion, a resource for the identification of misalignments between clients and carers and one that thus aids communication, and the collaborative development of beneficial programs of treatment (this is a benign, possibly positive consequence); it may also be conscripted into other more contested agendas, such as a resource for documenting a client's non-compliance, recalcitrance or other characteristic, or a resource that helps a client justify disengagements with the mental health system. It is precisely when these kinds of reflections become design material—visible, tangible possibilities—that that they can be reinserted into further participatory engagements with providers and clients in the design of technological possibilities and open them up to constructive stakeholder scrutiny, rather than treating them as technologists' problems to 'solve'.

Finally, it is noted that, while it is encouraging that approaches to research across various disciplines are increasingly embodying a shift from what has been referred to as Mode 1 research (i.e. that form of traditional research which is generated outside the context for which it is intended (Greenhalgh et al. 2016)), care must be taken that it is not co-opted in order to propagate business-as-usual masked as an authentic response to a matter of concern within a community of interest. In the first instance, findings from the systematic review presented in Chapter Four of this thesis highlight a trend toward restricted and tokenistic forms of youth participation in the design of mental health and wellbeing technologies. These findings pose important ethical questions around why and how young people are asked to be involved in research. A more local example was recently observed in the 2016 tendering process for the delivery of South Australian rural mental health services. As part of this process, service provider applicants were invited to participate in the 'co-design' of a Mental health and Alcohol and Other Drugs Treatment Service System by the Primary Health Network (PHN, the newly established service planning and commissioning body) (Primary Health Network Country SA 2016). The ill-defined co-design process was part of an attempt to operationalise the government's edict of a stepped care model of service delivery and regional planning and commissioning to ensure fit with local needs and limit service overlap and/or gaps. Exactly what authentic value was derived from the co-design process remains dubious because the process took place in a four-week period which also involved reading and assessment of every application by a panel, assessment by external expert opinion and advisement of successful applicants. The brevity of the process is suggestive of a focus on appearances over process or even outcome.

RECOMMENDATIONS

In light of the summary and discussion of results provided in this chapter, a number of overarching recommendations pertaining to technology design research and implementation are presented below. The recommendations also include practical 'how to' strategies, which are indicated underneath the recommendation in dot point form.

It is imperative young people must be given a voice with respect to the way in which mental health services are designed and delivered; this includes a voice in the design and implementation of technologies. A young person's lived experience of mental illness places them in a vital and unique position from which to evaluate the benefits and shortcomings of treatments and service delivery.

- A structural way in which to support this recommendation is through higher expectations by research funding bodies with respect to youth involvement in research (and service delivery). This would include required demonstration by researchers of youth participation beyond the level of consultation to attract competitive grant-funded projects; which are a primary source of funding in this space.
- Greater requirements for, and expectation of, process evaluation in participatory research, such that greater transparency and learning around process and impact are possible.

Research and development of new technologies should be considered in the context of the psychosocial and geographic disadvantage experienced by rural youth mental health consumers, and in the context of non-linear and crisis-centric engagements with the system typical of young people.

- Higher expectations with respect to the diversity of young people participating in research (level of diversity tied to funding success).

Reorientation of research into service delivery settings. Currently, the impetus is on researchers to find ways *into* clinical settings. Researching technologies in clinical mental settings is currently viewed as anomalous and complex to achieve. Conceptualising research in this space as translational (which implies knowledge generation predominantly outside the context of interest) is limiting. Transdisciplinary research is the ideal in this context. "It [transdisciplinarity] occasions the emergence of new data and new interactions from out of the encounter between disciplines. It offers us a new vision of nature and reality. Transdisciplinarity does not strive for mastery of several disciplines but aims to open all disciplines to that which they share and to that which lies beyond them." (The International Center for Transdisciplinary Research (CIRET) 1994)

- Provision of incentives for service involvement in research e.g. possibly embedded within key performance indicators that are tied to funding
- Restructuring the way in which eMental health and technology design projects are developed and funded. Currently, the research is funded within various discipline-specific silos which results in unintegrated research agendas.

- Privileging and prioritising (through funding) research that is long-term, participative and open to exploring where the 'matter of concern' lies.
- Trialling research and innovation in service contexts that is supported by a culture of learning for mental health professionals (given that risk aversion was identified as one of the major barriers to trying new and different ways of working, i.e. with technologies, by mental health professionals).

A complex systems approach to research that is sensitive to the interdependencies within the wider mental health system.

- Transition away from the design of technologies for individualised service contexts.

Greater attention must be paid to the level of communication, information sharing and integration both within and beyond the mental health system. This is a key source of disempowerment and disengagement in the help-seeking experience for young people.

- Incentivising sectors and organisations to share information.
- Addressing the culture of risk-aversion and self-preservation.

Balancing expectations on the workforce, with respect to technology use in practice, with organisational (and sector-wide) responsibilities (with respect to promoting greater technology use in mental health practice), is needed.

- Balancing workforce training with appropriate organisational policy and infrastructuring.

STRENGTHS OF THIS THESIS

The program of research presented in this thesis has a number of strengths. Firstly, the research followed an iterative process in which each study built on and informed the previous study. This process made it possible to utilise artefacts derived from research presented in Chapters Five and Six in the workshop study presented in Chapter Seven. These artefacts (e.g. current state help seeking map, clinical vignettes and personas) were used and embraced by mental health professionals in the workshops. This provided a check for rigor and trustworthiness with respect to the results of the earlier studies. In addition, the research findings were triangulated by the use of different methods (e.g. focus groups and interviews, observations and workshops) to explore the research aims in different ways and from different key stakeholder perspectives. In addition, this research makes a contribution to content (implementation of technology in mental health services) and methodology (application of user-focussed design methods within mental health service contexts).

An additional strength of this thesis is that it attempted to draw together historically disparate fields of research. As such, it interpreted and situated the research within a number of research disciplines (eMental health, health services research and design) in order to find commonalities and suggest a collective way forward. The transdisciplinary relevance of the research is supported by the range of journals to which the six peer-reviewed

articles were submitted, and in which they were successfully accepted for publication, spanning the fields of eMental health, mental health/health services research and design.

A final strength of this research was the variety of perspectives it sampled in recruiting the three major youth mental health services located in the region into the project and working with young people who were actively seeking help from those services. As such, in-depth and naturalistic data were obtained by speaking to and observing typical mental health professionals and young people rather than those with a particular interest in technology.

ISSUES TO OVERCOME

The strength of this research may also be considered its limitation. The transdisciplinary relevance of the research was such that it is not entirely positioned within one research field or another, with the relevant 'home' domains being health services research, e-health and design research. As such, the research may have unintentionally skirted over some seemingly core concepts or bodies of literature. A related issue is that the definition of technologies was kept intentionally broad due to the exploratory nature of the research, a factor which precludes drawing conclusions and making recommendations around the design and implementation of specific technologies. With this in mind, the research should also be considered in light of the fact that it took place in one rural South Australian region and hence may not be generalisable to other rural regions or metropolitan contexts. Furthermore, the research did not involve implementation of technologies; therefore, the data obtained is a result of attitudes, perceptions, and future intentions around the use of technology in rural, community-based youth mental health services. This data is, however, supported by triangulation of method and researcher observations.

Finally, it is acknowledged that this research has taken place within a rapidly changing mental health service delivery and eMental health landscape. When the PhD candidate commenced in early 2014, the majority of the research was focussed on technology as an alternative model of the delivery of mental health services. Since that time, research around integrated or blended forms of mental health service delivery has expanded and, as such, there have been changes to the way in which use of technologies in existing mental health services is perceived. See, for example, dedicated eMental health service provider training programs provided by Orygen, the National Centre of Excellence in Youth Mental Health (Orygen 2016), Australian National University (2016) and the Black Dog Institute (2016) as part of the federally funded eMH Prac initiative and ReachOut.com Professionals (ReachOut.com 2016).

FUTURE DIRECTIONS

Since a dearth of quality evidence exists around the use of technologies to facilitate traditional youth mental health care (Montague, Varcin & Parker 2014), it will be important for any future research to focus on the use and evaluation of technology in clinical mental health practice. To achieve this, future research should involve

establishing a culture and expectation of research and innovation within mental health service environments starting with available technologies. Given the rapid pace at which technology evolves and is superseded, there has been a call for alternative approaches to evaluation of technologies; that is, beyond randomised controlled trials (Nicholas, Boydell & Christensen 2016). As such, future research may involve, for example, experimental single case designs where each participant acts as their own control, to evaluate, in the first instance, available technologies (e.g. health apps). Combined single case designs allow for the elements of any treatment to be combined; they therefore enable flexible and individually tailored evaluation of technology and consumer outcomes (Dallery, Cassidy & Raiff 2013). At the same time, the unprecedented proliferation of personal technologies, nationwide network access, and consumer development kits (e.g. "maker" platforms such as Arduino, or open access software development kits for mobile operating systems) has meant that it has never been easier or cheaper to prototype and deploy technologies for evaluation. Building on this study and others like it creates a number of opportunities for technology design projects that iteratively develop and roll out small design interventions that pick up and explore the directions that have been outlined above.

It would also be beneficial if future research investigated the effectiveness of recently available training programs dedicated to upskilling mental health professionals in use of technologies in clinical mental health care (Australian National University 2016; Black Dog Institute 2016; Orygen 2016; ReachOut.com 2016). The most practical approach to this research would involve training a target group of mental health professionals within specified organisations. Useful research questions would include whether exposure to specific training results in greater use of technologies by mental health professionals with youth consumers and, in turn, whether this results in any improvements to consumer outcomes (e.g. in engagement with services or on measures of psychological distress or similar). A cohort study, using baseline and repeated measures throughout intervention, would allow for investigation of change of attitudes toward and actual use of technologies. An analysis strategy involving generalised mixed modelling would then enable the evaluation of trajectories of change at both the individual and population levels. Qualitative process evaluations to complement this design would also be desirable.

CONCLUDING STATEMENT

Greater use of new and existing technologies is projected to play a significant role in the Australian mental health system into the future. This research program presents an in-depth investigation of rural, community-based youth mental health services as technology implementation contexts, from the perspective of mental health consumers and professionals. It is hoped that this thesis will inform and encourage research, design and implementation of technology that prioritises the complexity surrounding, and meaningful participation of, young people, their support networks and the broader mental health system. This research has outlined positive contributions that technology could make to the experience of mental health help-seeking and service provision in the future, but also a range of consumer and workforce barriers that have and continue to influence the limited uptake of technologies to facilitate traditional youth mental health care. This program of research has demonstrated

application of PD to the investigation of the conditions and conflicts which characterise the context of technology use as opposed to the design of products. In this way, technology occupied a background role. In the foreground was the messy and contested space occupied by the various players who have a stake in accessing and providing mental health services.

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APPENDIX A: SEARCH STRATEGY SYSTEMATIC REVIEW (PAPER 1)

Search Strategy 1-19 June 14

Database(s): Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Search Strategy:

#	Searches	Results
1	Community-Based Participatory Research/	1992
2	(((Participatory or Participative or Cooperative* or Co-operative* or user-led) adj2 (design* or research or approach* or method* or process* or framework* or tool*)) or Co-design* or Codesign* or Co-research*).mp.	6980
3	1 or 2	6980
4	Mental Health/	21607
5	exp Mental Health Services/	74235
6	Mentally Ill Persons/	4363
7	mental disorders/ or adjustment disorders/ or Anxiety/ or exp anxiety disorders/ or anxiety, separation/ or affective symptoms/ or exp aggression/ or exp dissociative disorders/ or delusions/ or exp "schizophrenia and disorders with psychotic features"/ or schizophrenic language/ or paranoid behavior/ or exp eating disorders/ or exp factitious disorders/ or exp impulse control disorders/ or exp "attention deficit and disruptive behavior disorders"/ or child behavior disorders/ or child reactive disorders/ or exp mood disorders/ or depression/ or neurotic disorders/ or exp personality disorders/ or exp "sexual and gender disorders"/ or exp somatoform disorders/ or psychoses, substance-induced/ or exp Self-Injurious Behavior/ or dangerous behavior/ or exp impulsive behavior/ or depersonalization/ or exp obsessive behavior/	659392
8	Resilience, Psychological/	1501
9	(Mental health* or mental illness* or mental disorder* or mentally ill or behavio?ral health or abnormal psych* or depression or depressive or mood disorder* or personality disorder* or psychiatr* or schizophreni* or bipolar or compulsive* or obsessive* or impulsiv* or eating disorder* or self injur* or self harm* or suicid* or psychotic or abnormal psych* or phobi* or psychos* or resilien* or anxiety or anxious or stress* or well- being or wellbeing or wellness).mp.	1552579
10	4 or 5 or 6 or 7 or 8 or 9	1672973
11	3 and 10	1037
12	limit 11 to (english language and humans)	872

.mp.=title, abstract, original title, subject heading word, keyword heading word
/ = Search on Medical Subject Headings (MeSH terms) only
exp = exploded MeSH term

New citations brought in by re-run and addition of new terms n=227 after
internal deduplication. 227 citations taken into separate EndNote library.

Database(s): PsycINFO 1806 to May Week 4 2014

#	Searches	Results
1	(((Participatory or Participative or Cooperative* or Co-operative* or user-led) adj2 (design* or research or approach* or method* or process* or framework* or tool*)) or Co-design* or Codesign* or Co-research*).mp.	5674
2	mental health/ or community mental health/ or exp community mental health services/ or community psychiatry/ or exp mental health personnel/ or exp mental health programs/ or exp mental health services/ or primary mental health prevention/	116039
3	mental health services/	26489
4	"Mental Illness (Attitudes Toward)"/ or Homeless Mentally Ill/ or Psychiatric Patients/ or Mentally Ill Offenders/	33228
5	Mental Disorders/ or adjustment disorders/ or anxiety/ or social anxiety/ or exp anxiety disorders/ or generalized anxiety disorder/ or exp neurosis/ or panic disorder/ or phobias/ or exp affective disorders/ or affective psychosis/ or schizoaffective disorder/ or psychiatric symptoms/ or behavior disorders/ or addiction/ or attempted suicide/ or drug abuse/ or juvenile delinquency/ or self mutilation/ or aggressive behavior/ or antisocial behavior/ or behavior problems/ or conduct disorder/ or oppositional defiant disorder/ or antisocial personality disorder/ or exp dissociative disorders/ or exp personality disorders/ or delusions/ or exp schizophrenia/ or exp psychosis/ or borderline states/ or exp eating disorders/ or exp factitious disorders/ or exp impulse control disorders/ or behavioral disinhibition/ or impulsiveness/ or internet addiction/ or pathological gambling/ or pyromania/ or self control/ or exp attention deficit disorder/ or exp Gender Identity Disorder/ or exp somatoform disorders/ or exp self destructive behavior/ or exp stress/	607394
6	exp Coping Behavior/ or exp "Resilience (Psychological)"/ or exp Psychological Endurance/	43841
7	well being/ or life satisfaction/ or positive psychology/	31708

8	(Mental health* or mental illness* or mental disorder* or mentally ill or behavio?ral health or abnormal psych* or depression or depressive or mood disorder* or personality disorder* or psychiatr* or schizophreni* or bipolar or compulsive* or obsessive* or impulsiv* or eating disorder* or self injur* or self harm* or suicid* or psychotic or abnormal psych* or phobi* or psychos* or resilien* or anxiety or anxious or stress* or well- being or wellbeing or wellness).mp.	999615
9	2 or 3 or 4 or 5 or 6 or 7 or 8	1129889
10	1 and 9	1347
11	limit 10 to english language	1294

New citations brought in by re-run and addition of new terms n=293.

Re-run PubMed search

(Participatory design*[tiab] OR Participatory research[tiab] OR Participatory approach*[tiab] OR Participatory method*[tiab] OR Participatory process*[tiab] OR Participatory framework*[tiab] OR Participatory tool*[tiab] OR Participative design*[tiab] OR Participative research[tiab] OR Participative approach*[tiab] OR Participative method*[tiab] OR Participative process*[tiab] OR Participative framework*[tiab] OR Participative tool*[tiab] OR Cooperative design*[tiab] OR Cooperative research[tiab] OR Cooperative approach*[tiab] OR Cooperative method*[tiab] OR Cooperative process*[tiab] OR Cooperative framework*[tiab] OR Cooperative tool*[tiab] OR Co-operative design*[tiab] OR Co-operative research[tiab] OR Co-operative approach*[tiab] OR Co-operative method*[tiab] OR Co-operative process*[tiab] OR Co-operative framework*[tiab] OR Co-operative tool*[tiab] OR User-led design*[tiab] OR User-led research[tiab] OR User-led approach*[tiab] OR User-led method*[tiab] OR User-led process*[tiab] OR User-led framework*[tiab] OR User-led tool*[tiab] OR Co-design*[tiab] OR Codesign*[tiab] OR Co-research*[tiab] OR Community-Based Participatory Research[mh]) AND ((Mental Health[mh] OR Mental Health Services[mh] OR Mentally Ill Persons[mh] OR mental disorders[mh:noexp] OR adjustment disorders[mh] OR Anxiety[mh:noexp] OR anxiety disorders[mh] OR anxiety, separation[mh] OR affective symptoms[mh] OR aggression[mh] OR dissociative disorders[mh] OR delusions[mh] OR "schizophrenia and disorders with psychotic features"[mh] OR schizophrenic language[mh] OR paranoid behavior[mh] OR eating disorders[mh] OR factitious disorders[mh] OR impulse control disorders[mh] OR "attention deficit and disruptive behavior disorders"[mh] OR child behavior disorders[mh] OR child reactive disorders[mh] OR mood disorders[mh] OR depression[mh] OR neurotic disorders[mh] OR personality disorders[mh] OR "sexual and gender disorders"[mh] OR somatoform disorders[mh] OR psychoses, substance-induced[mh] OR Self-Injurious Behavior[mh] OR dangerous behavior[mh] OR impulsive behavior[mh] OR depersonalization[mh] OR obsessive behavior[mh] OR Resilience, Psychological[mh]) OR ((Mental health*[tiab] OR mental illness*[tiab] OR mental

disorder*[tiab] OR mentally ill[tiab] OR behavioral health[tiab] OR behavioural health[tiab] OR psychosocial[tiab] OR depression[tiab] OR depressive disorder*[tiab] OR mood disorder*[tiab] OR personality disorder*[tiab] or psychiatr*[tiab] OR schizophreni*[tiab] OR bipolar[tiab] OR compulsive*[tiab] OR obsessive*[tiab] OR impulsiv*[tiab] OR eating disorder*[tiab] OR self injur*[tiab] OR self harm*[tiab] or suicid*[tiab] OR psychotic[tiab] OR phobi*[tiab] OR psychos*[tiab] OR abnormal psych*[tiab] OR resilien*[tiab] OR anxiety[tiab] OR anxious[tiab] OR stress*[tiab] OR well being[tiab] OR wellbeing[tiab] OR wellness[tiab]) NOT Medline[sb])) AND English[la]

n=587 (30 more citations added using additional terms)

Scopus

(TITLE-ABS-KEY(((**participatory** OR **participative** OR **cooperative*** OR **"Co-operative*"** OR **"user-led"**) PRE/2 (**design*** OR **research** OR **approach*** OR **method*** OR **process*** OR **framework*** OR **tool***)) OR **"Co-design*"** OR **codesign*** OR **"Co-research*"**) AND SUBJAREA(**mult** OR **medi** OR **nurs** OR **vete** OR **dent** OR **heal** OR **mult** OR **ceng** OR CHEM OR **comp** OR **eart** OR **ener** OR **engi** OR **envi** OR **mate** OR **math** OR **phys** OR **mult** OR **arts** OR **busi** OR **deci** OR **econ** OR **psyc** OR **soci**)) AND ((TITLE-ABS-KEY(**"Mental health*"** OR **"mental illness*"** OR **"mental disorder*"** OR **"mentally ill"** OR **"behavioural health"** OR **"behavioral health"** OR **psychosocial** OR **depression** OR **"depressive disorder*"** OR **"mood disorder*"** OR **"personality disorder*"** OR **psychiatr***) AND SUBJAREA(**mult** OR **medi** OR **nurs** OR **vete** OR **dent** OR **heal** OR **mult** OR **ceng** OR CHEM OR **comp** OR **eart** OR **ener** OR **engi** OR **envi** OR **mate** OR **math** OR **phys** OR **mult** OR **arts** OR **busi** OR **deci** OR **econ** OR **psyc** OR **soci**)) OR (TITLE-ABS-KEY(**schizophreni*** OR **bipolar** OR **compulsive*** OR **obsessive*** OR **impulsiv*** OR **"eating disorder*"** OR **"self injur*"** OR **"self harm*"** OR **suicid*** OR **psychotic** OR **phobi*** OR **psychos*** OR "abnormal psych*" OR **anxiety** OR **anxious** OR stress*) AND SUBJAREA(**mult** OR **medi** OR **nurs** OR **vete** OR **dent** OR **heal** OR **mult** OR **ceng** OR CHEM OR **comp** OR **eart** OR **ener** OR **engi** OR **envi** OR **mate** OR **math** OR **phys** OR **mult** OR **arts** OR **busi** OR **deci** OR **econ** OR **psyc** OR **soci**)) OR (TITLE-ABS-KEY(resilien* OR wellness OR wellbeing OR "well-being")) AND SUBJAREA(**mult** OR **medi** OR **nurs** OR **vete** OR **dent** OR **heal** OR **mult** OR **ceng** OR CHEM OR **comp** OR **eart** OR **ener**

OR **engi** OR **envi** OR **mate** OR **math** OR **phys** OR **mult** OR **arts** OR **busi** OR **deci** OR **econ** OR **psyc** OR **soci**))) AND LANGUAGE(**english**)

New literature caught with additional terms n=916

Web of Science

Topic=(((Participatory or Participative or Cooperative* or "Co-operative*" or "user-led") NEAR/2 (design* or research or approach* or method* or process* or framework* or tool*)) or "Co-design*" or Codesign* or "Co-research*") AND Topic=("Mental health*" OR "mental illness*" OR "mental disorder*" OR "mentally ill" OR "behavioral health" OR "behavioural health" OR psychosocial OR depression OR "depressive disorder*" OR "mood disorder*" OR "personality disorder*" OR psychiatr* OR schizophreni* OR bipolar OR compulsive* OR obsessive* OR impulsiv* OR "eating disorder*" OR "self injur*" OR "self harm*" OR suicid* OR psychotic OR phobi* OR psychos* OR <mark>"abnormal psych*"</mark> OR resilien* OR anxiety OR anxious OR <mark>stress* OR "well being" OR wellbeing OR wellness</mark>)

N=970

Timespan=All years
Search language=English
Language limit=English

CINAHL

Thursday, June 19, 2014

#	Query	Limiters/Expanders	Results
S15	S12 AND S13	Limiters - English Language Search modes - Boolean/Phrase	821
S14	S12 AND S13	Search modes - Boolean/Phrase	844
S13	((Participatory or Participative or Cooperative* OR "Co-operative*" OR "user-led") W2 (design* OR research OR approach* OR method* OR process* OR framework* OR tool*)) OR "Co-design*" OR codesign* OR "Co-research*"	Search modes - Boolean/Phrase	2,420
S12	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11	Search modes - Boolean/Phrase	546,049
S11	(depression or depressive or "mood disorder*" or "personality disorder*" or psychiatr* or schizophreni* or bipolar or compulsive* or obsessive* or impulsiv* or "eating disorder*") OR ("self injur*" or "self harm*" or suicid* or psychotic or phobi* or psychos* or resilien*) OR (anxiety or anxious or stress* or "well-being" or wellbeing or wellness)	Search modes - Boolean/Phrase	393,002
S10	"Mental health*" or "mental illness*" or "mental disorder*" or "mentally ill" or "behavio#ral health" or "abnormal psych*"	Search modes - Boolean/Phrase	81,524
S9	(MH "Mental Disorders") OR (MH "Adjustment Disorders+") OR (MH "Mental Disorders, Chronic") OR (MH "Mental Disorders Diagnosed in Childhood") OR (MH "Attention Deficit Hyperactivity Disorder") OR (MH "Child Behavior Disorders+") OR (MH "Separation Anxiety") OR (MH "Neurotic Disorders+") OR (MH "Organic Mental Disorders+") OR (MH "Personality Disorders+") OR (MH "Pregnancy Complications, Psychiatric+") OR (MH "Psychophysiologic Disorders+") OR (MH	Search modes - Boolean/Phrase	304,402

	"Psychotic Disorders+") OR (MH "Sexual and Gender Disorders+") OR (MH "Substance Use Disorders+") OR (MH "Behavior, Addictive+") OR (MH "Compulsive Behavior") OR (MH "Depersonalization") OR (MH "Eating Disorders+") OR (MH "Self-Injurious Behavior") OR (MH "Social Behavior Disorders+") OR (MH "Stress+") OR (MH "Suicide+") OR (MH "Affective Symptoms") OR (MH "Anxiety+") OR (MH "Depression") OR (MH "Behavioral Symptoms")		
S8	(MH "Attitude to Mental Illness")	Search modes - Boolean/Phrase	2,701
S7	(MH "Psychiatric Patients") OR (MH "Mentally Ill Offenders") OR (MH "Psychiatric Care")	Search modes - Boolean/Phrase	11,283
S6	(MH "Psychiatric Home Care")	Search modes - Boolean/Phrase	186
S5	(MH "Psychiatric Service")	Search modes - Boolean/Phrase	301
S4	(MH "Mental Health Services+")	Search modes - Boolean/Phrase	39,665
S3	(MH "Hardiness")	Search modes - Boolean/Phrase	3,034
S2	(MH "Psychological Well-Being")	Search modes - Boolean/Phrase	7,324
S1	(MH "Mental Health")	Search modes - Boolean/Phrase	11,655

No. additional citations with new terms included: n=83

ProQuest– Subsets included

(((title((Participatory OR Participative OR Cooperative* OR "Co-operative*" OR "user-led") PRE/2 (design* OR research OR approach* OR method* OR process* OR framework* OR tool*))) OR (title("Co-design*" OR codesign* OR "Co-research*"))) AND (title("Mental health*" OR "mental illness*" OR "mental disorder*" OR "mentally ill" OR "behavio*ral health" OR "abnormal psych*" OR depression OR depressive OR "mood disorder*" OR "personality disorder*" OR psychiatry* OR schizophrenia* OR bipolar OR compulsive* OR obsessive* OR impulsive* OR "eating disorder*" OR "self injur*" OR "self harm*" OR suicide* OR psychotic OR phobia* OR psychos* OR resilien* OR anxiety OR anxious OR stress* OR "well- being" OR wellbeing OR wellness))) OR (((AB((Participatory OR Participative OR Cooperative* OR "Co-operative*" OR "user-led") PRE/2 (design* OR research OR approach* OR method* OR process* OR framework* OR tool*))) OR (ab("Co-design*" OR codesign* OR "Co-research*"))) AND (ab("Mental health*" OR "mental illness*" OR "mental disorder*" OR "mentally ill" OR "behavio*ral health" OR "abnormal psych*" OR depression OR depressive OR "mood disorder*" OR "personality disorder*" OR psychiatry* OR schizophrenia* OR bipolar OR compulsive* OR obsessive* OR impulsive* OR "eating disorder*" OR "self injur*" OR "self harm*" OR suicide* OR psychotic OR phobia* OR psychos* OR resilien* OR anxiety OR anxious OR stress* OR "well-being" OR wellbeing OR wellness)))

Retrieved 4148
Of these, n=581 unique

PAIS International (1972 - current)
PILOTS: Published International Literature On Traumatic Stress (1871 - current)
ProQuest Central
  • ProQuest Family Health
  • ProQuest Health & Medical Complete
  • ProQuest Health Management
  • ProQuest Nursing & Allied Health Source
  • ProQuest Psychology Journals
  • ProQuest Research Library
  • ProQuest Social Science Journals
  • ProQuest Sociology (1985 - current)

Social Services Abstracts (1979 - current)
Sociological Abstracts (1952 - current)

Informit

Health, Social Sciences subsets

("Mental health*" OR "mental illness*" OR "mental disorder*" OR "mentally ill" OR "behavio*ral health" OR "abnormal psych*" OR depression OR depressive OR "mood disorder*" OR "personality disorder*" OR psychiatr* OR schizophreni* OR bipolar OR compulsive* OR obsessive* OR impulsiv* OR "eating disorder*" OR "self injur*" OR "self harm*" OR suicid* OR psychotic OR phobi* OR psychos* OR resilien* OR ==anxiety OR anxious OR stress* OR "well-being" OR wellbeing OR wellness==) AND (((Participatory OR Participative OR Cooperative* OR "Co-operative*" OR "user-led") AND (design* OR research OR approach* OR method* OR process* OR framework* OR tool*)) OR "Co-design*" OR Codesign* OR "Co-research*")

Unique = 711 but lots of internal duplication
After internal deduplication n=?

arXiv.org (Cornell University)

Search interface won't allow searching on more than two terms at a time. Therefore searched design terms only and successively

Restricted to computer science section. N=22 but not relevant

Showing results 1 through 2 (of 2 total) for (ti:"participatory design" OR abs:"participatory design")

1. arXiv:1006.4474 [pdf, other]
   sTeX+ - a System for Flexible Formalization of Linked Data
   Andrea Kohlhase, Michael Kohlhase, Christoph Lange
   Comments: I-SEMANTICS 2010, September 1-3, 2010, Graz, Austria
   Subjects: Software Engineering (cs.SE); Artificial Intelligence (cs.AI)
2. arXiv:0910.1865 [pdf]
   Towards Participatory Design of Multi-agent Approach to Transport Demands
   Yee Ming Chen, Bo-Yuan Wang
   Comments: "International Journal of Computer Science Issues, IJCSI, Volume 4, Issue 1, pp10-15, September 2009"
   Journal-ref: Y. M. Chen and B. Wang, "Towards Participatory Design of Multi-agent Approach to Transport Demands ", International Journal of

Computer Science Issues, IJCSI, Volume 4, Issue 1, pp10-15, September 2009
Subjects: Multiagent Systems (cs.MA)

No matches were found for your search: (ti:"participative design" OR abs:"participative design")

No matches were found for your search: (ti:"user led design" OR abs:"user led design")

No matches were found for your search: (ti:"Co research*" OR abs:"Co research*")

Showing results 1 through 3 (of 3 total) for (ti:"cooperative design" OR abs:"cooperative design")

1. arXiv:1307.2421 [pdf, ps, other]
   Energy Efficient Coordinated Beamforming for Multi-cell MISO Systems
   Yi Huang, Jie Xu, Ling Qiu
   Comments: 6 pages, 2 figures, to be presented in IEEE GLOBECOM 2013
   Subjects: Information Theory (cs.IT)
2. arXiv:0910.2771 [pdf, ps, other]
   Cooperative Interference Management with MISO Beamforming
   Rui Zhang, Shuguang Cui
   Comments: accepted in IEEE Transactions on Signal Processing, June 2010
   Subjects: Information Theory (cs.IT)
3. arXiv:0905.3934 [pdf, ps, other]
   Cooperative encoding for secrecy in interference channels
   O. Ozan Koyluoglu, Hesham El Gamal
   Comments: Submitted to IEEE Transactions on Information Theory (submitted May 2009 and revised September 2010)
   Subjects: Information Theory (cs.IT)

Showing results 1 through 1 (of 1 total) for (ti:"co operative design" OR abs:"co operative design")

1. arXiv:0711.2486 [pdf]
   An annotation based approach to support design communication
   Onur Hisarciklilar (LGS), Jean-François Boujut (LGS)
   Journal-ref: Dans Proceedings of ICED'07 - International Conference on Engineering Design, Paris : France (2007)
   Subjects: Human-Computer Interaction (cs.HC)

Showing results 1 through 10 (of 10 total) for (ti:Co design* OR abs:Co design*)

1. arXiv:1404.4911 [pdf, other]
   Communication Delay Co-Design in $\mathcal{H}_2$ Distributed Control Using Atomic Norm Minimization

Nikolai Matni
Comments: Submitted to the IEEE Transactions on Control of Network Systems
Subjects: Optimization and Control (math.OC); Systems and Control (cs.SY)

2. arXiv:1403.1317 [pdf]
Hardware software co-design of the Aho-Corasick algorithm: Scalable for protein identification?
S.M. Vidanagamachchi, S.D. Dewasurendra, R.G. Ragel
Journal-ref: Industrial and Information Systems (ICIIS), 2013 8th IEEE International Conference on, pp. 321-325, 17-20 Dec. 2013
Subjects: Computational Engineering, Finance, and Science (cs.CE)

3. arXiv:1208.5604 [pdf, ps, other]
Optimal co-design of control, scheduling and routing in multi-hop control networks
F. Smarra, A. D'Innocenzo, M. D. Di Benedetto
Comments: 51st IEEE Conference on Decision and Control, 2012. Accepted for publication as regular paper
Subjects: Optimization and Control (math.OC); Systems and Control (cs.SY)

4. arXiv:1201.3881 [pdf]
Agent-Based μ-Tools Integrated into a Co-Design Platform
Alain-Jérôme Fougères
Comments: 10 pages; IJCSI International Journal of Computer Science Issues, Vol. 7, Issue 1, 2010
Subjects: Human-Computer Interaction (cs.HC); Distributed, Parallel, and Cluster Computing (cs.DC); Multiagent Systems (cs.MA)

5. arXiv:1101.5779 [pdf, other]
Co-Designing Multi-Packet Reception, Network Coding, and MAC Using a Simple Predictive Model
Jason Cloud, Linda Zeger, Muriel Médard
Comments: 8 Pages, 10 Figures, Submitted to WiOpt 2011
Subjects: Networking and Internet Architecture (cs.NI)

6. arXiv:1004.3263 [pdf]
DRMS Co-design by F4MS
Aissam Berrahou, Mourad Rafi, Mohsine Eleuldj
Comments: International Journal of Computer Science Issues online at this http URL
Journal-ref: IJCSI, Volume 7, Issue 2, March 2010
Subjects: Software Engineering (cs.SE)

7. arXiv:1002.0511 [pdf]
SOPC Co-Design Platform for UWB Systems in Wireless Sensor Network Context
Daniela Dragomirescu (LAAS), Aubin Lecointre (LAAS), Robert Plana (LAAS)
Journal-ref: Third International Conference on Systems ICONS Mexico (2008)
Subjects: Networking and Internet Architecture (cs.NI)

8. arXiv:0910.3736 [pdf, other]

A Fault-tolerant Structure for Reliable Multi-core Systems Based on
Hardware-Software Co-design
Bingbing Xia, Fei Qiao, Huazhong Yang, Hui Wang
Comments: 7 pages, 5 figures
Subjects: Hardware Architecture (cs.AR)

9. arXiv:0807.2282 [pdf]
Hardware/Software Co-Design for Spike Based Recognition
Arfan Ghani, Martin McGinnity, Liam Maguire, Jim Harkin
Comments: 6 pages
Subjects: Neural and Evolutionary Computing (cs.NE); Artificial
Intelligence (cs.AI); Computational Engineering, Finance, and Science
(cs.CE)

10. arXiv:cs/0612021 [pdf]
Multimodality and parallelism in design interaction: co-designers'
alignment and coalitions
Françoise Détienne, Willemien Visser
Journal-ref: Dans COOP'2006 Volume 137 (2006) 118-131
Subjects: Human-Computer Interaction (cs.HC)

Showing results 1 through 6 (of 6 total) for (ti:Codesign* OR abs:Codesign*)

1. arXiv:1206.1390 [pdf, other]
Fault-tolerant linear solvers via selective reliability
Patrick G. Bridges, Kurt B. Ferreira, Michael A. Heroux, Mark Hoemmen
Subjects: Numerical Analysis (math.NA); Distributed, Parallel, and Cluster
Computing (cs.DC); Performance (cs.PF)

2. arXiv:1004.3263 [pdf]
DRMS Co-design by F4MS
Aissam Berrahou, Mourad Rafi, Mohsine Eleuldj
Comments: International Journal of Computer Science Issues online at
this http URL
Journal-ref: IJCSI, Volume 7, Issue 2, March 2010
Subjects: Software Engineering (cs.SE)

3. arXiv:1002.1154 [pdf]
Performance Analysis of Software to Hardware Task Migration in
Codesign
Dorsaf Sebai, Abderrazak Jemai, Imed Bennour
Comments: International Journal of Computer Science Issues, IJCSI, Vol. 7,
Issue 1, No. 1, January 2010, this http URL
Journal-ref: International Journal of Computer Science Issues, IJCSI, Vol. 7,
Issue 1, No. 1, January 2010, http://ijcsi.org/articles/Performance-
Analysis-of-Software-to-Hardware-Task-Migration-in-Codesign.php
Subjects: Performance (cs.PF)

4. arXiv:0806.1385 [pdf]
Control-Scheduling Codesign: A Perspective on Integrating Control and
Computing
Feng Xia, Youxian Sun
Comments: 7 pages, 2 figures; A review paper

A Fault-tolerant Structure for Reliable Multi-core Systems Based on Hardware-Software Co-design
Bingbing Xia, Fei Qiao, Huazhong Yang, Hui Wang
Comments: 7 pages, 5 figures
Subjects: Hardware Architecture (cs.AR)

9. arXiv:0807.2282 [pdf]
Hardware/Software Co-Design for Spike Based Recognition
Arfan Ghani, Martin McGinnity, Liam Maguire, Jim Harkin
Comments: 6 pages
Subjects: Neural and Evolutionary Computing (cs.NE); Artificial Intelligence (cs.AI); Computational Engineering, Finance, and Science (cs.CE)

10. arXiv:cs/0612021 [pdf]
Multimodality and parallelism in design interaction: co-designers' alignment and coalitions
Françoise Détienne, Willemien Visser
Journal-ref: Dans COOP'2006 Volume 137 (2006) 118-131
Subjects: Human-Computer Interaction (cs.HC)

Showing results 1 through 6 (of 6 total) for (ti:Codesign* OR abs:Codesign*)

1. arXiv:1206.1390 [pdf, other]
Fault-tolerant linear solvers via selective reliability
Patrick G. Bridges, Kurt B. Ferreira, Michael A. Heroux, Mark Hoemmen
Subjects: Numerical Analysis (math.NA); Distributed, Parallel, and Cluster Computing (cs.DC); Performance (cs.PF)

2. arXiv:1004.3263 [pdf]
DRMS Co-design by F4MS
Aissam Berrahou, Mourad Rafi, Mohsine Eleuldj
Comments: International Journal of Computer Science Issues online at this http URL
Journal-ref: IJCSI, Volume 7, Issue 2, March 2010
Subjects: Software Engineering (cs.SE)

3. arXiv:1002.1154 [pdf]
Performance Analysis of Software to Hardware Task Migration in Codesign
Dorsaf Sebai, Abderrazak Jemai, Imed Bennour
Comments: International Journal of Computer Science Issues, IJCSI, Vol. 7, Issue 1, No. 1, January 2010, this http URL
Journal-ref: International Journal of Computer Science Issues, IJCSI, Vol. 7, Issue 1, No. 1, January 2010, http://ijcsi.org/articles/Performance-Analysis-of-Software-to-Hardware-Task-Migration-in-Codesign.php
Subjects: Performance (cs.PF)

4. arXiv:0806.1385 [pdf]
Control-Scheduling Codesign: A Perspective on Integrating Control and Computing
Feng Xia, Youxian Sun
Comments: 7 pages, 2 figures; A review paper

Journal-ref: Dynamics of Continuous, Discrete and Impulsive Systems -
Series B, vol. 13, no. S1, pp. 1352-1358, 2006
Subjects: Other Computer Science (cs.OH)

5. arXiv:0806.0130 [pdf]
Feedback Scheduling of Priority-Driven Control Networks
Feng Xia, Youxian Sun, Yu-Chu Tian
Comments: To appear in Computer Standards and Interfaces;
doi:10.1016/j.csi.2008.03.020
Subjects: Networking and Internet Architecture (cs.NI)

6. arXiv:0710.4641 [pdf]
UML 2.0 - Overview and Perspectives in SoC Design
Tim Schattkowsky
Comments: Submitted on behalf of EDAA (this http URL)
Journal-ref: Dans Design, Automation and Test in Europe - DATE'05,
Munich : Allemagne (2005)
Subjects: Software Engineering (cs.SE)

ACM (DL) Digital Library
Total n=63

15 had EndNote records manually created for them as they appeared to be
related to the topic. (Highlighted in yellow below.) Rest listed here for checking

(Abstract:participatory) and (Abstract:"Mental health*" or Abstract:"mental
illness*" or Abstract:"mental disorder*" or Abstract:"mentally ill" or
Abstract:"behavioral health" or Abstract:"behavioural health" or
Abstract:"abnormal psych*") n=4

(Abstract:participatory) and (Abstract:depression or Abstract:depressive or
Abstract:"mood or Abstract:disorder*" or Abstract:"personality or
Abstract:disorder*" or Abstract:psychiatr* or Abstract:schizophreni* or
Abstract:bipolar or Abstract:compulsive* or Abstract:obsessive* or
Abstract:impulsiv* or Abstract:"eating or Abstract:disorder*" or Abstract:"self or
Abstract:injur*" or Abstract:"self or Abstract:harm*" or Abstract:suicid* or
Abstract:psychotic or Abstract:phobi* or Abstract:psychos* or Abstract:resilien*
or Abstract:anxiety or Abstract:anxious or Abstract:stress* or Abstract:"well-
being" or Abstract:wellbeing or Abstract:wellness) n=59

Taking part: role-play in the design of therapeutic systems
Mark Matthews, Geri Gay, Gavin Doherty

April 2014   CHI '14: Proceedings of the SIGCHI Conference on Human Factors in Computing
Systems

1   Participatory design strategies to enhance the creative contribution of children with special

needs
Laura Malinverni, Joan MoraGuiard, Vanesa Padillo, MariaAngeles Mairena, Amaia Hervás, Narcis Pares

June 2014   **IDC '14:** Proceedings of the 2014 conference on Interaction design and children

2   Digital portraits: photo-sharing after domestic violence
Rachel Clarke, Peter Wright, Madeline Balaam, John McCarthy

April 2013   **CHI '13:** Proceedings of the SIGCHI Conference on Human Factors in Computing Systems

3   Proceedings of the 2014 conference on Interaction design and children
Ole Sejer Iversen, Lars Elbæk, Bo Stjerne Thomsen, Panos Markopoulos, Franca Garzotto, Christian Dindler

June 2014   **IDC '14:** Proceedings of the 2014 conference on Interaction design and children

4   Utilizing Self-Expression Template Method in User Interface Design - Three Design Cases
Leena Arhippainen, Minna Pakanen

October 2013   **AcademicMindTrek '13:** Proceedings of International Conference on Making Sense of Converging Media

5   Participatory design workshops with children with cancer: lessons learned
Susanne Lindberg

June 2013   **IDC '13:** Proceedings of the 12th International Conference on Interaction Design and Children

6   Understanding and supporting the use of accommodating technologies by adult learners with reading disabilities
Katherine Deibel

September 2006   **SIGACCESS Accessibility and Computing** , Issue 86

7   Designing a mobile diet diary application with and for older adults with AMD: a case study
Lilit Hakobyan, Jo Lumsden, Dympna O'Sullivan, Hannah Bartlett

September 2013   **BCS-HCI '13:** Proceedings of the 27th International BCS Human Computer Interaction Conference

8   Reflection through design: immigrant women's self-reflection on managing health and wellness
Deana Brown, Victoria Ayo, Rebecca E. Grinter

247

April 2014   **CHI '14:** Proceedings of the SIGCHI Conference on Human Factors in Computing Systems

9

Participatory design of business models
Jacob Buur

August 2012   **PDC '12: Proceedings of the 12th Participatory Design Conference: Exploratory Papers, Workshop Descriptions, Industry Cases - Volume 2**
, Volume 2

10

Participatory design process for an in-vehicle affect detection and regulation system for various drivers
Myounghoon Jeon, Jason Roberts, Parameshwaran Raman, Jung-Bin Yim, Bruce N. Walker

October 2011   **ASSETS '11:** The proceedings of the 13th international ACM SIGACCESS conference on Computers and accessibility

11

Lifestreams: a modular sense-making toolset for identifying important patterns from everyday life
Cheng-Kang Hsieh, Hongsuda Tangmunarunkit, Faisal Alquaddoomi, John Jenkins, Jinha Kang, Cameron Ketcham, Brent Longstaff, Joshua Selsky, Betta Dawson, Dallas Swendeman, Deborah Estrin, Nithya Ramanathan

November 2013   **SenSys '13:** Proceedings of the 11th ACM Conference on Embedded Networked Sensor Systems

12

FATA: um caminho para soluções interativas individualizadas para reabilitação
Luciana Correia Lima de Faria Borges, Lucia Vilela Leite Filgueiras, Cristiano Maciel

October 2010   **IHC '10:** Proceedings of the IX Symposium on Human Factors in Computing Systems

13

Supporting the design contributions of children with autism spectrum conditions
Christopher Frauenberger, Judith Good, Alyssa Alcorn, Helen Pain

June 2012   **IDC '12:** Proceedings of the 11th International Conference on Interaction Design and Children

14

Living Labs as multi-stakeholder platforms for the egovernance of innovation
Francesco Molinari

September 2011   **ICEGOV '11:** Proceedings of the 5th International Conference on Theory and Practice of Electronic Governance

15

Field evaluation of a collaborative memory aid for persons with amnesia and their family members
Mike Wu, Ronald M. Baecker, Brian Richards

October 2010   **ASSETS '10:** Proceedings of the 12th international ACM SIGACCESS

conference on Computers and accessibility

23
The participatory design of a sound and image enhanced daily planner for people with aphasia
Karyn Moffatt, Joanna McGrenere, Barbara Purves, Maria Klawe

April 2004   **CHI '04:** Proceedings of the SIGCHI Conference on Human Factors in Computing Systems

24
User-driven design of ontology-based, context-aware and self-learning continuous care applications
Femke Ongenae, Filip De Turck

October 2012   **CNSM '12:** Proceedings of the 8th International Conference on Network and Service Management

25
Making chocolate-covered broccoli: designing a mobile learning game about food for young people with diabetes
Marie Glasemann, Anne Marie Kanstrup, Thomas Ryberg

August 2010   **DIS '10:** Proceedings of the 8th ACM Conference on Designing Interactive Systems

26
Design research methods to understand user needs for an etextile knee sleeve
Ceara Ann Byrne, Claudia B. Rebola, Clint Zeagler

September 2013   **SIGDOC '13:** Proceedings of the 31st ACM international conference on Design of communication

27
Framing Participatory Practices in a Large Corporation
Delia Grenville

August 2012   **PDC '12: Proceedings of the 12th Participatory Design Conference: Exploratory Papers, Workshop Descriptions, Industry Cases - Volume 2**
, Volume 2

28
Motherhood and HCI
Madeline Balaam, Judy Robertson, Geraldine Fitzpatrick, Rebecca Say, Gillian Hayes, Melissa Mazmanian, Belinda Parmar

April 2013   **CHI EA '13:** CHI '13 Extended Abstracts on Human Factors in Computing Systems

29
IDEAS: an interface design experience for the autistic spectrum
Laura Benton, Hilary Johnson, Mark Brosnan, Emma Ashwin, Beate Grawemeyer

May 2011   **CHI EA '11:** CHI '11 Extended Abstracts on Human Factors in Computing Systems

30
Top-level decisions through public deliberation on the internet: evidence from the evolution of Java governance

250

Michael Kaschesky, Reinhard Riedl

May 2009   dg.o '09: Proceedings of the 10th Annual International Conference on Digital Government Research: Social Networks: Making Connections between Citizens, Data and Government

31 Cultural hybridity in participatory design
    Samantha Merritt, Erik Stolterman

    August 2012   PDC '12: Proceedings of the 12th Participatory Design Conference: Exploratory Papers, Workshop Descriptions, Industry Cases - Volume 2
    , Volume 2

32 Participatory design of an online therapy for youth mental health
    Greg Wadley, Reeva Lederman, John Gleeson, Mario Alvarez-Jimenez

    November 2013   OzCHI '13: Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration

33 Disclosure-Free GPS Trace Search in Smartphone Networks
    Demetrios Zeinalipour-Yazti, Christos Laoudias, Maria I. Andreou, Dimitrios Gunopulos

    June 2011   MDM '11: Proceedings of the 2011 IEEE 12th International Conference on Mobile Data Management - Volume 01 , Volume 01

34 An assistive robotic table for older and post-stroke adults: results from participatory design and evaluation activities with clinical staff
    Anthony L. Threatt, Jessica Merino, Keith Evan Green, Ian Walker, Johnell O. Brooks, Stan Healy

    April 2014   CHI '14: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems

35 Poster abstract: PiMi air community:: getting fresher indoor air by sharing data and know-hows
    Yixin Zheng, Linglong Li, Lin Zhang

    April 2014   IPSN '14: Proceedings of the 13th international symposium on Information processing in sensor networks

36 Connecting children to nature with technology: sowing the seeds for proenvironmental behaviour
    Bronwyn J. Cumbo, Jeni Paay, Jesper Kjeldskov, Brent C. Jacobs

    June 2014   IDC '14: Proceedings of the 2014 conference on Interaction design and children

37 Bodily experience and imagination: designing ritual interactions for participatory live-art

contexts
Lian Loke, George Poonkhin Khut, A. Baki Kocaballi

June 2012   **DIS '12:** Proceedings of the Designing Interactive Systems Conference

38

Supporting self-evaluation in local government via KDD
Hye-Chung Kum, Dean F. Duncan, C. Joy Stewart

May 2008   **dg.o '08:** Proceedings of the 2008 international conference on Digital government research

39

The development of novel eyes-free exercise technologies using participatory design
Kyle Rector

January 2014   **SIGACCESS Accessibility and Computing** , Issue 108

40

Participatory design with older adults: an analysis of creativity in the design of mobile healthcare applications
Jennifer L. Davidson, Carlos Jensen

June 2013   **C&C '13:** Proceedings of the 9th ACM Conference on Creativity & Cognition

41

Participatory design with proxies: developing a desktop-PDA system to support people with aphasia
Jordan L. Boyd-Graber, Sonya S. Nikolova, Karyn A. Moffatt, Kenrick C. Kin, Joshua Y. Lee, Lester W. Mackey, Marilyn M. Tremaine, Maria M. Klawe

April 2006   **CHI '06:** Proceedings of the SIGCHI Conference on Human Factors in Computing Systems

42

Embedding participatory design processes into everyday work activities: the case of video consultation services for paraplegics
Julia Klammer, Fred van den Anker, Monique Janneck

November 2010   **PDC '10:** Proceedings of the 11th Biennial Participatory Design Conference

43

Enabling mobile sensing through a DTN framework
Vasilis Maglogiannis, Giannis Kazdaridis, Donatos Stavropoulos, Thanasis Korakis, Leandros Tassiulas

September 2013   **WiNTECH '13:** Proceedings of the 8th ACM international workshop on Wireless network testbeds, experimental evaluation & characterization

44

Children's computer interaction in schools: a case study for promoting healthy computer use
Marina Louise Ciccarelli, Courtenay-Jane Campbell Harris

253

May 2009   **dg.o '09:** Proceedings of the 10th Annual International Conference on Digital
            Government Research: Social Networks: Making Connections between
            Citizens, Data and Government

59
The development of novel eyes-free exercise technologies using participatory design
Kyle Rector

April 2014   **CHI EA '14:** CHI '14 Extended Abstracts on Human Factors in Computing
             Systems

60
Understanding the challenges and opportunities for richer descriptions of stereotypical
behaviors of children with asd: a concept exploration and validation
Fnu Nazneen, Fatima A. Boujarwah, Shone Sadler, Amha Mogus, Gregory D. Abowd, Rosa I.
Arriaga

October 2010   **ASSETS '10:** Proceedings of the 12th international ACM SIGACCESS
               conference on Computers and accessibility

61
A participatory design workshop on accessible apps and games with students with learning
differences
Lisa Anthony, Sapna Prasad, Amy Hurst, Ravi Kuber

October 2012   **ASSETS '12:** Proceedings of the 14th international ACM SIGACCESS
               conference on Computers and accessibility

62
What health topics older adults want to track: a participatory design study
Jennifer L. Davidson, Carlos Jensen

October 2013   **ASSETS '13:** Proceedings of the 15th International ACM SIGACCESS
               Conference on Computers and Accessibility

63
Probing the potential of non-verbal group communication
Petra Sundström, Tove Jaensson, Kristina Höök, Alina Pommeranz

May 2009   **GROUP '09:** Proceedings of the ACM 2009 international conference on
            Supporting group work

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DIGITAL LIBRARY

((Mental* OR "behavioral health" OR "behavioural health" OR abnormal OR depression OR depressive OR "mood disorder" OR "personality disorder" OR psychiatr* OR schizophrenia OR schizophrenic OR bipolar OR compulsive OR obsessive OR impulsive OR "eating disorder" OR "self injury" OR "self harm" OR suicid* OR psychotic OR phobi* OR psychos* OR resilience OR resilient OR anxiety OR anxious OR stress OR "well-being" OR wellbeing OR wellness) AND participatory)

((Mental* OR "behavioral health" OR "behavioural health" OR abnormal OR depression OR depressive OR "mood disorder" OR "personality disorder" OR psychiatr* OR schizophrenia OR schizophrenic OR bipolar OR compulsive OR obsessive OR impulsive OR "eating disorder" OR "self injury" OR "self harm" OR suicid* OR psychotic OR phobi* OR psychos* OR resilience OR resilient OR anxiety OR anxious OR stress OR "well-being" OR wellbeing OR wellness) AND participatory)

n=39
Search is basic as limited to 5 wildcards and can't truncate within "". Need quotes for phrase searching. Co-design etc. would not work in addition to participatory.

APPENDIX B: PARTICIPANT INFORMATION SHEETS AND CONSENT FORMS (PAPER 3)

		Margaret Tobin Centre GPO Box 2100 Adelaide SA 5001 Telephone: (08) 8404 2615 Facsimile: (08) 8404 2101 Email: youngandwell@flinders.edu.au
	FLINDERS UNIVERSITY ADELAIDE • AUSTRALIA *Flinders Human Behaviour & Health Research Unit*	

Participant Information Sheet

Project: **How can mental health services use technology to better engage youth?**

Whether you decide to participate or not, involvement in this study will not impact on your access to mental health services in any way.

You are being asked to participate in a study undertaken by researchers at Flinders University which focuses on factors that affect the use of mental health services by rural youth. The study aims to gain insight into how best to engage with young adults in mental health service delivery and promotion of good mental health. Finally, the study aims to gain a deeper understanding of how young adults use technology and the best ways to integrate this into the delivery of new and existing mental health services.

Why is this study being carried out?
The Statewide Youth Mental Health Services is currently being developed. This new service will deliver specialised mental health services to young adults aged 16-24 years in South Australia and aim to determine the best ways to use technology to make mental health services youth friendly, easily accessible and responsive to rural young people's needs. An important part of this will involve discussions with young people around how they view wellbeing and how services can best work with youth to build trust and respect. We want to help create services that young people feel comfortable to use and that they recommend to their friends too.

Who is carrying out this study?
Miss Simone Orlowski, a PhD student, with the assistance of her researcher supervisors from Flinders University.
What does giving consent mean?

Giving consent means that you have read and understood the information sheet and decide that you are happy to participate by signing the consent form. We are happy to answer any questions you may have. If you wish, you can discuss this with relatives, friends and your personal doctor/mental health care worker.

What will you need to do?

If you take part in the study:

- You are being asked to contribute to a series of focus groups (group discussions) dedicated to the themes of: mental health, mental health services, being a young person in rural South Australia, technology, youth engagement and technology. You may also be asked to consent to an interview should your professional role equip you with specialist information requiring further discussion.
- You will be offered the opportunity to be involved in a series of workshops that are designed to make sense of the research carried out and make recommendations about how best to learn from participants' experiences and apply this to currently existing mental health services to improve them and to shape new ones. These workshops will take place on and off over 2014-2015 and you are free to attend as many or as few as suits you. The frequency of these meetings will be up to the group to decide, participants attending will play a role in deciding when and how often the meetings will take place.
- Photographs of materials produced at the workshops and audio recordings of discussions at the focus groups and workshops will be made, participants will not be identifiable from the photographs or audio recordings. No participants will be identifiable from these processes. Should you not agree to audio recordings, notes will be taken instead.

Benefits and risks

You will not receive any direct benefit as a result of your participation in the study. However, being involved in this study will give you an opportunity to tell provide your personal and professional views on mental health and mental health services. If you decide to, you will also have the opportunity to offer feedback and be involved in decision making about how to improve currently existing mental health services and shape new ones. You may feel distressed or anxious in responding to questions regarding personal information about your wellbeing and experiences with mental health services. If you are feeling distressed at any point you may choose to stop the interview and cease being involved in the study.

If you feel distressed after you have participated in this study, please contact either:

- your local doctor, counsellor or mental health worker

- the Lifeline 24-hour phone counseling service (ph. 131 114).

- the ACIS 24-hour mental health emergency service (ph. 131 465)

Should you need, the research team will be available to assist you to contact the above services.

Will I be paid for doing this study?

You will not be paid to take part in this study. However, your costs won't be any greater than they would be if you didn't join the study.

How will my privacy be protected?

This study will generate information about your professional opinions and experience of mental illness and with mental health services. Information gathered will be automatically de-identified, thus removing any means of identifying individuals involved. Once de-identified the data will be provided to the research team for analysis, the research team will include youth in Murray Bridge who have agreed to provide assistance to the study. Information will not be given to any other person without your permission. All personal information will be coded without names and stored in the Margaret Tobin Centre (Flinders University) under lock and key in the research office for a period of fifteen years in accordance with Flinders University requirements. After that it will be destroyed. Data on computers will be password protected. Project outcomes will be published in conference papers and journals but any publications arising from the study will not contain any personal identifying information.

It is important to understand that your contributions to study focus groups, should you choose to participate in them, cannot be guaranteed to remain confidential. Researchers will gain verbal agreement between all participants that they will maintain the anonymity of other members and the confidentiality of the discussions and contributions to the workshop, however this does not guarantee confidentiality will be maintained.

Is taking part in the study voluntary?

Yes. You don't have to participate in this study if you do not want to. If you choose to participate and then want to withdraw without giving a reason, that is OK – this will not effect your current or future treatment in any way. To withdraw from the study, please telephone Simone Orlowski on (08) 8404 2615.

If you have any further questions

This study has been approved by the SA Health Human Research Ethics Committee. If you want to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the executive officer on 8204 4507 or email research.ethics@health.sa.gov.au Executive Officer, Research Ethics Committees, Ms. Janet Bennett Tel: 8275 1876.

If you suffer injury as a participant in this research, compensation may be paid without litigation. However, compensation is not automatic and you may have to take legal action in order to receive payment.

Whether you decide to participate or not, you are guaranteed that your involvement will not impact on your ability to access treatment or other health services in any way ~ total confidentiality is ensured.

FLINDERS UNIVERSITY, SOUTH AUSTRALIA

CONSENT TO PARTICIPATE IN RESEARCH

I,

....

give consent to be involved in the study into:

How can mental health services use technology to better engage youth at risk?

- I have read and understood the Participant Information Sheets and Consent Form.
- I have had the opportunity to ask questions about the study and am satisfied with the answers and the explanations given to me.
- I know I will not be paid for my participation in this study.
- I have the opportunity to discuss my involvement with another person and have had sufficient time to make the decision to take part in this study.
- I give permission for audio recordings to be made of workshops, focus groups and interviews YES/NO
- I know that I may withdraw from this study at any time without jeopardising employment. If I refuse to participate, it will have no impact on my employment.
- I understand that the results of these studies may be published, but my identity will be kept confidential.
- I know that my answers will be completely confidential and no personal information, arising from study, which may identify me in any way, will be passed to any other Health service or department.
- The data will be stored in a secure data storage area for a period of fifteen years in accordance with Flinders University requirements.
- I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action in order to receive compensation

- I am over 18 years of age

Signature of Study Participant

Date

Printed Name

of Study Participant

Signature of Person Conducting
Consent

Printed Name Person Conducting
Consent

If you suffer injury as a participant in this research, compensation may be paid without litigation.

However, compensation is not automatic and you may have to take legal action in order to receive payment.

APPENDIX C: FOCUS GROUP AND INTERVIEW QUESTIONS (PAPER 3)

<u>Focus group questions – mental health practitioners</u>

The purpose of this series of focus groups is to investigate the current experience of mental health professionals working with youth in inner regional and rural South Australia. They aim to collect information to assist with identification of barriers and facilitators of youth use of specialised mental health services from a professional viewpoint. The focus groups will also explore current comfort level of use of technology in professional mental health practice and actual use of technology.

Focus Group Questions

1) What's it like to be mental health professional working in inner regional/rural South Australia?

2) We are interested in finding out more about the culture around collaborative mental health care in your local region. What has your experience been of interacting with other mental health and youth service professionals?

Prompt if necessary: is the only contact you have with other professionals by referrals?

Prompt if necessary: is there any co-location?

Prompt if necessary: how readily were you able to find other professionals to consult with and refer to?

3) a. Which elements of your current practice do you believe are most effective in being responsive to young people (16-24yrs)?

4) a. Why do you think young people prefer to seek help from their friends/peers?

b. What are the learnings from this that may be relevant for professional mental health services in terms of seeking to be more flexible and responsive to young people's needs?

5) a. What are the major concerns you have in the context of the work you do with young people?

b. What do you believe are the major strengths of the young people you work with?

6) a. If you came in and this place here (*insert name of relevant service*) was more welcoming to young people, what would it be like?

b. If you could change things in your professional work with young people, what would you change?

c. What might prevent a young person from coming here in the first place (*insert name of relevant service*)?

d. What might prevent a young person from continuing to use (*insert name of relevant service*) whilst it is still needed?

e. What keeps a young person coming back to use your service?

7) a. How comfortable do you feel using technology in your professional practice? Both with clients and for administrative purposes?

b. How could your current comfort level with technology be improved?

c. In which ways are you currently using technology in your professional practice?

d. What are the barriers to your use of technology in your professional practice?

e. In an ideal situation, what role do you see technology playing in your work as a mental health practitioner?

<u>Focus group questions – community stakeholders</u>

*The focus groups with mental health professionals will be supplemented with a series of focus groups with other relevant community stakeholders e.g. from Police, Fire, Ambulance, NGO's, local council representatives, teachers, Centrelink representatives **(Group 3 participants)**. The purpose of these focus groups is to gain understand youth mental health services in Murray Bridge within the broader context of other services working with youth in the community. The exact number of participants is unknown and subject to recruitment success but probably no more than 20. The participant makeup of the focus groups will aim to place participants from similar services together.*

Focus Group Questions – note this questions are subject to change based on findings from focus groups with mental health professionals.

1) What's it like to a professional working with youth in inner regional/rural South Australia?

2**) [Where relevant to the participant context]** We are interested in finding out more about the culture around collaborative youth services in your local region. What has your experience been of interacting with other mental health and youth service professionals?

Prompt if necessary: is the only contact you have with other professionals by referrals?

Prompt if necessary: is there any co-location?

Prompt if necessary: how readily were you able to find other professionals to consult with and refer to?

3) Which elements of your current professional practice do you believe are most effective in being responsive to young people (16-24yrs)?

4) a. Why do you think young people prefer to seek help from their friends/peers?

b. What are the learnings from this that may be relevant for youth services in terms of seeking to be more flexible and responsive to young people's socio-emotional needs?

5) a. What are the major concerns you have in the context of the work you do with young people?

b. What do you believe are the major strengths of the young people you work with?

6. a. If you could change things in your professional work with young people (and interactions with other youth-focussed services), what would you change?

b. What might prevent a young person from interacting with your service/organisation (*insert name of relevant service*)?

c. What might prevent a young person from continuing to use (*insert name of relevant service*) whilst it is still needed?

d. What keeps a young person coming back to use your service?

7) a. How comfortable do you feel using technology in your professional practice? Both with clients and for administrative purposes?

b. How could your current comfort level with technology be improved?

c. In which ways are you currently using technology in your professional practice?

d. What are the barriers to your use of technology in your professional practice?

e. In an ideal situation, what role do you see technology playing in your work as a youth service provider?

APPENDIX D: PARTICIPANT INFORMATION SHEETS AND CONSENT FORMS (PAPER 4)

FLINDERS UNIVERSITY ADELAIDE • AUSTRALIA *Flinders Human Behaviour & Health Research Unit*	Margaret Tobin Centre GPO Box 2100 Adelaide SA 5001 Telephone: (08) 8404 2615 Facsimile: (08) 8404 2101 Email: youngandwell@flinders.edu.au

Participant Information Sheet

Project: **How can mental health services use technology to better engage youth?**

Whether you decide to participate or not, involvement in this study will not impact on your access to mental health services in any way.

You are being asked to participate in a study undertaken by researchers at Flinders University which focuses on factors that affect the use of mental health services by rural youth. The study aims to gain insight into how best to engage with young adults in mental health service delivery and promotion of good mental health. Finally, the study aims to gain a deeper understanding of how young adults use technology and the best ways to integrate this into the delivery of new and existing mental health services.

Why is this study being carried out?
The Statewide Youth Mental Health Service is currently being developed. This new service will deliver specialised mental health services to young adults aged 16-24 years in South Australia and aim to determine the best ways to use technology to make mental health services youth friendly, easily accessible and responsive to rural young people's needs. An important part of this will involve discussions with young people around how they view wellbeing and how services can best work with youth to build trust and respect. We want to help create services that young people feel comfortable to use and that they recommend to their friends too.

Who is carrying out this study?
Miss Simone Orlowski, a PhD student, with the assistance of her researcher supervisors from Flinders University.

What does giving consent mean?

Giving consent means that you have read and understood the information sheet and decide that you are happy to participate by signing the consent form. We are happy to answer any questions you may have. If you wish, you can discuss this with relatives, friends and your personal doctor/mental health care worker.

What will you need to do?

If you take part in the study:

- I would like to interview you to ask you about what it is like to live with a mental health concern, your experiences of mental health services and how you use technology in your everyday life. I would like to ask questions about what it is like for you, your thoughts, your feelings as well as situations, events, places and people connected with your experience. The interview will take approximately 30-60 mins. If you choose to take part I will organise a location and time for the interview convenient for you. If you agree, an audio recording of the interview will be made so that an accurate transcript and summary of the conversation is possible. If you do not wish an audio recording to be made, notes will be taken instead.
- You will also be offered the opportunity to be involved in a series of workshops that are designed to make sense of the research carried out and make recommendations about how best to learn from participants' experiences and apply this to currently existing mental health services to improve them and to shape new ones. These workshops will take place over 2014-2015 and you are free to attend as many or as few as suits you. The frequency of these meetings will be up to the group to decide, youth attending will play a role in deciding when and how often the meetings will take place.
- Photographs of materials produced at the workshops and audio recordings of discussions will be made, participants will not be identifiable (as the photographs will only contain materials produced, not people) from the photographs or audio recordings.

Benefits and risks

Being involved in this study will give you an opportunity to tell your personal story related to your mental health and involvement with mental health services. If you decide to, you will also have the opportunity to offer feedback and be involved in decision making about how to improve currently existing mental health services and shape new ones. You may feel distressed or anxious in responding to questions regarding personal information about your wellbeing and experiences with mental health services. If you are feeling distressed at any point you may choose to stop the interview and cease being involved in the study.

If you feel distressed after you have participated in this study, please contact either:

- your local doctor, counsellor or mental health worker
- the Lifeline 24-hour phone counseling service (ph. 131 114).
- the ACIS 24-hour mental health emergency service (ph. 131 465)

Should you need, the research team will be available to assist you to contact the above services.

Will I be paid for doing this study?

You will receive a $30 voucher for the interview (choice of iTunes/Coles/Myer/other voucher). If you choose to participate in the workshops you will receive a once-off, up to $20 voucher (choice of iTunes/Coles/Myer/other voucher) for participation in these activities.

How will my privacy be protected?

This study will generate information about your experience of mental illness and with mental health services. Information gathered will be automatically de-identified, thus removing any means of identifying individuals involved. Once de-identified the data will be provided to the research team for analysis, the research team will include youth in Murray Bridge who have agreed to provide assistance to the study. Information will not be given to any other person without your permission. All personal information will be coded without names and stored in the Margaret Tobin Centre (Flinders University) securely in the research office for a period of fifteen years in accordance with Flinders University requirements. After that it will be destroyed using the University's dedicated secure process of this. Data on computers will be password protected. Project outcomes will be published in conference papers and journals but any publications arising from the study will not contain any personal identifying information.

It is important to understand that your contributions to study workshops, should you choose to participate in them, cannot be guaranteed to remain confidential. Researchers will gain verbal agreement between all participants that they will maintain the anonymity of other members and the confidentiality of the discussions and contributions to the workshop; however, this does not guarantee confidentiality will be maintained.

Is taking part in the study voluntary?

Yes. You don't have to participate in this study if you do not want to. If you choose to participate and then want to withdraw without giving a reason, that is OK – this will not affect your current or future treatment by your health services in any way. To withdraw from the study, please telephone Simone Orlowski on (08) 8404 2615.

Mandated Notifying Obligations

It is important that you understand that, as a mandated notifier, I am obliged to notify the Department for Education and Child Development, families SA through the Child Abuse Report Line when, in the course of the research, there is suspicion on reasonable grounds that a child has been, or is being, abused and/or neglected.

If you have any further questions

This study has been approved by the SA Health Human Research Ethics Committee. If you want to discuss the project with someone not directly involved, in particular in relation to matters

concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the executive officer on 8204 4507 or email research.ethics@health.sa.gov.au Executive Officer, Research Ethics Committees, Ms. Janet Bennett Tel: 8275 1876.

If you suffer injury as a participant in this research, compensation may be paid without litigation. However, compensation is not automatic and you may have to take legal action in order to receive payment.

Whether you decide to participate or not, you are guaranteed that your involvement will not impact on your ability to access treatment or other health services in any way ~ total confidentiality is ensured.

FLINDERS UNIVERSITY, SOUTH AUSTRALIA

CONSENT TO PARTICIPATE IN RESEARCH

I,

....

give consent to be involved in the study into:

How can mental health services use technology to better engage youth?

- I have read and understood the Participant Information Sheet and Consent Form.
- I have had the opportunity to ask questions about the study and am satisfied with the answers and the explanations given to me.
- I give permission for audio recordings to be made of my interview and workshops I attend YES/NO
- I have the opportunity to discuss my involvement with another person and have had sufficient time to make the decision to take part in this study.
- I know that I may withdraw from this study at any time without jeopardising my usual care or medical treatment. If I refuse to participate, it will have no impact on the services which I receive.
- I understand that the results of these studies may be published, but my identity will be kept confidential.
- I know that my answers will be completely confidential and no personal information, arising from study, which may identify me in any way, will be passed to any other Health service or department.
- I know that my answers will not in any way affect my treatment or access to any health services I am entitled to.
- I am aware that the data will be stored in a secure data storage area for a period of fifteen years in accordance with Flinders University requirements.
- I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action in order to receive compensation

- I am over 18 years of age. (*to be deleted for participants aged 16-17)

Signature of Study Participant

Date

Printed Name

of Study Participant

Signature of Person Conducting
Consent

Printed Name Person Conducting
Consent

If you suffer injury as a participant in this research, compensation may be paid without litigation.

However, compensation is not automatic and you may have to take legal action in order to receive payment.

APPENDIX E: INTERVIEW QUESTIONS (PAPER 4)

1) a. I am interested in what's it like being a young adult living in country Australia? Please tell me a little bit about what your interests are……………… (e.g. reading etc) and your family if you feel comfortable. *(prompt: can you give me an example a typical week/weekend in your life)*

2a How did it come to be that you started seeing *name of practitioner*? (How long have you been seeing him/her?

b. How would you describe your relationship with *name of practitioner*? Would you say they know the real you? Prompts to explain more……

c. Is there anything you leave at home and don't talk about in the session? Prompts to explain more if yes………

c. What has it been like, dealing with what you have been dealing with?

d. Could you please talk about any other experiences of seeking help you have had when things have been rough i.e. when you have been struggling socially or emotionally.

e. Please talk about the best experiences you have had with seeking help?

f. Could you explain further, anything specific the clinician did or said that you found helpful?

4) a. How do you find *name of service?*

b. If you were given the chance would you change things about the service? Please tell me more about that……….

c. If you were designing a service for people your age, how would it be?

d. Could you share with me any times you have found it difficult to seek help from professional services?

Prompt: What might prevent someone from coming to the service at all?

Prompt: What might/has prevented you from coming to the service once (i.e. once you have started using it and before your treatment is complete)?

e. Could you talk a little bit about the role friends have played in your journey up til now?

f. What would encourage you to recommend a friend to *name of service*?

5) What helps you get through difficult days? What keeps you going?

6) a. Have you sought help from technology-based or online sources?

b. If yes what attracted you to this form of help? If no, what has prevented you from doing so?

c. How helpful did you find it?

d. what role do you see technology playing youth mental health services?

e. What role does technology play in your own life?

APPENDIX F: PARTICIPANT INFORMATION SHEETS AND CONSENT FORMS (PAPER 5)

		Margaret Tobin Centre GPO Box 2100 Adelaide SA 5001
	FLINDERS UNIVERSITY ADELAIDE • AUSTRALIA	Telephone: (08) 8404 2615 Facsimile: (08) 8404 2101
	Flinders Human Behaviour & Health Research Unit	Email: youngandwell@flinders.edu.au

Participant Information Sheet

Project: **How can mental health services use technology to better engage youth?**

Whether you decide to participate or not, involvement in this study will not impact on your access to mental health services in any way.

You are being asked to participate in a study undertaken by researchers at Flinders University which focuses on factors that affect the use of mental health services by youth. The study aims to gain insight into how best to engage with young adults in mental health service delivery and promotion of good mental health. Finally, the study aims to gain a deeper understanding of how young adults use technology and the best ways to integrate this into the delivery of new and existing mental health services.

Why is this study being carried out?

The Statewide Youth Mental Health Services has recently commenced. This new service will deliver specialised mental health services to young adults aged 16-24 years in South Australia and aims to determine the best ways to use technology to make mental health services youth friendly, easily accessible and responsive in meeting young people's needs, particularly those who live rurally. An important part of this will involve discussions, interactions and observations with young people and their workers around mental health and how services can better meet young people's needs. We want to help create services that young people feel comfortable to use and that they recommend to their friends too.

Who is carrying out this study?

Miss Simone Orlowski, a PhD student, with the assistance of her researcher supervisors from Flinders University.

What does giving consent mean?

Giving consent means that you have read and understood the information sheet and decide that you are happy to participate by signing the consent form. We are happy to answer any

questions you may have. If you wish, you can discuss this with relatives, friends and your personal doctor/mental health care worker.

What will you need to do?

If you take part in the study:

- You will be giving permission for me, Simone Orlowski, to observe your sessions with your mental health worker.
- The aim of these observations is to gain insight into how mental health services work and to better understand the experiences of the young people who use them. I will NOT be making notes around your specific personal experiences – instead I will be focused on the nature of interactions that occur between you and you worker occur, the general structure of the session, tools and resources you may use or wish you could use, what is involved in preparing for sessions, what may/may not occur outside of sessions and how other people may or may not be involved in the process. Overall I am looking for ways that technology may assist in improving the experience for you and your worker.
- If you are comfortable and give your consent an audio recording will be made.
- We wish to design technology-based interventions that will assist in making it easier for young people like yourself get the mental health help that they need.
- This project sees young people and their mental health workers as the experts in the design process. Therefore, if you are interested we would love to provide you with further information around how you could be involved in the design process.

Benefits and risks

There are no direct benefits to yourself if you choose to participate in this study. Your participation will, however, provide valuable information around how we can design mental Health services to better meet young people's needs. Your participation in this study may result in you feeling distressed in having the researcher observe your session with your mental health worker. At any time if you become uncomfortable and wish the researcher to leave the session please say so and this will happen.

If you feel distressed after you have participated in this study and it is an emergency, please contact either:

- Emergency Services (ph. 000)
- your local doctor, counsellor or mental health worker
- the Lifeline 24-hour phone counseling service (ph. 131 114)
- Mental health triage (ph. 13 14 65)

Should you need, the research team will be available to assist you to contact the above services.

If you are distressed and wish to chat with someone (but it is not an emergency) please contact:

- beyondblue: https://www.youthbeyondblue.com/ - this website has information regarding available online chat and telephone services

Will I be paid for doing this study?

You will not be paid to take part in this study.

How will my privacy be protected?

This study will generate information about the operation of mental health services and the experiences of staff and consumers. Identifiable data will be available to myself and my supervisors for analysis. The data will be stored on password protected university servers for a period of fifteen years in accordance with Flinders University requirements. After that it will be destroyed. Information that is de-identified (thereby removing any means of identifying individuals involved) and aggregated will be used for others studies with the larger project in which this PhD sits. Project outcomes will be published in conference papers and journals but any publications arising from the study will not contain any personal identifying information.

Is taking part in the study voluntary?

Yes. You don't have to participate in this study if you do not want to. If you choose to participate and then want to withdraw without giving a reason, that is OK – this will not affect your current or future treatment by your health services in any way. To withdraw from the study, please telephone Simone Orlowski on (08) 8404 2615.

If you have any further questions

This study has been approved by the SA Health Human Research Ethics Committee. If you want to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the research and ethics policy officer Ms. Pamela Cooper on 8226 6431 or email hrec@health.sa.gov.au.

If you suffer injury as a participant in this research, compensation may be paid without litigation. However, compensation is not automatic and you may have to take legal action in order to receive payment.

Whether you decide to participate or not, you are guaranteed that your involvement will not impact on your ability to access treatment or other health services in any way ~ total confidentiality is ensured.

FLINDERS UNIVERSITY, SOUTH AUSTRALIA

CONSENT TO PARTICIPATE IN RESEARCH

I,

....

give consent to be involved in the study into:

How can mental health services use technology to better engage youth?

- I have read and understood the Participant Information Sheet and Consent Form.
- I have had the opportunity to ask questions about the study and am satisfied with the answers and the explanations given to me.
- I give permission for observation of my sessions with (insert name of worker) YES/NO
- I give permission for an audio recording to be of this session YES/NO
- I understand that the information noted down in the session will be done so way so that
- I have the opportunity to discuss my involvement with another person and have had sufficient time to make the decision to take part in this study.

- I know that I may withdraw from this study at any time without jeopardising my usual care or medical treatment. If I refuse to participate, it will have no impact on the services which I receive.
- I understand that the results of these studies may be published, but my identity will be kept confidential.
- I know that my answers will be completely confidential and no personal information, arising from study, which may identify me in any way, will be passed to any other Health service or department.
- I know that my answers will not in any way affect my treatment or access to any health services I am entitled to.
- I am aware that the data will be stored in a secure data storage area for a period of fifteen years in accordance with Flinders University requirements.
- I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action in order to receive compensation

---

Signature of Study Participant

Date

Printed Name

....

....

of Study Participant

Signature of Person Conducting
Consent

Printed Name Person Conducting
Consent

If you suffer injury as a participant in this research, compensation may be paid without litigation.

However, compensation is not automatic and you may have to take legal action in order to receive payment.

Participant Information Sheet

Project: **How can mental health services use technology to better engage youth?**

Whether you decide to participate or not, involvement in this study will not impact on your access to mental health services in any way.

You are being asked to participate in a study undertaken by researchers at Flinders University which focuses on factors that affect the use of mental health services by youth. The study aims to gain insight into how best to engage with young adults in mental health service delivery and promotion of good mental health. Finally, the study aims to gain a deeper understanding of how young adults use technology and the best ways to integrate this into the delivery of new and existing mental health services.

Why is this study being carried out?

The Statewide Youth Mental Health Services has recently commenced. This new service will deliver specialised mental health services to young adults aged 16-24 years in South Australia and aims to determine the best ways to use technology to make mental health services youth friendly, easily accessible and responsive in meeting young people's needs, particularly those who live rurally. An important part of this will involve discussions, interactions and observations with young people and their workers around mental health and how services can better meet young people's needs. We want to help create services that young people feel comfortable to use and that they recommend to their friends too.

Who is carrying out this study?

Miss Simone Orlowski, a PhD student, with the assistance of her researcher supervisors from Flinders University.

What does giving consent mean?

Giving consent means that you have read and understood the information sheet and decide that you are happy to participate by signing the consent form. We are happy to answer any questions you may have. If you wish, you can discuss this with relatives, friends and your personal doctor/mental health care worker.

What will you need to do?

If you take part in the study:

- Me shadowing you or a member of your staff over a number of days to gain a better understanding of work practice and roles.

This will involve:

- Attending team and/or clinical meetings
- Observation sessions with clients
- Attending other work-related events/tasks that occur on the designated observational days
- The aim of these observations is to gain insight into how mental health services work and to better understand the experiences of the young people who use them. I will NOT be making notes around specific personal experiences or information – instead I will be focused on the nature of interactions that occur in clinical sessions, the general structure of the session, tools and resources you may use or wish you could use, what is involved in preparing for sessions, what may/may not occur outside of sessions and how other people may or may not be involved in the process. I am also interested in work norms and culture and common problems and tensions in your work. Overall I am looking for ways that technology may assist in improving the experience for you and your clients. Where you deem appropriate audio recordings will also be made and photographs taken.
- We wish to design technology-based interventions that will assist in making it easier for young people to get the mental health help they need.
- This project sees young people and their mental health workers as the experts in the design process. Therefore, if you are interested we would love to provide you with further information around how you could be involved in the design process.
- Your participation in this study will also involve explaining the study to clients and gaining informed consent for researcher observations of clinical sessions.

Benefits and risks

You will not receive any direct benefit as a result of your participation in the study. However, being involved in this study will give you an opportunity to tell provide your personal and professional views on mental health and mental health services. If you decide to, you will also have the opportunity to offer feedback and be involved in decision making about how to improve currently existing mental health services and shape new ones. You may feel distressed or anxious in being observed or responding to questions regarding personal information about your work practice and experiences with mental health services. If you are feeling distressed at any point you may choose to cease being involved in the study.

If you feel distressed after you have participated in this study, please contact either:

- your local doctor, counsellor or mental health worker
- the Lifeline 24-hour phone counseling service (ph. 131 114).
- Mental health triage (ph. 131 465)

Should you need, the research team will be available to assist you to contact the above services.

Will I be paid for doing this study?

You will not be paid to take part in this study. However, your costs won't be any greater than they would be if you didn't join the study.

How will my privacy be protected?

This study will generate information about the operation of mental health services and the experiences of staff and consumers. Identifiable data will be available to myself and my supervisors for analysis. The data will be stored on password protected university servers for a period of fifteen years in accordance with Flinders University requirements. After that it will be destroyed. Information that is de-identified (thereby removing any means of identifying individuals involved) and aggregated will be used for others studies with the larger project in which this PhD sits. Project outcomes will be published in conference papers and journals but any publications arising from the study will not contain any personal identifying information.

Is taking part in the study voluntary?

Yes. You don't have to participate in this study if you do not want to. If you choose to participate and then want to withdraw without giving a reason, that is OK. To withdraw from the study, please telephone Simone Orlowski on (08) 8404 2615.

If you have any further questions

This study has been approved by the SA Health Human Research Ethics Committee. If you want to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the research and ethics policy officer Ms. Pamela Cooper on 8226 6431 or email hrec@health.sa.gov.au.

If you suffer injury as a participant in this research, compensation may be paid without litigation. However, compensation is not automatic and you may have to take legal action in order to receive payment.

Whether you decide to participate or not, you are guaranteed that your involvement will not impact on your ability to access treatment or other health services in any way ~ total confidentiality is ensured

CONSENT TO PARTICIPATE IN RESEARCH

I,

....

give consent to be involved in the study into:

How can mental health services use technology to better engage youth at risk?

- I have read and understood the Participant Information Sheets and Consent Form.
- I have had the opportunity to ask questions about the study and am satisfied with the answers and the explanations given to me.
- I know I will not be paid for my participation in this study.
- I have the opportunity to discuss my involvement with another person and have had sufficient time to make the decision to take part in this study.
- I give permission for the principal researcher to shadow me in my work YES/NO
- I am aware this includes team and clinical meetings and sessions with youth clients
- I give permission for an audio recordings to be made where I deem appropriate YES/NO
- I am aware that my participation in the study will involve explaining the study to clients and gaining informed consent for researcher observations of clinical sessions.
- I know that I may withdraw from this study at any time without jeopardising employment. If I refuse to participate, it will have no impact on my employment.
- I understand that the results of these studies may be published, but my identity will be kept confidential.
- I know that my answers will be completely confidential and no personal information, arising from study, which may identify me in any way, will be passed to any other Health service or department.
- The data will be stored in a secure data storage area for a period of fifteen years in accordance with Flinders University requirements.
- I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action in order to receive compensation

- I am over 18 years of age

Signature of Study Participant

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Date

Printed Name

----

of Study Participant

Signature of Person Conducting
Consent

Printed Name Person Conducting
Consent

If you suffer injury as a participant in this research, compensation may be paid without litigation.

However, compensation is not automatic and you may have to take legal action in order to receive payment.

APPENDIX G: DESCRIPTION OF OBSERVATIONAL STUDY FOR PARTICATING SERVICES (PAPER 5)

YOUNGANDWELL TOWNS

Access to mental health services is particularly difficult for rural young people (aged 16-24 yrs). Even though evidence-based e-mental health resources have significant potential in supplementing existing services, there is evidence that they are not used to their full potential, particularly in rural and remote areas. Further research is required to develop effective models of e-mental health services that can reach and improve outcomes for young people. (see more at https://www.youngandwellcrc.org.au/research/safe-supportive/young-and-well-towns/)

The current study

It seems logical for existing mental health services to explore the value of technology related additions and/or modifications aimed at increasing engagement of youth consumers (Montague, Varcin, & Parker, 2014; Blanchard, Herrman, Frere, & Burns, 2012). Young people (aged 16-24 years) are often cited as the demographic that stand to gain the most from this technology-based service reform (Ellis et al., 2012). This age group, who have been socialised in a technology-mediated world, have the greatest disease burden of any age group in Australia (Slade et al., 2009). Furthermore, it has been suggested they are increasingly reliant on online sources for mental health information and support, as traditional face-to-face mental health services struggle to engage them (Burns et al., 2013; Slade et al., 2009).

The overall aim of the current study (my PhD) is to investigate the above assumption of logic and ultimately design technology-based interventions aimed at enhancing rural and remote youth engagement with mental health services where possible and practical. Despite the potential of these interventions, limited uptake and/or adherence is a significant challenge. Therefore, the interventions are to be developed through user engagement and participation because it is thought that involving young people and professionals in intervention design may lead to better engagement.

The study began in early 2014. Phase 1 aims to gain an in depth and balanced understanding of the barriers to and facilitators of engagement with mental health services by rural youth. As part of this phase I have conducted:
- Focus groups and interviews with professionals working in rural mental health and key youth services in South Australia
- Interviews and focus groups with rural young people who have used services and those who have not in rural South Australia

To conclude Phase 1 I aim to complement the data from the interviews/focus groups/workshops with observations of rural mental health services working with young people. Human centred design, which takes consumer needs as its starting point, emphasises the role of observation in effective design (Plattner, 2015). Opportunities for observation to inform design for mental healthcare are often limited (Matthews et al., 2010). This observational sub-study represents a wonderful opportunity to generate depth of understanding of mental health service provision.

We hope to gain further insight and domain specific knowledge regarding youth mental health clinical practice, workflow and organisational culture. Tacit professional knowledge, organisational norms, culture and ways of working are often difficult to investigate via talk-based research methods such as interviews and focus groups - hence the observational approach. The data from phase 1 will inform Phase 2 of the study: co-design of technology-based interventions.

Practically, this means I will be present at Headspace Murray Bridge for the week starting July 20th. I am aiming to gain a broad perspective of the environment and ways in which you work. This will also include observation (and audio recording) of client sessions and various meetings where possible and acceptable. It may also include informal interviews. Field notes and quotes will NOT be around specific individuals, personal experiences, or details.

The study has ethics approval from the SA Human Research Ethics Committee, approval number *HREC-14-SAH-34*.

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APPENDIX H: PARTICIPANT INFORMATION SHEETS AND CONSENT FORMS (PAPER 6)

	Margaret Tobin Centre
FLINDERS UNIVERSITY ADELAIDE • AUSTRALIA *Flinders Human Behaviour & Health Research Unit*	GPO Box 2100 Adelaide SA 5001 Telephone: (08) 8404 2615 Facsimile: (08) 8404 2101 Email: youngandwell@flinders.edu.au

Participant Information Sheet

Project: **How can mental health services use technology to better engage youth?**

Whether you decide to participate or not, involvement in this study will not impact on your access to mental health services in any way.

You are being asked to participate in a study undertaken by researchers at Flinders University which focuses on factors that affect the use of mental health services by rural youth. The study aims to gain insight into how best to engage with young adults in mental health service delivery and promotion of good mental health. Finally, the study aims to gain a deeper understanding of how young adults use technology and the best ways to integrate this into the delivery of new and existing mental health services.

Why is this study being carried out?
The Statewide Youth Mental Health Services is currently being developed. This new service will deliver specialised mental health services to young adults aged 16-24 years in South Australia and aim to determine the best ways to use technology to make mental health services youth friendly, easily accessible and responsive to rural young people's needs. An important part of this will involve discussions with young people around how they view wellbeing and how services can best work with youth to build trust and respect. We want to help create services that young people feel comfortable to use and that they recommend to their friends too.

Who is carrying out this study?
Miss Simone Orlowski, a PhD student, with the assistance of her researcher supervisors from Flinders University.

What does giving consent mean?

Giving consent means that you have read and understood the information sheet and decide that you are happy to participate by signing the consent form. We are happy to answer any questions you may have. If you wish, you can discuss this with relatives, friends and colleagues.

What will you need to do?

If you take part in the study:

- You are being asked to contribute to a series of focus groups (group discussions) dedicated to the themes of: mental health, mental health services, being a young person in rural South Australia and technology. You may also be asked to consent to an interview should your professional role equip you with specialist information requiring further discussion.
- You will be offered the opportunity to be involved in a series of workshops that are designed to make sense of the research carried out and make recommendations about how best to learn from participants' experiences and apply this to currently existing mental health services to improve them and to shape new ones. These workshops will take place on and off over 2014-2015 and you are free to attend as many or as few as suits you. The frequency of these meetings will be up to the group to decide, participants attending will play a role in deciding when and how often the meetings will take place.
- Photographs of materials produced at the workshops and audio recordings of discussions at the focus groups and workshops will be made.

Benefits and risks

You will not receive any direct benefit as a result of your participation in the study. However, being involved in this study will give you an opportunity to provide your personal and professional views on mental health and mental health services. If you decide to, you will also have the opportunity to offer feedback and be involved in decision making about how to improve currently existing mental health services and shape new ones. You may feel distressed or anxious in responding to questions regarding personal information about your wellbeing and experiences with mental health services. If you are feeling distressed at any point you may choose to stop the interview and cease being involved in the study.

If you feel distressed after you have participated in this study, please contact either:

- your local doctor, counsellor or mental health worker

- the Lifeline 24-hour phone counseling service (ph. 131 114).

- Mental health triage (ph. 131 465)

Should you need, the research team will be available to assist you to contact the above services.

Will I be paid for doing this study?

You will not be paid to take part in this study. However, your costs won't be any greater than they would be if you didn't join the study.

How will my privacy be protected?

This study will generate information about your professional opinions and experience of mental illness and with mental health services. Information gathered will be automatically de-identified, thus removing any means of identifying individuals involved. Once de-identified the data will be provided to the research team for analysis, the research team will include youth in Murray Bridge who have agreed to provide assistance to the study. Information will not be given to any other person outside the research team without your permission. All personal information will be coded without names and stored in the Margaret Tobin Centre (Flinders University) under lock and key in the research office for a period of fifteen years in accordance with Flinders University requirements. After that it will be destroyed. Data on computers will be password protected. Project outcomes will be published in conference papers and journals but any publications arising from the study will not contain any personal identifying information.

It is important to understand that your contributions to study focus groups, should you choose to participate in them, cannot be guaranteed to remain confidential. Researchers will gain verbal agreement between all participants that they will maintain the anonymity of other members and the confidentiality of the discussions and contributions to the workshop, however this does not guarantee confidentiality will be maintained.

Is taking part in the study voluntary?

Yes. You don't have to participate in this study if you do not want to. If you choose to participate and then want to withdraw without giving a reason, that is OK – this will not affect your current employment in any way. To withdraw from the study, please telephone Simone Orlowski on (08) 8404 2615.

If you have any further questions

This study has been approved by the SA Health Human Research Ethics Committee. If you want to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the research and ethics policy officer Ms Pamela Cooper on 82266977 or email HealthHumanResearchEthicsCommittee@sa.gov.au.

If you suffer injury as a participant in this research, compensation may be paid without litigation. However, compensation is not automatic and you may have to take legal action in order to receive payment

Whether you decide to participate or not, you are guaranteed that your involvement will not impact on your ability to access treatment or other health services in any way ~ total confidentiality is ensured.

FLINDERS UNIVERSITY, SOUTH AUSTRALIA

CONSENT TO PARTICIPATE IN RESEARCH

I,

....

give consent to be involved in the study into:

How can mental health services use technology to better engage youth at risk?

- I have read and understood the Participant Information Sheets and Consent Form.
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- I know I will not be paid for my participation in this study.
- I have the opportunity to discuss my involvement with another person and have had sufficient time to make the decision to take part in this study.
- I give permission for audio recordings to be made of workshops, focus groups and interviews YES/NO
- I know that I may withdraw from this study at any time without jeopardising employment. If I refuse to participate, it will have no impact on my employment.
- I understand that the results of these studies may be published, but my identity will be kept confidential.
- I know that my answers will be completely confidential and no personal information, arising from study, which may identify me in any way, will be passed to any other Health service or department.
- The data will be stored in a secure data storage area for a period of fifteen years in accordance with Flinders University requirements.
- I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action in order to receive compensation

- I am over 18 years of age

_____

Signature of Study Participant

                                                                                    Date

....

Printed Name

of Study Participant

Signature of Person Conducting

Consent

....

Printed Name Person Conducting

Consent

....

....

If you suffer injury as a participant in this research, compensation may be paid without litigation.

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Adelaide SA 5001

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Facsimile: (08) 8404 2101

Email: youngandwell@flinders.edu.au

FLINDERS UNIVERSITY
ADELAIDE • AUSTRALIA

Flinders Human Behaviour & Health Research Unit

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Miss Simone Orlowski, a PhD student, with the assistance of her researcher supervisors from Flinders University.

What does giving consent mean?

Giving consent means that you have read and understood the information sheet and decide that you are happy to participate by signing the consent form. We are happy to answer any questions you may have. If you wish, you can discuss this with relatives, friends and your personal doctor/mental health care worker.

What will you need to do?

293

If you take part in the study:

- You are being asked to contribute to a series of focus groups (group discussions) dedicated to the themes of: mental health, mental health services, being a young person in rural South Australia, technology, youth engagement and technology. You may also be asked to consent to an interview should your professional role equip you with specialist information requiring further discussion.
- You will be offered the opportunity to be involved in a series of workshops that are designed to make sense of the research carried out and make recommendations about how best to learn from participants' experiences and apply this to currently existing mental health services to improve them and to shape new ones. These workshops will take place on and off over 2014-2015 and you are free to attend as many or as few as suits you. The frequency of these meetings will be up to the group to decide, participants attending will play a role in deciding when and how often the meetings will take place.
- Photographs of materials produced at the workshops and audio recordings of discussions at the focus groups and workshops will be made.

Benefits and risks

You will not receive any direct benefit as a result of your participation in the study. However, being involved in this study will give you an opportunity to tell provide your personal and professional views on mental health and mental health services. If you decide to, you will also have the opportunity to offer feedback and be involved in decision making about how to improve currently existing mental health services and shape new ones. You may feel distressed or anxious in responding to questions regarding personal information about your wellbeing and experiences with mental health services. If you are feeling distressed at any point you may choose to stop the interview and cease being involved in the study.

If you feel distressed after you have participated in this study, please contact either:

- your local doctor, counsellor or mental health worker

- the Lifeline 24-hour phone counseling service (ph. 131 114).

- the ACIS 24-hour mental health emergency service (ph. 131 465)

Should you need, the research team will be available to assist you to contact the above services.

Will I be paid for doing this study?

You will not be paid to take part in this study. However, your costs won't be any greater than they would be if you didn't join the study.

How will my privacy be protected?

This study will generate information about the operation of mental health services and the experiences of staff and consumers. Identifiable data will be available to myself and my supervisors for analysis. The data will be stored on password protected university servers for a

period of fifteen years in accordance with Flinders University requirements. After that it will be destroyed. Information that is de-identified (thereby removing any means of identifying individuals involved) and aggregated will be used for others studies with the larger project in which this PhD sits. Project outcomes will be published in conference papers and journals but any publications arising from the study will not contain any personal identifying information.

Is taking part in the study voluntary?

Yes. You don't have to participate in this study if you do not want to. If you choose to participate and then want to withdraw without giving a reason, that is OK – this will not effect your current or future treatment in any way. To withdraw from the study, please telephone Simone Orlowski on (08) 8404 2615.

If you have any further questions

This study has been approved by the SA Health Human Research Ethics Committee. If you want to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the executive officer on 8204 4507 or email research.ethics@health.sa.gov.au Executive Officer, Research Ethics Committees, Ms. Janet Bennett Tel: 8275 1876.

If you suffer injury as a participant in this research, compensation may be paid without litigation. However, compensation is not automatic and you may have to take legal action in order to receive payment.

Whether you decide to participate or not, you are guaranteed that your involvement will not impact on your ability to access treatment or other health services in any way ~ total confidentiality is ensured.

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- I have the opportunity to discuss my involvement with another person and have had sufficient time to make the decision to take part in this study.
- I give permission for audio recordings to be made of workshops, focus groups and interviews YES/NO
- I know that I may withdraw from this study at any time without jeopardising employment. If I refuse to participate, it will have no impact on my employment.
- I understand that the results of these studies may be published, but my identity will be kept confidential.
- I know that my answers will be completely confidential and no personal information, arising from study, which may identify me in any way, will be passed to any other Health service or department.
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- I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action in order to receive compensation

- I am over 18 years of age

Signature of Study Participant

                                                                Date

                              ....

Printed Name

                              ....

of Study Participant

Signature of Person Conducting
Consent

Printed Name Person Conducting
Consent

If you suffer injury as a participant in this research, compensation may be paid without litigation.

However, compensation is not automatic and you may have to take legal action in order to receive payment.

APPENDIX I: EXPANDED EXPLANATIONS OF WORKSHOP PROCEDURES (PAPER 6)

Visioning phase: Workshop 1

Procedure

The intention of this workshop was to: (1) investigate the ways in which mental health professionals see technology as able to support their work and young people's help-seeking; and (2) discuss the barriers to achieving this.

After initial introductions were carried out, an overview of the series of workshops was provided along with an explanation of the expectations and goals of the workshops. Next, in order to ground all participants in the design context a current state map of youth rural youth mental health help-seeking developed from the results of phases 1 and 2 of the project was presented to and discussed with participants

The remainder of the workshop was developed around consensus building techniques. First participants were given the following prompt: *In an ideal world (with no restrictions)……….*

"How might we integrate on-and-off line services and resources to empower rural young people in the management of their health?" Participants were then given 10 minutes to list on separate post-it notes as many responses as they could to the above prompt. Various guidelines were provided and assumptions discussed (e.g. more than one word, less than a sentence; think physical, digital & experience-based ideas and the integration of these; think equity & diversity of client groups; no wrong answers; everyone present has the wisdom to address the topic; defer judgement; go for quantity [aim for 10, with 5 as a minimum]). In order to seed this task participants were first asked to discuss with the person next to them how the above prompt had/had not been part of their work experience so far. Further prompting was required and thus four vignettes (generated from the results of phases 1 and 2 of the research) were provided.

After the brainstorming exercise the participants were then instructed to choose their best 3 answers (with guidelines such as: 'the ones that excite you' or one idea from each of the following categories: 1. the rational choice; 2. the most likely to delight; and 3. the long shot). Participants were then paired up by the workshop facilitator (this ensured maximum diversity in professional backgrounds where possible) and asked to share their three best ideas with one another. At the end of this activity participants were asked to have 5-8 best ideas listed on separate post-it notes (they were instructed to look for overlaps between their ideas and to decide together how to remove any duplicates).

One representative of the pair then explained their ideas to the whole group and placed the post-it notes on a large post-it note taped to the wall – during this process participants were encouraged to seek clarification or ask questions where necessary. After each group had reported back the ideas were sorted into themes as a group (a process which was led by the group facilitator) and then named. The remaining time was spent critiquing the ideas as a group (i.e. discussing why they were not possible in the current service delivery context).

It should be noted that two participants were unable to be presented in the rural location so they participated from a metropolitan location via video-conferencing facilities.
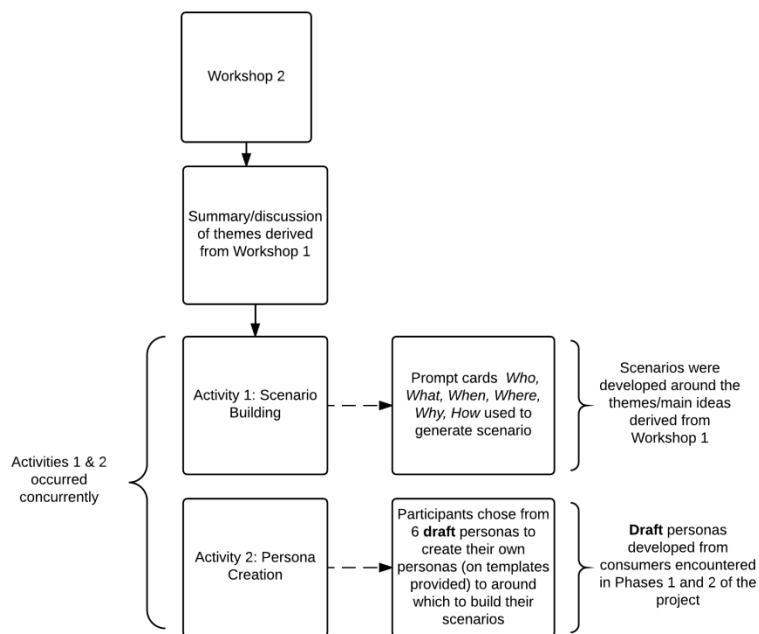

Overview of workshop 1
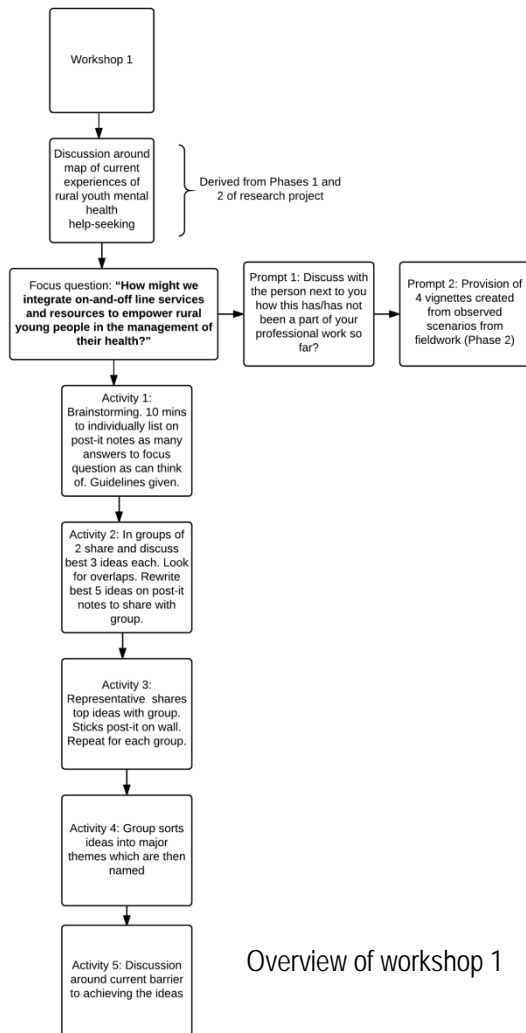
Scenario Building Phase: Workshop 2

Procedure

The intention of this workshop was to build on the themes generated in workshop 1 by investigating from a mental health professional perspective, both the *circumstances* and the *clients* they saw as applicable to the various technological possibilities discussed so far.

The workshop began with an overview of the major themes and ideas generated in the first workshop. The participants were then divided in to small groups (once again the groups were chosen to ensure maximum diversity of professional background) and assigned a theme from those generated in workshop 1. They were also given six prompt cards labelled *Who? What? When? Where? Why? and How?* and A3 sized piece of cardboard. Participants were instructed to use these prompt cards and the theme they were assigned to generate a scenario around which the theme (and possible technology-based solution embedded within it) could be built.

The groups were also provided six pre-crafted personas (which had previously been generated in phases 1 and 2 of the project). The purpose of the pre-crafted personas was twofold: (1) to act as starting point around which to flesh out their assigned theme and possible technology-based solution while attempting to build the scenario; and (2) to act as a template around which to build their own personas, to achieve this participants were given an adapted persona template and asked to complete it to produce an expanded/modified persona. The above process was then repeated for a second theme and persona.

Overview of workshop 2

Mock-up phase: Workshop 3

Procedure

Many different methods and rationales exist for creating artefacts. In the third and final workshop intentional use of 3D arts and crafts materials was employed to create mock-ups (low-fi representations of future technologies). Inspired by the work of Xie et al. (2012), use of existing objects was employed to limit the pressure participants

felt to draw. It was intended that workshops provide a chance to be creative while working with existing objects to create new ways of working and interacting.

Four scenarios were devised (based on the content and output generated in the first two workshops) before the workshop. The scenarios are listed in table X.

Table X
Scenarios for Workshop 3 Mock-up Activity
Framing Statement: Mary-Jo has been seeing her counsellor Sophie for 2 months, she has been depressed and finds it difficult to get to school or do any homework…………
Scenario 1: At their most recent appointment Sophie tells Mary-Jo that she is leaving her job and she will be assigned a new counsellor to work with. After 4 sessions Mary-Jo was just starting to feel like she could open up to, and trust, Sophie. • How can technology make this transition easier? • What would the technology look like? Build it……..
Scenario 2: Along with her fortnightly appointments with the counsellor, Mary-Jo often sees her local GP to access medication (anti-depressants). She also works with Drug and Alcohol services to reduce her dependence on marijuana. It often becomes confusing as to who she needs to see on which day and she gets pretty sick of repeating the same information to each person and getting different, often conflicting, responses from them. • How can technology make this process easier? • What would the technology look like? Build it……..
Scenario 3: As part of their work together Mary-Jo has been trying to improve her sleep – trying to get to sleep earlier in the evening and wake up earlier the next morning instead of sleeping in until midday. Mary Jo and Sophie have also been trying to understand what triggers her depression (i.e. when she feels the saddest and lowest) and establish strategies to improve her mood at these times. At the moment Mary-Jo keeps a diary to track her mood but she often forgets to fill it out and bring it to her sessions with Sophie. They also track her mood via questionnaires they fill out in their sessions together. The results get stored on Sophie's

computer which she unable to access in sessions – this makes it difficult to track and visualise Mary-Jo's progress.

- How can technology assist Mary-Jo to sleep and track her mood better and to involve her counsellor in this process?
- What would the technology look like? Build it……..

Scenario 4: Mary-Jo doesn't always make to her sessions with Sophie. Sometimes she feels so sad and low she stays in bed all day – sometimes for days at a time. At these times she would like to be able to connect with Sophie but physically she just can't get there to see her. After missing a session it is difficult to gain the motivation to go back.

- How can technology assist Mary-Jo and Sophie to connect even when Sophie can get in to see her?
- What would the technology look like? Build it

For this workshop the participants were divided into 4 groups. Group 1 consisted of two rural youth mental health service users. Group 2 was made up of three mental health professionals each with experience in different parts of the mental health system. Group 3 was made of two mental health professionals of diverse work backgrounds and Group 4 consisted of two young people interested in mental health (who were non-service users themselves).

After a brief overview of the content and output of the prior two workshops and an explanation of the goals of the current workshop, the participants sat around a large table filled with the arts/crafts supplies. Initially each group was assigned a different scenario and asked to build the technology (following the prompts) with the objects/materials they deemed appropriate. After 30-40 minutes each group was given a second (but related) scenario from and asked to modify their existing mock-up to accommodate the additional need(s) the new scenario spoke to. Throughout the building process the groups were asked to fill out a table which detailed their thought processes.

Halfway through the workshop the groups who had received the *same* scenarios (albeit in a *different* order) were combined. In practice this meant that a group consisting of mental health professionals and a consisting of young people were combined. Group 1 combined with Group 2 and Group 3 combined with Group 4. The groups were then asked to explain their designs to each other and note down on Venn diagram the perceived similarities and differences between their designs.

Next the newly formed youth/mental health professional groups were asked to combine the best/most effective parts of each of their designs to come up with one overall design to meet the needs of the scenarios they were

assigned. Again they were asked to note down the reasons for their decisions. The workshop then closed with the two combined groups explaining their designs to one another.

Participants were also asked to complete an evaluation form regarding their experience of the project. A short exit interview was also carried out with participants either before they left the workshop or the next day over the phone.
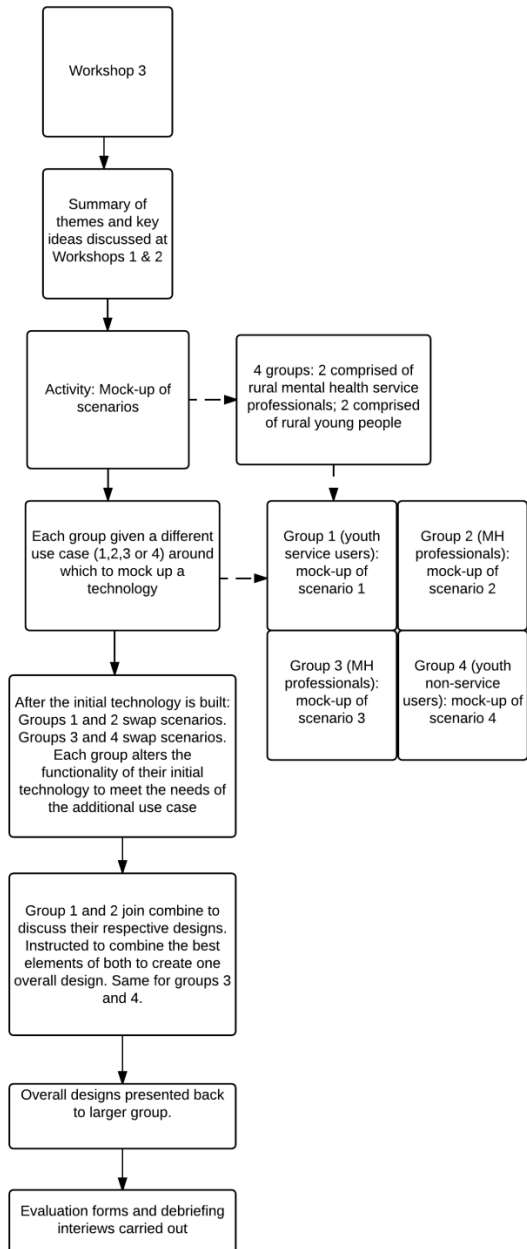
 Overview of workshop 3

APPENDIX J: EXAMPLES OF ARTIFACTS WORKSHOP 1 (PAPER 6)

Current state help-seeking map

Current experience of health help-seeking for young people

Orlowski & Antezana, 2015
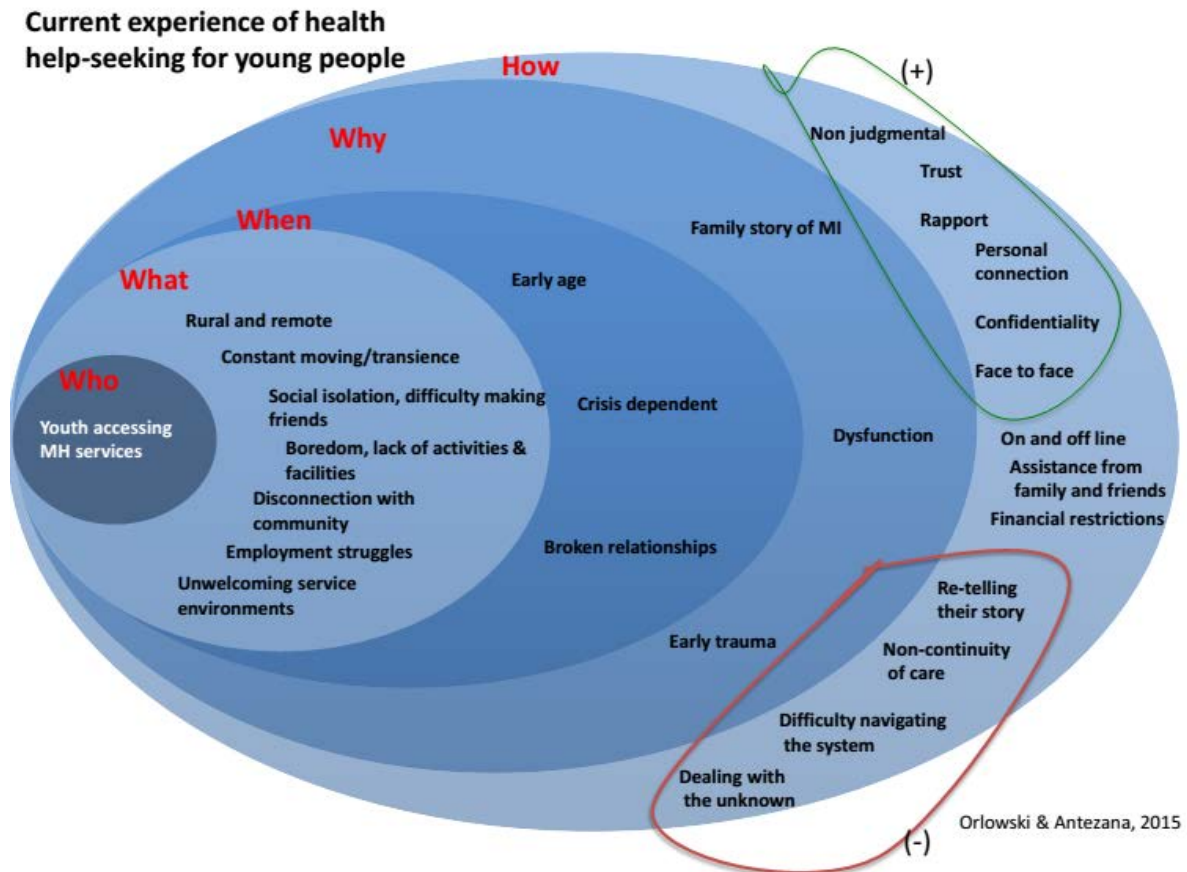
Workshop Vignettes

Sam, aged 19 years, was presenting with mood and anxiety concerns, substance abuse problems and a physical health condition. Recently his care had been shared between sites one and two due to fluctuating levels of risk and a perceived need for more assertive care by site two. Recently Sam's care had involved the following people: a case worker at each of the services, a consultant psychiatrist and a specialist youth worker, a GP, a psychologist (who had recently just resigned thus a new one would need to be assigned) and another non-government agency. During the meeting, it was also indicated that a drug and alcohol worker would come on board. This led one staff member to exclaim there is "a hell of a lot of a people involved with [Sam]". Staff discussed the need for all individuals/services

involved with the client to "sing from the same song sheet" in terms of Sam receiving similar/complementary messages around his care.

Brad, aged 20, is seeking psychological help for situational depression and anxiety around lack of employment and direction after high school completion. He is 20 minutes late for his 12:30pm appointment with his psychologist because he overslept. Together they are working on strategies to access further education and/or employment and his motivation around this. Brad draws a lot throughout the session to help articulate his thoughts and feelings. Both Brad and his psychologist takes notes on pieces of paper throughout the session to remind them of agreed on action points. The psychologist questions him around his sleep, diet and exercise. In discussing his reverse sleep pattern, he refers to the Sony band on his wrist. He is able to show graphs of his sleep time, length and quality over the last few months.

APPENDIX K: PERSONA TEMPLATE WORKSHOP 2 (PAPER 6)

NAME

Use a realistic name. Don't use names of clients.

DESCRIPTOR

What type of persona is it. Describe the most prominent differentiator.

QUOTE

Capture the essence to one or two points that could come out of the persona's own mouth -
so to speak.

Just sketch your
first impression!

WHO IS IT ?

Sketch the personal profile. age. location. job title/education. socio-demographic background - what kind of person is it? What is their level of expertise regarding technology?
What is their diagnositc and help-seeking history?

WHAT GOALS?

What is the supreme motivator? What are (latent) needs and desires?

WHAT ATTITUDE?

What is the point of view? What is the expectation. perception of the service? What motivates the
persona to use the intervention/product

WHICH BEHAVIOUR?

What does he/she do? Tell stories about their behaviour while using the intervention/product. Channel usage for various needs (internet. visiting comparable sites. mobile. social media). What
works well. **what are the frustrations.** what is stopping him/her from choosing a function. service or product?

What should the product/intervention definitely do? What must it never do?

Which persona(s) would this product/intervention not work for?

APPENDIX L: EXAMPLES OF PERSONAS WORKSHOP 2 (PAPER 6)

Tom is 21 years old. He left home at a very young age and has lived in more towns in the region in the last 5 years than he can count on two hands. Throughout the moves, however, he has stuck with the same mental health worker after many unsuccessful attempts at help seeking which involved hospitalisations (against his will) after suicide attempts. Like him, his mother has suffered with a mood disorder throughout her life. He has moved to the area for cheap rent and because he has burnt all of his bridges with his friends in the last placed he lived. He is unemployed and rarely leaves the house due to lack of finances and motivation. He lives with his girlfriend and they spend most of their time smoking dope. Through his job service provider Tom has just started a vet course in business management and loves going there as it gets him out of the house.

Tiffiany is 16 years of age. She has been engaged with mental health services and professionals from a very young age. Around year 9 she started seeing and hearing things so her mother took her to the local Headspace. After being told she was making things up by her first mental health worker– it took years for her to get the correct diagnosis - she has now found a psychiatrist who completely understands what she is going through and together they have found the medication that works for her. Tiffany moved into the area in year 9 and has found it very difficult to make friends ever since, she is very reliant on her boyfriend and mother for support who both make sure she gets to her appointments, even on the days when she so low she finds it difficult to get out of bed. Her psychiatrist recommends apps to her to assist with her irregular sleeping patterns and is keen to see how technology can help her with her mental health.

Scenario

Mary-Jo has been seeing her counsellor Sophie for 2 months, she has been depressed and finds it difficult to get to school or do any homework............

Scenario 1

At their most recent appointment Sophie tells Mary-Jo that she is leaving her job and she will be assigned a new counsellor to work with. After 4 sessions Mary-Jo was just starting to feel like she could open up to, and trust, Sophie.

- *How can technology make this transition easier?*
- *What would the technology look like? Build it.........*

Scenario 2

Along with her fortnightly appointments with the counsellor, Mary-Jo often sees her local GP to access medication (anti-depressants). She also works with Drug and Alcohol services to reduce her dependence on marijuana. It often becomes confusing as to who she needs to see on which day and she gets pretty sick of repeating the same information to each person and getting different, often conflicting, responses from them.

- *How can technology make this process easier?*
- *What would the technology look like? Build it........*

Scenario 3

As part of their work together Mary-Jo has been trying to improve her sleep – trying to get to sleep earlier in the evening and wake up earlier the next morning instead of sleeping in until midday.

Mary Jo and Sophie have also been trying to understand what triggers her depression (i.e. when she feels the saddest and lowest) and establish strategies to improve her mood at these times. At the moment Mary-Jo keeps a diary to track her mood but she often forgets to fill it out and bring it to her sessions with Sophie. They also track her mood via questionnaires they fill out in their sessions together. The results get stored on Sophie's computer which she unable to access in sessions – this makes it difficult to track and visualise Mary-Jo's progress.

- *How can technology assist Mary-Jo to sleep and track her mood better and to involve her counsellor in this process?*
- *What would the technology look like? Build it........*

Scenario 4

Mary-Jo doesn't always make to her sessions with Sophie. Sometimes she feels so sad and low she stays in bed all day – sometimes for days at a time. At these times she would like to be able to connect with Sophie but physically she just can't get there to see her. After missing a session it is difficult to gain the motivation to go back.

- *How can technology assist Mary-Jo and Sophie to connect even when Sophie can get in to see her?*
- *What would the technology look like? Build it........*

APPENDIX N: EVALUATION FORMS WORKSHOP 3 (PAPER 6)

Prototyping Workshop 17th Dec 2015 (youth participants)

Scenarios completed: 1&2   ☐   3&4   ☐

Age: ☐

Gender: M   ☐   F   ☐   Different identity (please state) _____

Have you ever sought help for your mental health?   Y/N

Have you ever sought online help for your mental health?   Y/N

What worked well about the process/activities?

1.

2.

3.

What could we improve for next time?
1.

2.

3.

Is this an experience you would be part of again and/or recommend to others? Please give reasons for your answer

Why did you decide to participate in this research? Were you're expectations met? Please give reasons for your answer

Any final comments or things we should know?

Scenarios completed: 1&2   ☐   3&4   ☐

Which workshops did you participate in?   1   2   3
                                                  ☐   ☐   ☐

1.

2.

3.

What could we improve for next time?

1.

2.

3.

Is this an experience you would be part of again and/or recommend to others? Please give reasons for your answer

Why did you decide to participate in this research? Were you're expectations met? Please give reasons for your answer

Any final comments or things we should know?

APPENDIX O: PROJECT ETHICS APPROVALS

Government of South Australia
SA Health

SA Health Human Research Ethics Committee
Level 10, Citi-Centre Building
11 Hindmarsh Square
ADELAIDE SA 5000
Telephone: (08) 8226 6367
Facsimile: (08) 8226 7088

Ms Simone Orlowski
PhD Candidate
School of Medicine
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
ADELAIDE SA 5000

Dear Ms Orlowski

HREC reference number: HREC/14/SAH/34

Project title: e-Mental Health Service Model – How can mental health services use technology to better engage youth at risk

RE: HREC Application – Approval

Thank you for responding to the issues raised by the SA Health HREC in relation to the above project. Your response was reviewed by a sub group of the HREC out-of-session.

I am pleased to advise that your application has been granted full ethics approval and appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research*.

Please note the following conditions of approval:
- The research must be conducted in accordance with the 'National Statement on Ethical Conduct in Human Research.'
- A progress report, at least annually, must be provided to the HREC.
- When the project is completed, a final report must be provided to the HREC.
- The HREC must be notified of any complaints by participants or of adverse events involving participants.
- The HREC must be notified immediately of any unforeseen events that might affect ethical acceptability of the project.
- Any proposed changes to the original proposal must be submitted to and approved by the HREC before they are implemented.
- If the project is discontinued before its completion, the HREC must be advised immediately and provided with reasons for discontinuing the project.
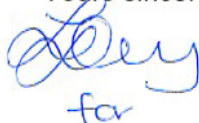
HREC approval is valid for 3 years from the date of this letter.

Should you have any queries about the HREC's consideration of your project please contact Lauren Perry, Executive Officer of the HREC, on (08) 8226 6431 or hrec@health.sa.gov.au

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a SA Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained via the completion of a Site Specific Assessment form. Please contact David van der Hoek via email at ResearchGovernance@health.sa.gov.au to discuss this process further.

The HREC wishes you every success in your research.

Yours sincerely

for

Prof Andrew Alston
DEPUTY CHAIRPERSON
HUMAN RESEARCH ETHICS COMMITTEE

16/4/14

Ms Simone Orlowski
PhD Candidate
School of Medicine
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
ADELAIDE SA 5000

Dear Ms Orlowski

HREC reference number: HREC/14/SAH/34

Project title: e-Mental Health Service Model – How can mental health services use technology to better engage youth at risk

Thank you for submitting a modification request in relation to the above project, namely the amendments recruitment of participants. This was considered out-of-session by the Chairperson of the SA Health Human Research Ethics Committee.

I am pleased to advise that ethics approval has been granted to your modification request.

Please note that all original conditions of ethics approval continue to apply.

Should you have any questions or concerns, please contact Lauren Perry, Executive Officer of the HREC, Ph 8226 6431 or Email hrec@health.sa.gov.au

We wish you well with your research.

Yours sincerely,

Dr David Filby
CHAIRPERSON
HUMAN RESEARCH ETHICS COMMITTEE

6/5/2014

Government of South Australia

SA Health

Ms Simone Orlowski
PhD Candidate
School of Medicine
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
ADELAIDE SA 5000

Dear Ms Orlowski,

HREC reference number: HREC/14/SAH/34

Project title: e-Mental Health Service Model – How can mental health services use technology to better engage youth at risk?

Thank you for submitting a modification request in relation to the above project, namely the sub-study involving observations of mental health team members at clinic/team meetings and when engaging with consumers to see how they practice and use technology. This was considered out-of-session by a sub group of the SA Health Human Research Ethics Committee.

I am pleased to advise that ethics approval has been granted to your amendment.

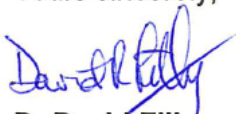| Document	Version	Date
Notification of amendment	1.0	16 June 2015
SA Health Core Application Form		16 June 2015
Participant Information Sheet and Consent Form_ Youth Clients	1.0	16 June 2015
Participant Information Sheet and Consent Form_ MH Professionals	1.0	16 June 2015
In Principal Support from Josephien Rio, Practice Consultant - Murray Mallee Community Mental Health Team (MMCMHT)	1.0	26 March 2015
In Principal Support from Simon Moody, Team Leader, Mental Health Team (CHSA MMCMHT)	1.0	22 April 2015
In Principal Support from Frauke Hobbs, Headspace Manager	1.0	25 March 2015
In Principal Support from Frauke Hobbs on behalf of Headspace Staff	1.0	10 June 2015
In Principal Support from Josephien Rio on behalf of MMCMHT Team	1.0	11 June 2015

Please note that all original conditions of ethics approval continue to apply.

Should you have any questions or concerns, please contact the Executive Officer of the HREC, Ph 8226 6431 or Email hrec@health.sa.gov.au

We wish you well with your research.

Yours sincerely,

Dr David Filby
CHAIRPERSON
HUMAN RESEARCH ETHICS COMMITTEE
25/06/2015

Government of South Australia

SA Health

SA Health Human Research Ethics Committee
Level 8, Citi-Centre Building
11 Hindmarsh Square
ADELAIDE SA 5000
Telephone: (08) 8226 6278

Ms Simone Orlowski
PhD Candidate
School of Medicine
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
ADELAIDE SA 5000

Dear Ms Orlowski,

HREC reference number: HREC/14/SAH/34

Project title: e-Mental Health Service Model – How can mental health services use technology to better engage youth at risk?

Thank you for submitting a modification request in relation to the above project. This was considered out-of-session by a sub group of the SA Health Human Research Ethics Committee.

I am pleased to advise that ethics approval has been granted to your amendment.

Document	Version	Date
Email Notification to Participants	1.0	29 October 2015
Participant Information Sheet and Consent Form_ MH Professionals	3.0	29 October 2015
Core Application Form	7.0	29 October 2015

Please note that all original conditions of ethics approval continue to apply.

Should you have any questions or concerns, please contact the Executive Officer of the HREC, Ph 8226 6278 or Email hrec@health.sa.gov.au
You are reminded that this letter constitutes ethical approval only. You must also send amendments to the site's Research Governance Officer (RGO).

We wish you well with your research.

Yours sincerely,

Catherine Blaikie
CHAIRPERSON
HUMAN RESEARCH ETHICS COMMITTEE
03/11/2015

HREC/14/SAH/ 34 – e-Mental Health Service Model – How can mental health services use technology to better engage youth at risk?

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Government of South Australia

SA Health

Ms Simone Orlowski
PhD Candidate
School of Medicine
Faculty of Medicine, Nursing and Health Sciences
Flinders University
GPO Box 2100
ADELAIDE SA 5000

Citi Centre Building
Level 8, 11 Hindmarsh Square
Adelaide   SA   5000

PO Box 287, Rundle Mall
Adelaide SA 5000
DX 243

Tel   08 8226 6278

Dear Ms Orlowski,

HREC reference number: HREC/14/SAH/34

Project title: e-Mental Health Service Model – How can mental health services
use technology to better engage youth at risk?

Thank you for submitting a modification request in relation to the above project.
This was considered out-of-session by the Chairperson of the SA Department for
Health and Ageing Human Research Ethics Committee.

I am pleased to advise that ethics approval has been granted to your amendment
on the condition that data are only to be used for this study unless further ethics
approval is given otherwise.

Document	Version	Date
Notification of Amendment	1.0	04 December 2015
Participant Information Sheet and Consent Form_ Youth	3.0	04 December 2015
Core Application Form	8.0	04 December 2015

Please note that all original conditions of ethics approval continue to apply.

Should you have any questions or concerns, please contact the Executive Officer
of the HREC, Ph 8226 6278 or Email hrec@health.sa.gov.au
**You are reminded that this letter constitutes ethical approval only. You must
also send amendments to the site's Research Governance Officer (RGO).**

We wish you well with your research.

Yours sincerely,

Catherine Blaikie
CHAIRPERSON
HUMAN RESEARCH ETHICS COMMITTEE
11/12/2015

HREC/14/SAH/ 34 -- e-Mental Health Service Model – How can mental health services use technology to better engage
youth at risk?