

## Socially responsible emental healthcare

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### Abstract

*Mental health has long held a stigma that has made it difficult for people to seek help. Community-based socially responsible online interconnectivity and increased access are central themes underpinning the successful delivery of recovery orientated health care models and better mental health outcomes in regional Australia. An interpretivist study involving 27 clinicians and 13 clients sought to determine how future expenditure on ehealth could improve mental health treatment and service provision in the western Murray Darling Basin. A key implication of the study is that through the use of targeted ehealth strategies it is possible to increase both the accessibility of information and quality of service provision whilst returning best value to Government. Another is that connectivity through the use of multiple access points, such as information kiosks in community centres, have the ability to mitigate isolation, improve information flow and interaction, as well as mitigate rising costs.*

### Keywords

Youth, seniors, ehealth, regional, rural.

### INTRODUCTION

New technology is changing the way mental healthcare is administered and has the potential to increase access to services for people living in regional areas. However, its adoption and implementation needs to take place in a socially responsible way, in order to take account of the vulnerable nature of people suffering mental illness, and the social stigma that surrounds such illness. Mental health costs the Australian economy \$13 billion pa (Access Economics 2009), and those costs are increasing. Although multidisciplinary care approaches assist in the treatment of mental health (Paterson and Jones 2011; Roth 2008; Zwar et al. 2008), they tend to be clinic-based and largely inaccessible to people in regional communities. Recent school-based prevention programs involving the wider, local community have shown that the social stigma can be overcome and that young people can be encouraged to seek help early (Banes et al. 2013). However, more generally only 35% of those with a mental disorder receive any care for their disorder (Christensen and Hickie 2010).

Collective social responsibility is more than just new policy, it is about everyone pitching in to make a difference. Boston et al. (2010) described policy in ethical terms, even though philosophers debate whether group morality, including collective responsibility is even possible, as opposed to individual moral agency (Smiley 2010). But in the light of recent regional mental health initiatives (Banes et al. 2013) it has been shown that wider community involvement can break down stigma and improve access to services. That is, it is not just technology that brings about change, but collective social responsibility involving the wider community, is also helpful. As nations increase the provision of high speed internet access for the wider society, the possibilities for increased benefits to people suffering mental illness increases, but technology alone is not enough.

This paper explores the challenges of mental health service provision in regional Australia, from a collective, socially responsible perspective, following the results of a study that investigated how future expenditure on ehealth could improve mental health treatment and service provision in the western Murray Darling Basin (MDB). In particular the recovery versus rehabilitation approach is explored, and particular technologies that study participants proposed as a way to increase community support for people with mental illness. The study found that infrastructure considerations need to support face to face communication and need to be accessible, not only between professional providers, but across peer support and carer networks, to holistically support the social roles required as part of any recovery orientated approach. Yet however beneficial, ehealth was seen as a supplement to, rather than a replacement for, care, because technology alone cannot adequately mitigate against

the social withdrawal that is a frequent occurrence in the early stages of some mental illnesses, such as depression.

## MENTAL HEALTHCARE IN AUSTRALIA

The Australian government created the National E-Health Transition Authority (NEHTA) in 2005 to coordinate the implementation of e-health strategies. These strategies work on a number of features endemic to the national system. These are that information and communications technology (ICT) is underutilised in the health care system and its ongoing development has significant potential for both financial and health benefits, capable of revolutionising chronic health care. Australian health care has a multitude of providers all delivering services in their own way. A key understanding is that much of the technology already exists and thus most of the costs of ehealth are incurred by changing business practices rather than purchasing new ICT systems (NEHTA 2012).

Electronic patient record systems are particularly valuable to rural clients who frequently need to be transferred from small medical practices to larger regional ones. Since 2010, NEHTA has developed unique health identifiers for all clients, practitioners and Australian healthcare organisations and established the Health Identifiers Service (NEHTA 2010). Health identifiers are numbers assigned to uniquely identify healthcare providers and recipients, providing an important building block for the Patient Care Electronic Health Record (PCEHR) as they contain summaries of clients' health information such as regular medications, key elements of treatment history and current diagnoses, and provide a means for secure access to clients' eHealth records.

Whilst the creation of digital records may seem prosaic, the movement away from paper based recording is a significant leap for health care in rural Australia because of its ability to be shared across platforms and service structures. Clients also benefit through the ability to access and update their own medical records. Early and timely access to client information is expected to create increased efficiency because interventions and treatments will be more responsive and less likely to be subject to human error in diagnosis especially for those requiring emergency and acute care. Information sharing, thus inter-connectedness, is currently constrained by a largely heterogeneous health system delivered through a multitude of providers all working autonomously throughout the system. Digital records and ICT have the ability to embrace these differences. Rather than relying on a centralised model, it is capable of supporting flexible self-managed structures. This makes ehealth ideally suited to support management and governance complexity, capable of providing additional value-add both up and down stream as the sector grows. That said, a key inhibitor that differentiates rural and remote health services to its metropolitan counterparts, is the lack or absence of market forces, where competition is the exception rather than the rule and the small number of suppliers mean that economies of scale and scope are absent with health businesses tending towards monopolies rather than free markets (Global Access Partners 2007). There is a need in regional areas to mitigate access challenges, overcome isolation and the rising access costs due to time and travel. Thus the National Health Rural Alliance has called on governments to moderate and augment the development and implementation of tailored ehealth solutions through subsidies and investments to rural and remote Australia to ensure equity of access (Congress on National Health Reform 2009).

Considerable ignorance about the ehealth market and product offerings have been in evidence (Kambouris and Hine 2011), limiting adoption and recognition that there is an inherent conflict between scientific innovation and needs based development in the product design of ehealth. The working ehealth record as a technology push innovation is meeting latent needs (and benefits) that most users are not aware of. This can present significant challenges for the implementation of any strategy when the customer cannot understand or conceive of the benefit of a product because they don't know it exists or are unable to recognise its value.

## COMMUNITY CONNECTEDNESS: A RECOVERY ORIENTATED APPROACH

A recovery oriented approach has been adopted by the Australian Department of Health as a guiding philosophy, most specifically in the area of adult mental health. The concept of recovery is not new and has been used by people with a mental illness since the 1980s. The recovery model moves away from the service paradigm towards a community process approach where those elements long identified as part of the social determinants of health such as housing, education, income and employment are all seen as critical parts of the system to support the central person who in turn is given the power to select the resources they require (Bruce et al. 2012). The collective social benefits to the well-being of people within it have long been recognised in various areas (Burmeister 2012; Burmeister et al. 2012; Kimmmerle et al. 2013; Williams and Durrance 2008), including for the mental well-being of community members (Burmeister 2010; Carling 1995). Recovery emphasises the need for a comprehensive community based service system that works in a positive manner to address the full impact of mental illness and can best be described as: *the journey toward a new and valued sense of identity, role and purpose outside the parameters of mental illness; and living well despite any limitations resulting from the illness, its treatment, and personal and environmental conditions.* (Queensland Health 2005) Research supports that even people seriously affected by mental illness can and do recover and can be recognised as whole, equal

and contributing members of the community, with the same needs and aspirations as anyone else. As a result, basic elements of citizenship such as ability to live independently, form social relationships and access employment opportunities, need to be considered.

It is important to understand the philosophical differences between rehabilitation and recovery. On the one hand, rehabilitation refers to the services and technologies that are made available to disabled persons so that they may learn to adapt to their world. On the other hand, recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of the disability (Deegan 1988). The key consideration here is that recovery forms the basis upon which rehabilitation services can be developed, and therefore rehabilitation services should be considered as just one component of a comprehensive service system that collectively works towards the goal of recovery (SANE Australia 2001). Recovery is an extremely social process that involves being with others and reconnecting with the world. The notion of community integration is drawn from the larger disability and civil rights movement and is founded on a belief that all people have a right to full community participation and membership. Regrettably many individuals still face substantial stigma and discrimination, and it is also common for individuals to accept and internalise these negative stereotypes. It is important that people with a mental illness are recognised as whole, self-determining persons, able to make choices, take responsibility, live with consequences and exert control over their own recovery process (New Zealand Mental Health Commission 1998; Queensland Health 2005)

## METHODOLOGY

In order to understand the nature of mental health services in rural Australia, an interpretive study utilising qualitative techniques to interpret meaning and to analyse participant understandings was undertaken. The methodology was informed by Schwandt (2003) who argued that such a process helps to explore how people in a particular social context interpret mental health services and reveal meanings that constitute those perceptions. Interviews were conducted with mental health service users and practitioners in the western Murray Darling Basin (MDB) region of NSW between November 2011 to July 2012. The key question for this study was “What mental eHealth services will best meet the future needs of the western Murray Darling Basin?” The interviewees were chosen on the basis of criterion sampling based on age, location, and length of experience, in order to give an understanding of professional experience across the region. The sample size of practitioners was limited to 27 participants spread geographically across the area of the western MDB. Sampling of mental health service users reached saturation after only thirteen interviews when it became evident a limited range of servicing patterns were present, with no new data emerging very early in the interview stages of the project. Ten of the thirteen participants recorded their mental health servicing experiences over a period of one month (30 days), which was used to support and provide depth to consumer perceptions and analysis.

The study was conducted in an area of Australia where service providers cover large geographical territories. Additionally, Australian government funding has meant that there are limited numbers of mental health practitioners and only one psychiatrist living in the area. Thematic analysis of participant views led to seven themes including age group, support networks, mental health services, mental health illnesses, information seeking, e-health and community perceptions.

## FINDINGS

Interviews for both stages of the study found that the advent of telemedicine has had a positive effect on rural hospitals and has improved capacity for mental health services especially through access to specialist mental health advice. As a result funding and policy changes should continue to build upon this success across the MDB to broaden this reach.

### Telemedicine: a capacity builder for community connectedness

Interview data suggests that mental health services providers outside the hospital environment would also benefit from telemedicine type access to specialist services without having to refer clients to already overworked hospital services. Providers outside the hospital setting complained about the lack of mental health services right across the western MDB, as seen in the following exemplary quotation: *There is a real lack of appropriate services and a lot of people go untreated and undiagnosed because there aren't the services on the ground ... So teleconferencing has been discussed but it's about the infrastructure, and technology and things which we don't have the capability for at the moment.* (Psychologist)

It should also be noted that telephony services such as Accessline were working well, thus telemedicine is a capacity builder for community connectedness. Telemedicine also has benefits for consumers of mental health services. There is increasing evidence that internet-delivered treatments are effective, efficient and cost-effective for anxiety (social anxiety, panic disorder), depression, post-traumatic stress disorder, eating disorders, and

obsessive-compulsive disorder, using cognitive behaviour therapy, psycho-education and/or exposure techniques (Georgantzi and Gheno 2012).

### Community-based service access

Economic disadvantage was a frequent occurrence. One single parent with an adult child suffering severe mental illness lamented the lack of access to basic services, such as the dental care they needed. Faced with such basic needs, it is little wonder that mental health recipients frequently cannot afford the technology that would give them access to the services they require. One of the recommendations from a service provider in Griffith was that information kiosks with privacy booths be installed in rural community centres or meeting places. This would serve to decrease the inequitable access challenges faced by rural consumers compared to their urban counterparts. Furthermore, the local community would need to ensure its maintenance, and technical support. Although this is an initiative that has merit, there is still the social stigma to overcome for anyone using the device, particularly in small rural communities, where everyone will soon know that a particular person has been making use of the mental health information kiosk. A publicly available communication kiosk that affords privacy to the mental health consumer would permit a level of virtual face to face contact that is not currently available to rural people in the western MDB.

### Community connectedness mapped in real time

The study highlighted that in a regional context, there is a need to improve practice for some service providers whose staff travel regularly in rural and remote parts of the region. Infrastructure such as GPS, Smartphones or tablet computers can better support the capture of data 'on the road', which in turn increased accuracy, relevance and quantity of information sharing. Such views are demonstrated in the wide-spread comments of service providers across the western MDB, only a few of which are reproduced here:

*The majority of my clients are in Leeton at the moment. I have a client in Hay, Hillston, Goolgowi. Yes more that way – just thinking where else – Yanco which is practically Leeton. ... I've got clients in Barellan. I have had clients in West Wyalong, ... Narrandera ... Ardlethan. ... Hay is like a grey area, the case worker in Deniliquin normally services Hay, but if he's a bit overwhelmed then I pick it up. (Case worker)*

*Phone counselling is a significant part of my work, I would suggest, probably it could be as much as 40% because I spend a lot of time in the car, so it gives me a great opportunity to be able to speak with clients on the phone. (Social Worker)*

*My role's an area role so part of my area is Deniliquin, so my area's bordered by Hay, Narrandera, Deniliquin, so it's a really big geographic area. (Clinical Nurse Consultant)*

The above quotations illustrate only part of the challenge of servicing mental illness in regional areas. Not shown are the frustrations of arranging to meet clients, driving long distances, and finding they are not there. Sometimes due to their illness, such as an inability to get out of bed or out of the house, other times for other reasons. Service providers also told of the lack of funding, such that even GPS was frequently not available, meaning that in remote areas, clients were difficult to locate. Yet another challenge was that services regularly change, as government funding priorities change, as services move location, merge with others, or go out of business.

One service manager addressed the need to help people like herself to locate other services that can assist clients. She found it difficult to keep track of complimentary services, to whom she might refer clients. She envisaged an interactive map of Australia that could be accessed by service providers and clients: ... *updated regularly to resources that are relevant to every area ... I'd really like to see it just mental health specifically. But like I said if you're looking at say Broadmeadows in Melbourne, what mental health services and what support groups and what is there out there for that area? Because people in, for example, the person in that area doesn't even know what's there. ... So how can I find out too, without exhausting energy trying to locate stuff and you don't even know where to look. ... You click on NSW and then you can click on Riverina and you click on Griffith and da, da, da. Community Mental Health comes up and to get them you've got to phone access line which is this, Personal Health and Mentors Program is there and this is what it is for. ... That's for Carers and Families through Schizophrenia Fellowship and just have it simple and comprehensive.*

Such an interactive map of community services has the potential to be a key resource for achieving the better coordination of services across regions. The potential for an interactive internet based map for professionals who travel frequently could add significant benefit to referral accuracy and service response times especially in relation to associated or complementary services. For many personnel, the study highlighted that they were not aware of what complementary services, if any, were available to clients, especially when visiting the more remote locations and small towns.

## DISCUSSION

Although this study was restricted to one particular region of country New South Wales, the western MDB, the implications arising from this study are transferable to other country settings. For the majority of people treated in the western MDB, the high prevalence mental illnesses common to the nation are also such in this region. Furthermore, the challenges faced in this region tend to arise at an early age, which is supported by an OECD (2012) report, which identified that the focus of infrastructure and servicing should go to youth and young adults, to high prevalence mental illness and to early treatment.

Many regional communities rely on the interdependency within the family and broader community, where it is essential that the family is involved and plays a primary role in any treatment. It should be noted that the further west one travels in the western MDB, the higher the percentage of indigenous residents. Whilst the concept of recovery is also complementary to Indigenous practices and heritage, it is important that service providers recognise the historical context that uniquely frames the Indigenous experience (NSW Department of Health 2006).

### Community support

One of the social implications from this study relates to overcoming isolation through supplementing, rather than replacing, physical face to face contact with virtual contact. A critical success factor for the recovery process is a positive practice culture adopted by those who provide service and a focus from the illness to the person to concentrate on strengths rather than weaknesses (Jacobson and Greenley 2001). This goal cannot be reached solely through professional services and the literature makes frequent reference to the importance of family, friends and peers who believe in or stand by the person through their recovery process and these people do not need to be professionals (Buckley et al. 2012).

Study participants gave multiple examples of, particularly depression-related, isolation being exacerbated by rural life. It is too easy for a male farmer to isolate himself, without anyone noticing. Similarly, children growing up on farms are socially isolated and disempowered to do much about it. Urban children may have Internet contact with others, or can simply step outside their home to see people. But a child growing up on a farm typically may have no Internet connection, or at best a very poor one, and their social contact can be limited to school attendance. In addition, children within farming communities are an integral part of the workforce and when combined with school travel time (such as over an hour each way by bus), have less 'free' time than their metropolitan counterparts for usage of internet and related communications. Correspondingly, face to face contact is often limited to adult farm workers and their own immediate family members, compounding this isolation.

An almost universal view amongst the regional and rural mental health professionals interviewed was that virtual contact can at best be a supplement. People need to be removed from the environment that is contributing to their mental illness, and therefore virtual contact that only takes place on an isolated farm, is insufficient. Thus ehealth in this context is an aid, but not a complete solution to overcoming rural isolation. For many, relating with peers is an extremely valuable form of connection. This can be through peer delivered services, advocacy or the sharing of personal stories of recovery. One study correlates the size of people's social support networks directly with the success of the recovery process, establishing the importance of interpersonal relations in this process (Young and Ensing 1999).

Similarly, several studies emphasise that people with a psychiatric disability usually have social networks roughly half the size of the general population and are less reciprocal in nature, as they are more likely to contain family rather than peers. It should be someone who can be trusted to be there during times of need and this impact cannot be underestimated (Carling 1995). The ability to create these social connections as limited social supports have been found to be important to recovery, and 'the absence of social supports is associated with increased psychological distress' (Wilson et al. 1999).

### The focal point of community support: The GP

The general practitioner (GP) is most often the first point of contact for people with mental health and their families. Over 80% of individuals visit a GP with low prevalence disorders (Jablensky et al. 1999). As a result the current model for the delivery of mental health programs for treatment is in partnership with existing primary care or local general practice systems (Christensen and Hickie 2010) or through a virtual clinic environment supervised by health professionals (Andrews and Titov 2010). However given the current bottlenecks due to the undersupply of GPs across the western MDB, it is important that treatment delivery models be expanded to allow automated or self-help interventions to genuinely reform access.

More needs to be done to provide additional capacity to the support networks, especially carers, with information about how they can improve their own care giving. In part this is a policy issue, in that carers are frequently excluded from the consultation between the medical professional and the client for confidentiality reasons and as one participant pointed out, Medicare only directly funds the consumer. As GPs participating in the study pointed out, often the carers, aside from needing to be better informed about how to provide care, also need to see professionals as the lack of respite in care giving, especially in remote settings, can create its own health issues, placing carers at risk due to the many pressures that the burden of care places upon them. This is compounded in rural and remote settings where there is poor access to other support systems such as quality respite, and environmental factors such as the inability to escape isolation in many rural settings (the farm) which traps the carer, their families and persons with a mental illness in a perpetual cycle.

## CONCLUSION

The study reported here was an interpretive investigation conducted from November 2011 to June 2012 across the western MDB. The findings highlighted a range of unique factors where ehealth provides the potential to play an important role community connectedness. There is support for the view that the recommendations arising from the study, particularly a community-based information kiosk and an interactive map of currently available services, can be transferred to other regional and rural contexts, because of the similarity of issues especially in relation to social isolation, geographic distance, labour shortages and the impacts of these factors on access and connectivity. The recommendations pay particular attention to connectivity and the ability of technology to overcome both physical and social barriers in relation to mitigating key factors that contribute to poor mental healthcare outcomes.

Yet technology alone is not a solution, because the recovery process necessarily involves community social interaction. The recovery concept involves a cultural and philosophical shift that affects every level of service delivery and the shift away from the concept that people with a mental illness are incapable of making decisions. This comes with its own unique set of ethical issues regarding privacy and confidentiality. Issues such as the concept of coercion through involuntary hospitalisation and treatment, and conflictual values, require a balance between affirming the rights of the individual, ensuring decisions are arrived at competently and do not involve serious risk, and that interventions are not derogatory or seen as punishment. Thus recovery and therapeutic relationships should not be endangered by unnecessary patient supervision and coercive models of care (Rudnick 2002; Stern et al. 1999; Szumukler et al. 1999 ). There is a need to implement holistic solutions, which aid the recovery oriented approach, and which go beyond episodic care, to incorporate a person centred approach that extends beyond the patient and is capable of including peer and carer support. Not least is the opportunity and recognition that technology is capable of providing hitherto unparalleled support, going where traditional medicine cannot, especially in relation to its ability to support the creation, development and maintenance of those social roles that are seen as critical to ongoing recovery and meaningful contribution, both at the economic and social level, for any person with a mental illness.

This study evidences that if successful ehealth and telemedicine practices are broadened beyond the acute hospital environment there is significant potential to not only support but increase provider contact because of its ability to overcome the digital divide and the tyranny of distance. A combination of both face to face and digital access, as part of any ongoing management planning process, has the ability to not only support better quality of access, but increased access in itself. A recurring note throughout the study was the chronic shortage of skilled labour that was expected to be ongoing. The ability of ehealth to stretch the reach of these critical resources cannot be overstated.

There was an almost universal view amongst the mental health professionals interviewed that virtual contact can at best be a supplement. People need to be removed from the environment that is contributing to their mental illness, and therefore virtual contact that only takes place on an isolated farm, is insufficient. Thus ehealth in this context is an aid, but not a complete solution to overcoming rural isolation.

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