The ethics of eMental health in Australia's Western Murray Darling Basin

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eHealth for people in rural and remote Australia living with a mental illness is increasingly being recommended for treatment and support options. In a study of mental health service users and practitioners, the authors found that many of those encouraged to take up eMental health options were unable to afford the technologies required. Additionally, service users interviewed resided in areas poorly serviced by Internet networks, and often travelled long distances to access face-to-face treatment, rather than endure long waiting lists and the challenges of eHealth technologies. In this artcle, the authors use Wadhwa and Wright (2013), and Fisk and Rudel's (2013) frameworks for the ethical treatment of people with mental illness, in order to explore the challenges and benefits of using eMental Health in Australia's Western Murray Darling Basin.

There has been a mixed response to eHealth treatment for people with mental illness globally. Globally, telepsychiatry has been found to be useful in providing information and follow-up in conjunction with face-to-face treatment (Dijksman, Dinant & Spigt, 2013; Ennis et al., 2011; Jones & Ashurst, 2013). What little has been done in the context of rural and remote Australia similarly tends to focus on telepsychiatry (D'Souza 2000; Griffith & Christensen, 2007; Hawker et al. 1998). Some argue that eHealth is a reasonable approach to treatment for mental illness (Hawker et al., 1998; Rajkumar & Hoolahan, 2004). However, Judd et al. (2002) argued against the use of eHealth for treating people with mental illnesses.

Those who find that online eHealth is an appropriate way of approaching treatment for regional service users with mental health suggest it is worthwhile due to the difficulties implicated in travelling large distances (Burmeister, Islam, Dayhew, & Crichton, 2015; Griffiths & Christensen, 2007; Lessing & Blignault, 2001), follow-up and monitoring service user's once they are no longer in an acute state of illness (Jones & Ashurst, 2013), and where health practitioners are proactive about engaging with eHealth technologies (Wade, Eliott & Hiller, 2014). Still others only advocate for eHealth in order to keep accurate service user's records and only where such data bases can be monitored and managed by service users themselves (Ennis et al., 2011). Global research about eHealth in the mental health context has explored a range of areas. eHealth has been shown to break initial barriers of social inclusion for people with mental illnesses (Ryan, Clark & Dixon, 2013). However, it has also been argued that the unreliability of Internet connections and telephone networks makes eHealth a hindrance to becoming well (Wood et al., 2012). Thus, the general consensus is that forms of eHealth (including telepsychiatry and online treatment programs) in the treatment of mental health should not be used as an all-encompassing form of treatment in absentia of face-to-face therapy and support.

The measurements of the ethics of eHealth tend to be directed at the affordability, accessibility, service user's management and privacy of eHealth data, and service user's information (Wadhwa & Wright, 2013). While these models of ethical use of eHealth tend to be focussed on physical illnesses such as cardiac and diabetes monitoring, they are still applicable to the mental health context. Having said that, there is a growing body of literature that questions the nature of, and tries to seek solutions to, ethical problems such as privacy

for service users with mental illness (Burmeister, 2000; Burmeister, 2016; Carlson et al., 2015; Teipel et al., 2016). This literature does question the efficacy of current systems due to affordability and the risk to service user's privacy (Crichton & Burmeister, 2014; Burmeister et al., 2015; Spiranovic, 2015).

This paper argues that while there are some elements of eHealth that are useful in the monitoring of people's mental health in the Western Murray Darling Basin (MDB) region of Australia, the ethical considerations (especially affordability, accessibility, and effectiveness) need to be explored in much more detail. eHealth is arguably useful for monitoring and keeping in touch with people with mental illnesses when a service user's condition has been stabilised. However, our research shows that some service user's still do not find eHealth useful even for this purpose and prefer to travel vast distances for their check-ups and monitoring. Thus, the conundrum of eHealth for mental health in the Western MDB is this: while eHealth seems more reasonable and has had some success, there is still resistance to it amongst practitioners and service user's due to accessibility, affordability, and the effectiveness of face-to-face human contact.

Following on from the work of Wadhwa and Wright (2013), this article questions the ethics of adopting eHealth for mental health given that research about the impact on isolation of people with mental illness is inconclusive, the adequacy of privacy measures, whether eHealth genuinely enables and encourages service user's autonomy, and whether the harm that potentially arises from eHealth outweighs the benefits. Further, there is an ethical question of whether service user agency in access, choice and surveillance (as described by Fisk & Rudel, 2013) is being considered. This article focuses on the dominant ethical issues that arose for our research interviews with service users and mental health practitioners, in particular the issues of access and choice (as outlined by Fisk & Rudel, 2013). In our research, these ideas manifested as questions about the cost of technology, availability of

practitioners, and reliability of Internet services. Wadhwa and Wright's (2013) important question about the extent to which technology becomes a substitute for human contact, and the danger of isolation is also significant to the majority of participants in our research.

Some of these ethical questions have another side. The question of isolation and agency is taken up by some participants as a potential benefit as well as a potential harm. As shown below, our participants did speak of the positive aspects of eHealth in the treatment of and recovery from their illnesses. Similarly, the capacity for knowledge gathering and information sharing was significant and gave service users a sense of community.

This paper therefore draws on Fisk and Rudel (2013), and Wadhwa and Wright's (2013) frameworks of ethical conduct using those as a framework of analysis. In doing so the paper argues that before making eHealth the only treatment and follow-up option available to service users in rural and remote regions of Australia, analysis using ethically aligned frameworks such as those of Fisk and Rudel (2013), and Wadhwa and Wright (2013) need to be considered. Ethical and moral considerations including access, surveillance and affordability are considered below from the point of view of mental health service users and practitioners. We acknowledge that the frameworks chosen for analysis (Fisk & Rudel 2013; Wadhwa & Wright, 2013) are not theoretical frameworks in terms of being "an account of the world which goes beyond what we can see and measure" (Scott & Marshall, 2009, p.760). These frameworks are though ways in which interpretations of existing issues and considerations of appropriate service provision can be measured. Fisk and Rudel (2013), and Wadhwa and Wright (2013), are thus, conceptual tools with the capacity for interpretivist researchers to make assertions about the lived experience of, and ethical application of, eHealth service use in the mental health context. The research reported in this article is qualitative research informed by the interpretivist tradition (Neuman, 2000,

p.158). As indicated in Neuman's (2000, p.71) discussion of interpretivism, the point is to acknowledge and explore the subjective meaning of human behaviour and action. In our research, we have positioned interpretivist social science alongside ethical conceptualisation in order to explore the links between the subjective experience of mental health service users and practitioners, and the ethical implementation of appropriate services. In deference to the importance of the subjective experience in our work, it is important to make a short acknowledgement of the use of language. As part of our research design, we interviewed people who were in out-patient treatment programs for mental illness, people who are using available services to manage their illness regularly and people who use services periodically. Not all the services accessed by these participants or employing the practitioners we interviewed are medical services, and therefore the term "patient" does not apply to all. The authors have, in the interests of confidentiality and accuracy, chosen to refer to this group of participants as "service users."

The ethics of eMental Health and the tyranny of distance: Conceptual framework

The logic of suggesting eHealth for mental health management and treatment seems reasonable given the vast distances our research participants' travel. However, as we argue in the cases presented below, it is not the panacea it first appears. The research undertaken asked participants to indicate how far they travel to visit service users (in the case of practitioners) and to access services (in the case of service users). Many practitioners and service users are travelling up to three hours to provide or receive services. Some communicate with practitioners by email over a distance that would take 4 – 6 hours to travel by car. Some practitioners serviced an area the size of the Island of Bali (Indonesia). The ethics of travelling this far is (as noted below) found in the question of affordability. As Wadhwa and Wright (2013) note, the ethics of eHealth need to take account of affordability and accessibility of services in the physical

health context. Given that similar concerns have been raised by various studies (National Mental Health Commission, 2014; Pakrasi et al., 2015), such ethical parameters appear equally valid for mental health. Fisk and Rudel (2013) add another dimension in their assessment of the agency of service users. They suggest agency is a significant mechanism for enabling mental health, recommending the use of strategies that maximise choice and access, but work with service users about the level of surveillance they require.

Further, the remoteness and distance from major cities has meant slower Internet service upgrades so that many participants were still struggling to receive adequate mobile telephone reception let alone stable or affordable Internet services. The Australian Government services Australia according to population in need (measured by percentage of population). Thus, in rural and remote Australia the population is lower and the percentage of people in need of services is lower. Arguably the expense (travel costs as well as remote living subsidies) of sending someone to the regions prevents what we have found to be adequate face-to-face service provision for mental health in the regions. While eMental Health has been shown to be a useful concept for young people and in cities, older people tend to find that face-to-face treatment is preferable. In our sample, younger participants were happy to have been able to receive a text of support at a crucial time of day during an acute phase of their illness, and some older people were managing their illnesses with the help of their city-based therapists by email. However, most people were more willing to travel vast distances to make contact with a psychiatrist or other mental health professionals when they were becoming unwell or in the midst of an acute episode. Therefore we argue that eHealth has its merits in our sample region, but we are not serviced adequately by either telecommunications technology or face-to-face therapists. As will be seen throughout this paper, it is this inconsistency between availability, affordability, distance and

usefulness that constitutes criteria that should form the basis of ethical service provision for people with mental illness in our region. These issues are not being addressed by current service provision and are only noted superficially by Australian government policy.

Methodology

A qualitative investigation of mental health in the western MDB was undertaken. Utilising the interpretive methodology outlined by Neuman (2000), in which the importance of subjective experience is emphasised, this study used criterion sampling and semi structured interviews. There were two stages to the project. In the first stage, semi structured interviews with 27 mental health practitioners were conducted. In stage two, 13 semi structured interviews with mental health service users were conducted. Sampling in stage one began with Charles Sturt University's School of Psychology and contacts in local mental health service providers, and an invitation sent to potential participants through the University's community newsletter. Potential participants then made contact with the researchers, the participant information sheet was provided and a time for interview was made.

In the second stage a postcard sized information card was circulated amongst general practice medical clinics, posted on bulletin boards in Wagga Wagga and surrounding towns, and an advertisement was placed in the "Community Diary" broadcast by local volunteer run radio station 2AAA FM. Participants were asked to contact the key researcher and eligibility for participation was then judged according to age (all participants were over 18 years old), capacity to provide consent (all participants needed to be able to give informed consent without support), and current mental health status (participants needed to have been well for at least 6 months and be in contact with a mental health practitioner). Participants in this stage were also asked to keep a journal of their experience of use of telehealth services and use of other services. This paper uses only data from the semi structured

interviews because few participants completed the journal task to a degree that provided information that was not also collected in the interviews.

Approval was provided by the Charles Sturt University Human Research Ethics Committee. All interviews were analysed using thematic analysis techniques and voice sheets. In line with interpretive work that focuses on the subjective experience of participants, thematic analysis and voice sheets were used according to protocols described by Morse (2008). In this method of analysis, categories are developed using participants own words and language. Each voice sheet represents one category and includes all parts of the interview transcript from all participants related to that category. Initially service users and service practitioners were analysed separately. It became clear that some categories crossed the experience of both service users and practitioners. In terms of the ethical framework used in this paper, most of the categories in the analysis of the data emerged amongst both service users and service practitioners.

Analysing qualitative data using inductive methods can, once categorised, be further interpreted using existing research and evidence. Spicer (2008) writes of the iterative process in which qualitative analysis uses both inductive and deductive reasoning. This process involves moving from deduction by examining the existing knowledge, and induction using a similar process. The result of such a process is that interpretivist work will include discussions of data in which researchers move between participants subjective experience and researchers interpretation using existing knowledge present in published research. The discussion below makes use of this process.

This paper presents data collected during the course of this project, as well as informal follow-up conversations with some participants conducted in 2015.

The Western Murray Darling Basin: The site of investigation

The investigation that formed the base of the data collection and considerations for

this paper was conducted in a 1,000 km² area known as the Western MDB. This region was chosen due to the (recently phased out) scope of the Australian federal government's free health jurisdiction known as Medicare Local. In this region, two million people are resident. Australia's mental health rates tend to be around 30% of the population (with more known to be resident in rural and regional areas) and thus in this area we expect that (conservatively) around 600,000 people will experience mental ill health at some point in their life-time.

The current services available for face-to-face treatment include one resident psychiatrist (located in the city of Wagga Wagga), two psychiatrists who fly in and out from Sydney once each per week, and a number (no one could accurately tell us) of mental health nurses, private psychologists, and counsellors. Most of the mental health treatment work has been taken up by local general practitioners who act as temporary counsellors and supply referrals to psychologists, counsellors, psychiatrists and other appropriate service providers. There are two Emergency Departments (one in Griffith and one in Wagga Wagga – which are approximately 190 km apart) with facilities to conduct teleconference assessments with psychiatrists in Sydney in the case of service users presenting with mental illness.

In the Western MDB and the region known as the Riverina, the major centre of Wagga Wagga is home to approximately 63,000 residents. Wagga Wagga is located approximately 460 km south west of Sydney, 450 km north of Melbourne and 240 km west of Canberra. Many service users in our study were found to drive to these cities to see psychiatrists or consult with their preferred psychologist. They explained this was because it was more financially affordable and the waiting times shorter than accessing local practitioners, or because they had developed relationships with those practitioners before moving to the Western MDB.

Data Analysis and Discussion

In the analysis of the interviews conducted, there were some clear themes. The first was the expense of face-to-face treatment, as well as the availability of practitioners in the Western MDB. This challenge indicates a need for eHealth as a treatment and post treatment monitoring method. However, our participants were challenged by the expense and reliability of Internet connections and the technology required to access eHealth services, and so were more inclined to travel large distances than to access eHealth options (a second dominant theme throughout the research). Additionally, privacy concerns in the online space as well as the importance of face-to-face contact with other people make eHealth options less viable for people with mental illnesses. The challenges of living rurally and remotely position rural and remote residents at risk of social isolation. When those residents have mental illnesses with symptoms that include isolation and disconnection from other people, there is a greater risk to mental illness and chances of recovery from illness. Thus, eHealth can be a help and a hindrance to people with mental illness. In this paper, the term "recovery" appears many times. In academic research it is a contested term. Burmeister and Marks (2014) contend that to recover requires person centred, directed and appropriate servicing to people with mental illnesses. The outcome of this is a person with a mental illness who is a contributing member of their community who has a sense of self-worth and self-esteem. We do not wish to enter the debate about or engage with the recovery model as many have (see Carling, 1995 and Jacobsen & Greenley, 2001 for an extended discussion), instead it is sufficient to define the term "recovery" in the way that the service user participants did – to no longer be in an acute phase of their illness.

Finally, having established that eHealth is both useful and contains potential harms, we argue for a middle ground of sorts. To ethically mediate the effects of mental illness and take account of the challenges for rural and regional mental health service users and

practitioners, we argue that eHealth be used as a check-in, follow-up, and information distribution method rather than direct treatment.

The Challenges of Mental Health Treatment in the Regions

The expense of mental health practitioners. One ethical limitation is affordable access to health treatment. In Australia, we have systems that minimise the cost of treatment, however, many long term and ongoing illnesses require regular treatment that is not always covered by government rebates. Added to this is the challenge of attracting mental health practitioners to rural and remote areas. With a minimal number of practitioners and a growing number of potential service users, the cost of treatment can preclude service users from seeking the required support from professionals. Some have found face-to-face self-help groups useful (local support groups and online chat networks were some of the online services used by our research participants). However, when a service user needed regular monitoring, they were inclined to travel to major cities rather than pay the fees or endure the waiting list times in their local area. As one service user said:

> *It's actually cheaper for me to drive over to Canberra and see him, than to see any of the psychiatrists that are practicing here in Wagga. So ridiculous as it is, it's, yeah that sort of works out best financially. But I mean I drive for 2 ½ hours to get there, I have a 10 minute appointment with him, all he does is look at my bloods, order more blood tests "How are you going, everything okay?" "Good" "Yep see you later" that's it. There's no psychotherapy involved. So what [sic] would be something I could really easily do via video conference or Skype, anything like that you know, but I don't think he's up for that sort of technology... (Female service user, early 40s, ill-defined diagnosis)*

As this participant noted, she found it cheaper to travel and more convenient than waiting the time required by the local psychiatrist. This is one occasion where a service like Skype would be useful. However, as Wade, Elliot and Hiller (2014) found, such possibilities are only useful if the practitioner is willing to provide and engage with the service. For the service user above, the idea of video conferencing or Skype would have made a big difference, however the psychiatrist was not willing to use a telepsychiatry service. Later in her interview this participant highlighted a further problem she would have with this option, her rural Internet connections (even ordinary phone and mobile services) were unreliable. Thus, there are two issues here. The first issue is the willingness of practitioners to engage with technology, and the second is the reliability of Internet and phone connections in rural, regional and remote Australia. Another participant found email contact with her psychologist (a four-hour drive away) was useful because both parties (service user and practitioner) were willing to engage and make adequate use of the service, and she had face-to-face support from her local general practitioner. Thus, the non-availability of practitioners made travel necessary for many of our service user participants.

Availability of practitioners. Although there are a number of practitioners in the Western MDB, an interview with the CEO of the local General Practitioners Network indicated that there were many more vacancies than could be filled. In the Western MDB, this problem has delayed the recovery of some service users. As one participant told us:

> *It's not perfect at the moment because I can't get in to see a psychiatrist… it's a year waiting list. (Female service user, early 20s, severe anxiety)*

Concerns by practitioners were that people would need to move to major cities or better-serviced areas in order to access the necessary treatment.

> *I've already got issues where I've got a client who needs a psychiatrist and a clinical psychologist, and I can't*

access it here. This person will have to; probably move to Sydney to get help. (Provisional Psychologist)
the more likely you are to lower your inhibitions around accessing services where you think that there may be benefit to you so if you are convinced of the benefit to you of accessing help through video conferencing if that for instance is the only thing that's available or you have to travel 300 kilometres to get the face to face then you may be more likely to do that. (Psychologist)

Part of the ethical management of general health services for Wadhwa and Wright (2013) was the availability of appropriate services. With increasing migration to cities during a recent long and difficult drought (Kettlewell, 2010) the problem was further exacerbated. This migration is in part reasonable when work is hard to find. However, some people are connected to the land (especially families who have strong roots and Australia's Indigenous people whose identity is bound to the land of their ancestors: Ganesharajah, 2009) and this is not an option for all rural, regional and remote residents.

To be able to engage successfully with a practitioner in another town or in a major city without the expense of travel would be useful. However, as iterated in more depth below, this should not and does not preclude the need for appropriate face-to-face treatment. Thus, the availability of face-to-face treatment for mental health is as important as the availability of reliable eHealth technology.

Barriers to appropriate intervention.
The primary barriers to appropriate mental health intervention using telehealth technologies have been noted already. In this section the ethics of these barriers are more clearly outlined. In effect, the availability and security of telehealth is still tenuous. To provide appropriate services, governments and relevant agencies need to provide secure services that can be reliably accessed in rural and remote areas. Additionally, the isolation already part of rural, regional and remote

residents' experience needs to be addressed more purposefully and strategically in order to avoid any further exacerbation of mental illness. Isolation is a significant problem for people with illnesses such as depression and anxiety. eHealth has the potential to provide another means for both exacerbating isolation and providing an alternative means for engagement (Dow, et al., 2008; Edwards et.al, 2013). Thus, we have another conundrum – to offer technology at the risk of further isolation (as expressed by many practitioners interviewed for this study) and escalation of mental illness, or provide technology in order to mediate that isolation and provide a potential aid for recovery.

Telecommunications availability and security. Economic disadvantage is another ethical consideration. People with mental illness are frequently in the lowest socio-economic levels of society. In the discussions of availability and security of telecommunications technologies, participants highlighted the issue of the cost of technology. For some people with mental illnesses, work capacity is significantly hampered. Australia's social welfare system allows for some payment for living expenses and some subsidised medical treatment. However, at this stage, the cost of technology (computers, Skype, smart phones, and Internet connectivity costs) is not a subsidised expense for people with mental illness. Some devices are rebated for other health conditions (for example insulin pumps and internal defibrillators), but as yet technology is not rebated for mental health conditions. Therefore, as one service manager noted, some service providers are reluctant to prescribe eHealth options and some services are considering the installation of free access computers.

Skype would be a benefit but I do doubt that many clients would have the facility for that. Not a lot of clients have computers. One of our plans is to provide 2 computers out in the front room so that clients can come in and access those when they need to. (Service Manager)

The privacy of service users using a

computer to communicate with practitioners from a public access computer was not considered useful by service providers or service users interviewed. Participants expressed discomfort with public access devices because they were concerned about people accidentally or purposely seeing written communication or overhearing verbal communications. Thus, while the idea of public access telecommunications systems seems like a good idea, participants were more comfortable with the suggestion that these could be used for information gathering in a relatively private place (for example a booth or kiosk) rather than open access in a public space like a library or service provider's "front room". This may not be a problem for city residents, because of the idea presented by one family counsellor/ social worker below:

There still seems to be a real fear around being able to use not only the technology, but the confidentiality of some of that technology. Rural people and that are – are very much, very private; I find them more private than city people, and they're very concerned with the confidentiality and the privacy of some of the new technologies. (Family Counsellor/Social Worker).

However, the questions of privacy and confidentiality were raised by many participants. Burmeister et al., (2015) show that there is a way to mitigate such privacy concerns through centralised data, managed by a trusted agency. Ethically, the concerns of privacy and accessibility do need to be addressed. Fisk and Rudel (2013) argue that where service users do not have control over the information they share with practitioners, they feel overly surveilled. Similarly, Ennis et al. (2011) argue that service users should have control over their own information in order to be able to mediate some of the power relationships involved in medical interactions, as well as giving service users control over their own circumstances. Ethically, privacy is a very important

component of the potential for humans to exercise agency. Access and privacy therefore need to be considered carefully in the context of the implementation of eHealth.

The importance of human contact. Overwhelmingly, face-to-face, real time human contact was described as part of the process of recovery for the people with mental illnesses interviewed in this study.

In the last 15 months I've started to come out and do things and so I'm in a book club so I've got friends, that I didn't have friends before. So you can talk to them and they'll go, oh yeah I did that too and you're like, really oh good, that's normal then. So which is awesome because I've never had that. So I've you know got a handful of people that I can rely on... the person that I was married to was quite reticent and we were on a farm. (Female service user, 40-49, Personality disorder).

Similarly, a young girl's experience moving from a very small rural town to her family farm shows the strong link between mental ill health and social isolation.

I loved going to school, I didn't pick up a pen until the beginning of year 11. I didn't think I'd live long enough to use the information. I didn't care, I just went because there were people and I can't stress enough how lonely it was moving to the farm from in town and it's not like I saw many people when I lived in town. (Female service user, now 21, Depression/suicidal).

Building trustworthy relationships with other people as well as practitioners was important to those participants who had lived on farms away from towns. While both the participants above were happy to use technology in some circumstances (when the Internet connections were reliable and phone calls unmonitored) they both indicated that recovery began when they started communicating with other people face-to-face in real time.

So people, especially when they're suffering from illness and they've had a lot of difficult circumstances or if

traumas' involved or that face to face contact is often the first step to recovery and building rapport. (Mental health recovery support worker)

All the practitioners interviewed emphasised that face-to-face treatment in initial stages of an illness, and during acute stages of illness were more important than phone or other telecommunication. As Lu et al. (2014) found, face-to-face engagement with other human beings, adequate opportunities for building social capital within community (Bourke, 2003), and growing supportive networks of local people are critical to the recovery of people with mental illness and preventing the acquisition of mental illness.

Conclusion

This paper has covered some contrasting issues for the use of eHealth in the treatment and management of mental illness in the Western MDB. The area of eHealth for the treatment and management of mental illness is still in its fledgling stage. As researchers and scholars, it is important to continue questioning the ethics, politics and roll out of eHealth services. Consideration of technology infrastructure, ethical service treatment, the nature and importance of human face-to-face contact, and the nature of, treatment and management for mental illness in rural, regional and remote areas of Australia are important and ongoing bases for research. Other areas requiring investigation include telecommunications privacy, the uptake of technology by rural, regional and remote residents, as well as cultural implications of and treatment of mental illness in rural, regional and remote areas of Australia and globally.

We have argued above that there are some ethical considerations for the development of infrastructure (reliability and accessibility of technology, and agency of service users among those) that need to be taken into account in the development of mental health services. The participants in this study further outline some of the benefits to their mental health and provision of services by using eHealth. However, we must be aware of the current capacity for appropriate interventions and should not exclude the very real need for accessible and affordable face-to-face contact with practitioners and other people in the treatment, recovery and management of mental health.

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