

Health Technology Research: Learnings from a Youth Mental Health Context

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ABSTRACT

This paper presents the perspective of a health researcher carrying out a participatory design PhD in youth mental health. It debates the ethical implications of prioritising the distal effects of health technologies when developing and defining project goals. Defining project success in this way has implications for multidisciplinary leadership and collaboration from the project outset. Habermas' theory of communicative action as "communication oriented toward reaching consensus through open and receptive debate" provides a way of thinking about the type of interaction needed for an ethical and multidisciplinary model such as this to flourish. Such an approach may help to better facilitate the introduction of technology into a complex, open system such as health. Examples of this system are presented and associated ethical implications and learnings are discussed.

ACM Classification Keywords

H.5.2. User interfaces (e.g. HCI): Miscellaneous

INTRODUCTION

With one in four young people (aged 16-24yrs) meeting the criteria for a mental illness in the past 12 months [1] and only 30% of these accessing help, [1,2] technology-based interventions have been increasingly touted as game changing solutions to reverse this negative trend [3-5]. The limited engagement with face-to-face services

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is often linked to financial, geographic, disease-specific, physical and stigma-related barriers [6-8]. It is in this context that the perceived increase in accessibility, flexibility and consumer engagement, along with cost reductions associated with e-mental health are championed [9].

The current program of research has engaged various representatives of the mental health workforce and youth clients (aged 16-24yrs) principally from one rural South Australian region. Our aim was to better understand: 1. the complexities of design and implementation of technologies in a mental health organisational context; and 2. best practice around end user involvement in design in this space. The research has involved a number of phases. Phase 1: systematic review of the use of participatory research in development of technology-based youth mental health and wellbeing interventions. Phase 2: scoping study (n= 4 focus groups, n= 8 interviews with frontline mental health workers and support/management staff, n=10 interviews with current youth clients). Phase 3: a 2-week observational study at two public rural South Australian youth mental health services. The observations included shadowing staff in their daily work, including sitting in on consultations/sessions with clients. Phase 4: series of 3 participatory design workshops with key stakeholders (currently underway) – the focus of design is around the integration of on and offline mental health services and resources to empower rural young people in the management of their health. Specifically we are looking at ways to increase information sharing and connectedness between the key stakeholders involved in a young person's care e.g. eliminating the need for young people to repeat their story (their personal and clinical history) to the many service providers involved in their help seeking journey.

It is in this context we: 1. debate the ethics around multidisciplinary collaboration in health technology

research; and 2: discuss learnings and insights from working in the youth mental health space.

PROJECT GOALS

Broadly speaking, ongoing debate exists around Human Computer Interaction's (HCI) contribution to health and wellbeing technologies [10]. Smith et al 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 [11,12].

From an egalitarian standpoint we argue that these distal effects - for example improved mental health in youth - should form the primary goal of the health technology project from the outset. Privileging the distal effects of health technologies as goals for the entire project (including the development phase) suggests that the field of health technology research is one to be shared equally by the various relevant research disciplines and the population of vulnerable individuals eventually intended to use them. If projects start out with a restricted HCI focus, which gradually shifts toward health as the clinical trial phase is reached, one may argue that eventual traction and uptake in the field cannot be of the highest priority. This leads to the question as to why the health field would be interested in this type of 'collaboration'. An ethical understanding of the ways in which technology can and should impact health demands inclusive collaboration from project outset; if the goal of the project is, for instance, *improved mental health in youth*, technology can be viewed as a strategy (process of achieving this goal). This way of conceptualising a health technology project has significant implications for whose ideas are valued and at what stage of development, particularly for the various disciplines and other key stakeholders. It also leaves open the possibility that technology could prove to be a deleterious strategy, or have neutral or negative distal effects for this vulnerable group.

HABERMAS' THEORY OF COMMUNICATIVE ACTION

Habermasian theory describes the role of varieties of communication that result in different actions, the most positive of which is *communicative action*. This type of interaction is oriented toward reaching a shared understanding through open and receptive debate. It sits in contrast to *strategic action* which is interaction based on achievement of self-interested objectives [13,14].

A model for collaboration in health technology research

Much can be taken from this theory to inform the type of ethical interaction that could underpin health technology projects that hold up distal effects of technologies as overarching goals. A primary skill of the project manager should therefore be in facilitating ethical collaboration through establishing communicative action among the diverse key stakeholders. If each of the interested stakeholders of a health technology project view the collaboration solely from their own discipline-specific viewpoint (the assumption that underpins the bounded viewpoint), the idea of collaboration appears misplaced or at best narrowly defined. Communicative action offers a

different way forward for thinking about ethical inclusion in this space.

Valuing and integrating multiple viewpoints to achieve consensus opens up new possibilities around *who* should be involved from the project outset, *why* and most importantly *how*. Of particular note are the health professionals and clients who are the intended users of the technology. Guidelines in design of mental health technologies suggest working with research oriented mental health professionals (in favour of those mental health professionals who have no experience and/or interest in research) on the basis that they will likely be more understanding and accommodating of the HCI technology development process [15,16]. However, *there exists a divide in mental health services between research and practice*. Choosing to include only research-oriented practitioners in research projects may assist with demonstrating feasibility but not be representative of a real world situation if future uptake and adherence is important. This practice also holds deep ethical implications for which stakeholders are given the opportunity to participate and ultimately whose voice is privileged in design.

Given the particular ethical considerations necessary for engaging with people with mental health disorders, an oft-repeated assumption of HCI research in this space is the belief that there are limited access to mental health clients and workplaces [15,16]. Our experiences challenge this position, particularly its validity but also its ethical and moral implications.

PROJECTS IN MENTAL HEALTH

Mental health (and health more broadly) can be conceptualised as an open, complex system. If, we as health technology researchers wish to see traction and uptake of technologies in the field, a solid appreciation of this context is surely needed. Here again we find further support for meaningful and ethical collaboration between health and HCI from project inception. This final section will discuss a sample of some high level (and hard won) learnings around insights around conducting projects in the youth mental health space (N.B. the client scenario was observed in phase 3 of the research).

Who are we designing for?

Mental health technology guidelines have had a disproportionate focus on psychology [15,16]. It is vital to understand, however, that *mental health care settings and/or professionals* are extremely diverse. Many professions, work roles, organisations and services comprise the mental health sector, and young people seeking help may be engaged with any number of these. This holds great significance for the types of technologies that will ultimately be usable, useful and efficacious and opens up many more opportunities for design.

Sam, aged 19, was a perfect example of this complexity. He was presenting with mood and anxiety concerns, substance abuse problems and deteriorating vision. Recently his care had been shared between two mental health services due to fluctuating levels of risk and a perceived need for more assertive care. His case was

discussed during a joint case review meeting between the two services. 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 General Practitioner (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. His case was raised in the meeting due to the GP's concern that "that the medical management sits with her". The client had previously seen the GP to access medication prescribed by the psychiatrist. At this point the GP had not seen Sam in 4 months (failure to attend appointments) and conflicting reports existed as to whether he had in fact filled the script and commenced the medication. The GP was concerned as 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 leaves her is a bit in no man's land". Staff also discussed the need for all those individuals/services involved with the client to "sing from the same song sheet" in terms of Sam receiving similar/complementary messages. Multiple medico-legal, design and technology-based ethical implications are embedded in this scenario.

Design considerations

As in Sam's case, many young people encountered throughout the research presented with comorbid conditions which included multiple mental health concerns, physical and/or intellectual disabilities, 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 were struggling to support themselves financially. In addition many experienced restricted access, both financial and physically, to the internet. Given the profile of disadvantage and disability many mental health clients face, designs and technologies that assume specific levels of capacity, literacy or regular and reliable access to the internet will (unethically) exclude a large majority [17,18]. In the event that access is available, the nature of mental illness can mean personal capacity to utilize the technology is underdeveloped [17,18]. It is ethically appropriate that HCI not assume that technology is universally acceptable.

Mental health principles of recovery and independence support the notion of integrated models of health technology design.

People dealing with mental illness are capable of meaningful contributions. Mental health clinicians can act as gate keepers around which clients they view as appropriate for participation in research. Reciprocal working relationships built over time help to break down these barriers and open up wonderful opportunities for learning from all perspectives – that of research, clinical practice and client. Recognising, enabling and valuing these perspectives early on in a human centred design project can be of great value to achieving appropriate and ethical outcomes for clients in this space.

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