

Stories of Recovery

FROM THE BUSH

Unravelling the experience of mental illness, self and place

RESEARCH REPORT

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*Stories of
Recovery*
FROM THE BUSH
Unravelling the experience of mental illness, self and place

This research report was launched at Fairview Artspace,
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Report: <http://handle.uws.edu.au:8081/1959.7/uws:35379>

Catalogue: <http://handle.uws.edu.au:8081/1959.7/uws:35492>

WARNING ABOUT IMAGES

The researchers warn Aboriginal and Torres Strait Islander people that this publication may contain images of people who are deceased. We do not wish to upset or cause distress to living relatives and community members

ABBREVIATIONS

ATAPS	Access to Allied Psychological Services
ATSI	Aboriginal and Torres Strait Islander people
MHCC	Mental Health Coordinating Council
Neami	North Eastern Alliance for improving mental health and wellbeing
PHaMs	Personal Helpers and Mentors service
PIR	Partners in Recovery
ROSSAT	Recovery Oriented Service Self-Assessment Toolkit

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SUMMARY

This whole illness is a journey – it's a road that never really ends but it can get smaller and the pain can get less as you go on (P 19¹).

A major mental illness will be experienced by almost half of the Australian population during their lifetime (ABS 2007). People with mental illness are at greater risk of poor physical health, co-morbidity and decreased life expectancy (Harker and Cheeseman 2016). They are also more likely to experience suicide, social isolation, discrimination, homelessness, and unemployment (Lee et al 2013). Those living with severe and persistent mental illness are among the most disadvantaged and stigmatised in society (Henderson, Evans-Lacko and Thornicroft 2013). The Partners in Recovery (PIR) initiative aims to better support people living with severe and persistent mental illness by providing a more co-ordinated system response to their mental health needs (DoH a). However, community-managed mental health organisations are 'not well described in current data collections' (AIHW 2014:386) which implies that what they do and how effective they are may not be well understood.

As can be seen from the data cited above, dominant cultural stories about mental illness tend to be problem-centred. They speak of burden, difficulty, hopelessness and sometimes death. The *Stories of Recovery* project aimed to uncover less dominant stories to learn more about what works in the service system and wider community to support people experiencing severe and persistent mental illness. Twenty six participants of the Western NSW Partners in Recovery (PIR) program contributed to this study. In qualitative interviews people were asked how their identity, relationships and experiences of social inclusion are shaped by their lived experience of mental illness; how that lived experience is impacted by living in regional and rural NSW; and what they have found helpful and supportive in their recovery journeys. The research was funded by Marathon Health and conducted by Western Sydney University in partnership with The Benevolent Society.

The aim was to learn more about what works in the service system and wider community to support people experiencing severe and persistent mental illness and who have complex needs. In doing so, the project uniquely brought together the principles of recovery, trauma-informed practice and collective impact to inform the design and conduct of the research. Participant's knowledge and experience was made the centre of the research through the use of visual research methods. The photovoice methodology provided participants with a means of creatively exploring the research questions so they could tell *their* stories of re-

covery and living in the community; explore *their* experiences of the service system; and, more broadly, tell us what works to support people on their journey.

Overwhelmingly, the research findings provide evidence which supports the Recovery model. These findings are articulated under four key themes that demonstrate the centrality to wellbeing of: connections and belonging; skills of survival and resilience; contributing to the social fabric; and person-centred services in both clinical and non-clinical settings. The findings provide unique perspectives offering innovative possibilities for policy development and service provision. In particular the findings enlarge current understandings of connection and social inclusion to include nature, animals and family history, however troubled that may be. While supportive of the recovery model the findings also call for increased community capacity building; a focus on measuring the recovery practices of a service rather than client outcomes; and working towards minimising the clash of cultures people often experience as they move between clinical and non-clinical settings.

Our findings also support a move away from a deficit approach to people experiencing mental illness. The data demonstrates they contribute to social capital in communities and families through the ups and downs of illness. Highlighting this could significantly contribute to reducing stigmatisation and discrimination.

Furthermore, the findings show that the inclusive and creative research design enhanced a sense of positive identity for the participants who spoke about what they believe is necessary, important and sometimes unhelpful from service providers. The knowledge that a person is making a contribution to improving service provision and challenging stigmatisation can, in itself, be a contribution to their wellbeing. Most powerfully the findings show that participants want the opportunity to tell their stories and be heard: the positive impact of this on wellbeing, regardless of complexity of illness, cannot be overstated.

Based on the findings generated by the *Stories of Recovery* research, this Report makes clear and achievable recommendations for regional communities and service systems to better support people experiencing severe and persistent mental illness.



¹P1, P2 etc. refers to the research participants. The numbers correspond to the order of interview. The authors recognise that using numbers is not a relational way to speak about people. However our concern was to protect people's identities fully in terms of who said what.



OVERVIEW OF KEY FINDINGS AND RECOMMENDATIONS

KEY RESEARCH THEMES

The research findings are organised into the following themes which are fully detailed in the 'Findings and Discussion' section beginning on page 14:

Theme 1: Connection and Belonging

For the people in this research *being connected* was as fundamental to successful recovery as clinical and non-clinical services and supports. Connection is well known to be important to recovery, a positive identity and wellbeing (Glover 2012; Hsu and Kjoller 2011). However understandings of connection are often restricted to social connections and belonging to groups. This research demonstrates that connections to nature and wild places, animals, personal histories, family and spirituality are also essential to recovery and wellbeing: *I belong out in the nature – I love that – and I love being there (P1)*. Data also indicated that a connection to the broader social fabric, place and history was fundamental to a person's ability to cope, and seek support at times of need. History was also found to be important to identity development and belonging no matter how traumatic or difficult: *I just want something' to keep goin' in the family 'cos all our family suffers from depression (P3)*. The integration and acceptance of a person's history, both by clients and service personnel, is key to the recovery journey. Having responsibility and taking care of something other than self was also central: this could be friends, family, animals or gardens. A wide variety of connections are central to a person's positive identity and feelings of belonging and acceptance.

Theme 2: Learning to dance in the rain – survival

The research data revealed powerful stories of loss, grief, stigma and struggle. It was apparent that people were no longer shocked by their own stories of abuse which had become normalised or expected: the stigma was internalised. There were numerous stories of deaths: *My life really fell apart when my dad passed away four years ago (P17)*; familial separations: *my baby is one now and he probably won't remember me*

(P6); loss of jobs and careers; loss of housing and security; experiences of violence and abuse. For some the struggle to be heard and taken seriously was the hardest struggle of all. At the same time, there were also stories of hope and renewal. For many participants the losses and struggles they had experienced provided motivation for making changes to their lives: getting educated; finding work and housing; learning how to budget; and manage their illness: *I'm trying to get into things ... and all that to get my kids back... all the services I need, all the courses at TAFE I need, all the other medical things I need (P6)*. Almost all participants spoke of life-changing pivotal moments and actively developing their identities in positive and self-determined ways. Many participants embraced self-discovery, learning and creative activities of various types, some of which act as a means for relationship building, social connection and identity beyond mental illness. There was a strong theme of perseverance and acceptance: that life may always be a struggle but that having dreams, setting goals and accepting help were beneficial and contributed to people moving forward.

Theme 3: Contributing to the social fabric

The main story in the literature about people living with a mental illness is one of their needs: their need for services, for medication, for programs and for help and support and/or the financial cost to society (NMHC 2014 for example). There is less said about how and what people contribute. The participants in this research were very clear about what it is they have to offer and how they contribute in many ways. They position themselves as active and contributing members of networks of relationships: *There's a fair few people at home who need to be introduced to each other and are interested in music and I'm hoping to help get them together and maybe even join myself (P2)*. People contribute to the social fabric through working, volunteering, caring work and sharing their knowledge and experience. Reciprocity was important to people: they believed that they had something to offer that was useful. The collective and individual benefits of participation in, and engagement with, the local community or society in general are well accepted and

range from increased health and well-being to decreased crime rates. Indeed, social relationships are as vital to our well-being as food, shelter and cleanliness. Social capital is the most commonly used term to reflect these collective benefits. However, when talking about people living with mental illness it is generally assumed the relationship goes one way: that social capital is a resource to be used. The data challenges us to move away from this deficit approach as people provided many examples of their contribution to social capital in their communities and families through the ups and downs of their illness.

Theme 4: Service provision - what works and what doesn't?

Participants reported that access to, and support from, staff with a lived experience of mental illness working within mental health services is essential to service accessibility and engagement: *Because you're meeting people out there hasn't got a mental illness and they don't understand. The workers know... They understand about how we feel and what we go through and stuff like that (P17)*. The services people spoke positively about were operating from a recovery oriented practice framework. They were clear that recovery is a journey not an end point and key to this were services which maintained hope that people with severe or persistent mental illness and complex needs could attain a better quality of life, despite the fact that they may never fully recover. Participants wanted staff to understand the support needs arising from social isolation, complex experiences of grief and loss and the impacts of violence or abuse. The data showed it was important that clients and providers worked together towards goals; respectfully discussed options and choices; and that clients were seen and listened to as whole people: *If it was something and I was really, really bad they'd work towards getting a solution for me, some way to help myself (P22)*. When participants' were not treated in this holistic manner they expressed frustration and pain. The data also indicated that participants were often negotiating different cultures across service settings, which was at best frustrating and at worst placed them at risk.

RECOMMENDATIONS

This research provides clear, consumer led, evidence of what works for people living with a mental illness in regional and rural NSW. At a time of significant system change we make the following recommendations to incorporate this data into policy development, service models and foci across clinical, community and mainstream settings:

1. Core principles of the Partners in Recovery model be maintained and expanded to include trauma informed practice across all service settings.

The research demonstrates that to support people effectively and enhance wellbeing, services must put policies and practices in place which enable people to be understood and treated holistically. This includes understanding that people are embedded in, and contributing to, the broader social fabric. People who have a mental illness are social actors with complex identities living within a web of complex relationships. Their illness is only one part of this. Recommendation 1 can be achieved by:

- a. Applying a 'no wrong door approach' to all services' models including an information exchange process, with consent from consumers, and the employment and training of key service personnel who have the ability to negotiate and approve flexible, person-centred, decision-making processes.
- b. Recognising the cultural clash existing between holistic person-centred and illness-centred approaches to service provision. Conversations between clinical and non-clinical services need to be facilitated to close this cultural gap where it exists.
- c. Maintaining and expanding the employment of people with a

lived experience of mental illness in both clinical and non-clinical settings. People with lived experience could be utilised as cultural bridges, advocates and translators between services and community.

- d. Developing a stronger focus on community capacity building and a networked approach to care plans. People are already, to a greater or lesser extent, embedded in communities, places and relationships. These could be further exploited and developed by building community resilience and compassionate communities.
 - e. Measuring the Recovery orientation of staff and services through tools such as the ROSSAT (MHCC), not relying only on measures of service outputs and recovery outcomes for people using services. This embraces a human rights perspective to 'recovery' and removes the individualised and illness centred approach (Forrest 2014).
 - f. Expanding systems and procedures which incorporate co-design and consumer input in service and policy development. The role of peer workers and volunteers could be increased to facilitate this. Focus on enabling choice, control and opportunity plus relationship based service provision.
 - g. For people with multi-layered experiences of grief, loss, abuse and stigmatisation, providing care embedded within relational frameworks that are sustained, trustworthy and reliable. The strength of these relationships and the effectiveness of recovery oriented service provision which focuses on collective impact must be at a minimum safeguarded during the changeover to a new, individualised funding framework.
2. **Increase service impact and outcomes through broadening definitions of 'connection' in policy and practice to include nature and wild places, animals, spirituality, personal and family history and memorabilia.** Recommendation 2 can be achieved by:
- a. Service Providers understanding that personal and family history and memorabilia are important to a person's wellbeing and identity, regardless of an individual's past experiences such as a child trauma history.
 - b. Service providers in both clinical and non-clinical settings increasing the use of animals within the service environment by: having residential animals in acute settings, or having animal visitors; implementing a pets as therapy programme; supporting people to foster or adopt animals; linking people with animal care services to volunteers; or linking pet owners with non-pet owners to share responsibilities such as walking the animal.
 - c. When crisis planning, integrating a crisis plan for dependents and animals in a person's care. This includes working with a person when they are well to prepare and plan ahead for the care of dependants and pets should there be a crisis including gaining relevant consents and developing a communication alert system for appropriate authorities and services.
 - d. Reforming services to better utilise space and place to enhance service quality through: incorporating 'place based' activities into the more traditional psycho-educational programs offered across service settings; applying flexible service delivery which incorporates options for individual meetings to take place outside; and providing accessible gardens and green spaces in service and hospital settings.
 - e. Undertaking the development of virtual services with caution and flexibility to accommodate people who have limited access

to newer technologies; or those who do not have the skills or confidence, or a preference for, using such technologies. Access limitations in regional areas such as limited phone reception and internet access must be taken into account when developing technological solutions in order to improve service provision and access. Services must be designed so that people with access barriers are not disadvantaged.

3. Regional communities are a part of the solution to reducing stigma and discrimination towards their citizens. As such, they can take a greater responsibility for their role in developing tolerance, acceptance and belonging for people living with mental illness. Recommendation 3 can be achieved by:

- a. Councils, community businesses and groups seeking training and support in inclusive practices. This could be embedded in council social planning and chamber of commerce procedures and guidelines, for example.
- b. The development of a system of community safe places such as hairdressers, butchers, cafes, banks etc. where people with a mental illness can go, knowing that they will be treated with respect.
- c. Building on current capacity by celebrating and acknowledging the role of carers and the families of people with a mental illness. Further developing avenues where carers can share their knowledge and skills in community settings.
- d. Services working with organisations and community groups to provide opportunities for people with a mental illness to join activities, groups, and organisations which are not mental illness specific, thus increasing inclusion and reducing stigma.

4. Further develop and prioritise systems, procedures and opportunities for service users, no matter how complex their needs, to speak and be heard; to be treated with respect and dignity. Recommendation 4 requires a values shift and can be achieved by:

- a. Understanding that people who live with mental illness have capabilities, strengths, resilience, insight and wisdom. The people in this research were not passive recipients of services and their mental illness, while at times may be severe, was not their whole story. While people may need symptom control, for example, this needs to be done in relationship with them as self-determined people.
- b. Services developing a culture of trust. Service users have a high degree of expertise in their own lives and their own illness. This expertise should be sought and valued when care plans are negotiated. The tensions between duty of care and dignity of risk

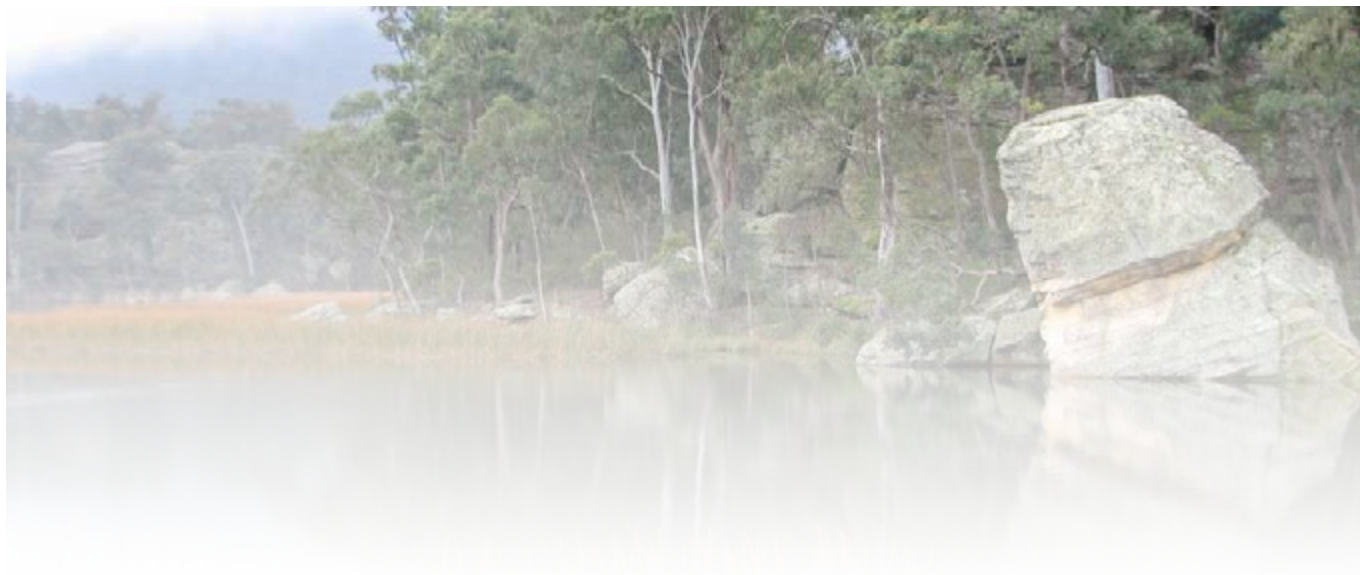
must be discussed with service users at intake and throughout the care relationship, even when this conversation is difficult.

- c. Services strengthen their privacy culture and compliance to ensure that service users are in control of their own story, and respecting that a person's information belongs to them is at the forefront of services. An individual can choose when and how to share their information unless, in extenuating circumstances, duty of care prevails.
- d. Services reconsider information collection procedures to ensure they are applied through a trauma informed lens; putting the person's voice in the centre; minimising re-telling history and experiences that are unnecessary to the current service provision and collecting only enough information as is required for service provision.
- e. Providing ongoing, systematic opportunities for people to provide feedback to service providers to shape policy and service development where people receiving the service are conceived as major stakeholders whose opinions matter. The data clearly demonstrates that people living with often very complex illnesses are capable of stating what works for them, what they need and what their hopes and aspirations are.

5. Three areas for further research are strongly suggested by this current project:

- a. Mapping the 'missing middle' in mental health service provision through uncovering what works well from the perspectives of the clinical and non-clinical workforce across a broad spectrum of mental health services in rural NSW. This would lead to: 1) better service implementation in a regional and rural service system that has been criticised for its inability to adequately work with people between intensive clinical support and social support – i.e. the 'missing middle' in mental health; and 2) influence future service design.
- b. Expanding the current research to include a comparative study in other regions and states with a focus on remote and urban areas to explore if and how the findings of the current study resonate nationally.
- c. Developing the recovery informed research methodology piloted in this study, to further explore sense of place and the centrality of companion animals in the recovery journey. In this way there will be congruence between what is being researched and how it is being researched. This combination of methodology and a focus on place and animal led recovery practices is potentially ground-breaking.





BACKGROUND

Australia began to orient its mental health policy towards the community-based recovery model to address the prevalence and costs of mental illness. A trend already apparent in England (Perkins and Slade 2012), this framework for supporting people who have severe and persistent mental illness is holistic, socially inclusive and process-oriented. It aims for a policy culture embedded in the ‘lived experience and insights of people with mental health issues’, prioritising their knowledge and experience, as well as that of their families and support networks (CoA 2013). Indeed, the very concept of recovery was ‘conceived by, and for, people living with mental health issues to describe their own experiences and journeys and to affirm personal identity beyond the constraints of their diagnoses’ (COA 2013). Although the recovery model reflects a shift from traditional crisis and clinical interventions, these still predominate in the delivery of mental health services.

While best-practice policy frameworks emphasise prevention, early intervention, self-determination and community-based approaches, Australia still relies overwhelmingly on acute, hospital-based care for the treatment of people with mental illness (NMHC 2014; NMHCCF 2012). The National review of Mental Health recommended a shift of funding priorities from hospitals and income support to community and primary health care services (NMHC 2014). The majority of mental health servicing takes place in one-to-one clinical contexts in government-run health department community and hospital care settings referred to as ‘community mental health care’ (AIHW 2015). This is now accompanied by government subsidised psychology services whereby GPs are able to refer individual consumers to private mental health professionals who deliver focussed psychological strategies under the Access to Allied Psychological Services (ATAPS) scheme.

In a complementary and growing structure it is “specialised community support services provided by non-government organisations” that have taken up the Recovery movement’s socially inclusive and consumer-led philosophy (AIHW 2014:386). The Partners in Recovery (PIR) initiative aims to better support people living with severe and persistent mental

illness by providing a more coordinated system response to their mental health needs (DoH a). Key principles include: services are recovery oriented; have flexibility in roll out; are complimentary to existing service systems; and result in a better coordination of systems (DoHA). However, community-managed mental health organisations are ‘not well described in current data collections’ (AIHW 2014:386) which implies that what they do and how effective they are may not be well understood. It is within this context that the current research seeks to understand more about what is effective within the service system and what impact living in a regional or rural location may have on a person’s experience of the service system.



In order to improve the wellbeing of people with lived experience of severe and complex mental illness, the recovery model recognises that a positive sense of identity, peer relationships and social inclusiveness are crucial factors (Hsu and Kjoller 2011). Further, that overcoming the sense of loss associated with mental illness requires social and reciprocal relationships (Henderson 2010). It is unsurprising therefore, that community-based approaches reduce the prevalence and length of institutionalisation when supported by policy frameworks emphasising prevention, early intervention, self-determination and community support (Tew et

al. 2012). These all aim to achieve reduced social isolation alongside increased social inclusion. Furthermore, collaborative community care is more cost effective and practical than extensive reliance on hospital-based services (Lee et al. 2010).

icantly, in its 'revision of the language, theory and practice of supporting people with lived experience of mental health issues', the Recovery model seeks to challenge stigmatisation (COA 2013). This is important because the stigma associated with mental illness serves to isolate people and, in turn, social isolation is a key factor in the persistence of complex mental health issues (Hsu & Kjoller 2011; Perkins & Slade 2012; AIHW 2015). However, 'isolation' can also be geographic. Compared to urban centres, people living in rural and regional areas often have less access to mental health services, yet they are 16% more likely to depict themselves as experiencing mental health issues (ABS 2011). It is against this background that in 2015 Marathon Health funded a research partnership between Western Sydney University and The Benevolent Society.

The resulting *Stories of Recovery* from the Bush project asked participants of the Western NSW Partners in Recovery (PIR) program how their identity, relationships and social inclusion is shaped by their lived experience of mental illness; how that lived experience is impacted by living in regional and rural NSW; and what they have found helpful and supportive in their recovery journeys. Dominant cultural stories about mental illness tend to be problem-centred. They speak of burden, difficulty, hopelessness and sometimes death. This project aimed to uncover less dominant stories to learn more about what works in the service system and wider community to support people experiencing severe and persistent mental illness and complex needs. We wanted to hear what works for people, what their motivations, joys and desires are, and how place impacts their recovery journey.

In keeping with the recovery model, we made participant's knowledge and experience the centre of the research. However, we also utilised an arts-based research approach that could 'give back' to the participants. According to Neilsen, King and Baker (2015:1), mental health recovery is promoted through 'engagement in creative arts' because it can offset the isolating tendencies of mental illness and promote a sense of agency, confidence and self-worth. Indeed, the creative arts have a long history in a range of therapeutic contexts (Hogan 2001) and their contribution to wellbeing is acknowledged (Stickley 2010; McNiff 2004). However, the use of visual research methods (Rose 2012) is also a well-established means for eliciting social knowledge (Pink, Hogan and Bird 2011). In combination with narrative, it is strongly inclusive of participant perspectives while generating scholarly data and outcomes (Horsfall and Titchen 2009; Edgar 2004).

The photovoice method was used in this project to uncover the silences of people experiencing mental illness who are often seen as 'voiceless'; either because they are perceived as not having anything, or are unable, to communicate. The research worked as a connecting thread between the participants and the service environment. We tailored the project and research questions to obtain data that was holistic and created a body of knowledge around a person's past, present and future. Photovoice provided participants with a means of creatively exploring the research questions so they could tell *their* stories of recovery and living in the community; explore *their* experiences of the service system; and, more broadly, tell us what works to support people on their journey. In communicating their stories and experiences through text and image, we hoped the participants would also experience increased personal agency, confidence and self-worth as well as the benefits of increased community engagement.





RESEARCH DESIGN

The research approach uniquely operationalised three key mental health frameworks: it brings together the recovery model with trauma-informed practice and the principles of collective impact which provided the basis for a coherent and consistent model of research design and implementation. First, the recovery paradigm holds that people with lived experience of persistent and severe mental illness are the experts in their own recovery and we have therefore placed participants at the centre of knowledge generation. The recovery oriented methodologies are designed to uphold the principal elements identified by people with lived experience as important to personal recovery including “connectedness; discovery; hope; active sense of self and ability to respond/take control” (Glover 2012:8). We designed the research so that it could be flexible and responsive in practice. We conducted the research in partnership with the participants, maintaining respect and providing them with real choices in the way they engaged with the research to ensure their dignity was maintained.

Second, the design and conduct of the research was trauma-informed, emphasising “safety, trustworthiness, choice, collaboration and empowerment” (MHCC 2013). Consumers who engage with mental health services are often “trauma survivors” (MHCC 2013). We used the understanding of the impacts of traumatic stress to design research that could support participant control, choice and autonomy and to also provide opportunities for power sharing and collaborative decision-making. In creating a space for participants to take part in a journey of self-authoring, the research focus was on strength and resilience but we were careful to provide a safe physical and emotional environment for participants. This was extended also to support workers and researchers, ensuring appropriate safety measures were in place for the duration of the research.

Third, in maintaining the integrity of the Partners in Recovery (PIR) commitment to Collective Impact, the research applied Collective Impact principles at a smaller scale through the systematic design and

implementation of the project. Collective impact initiatives are those that involve a “centralized infrastructure, a dedicated staff, and a structured process that leads to a common agenda, shared measurement, continuous communication, and mutually reinforcing activities among all participants” (Kania and Kramer 2011: 39). These features were evident in the multi-organisational landscape across which the research was conducted, enabling a strong commitment to the research participants and their engagement in the project and facilitating an extremely high retention rate. At all times we were mindful that the ‘self’-authored person is embedded in a complex web of familial, community and social relationships. The recovery oriented, trauma-informed, collective impact design ensured integrity between the methodological approach and the substantive investigation of mental health recovery in rural and regional areas.

RESEARCH AIMS AND QUESTIONS

Aims

- To further develop knowledge and understanding of mental health recovery by giving preference, voice and visibility to the self-generated stories, photographs and aspirations of people with lived experience of complex, severe and persistent mental illnesses from regional and rural NSW.
- To use these insights to positively influence policy and funding models to further support effective, evidence based community options for people with lived experience of mental illness in regional and rural NSW.

Questions

- How does the lived experience of mental illness shape identity, relationships and social inclusion of participants of the Partners in Recovery (PIR) program?

- What effect does living in regional and rural NSW have on this lived experience?
- What have people found helpful and supportive in their recovery journeys?



METHODS AND PROCEDURES

In exploring the research questions, the methods needed to enable participants to remain in control as much as possible and to hopefully gain from their participation in the research process (see Horsfall & Titchen 2009). As researchers, we needed to be particularly sensitive when asking people to talk about potentially emotional or distressing experiences that could leave them feeling vulnerable and exposed. Creative, qualitative research methods are increasingly being employed in situations of emotional sensitivity (Horsfall & Titchen 2009; Yardley 2008; Horsfall & Welsby 2007; Davidson 2004). We therefore designed and conducted the research using a creative qualitative approach, based on the technique of Photovoice, combined with group workshops and individual interviews.

These methods provide people with a conversational space so they can speak if, and how, they want about deeply felt issues thereby enabling researchers to understand what matters to participants and why. Creative methods can also facilitate people 'noticing' with fresh eyes that which has become familiar, helping to 'get beneath the surface' of common everyday things (Diamond and Van Halen-Faber 2002). This is important because some aspects of the recovery journey, such as relationships and places, are often not talked about or are seen as an unremarkable part of people's everyday lives. The photovoice method provided a basis for us to carefully and sensitively document these subjective experiences in the research.

The research included five stages over a 12 month period (2015-2016) and was conducted by the Chief Investigators (CI) Professor Debbie Horsfall and Ms Amie Carrington, together with Senior Researcher (SRA), Dr Joy Paton:

Stage 1: Photovoice Workshops

Like other visual arts, photography is a means for communicating that which is unspoken or difficult to speak of (Booth and Booth 2003). The photovoice method places the research participant as the expert in analysis of their own life and experience. It also provides a form of 'distance' that can enable people to think critically in reflecting on their lives (Freire 1970). Using cameras allows participants to convey visual stories and to communicate in a way that expresses their own images, thoughts, words and reflections. These images then lay the basis for further exploration, including previously unexamined areas of their life and experience (McIntyre 2003).

The photovoice workshops were designed to introduce the research project in more detail as well as to demonstrate the photovoice technique and to begin relationship building between the researchers and participants. This is crucial to trauma-informed research. In total, four workshops were conducted by CI Horsfall and SRA Paton: Mudgee x 2, Dubbo x 1 and Wellington x 1 with up to 12 participants per workshop (including support staff). The workshops were held in community settings such as church halls and community centres and lasted for 3 hours. Refreshments were provided and support staff from the PIR and PHaMs program, along with carers, attended to help participants and researchers as needed. In total 26 participants attended one small group workshop. The workshops were hands on and focussed on skill and relationship building (see Appendix 3). Participants were given a copy of the research documents (see Appendices 1-5) and disposable cameras with capacity for up to 28 photographs. We asked them to take photographs over the following two weeks recording what was important and helpful to them on their recovery journey.

Stage 2: Telephone Interviews

During the two-week period in which participants were taking their photos, SRA Paton made two or three follow-up telephone calls to offer support and encouragement, to problem solve and to further maintain and build relationships between the participants and the researchers (see Appendix 4). Field notes were also taken. At the end of the period, participants returned their cameras for development and the photographs were subsequently discussed by participants with a researcher in individual interviews.

Stage 3: Individual Interviews

The purpose of the individual participant interviews was threefold: to discuss their photographs; choose images for the exhibition; and begin the process of constructing the written narratives that would hang alongside their photographs in the exhibition. The semi-structured interviews were conducted by CI Horsfall or SRA Paton (see Appendix 4). They lasted no more than two hours and were audio recorded. One participant did not consent to audio-taping but did consent to written field notes being taken. The interviews took place at The Benevolent Society Mudgee, NEAMI in Dubbo and the Wellington Information & Neighbourhood Services centre. These were supportive and familiar places for most of the participants and the researchers. Support staff from PHaMs and PIR were available during the interviews for either the researchers or participants if required, usually outside the interview room.

The visual data (photographs) formed the focus of the in-depth interviews with individual participants. We invited them to look at the photos and to discuss those they felt were of most significance. In these discussions we focussed on stories of recovery prompted by the photographs and guided by a series of questions previously given to the participants (see Appendix 4). This process enabled us to understand what was helpful and supportive in terms of the participant's recovery journey *from their point of view*. Participants were then invited to choose photos for inclusion in the exhibition and to add anything of significance that they wanted to be reflected in their one-page summary narrative.

Stage 4: Exhibition

The capstone experience for research participants was the photographic exhibition that accompanied the launch of this report. Alongside the photographs chosen by participants for enlargement and display was a one-page narrative summarising the recovery stories emerging from discussion of their photos. The narratives reflected the participant's own voice, with text drawn directly from their recorded interviews. The exhibition provided participants with a very tangible opportunity to make a significant statement, through images and text, about their lived experience of mental illness and recovery. The willingness to portray their

experiences in such a public forum took great courage and is one way these participants have challenged the stigma and discrimination that so often surrounds mental illness. In addition, some participants took up the opportunity to contribute (or develop) their skills in co-organising the exhibition opening and launch of the report.

Stage 5: Data Analysis (how and what was analysed)

With the permission of participants, the individual interviews were audio recorded and later transcribed, providing a rich data set for analysis. In collaboration with the participants, the interview transcriptions were also used to develop the one-page summary narrative for exhibition. Analysis of the de-identified interview transcripts was interpretative, qualitative and data-driven. The research team (CI Horsfall, CI Carrington and SRA Paton) conducted a dual analysis that pursued answers to the research questions on the one hand while allowing themes to emerge on the other. We analysed the data in terms of the key ideas, concepts and themes that people spoke about; what they thought was important; and the overall story they were telling us.

Concurrently, we looked to see how the data answered the research questions; or if there were silences and gaps; or unexpected things that had been said. This was read against the current literature and expert knowledge of The Benevolent Society Community Programs Manager, Ms Amie Carrington. The qualitative approach was a rigorous, data-driven process. To ensure validity, research team members analysed the data individually identifying key categories and ideas. We then had two day-long meetings where we discussed our analysis of the data and developed the themes collaboratively, checking and re-checking the raw data as we went. Additionally SRA Paton and CI Horsfall developed one-page narratives from each participant's transcript for use in the exhibition. This served as a further data analysis tool as we were in negotiation with participants about their narratives and had gone through a concentrated process of distillation of each person's data.

Ethics

Participants were fully informed about the project and advised what the research team would do with the photographs and other information collected in the process of the research. All participants had the opportunity to read an information sheet and sign a consent form at the photovoice workshops that provided details about the project, the use of photography and what would be done with the data that was collected (see Appendices 1 and 5). We actively re-negotiated consent again at the interviews and in telephone follow-ups. We employed an inclusive ethical approach which did not target people based on diagnosis. An audio recording of the Participant Information Statement and Consent Forms was made available to all participants and was also accessible from smart phones. Support staff and carers also assisted people, where necessary, with the informed consent process especially during the workshops. We provided as much information as possible through multiple formats, building rapport and trust throughout the process. All the photographs in this report, in other publications, and in the exhibition are used with the consent of participants (see Appendix 5). Photographs of identifiable people were only included with their written permission (see Appendix 5). The project received ethics clearance from Western Sydney University (H11225) and The Benevolent Society prior to commencement.

RECRUITMENT AND PARTICIPANTS

Research participants volunteered from the Partners in Recovery (PIR) project in Western NSW. Invitations were open to participants and consumer reference group members within PIR (see Appendix 2). 26 people experiencing persistent and severe mental illness attended photovoice workshops with 24 progressing through to the interview and exhibition



stages (after having attended their respective workshops, two people withdrew from the project prior to the interview stage. No further information was provided). The research approach and methods enabled participants to express their stories, knowledge and experience in a safe way, contributing to the project's very high retention rate (>92%). Important to the success of the methodology was the collaborative approach between the research team and support people (both carers and staff) that provided opportunities for participant leadership and co-design.

Many of the research participants had multiple and intersecting vulnerabilities including dual diagnoses, being poor and sometimes challenged in terms of literacy and numeracy. Some were managing their participation in the research around the effects of medication (which may impact short term memory); receiving shock treatment; being in and out of hospital; or experiencing homelessness or other significant traumatic events, including of a criminal nature. To facilitate participation in the research, we used community settings and enabled people to take the research back into their own homes in their own time with appropriate supports to ensure their successful participation. The collaborative framework around individuals, supports, carers, families and researchers was a *collective impact* and relationship building exercise. This, together with the determination and resilience of the participants themselves, meant they were able to be a part of a potentially challenging research project that asked for a significant commitment of personal time and energy.

Snapshot of the Participants: Demographics

Age/Gender/ATSI: Sixteen 16 (62%) women and 10 (38%) men initially took part in the research with an age range of 19-70 years and a spread of ages between the decades (see Table 1). Seven (7) (27%) participants identified as being of Aboriginal and Torres Strait Islander (ATSI) descent. All participants were being supported by a combination of community based services and health services.

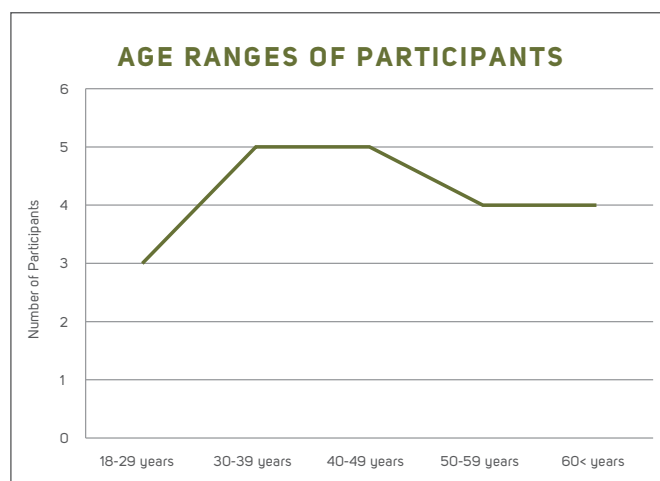


Table 1 showing the number of participants in each age range

Diagnoses: Depression (16) followed by Schizophrenia (10) were the most prevalent diagnoses, followed by anxiety (6), bipolar disorder (4) post-traumatic stress disorder or trauma (3) and obsessive compulsive disorder (1) (see Table 2). Nine (9) participants had more than one primary diagnosis. Note: Table 2 data appeared to under-represent personality disorder and schizophrenia in the research cohort. After discussions with PIR, we believe this may be due to under-reporting at the time of their data-collection due to the stigma commonly associated with such diagnoses.

Service supports: All participants had multiple service supports in place (see Table 3). Seventeen (17) people identified the GP/GP clinics (Primary Health Services) as their main support. Next came NGO Mental Health programs, predominately the Personal Helpers and Mentors service (PHaMs) (13). Other services were Specialist Clinical Mental Health (12) such as psychology and psychiatry and Public Community Mental Health Services (10). No single service was accessed by all the research participants other than PIR; the number of services in place for per person ranged from 1-9.

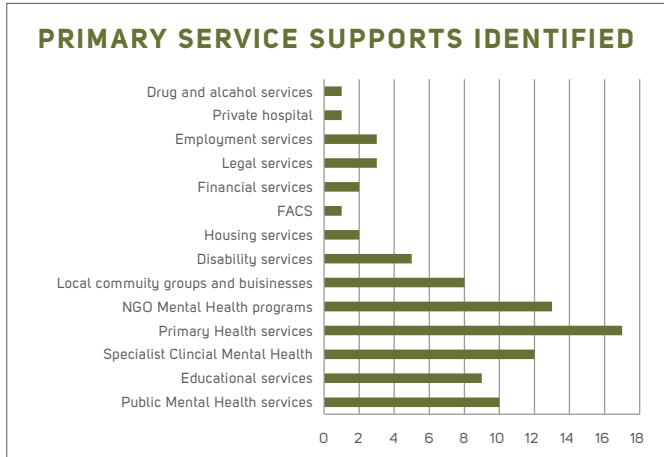


Table 2 showing the number of people experiencing a specific mental health diagnosis

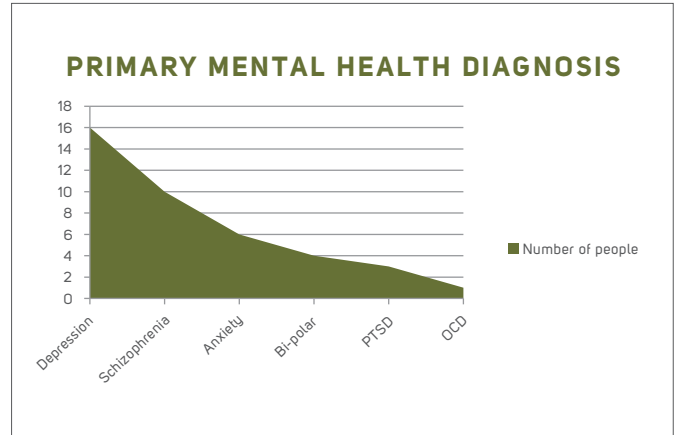


Table 3 showing the number of participants identifying with each service



FINDINGS AND DISCUSSION

THEME 1: CONNECTION AND BELONGING

The findings significantly add to current discussions of isolation and connection for people living with mental illness, and offer alternatives for support services which aim to increase connections for people. The data suggests connections to wild places, gardens, pets, memories and memorabilia, for example, played a large part in supporting the wellbeing of people. The findings also show that people believed it was vital to create and maintain connections to something bigger than themselves. In this theme a connecting thread is the agency of the participants in seeking, affirming and speaking about connections, trust and safety. They demonstrated a clear understanding of the importance of different types of connections to their wellbeing and emotional safety and were mindful about what worked for them incorporating this into their lives. These included: their relationship with the natural world; keeping memories alive; and understanding their 'sense of place'.



Home is also important in terms of belonging and for many of the participants, home was sometimes transient and insecure. A number of people talked about having moved in the previous 12 months. Nonetheless home was important in terms of feeling safe and secure: *Well that's where I feel very safe too, in my lounge-room. It's just a place that I love to be (P1)*; having some privacy and freedom or a place to call your own; establishing an identity and being creative. It could also offer respite from the demands of the outside world. While participants had a variety of living arrangements it is notable that around 25% of people lived on rural properties or in outlying areas. The down side to home for a few of the participants was that they could at times retreat inside and not be able to leave their home without support: *I don't want to leave the house or do anything. I just sit in my chair all day and stare out the door (P17)*.

Nature and wild places

I belong out in the nature – I love that – and I love being there (P1).



Overwhelmingly people spoke of the importance of the natural world whether this was a farm, park, garden or wilder places such as creeks, the bush, or the ocean. Without exception 'outside' was seen as important to their wellbeing; *it makes me happy...just seeing new growth and how beautiful things can be in the garden (P22)*. People spoke of feeling peace, of being able to slow down, to be alone, to empty their minds, to focus on the ants, the birds, the flowers or just the wind in the trees: *It's really a magic area... getting outdoors and being in the environment and being just present with the environment and that helps with my mental wellbeing. It's an energiser – it tops me up, it fills me up (P11)*. They talked about feeling at ease within nature, of belonging: *every time I go out there I feel like I'm at home again (P4)*. There was a sense of spaciousness and of knowing that they have a place in this world, that they are part of nature. The endurance of the natural world was comforting;



it will always be there for them to access. The tree they used to sit under is still there, for example: *I used to have this tree when I lived on my parents property and I'd go and sit up against it and it had this kind of spot where my butt used to sit and the grass is all flat (P18)* and so are the creeks and mountains: *I think the aboriginal name was something like Coomerballon or something like that... I used to climb them when I was a kid (P2)*. People also spoke of feeling safe and secure in the natural world in addition to being nourished: *I even like going to sleep in the park sometimes (P6)*. At times people actively sought that feeling of safety and trust from the natural world.

People also spoke about wild places, nature and the non-human as nurturing their connection to themselves, and these are places I can go AND disconnect a bit if I want to. *I don't have to be fully present in the moment. I can sort of be there in my own little mind you know (P1).* For others it was about spirituality, *the environment it just goes on with or without you and you're just part of that and it's going to occur anyway (P11),* or connection to a higher order: *and rainbows when I needed something positive – to see something positive – especially from God because my faith in the sky just happened to be up in the sky (P9).* For most of the participants the benefits of living in regional NSW with easy access to nature and wild, natural places outweighed the potential lack of services and isolation a regional or rural lifestyle can bring. Indeed many spoke of nature as saving them from the worst effects of their illness. People were also aware that this could be a double-edged sword: *where I live there's just so much open space. So that means a lot to me – just being able to get out and have nothing but trees and things around me – it calms me. When I'm in crowds the anxiety just goes sky-high. At the same time it's very lonely so it's kind of a double-edged sword a bit (P21).*



History, memories and memorabilia

That lounge is 30 odd years old and it reminds me of yesterday, you know. Good memories that I had so in that it's safe for me to sit there and feel comfortable and still have memories of the past and good memories, you know (P1).



A further theme in terms of connection and belonging was that of having, and keeping alive, history and memories: *that's my mum's rose garden... and where we used to sit in summer...dad built an old tin roof over the bbq there(P2).* This could be family history which is attached to the particular place people now live: *'You know now son, Mudgee's history now sits on your shoulders'... me auntie was tellin' me that on Friday 'you're the new generation' ... and I will tell my kids that, 'Mudgee has a lot of history to do with you' because... my kids would be I think the ninth generation of Mudgee (P8);* or the telling and re-telling of family stories, of re-counting where they had lived and where they were from. Numerous items took on special significance and became symbols for

people reminding them of good times, of being loved, and helping them keep relationships alive: *And these are my Japanese dolls...they were a gift from my brother when he was overseas...and they're pretty precious to me (P24).*

What was clear was that memories and history – whether good or bad – enabled people to stay connected to family, to place, to where they came from and who they were as well as giving them a secure place from which to build dreams and hopes for the future: *all my life I grew up around farms ...my grandfather used to be a horseman...there's a lot of history...and that's something I would love to have in my generation for the next generation (P3).* This was true across ages and genders. The youngest participant, for example, had numerous photos of family items and memorabilia which were important to her: *This was an old clock that has been passed down. I'm actually surprised it still works. It's been passed down about 10 times in our family on my mum's side, from Portugal (P20).* This particular quote also shows how history and memorabilia are linked to a person's identity and social connections.

Family is important no matter what

I've got two sisters – I'm their big brother, their medium brother and their little brother! 'Cos I'm the only one (P5).



Without exception families were crucial to participant's stories, regardless of what might be considered good or bad experiences: *I just want something' to keep goin' in the family 'cos all our family suffers from depression (P3).* Family relationships were complex, and absolutely necessary to people's stories of themselves: *He's actually like a friend's kid who basically classes me as his aunty (P15);* to their stories of survival and support, *my father he was also pretty important in recovery (P24);* and to their stories of pain and hurt. Family members were often important in terms of stability, acceptance and support. At least a third of participants had lived, or were still living, with their family, often their mothers or grandmothers. At the time of interview four participants had recently lost their mother, grandmother or father: *I'm the only child in the family and after me Mum passed away I didn't know who to turn to, what to turn to (P13); My life really fell apart when my dad passed away four years ago (P17).* For all four of these people this loss also meant they had to move due to the loss of the family home. Others recounted stories of neglect, abuse and/or abandonment either from their family of origin, *My dad – it's incredible what people done and why I'm unwell (P23);* or from intimate partners. What was clear was that everyone was connected to a very complex web of relationships and family formed the bedrock of a person's story of self and connection. While a whole range of family experiences were recounted, whether positive, negative or a combination, what was important to the participants was the acceptance that family is family and central to a person's identity and connection.

Community belonging

It's all I know and I've got family and friends here (P3).



Being connected and belonging to community takes many shapes and forms. For some participant's it was about being part of a creative community through the music they play, or sing, or compose: *the acoustic guitar – it's just got a beautiful tone... It takes you back to the traditions of folk music and country music and that sort of thing (P2)*. Again the sense of history and tradition played an important role, it was important that the community was an enduring and stable one: *Google and you'll see me something traditional there – like my name and I have some 50 something movies on my YouTube because I have a YouTube channel and I put some of the songs – which when I launched the CD I went to do some televisions shows and yeah I have some nice traditional costumes with lots of cross stich (P4)*.



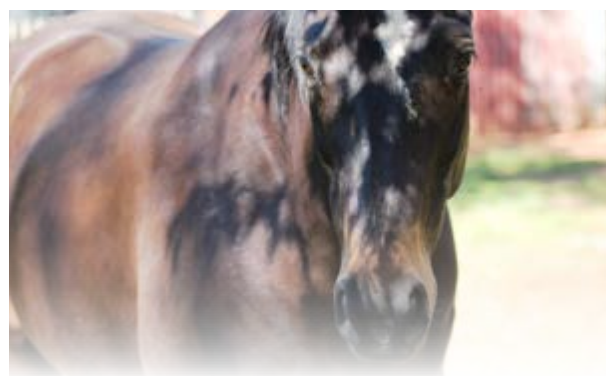
Knowing people in the community was important to participants. They spoke of friends and neighbours who were helpful in various ways such as looking after the children when the participants needed to go into hospital. Being visible and known was comforting and reassuring: *I love them so dearly and he's like a godfather to me at the Friendly Pharmacy...Been going there ever since he opened his doors (P23)*. Living in a regional centre was seen by most as preferable to city living as it was quieter, more easily navigated with just enough services, although these views did vary depending on which of the towns people were speaking about. However most felt a sense of belonging, even if that meant they could walk to the library, or pop into the supermarket as needed.

While the smaller size of the community enabled people to form meaningful relationships with others (shopkeepers, neighbours, the priest), for some, the lack of anonymity was difficult: *Especially in the country communities because I find you walk down the street and everyone*

says, 'How's your new grandbaby?' and you think, 'What do I say?' I don't want everyone knowing my business so yeah, it is tough (P21). In a smaller community the stigma of mental illness can be harder to escape: *You get some people that talk to ya like rubbish, garbage (P17): Well this town unfortunately has got a bad name... I feel it puts me at a disadvantage for jobs (P16)*. Additionally essential services may be in the next town which can be many miles away resulting in costly and time consuming travel, up to 2.5 hours to see a specialist. However, for the majority of participants the downsides of regional and rural living were compensated for by easy access to wild places, to peace and isolation highlighting that isolation is much more complex than just where people live.

Pets and other creatures

It was just like love at first sight. He jumped up on me and I grabbed him and we've been together ever since (P3).



Animals and pets were vitally important to almost everyone in the research; they were spoken about as often as family. Having a loyal friend who gave unconditional love and was accepting no matter what were the key themes of connection here. We talk about this in more depth in theme 2. However we also believe that animals and pets are important to connection and working against isolation. For most participants the animals were dogs and cats, however horses were also important: *That's my horse ...He means the world to me...he's always there and he loves me...I've got a real spiritual connection with him... whenever I'm sad I go for a ride. He's just so in tune with my moods. It doesn't matter – you lunge him and have him buck and be silly but the minute I go to get on him he just stands so still and he's just perfect when I get on him 'cos I'm slow getting up with my back and my weight. He just knows to stand still and he looks after me (P21)*. This person's description of her deep and powerful connection with her horse was echoed across the research with dogs, cats and birds.



If people did not have a pet they made time to connect with wild animals and birds or those in parks or the Zoo. Connections with animals and birds were important to well-being; they enabled reciprocal relationships where participants both received and gave love and affection. Pets also provided a safe mechanism to form connections via dog breeder groups, puppy day care, or animal rescue communities, for example.

Technological connections

I don't go to town much. I guess [information] needs to be over television or social media or something like that (P21).

We have included this as a sub-theme because provision of services is moving towards, at least some, reliance on technology as promoted in the Australian government's E-mental health strategy (DoH b). Indeed, suicide prevention apps are currently being trialled nationally and internationally (see beyondblue and Monash University and the BeyondNow app, for example). For the research participants, use of technology was hardly mentioned. When asked what they found useful no-one mentioned using phone services, 1800 numbers or the mental health helpline (24 hour number staffed by people in the regions); one person suggested Facebook could be useful to inform people what services were available. Of course, this does not mean that they did not, or had not, used these services. However, when asked to speak about services people talked about face to face connections. Of the 26 initial participants, fifteen people provided a mobile phone number (most were not smart phones) and six provided an email contact. In the follow ups between workshops and interviews, phone and email contact often proved ineffective and we relied on support workers physically meeting people to communicate about interview times, narrative development and the exhibition. Embodied physical connections, it seems, are what people seek, at least for the participants in this research. This has implications for services to ensure accessibility when using different modes of communication and service delivery.

THEME 2: LEARNING TO DANCE IN THE RAIN² - SURVIVAL

Loss and grief

I no longer have a home of my own (P21).

And my friends when I fell mentally unwell I lost all my friends (P18).

We lost three of my family members within three years... catastrophe after catastrophe (P2).

I wasn't crazy just going through a lot of stress (P7).



We were struck by the powerful stories of loss and grief that people told us. For such a small group of participants there were numerous stories of deaths of close relatives: *My life really fell apart when my dad passed away four years ago (P17)*; of separation from children: *my baby is one now and he probably won't remember me (P6)*; loss of jobs and careers due to illness: *left the police force and I went into deep depression (P11)*; loss of freedom; loss of security and safety due to transient housing or experience of everyday acts of, sometimes extreme, violence and abuse; loss of friendships and all that was once familiar as people moved to areas where housing was cheaper and perhaps closer to services; and loss of the body and its previous abilities as it was taken over by medications and weight gain: *I was always pretty fit when I was young. It's only since I've had mental health issues I've really put on the weight and that (P2).*

Participants live with these losses every day. The result is a loss of identity and loss of an imagined or future self - as parent, worker, sportsperson. They also result in the loss of potential identities, choices and options for people, such as living independently, or living without



medication. The cumulative effect of these losses is one of disadvantage exacerbated by unemployment/ underemployment as people struggle to negotiate finding work. For example, a participant aged 57 years had severe depression and was trapped in a cycle of having to look for work: *What I've always found hard, for someone that's worked all my life, as far as the government is concerned I still get treated the same as people that don't work and don't want to work, have never worked. I've got to turn up at these recruitment agencies, produce proof of jobs I've applied for. If by June this year I can't get a job I've got to do voluntary work. I just find it so unfair for someone my age who worked continuously since I left school (P16).*

Hope and renewal

But I keep goin' 'cos it gets better - I reckon. I couldn't kill meself - I couldn't do that. I reckon life gets better. You live day by day. Might be bad one day, the next day's alright. And the next day's bad and the next day's alright and it could get a lot better or a lot worse - you don't know. You don't really know what's goin' to...but again life goes on (P17).



For many participants the losses and struggles they had experienced provided strong motivation for making substantial changes to their lives; getting educated, secure work and housing, learning how to budget and how to manage their illness. This is exemplified by participant P6: *I'm trying to get into things ... and all that to get my kids back... all the services I need, all the courses at TAFE I need, all the other medical things I need. I'm going to use all that and just keep going...because I have this strong thing in myself that I need my boys. Like my boys are my world and I'll do anything to get them boys back (P6).* For other participants it could be that they wanted independence and the freedom and skills to pursue their dreams. These dreams could be about relationships, about learning to drive, of being able to go to the coffee shop on their own. The dreams and desires of participants were many and varied. However, they all had dreams and a sense of moving forward in their lives; *they had goals and aspirations which they could articulate: and I have filled in my details and left them with Bunnings - I wouldn't mind working in there (P16).* There was a strong sense of movement and a belief that things would get better and that they were active players in this: *I'm looking forward to stepping out and starting to meet people and like you said, I'm having a sense of belonging (P1).*

² This is taken from a popular motivational saying: Life is not about waiting for the storm to pass: It's about learning to dance in the rain. Anonymous n.d.



Many participants used images of nature as metaphors to explain their illness, their lives or their journeys. Trees in particular were a central motif of the photographs and the stories: *That tree reminds me of me a little bit. It's still alive but it hasn't improved since I've been here... I think it probably needs to be pruned so that it'll sort of grow up instead of out (P16)*. Trees that were pruned too hard but kept coming back; small saplings that pushed their way up through the cracks in the concrete; sick trees that were carefully watered and nurtured back to health and vigour; twisted trees that were beautiful and brave as they struggled to the light: *Just the strength of the trees you know. One day I'm going to be strong like that (P1)*. Trees appeared to represent resilience in the face of adversity and complex trauma: *Yeah you know the tree – like this one – fall off already but that one keep going no matter what - even if its hurt (P4)*. The photos of nature also gave people the images and words to speak about their struggles, to talk about difficult things and to explain their journeys: *I find solace in creation, in it's rhythm – you know, day and night, day and night and in seasons. Seasons I find important (P9)*.

Stigma and struggle

That's the Tree of Life...for 20 years it grew up to half a metre then died. Half a metre. Died. I think it's 20 years before it finally took off...It rolled over 20 years and become stronger and stronger (P 23).



The data shows that many people were fearful of not being able to achieve what was needed, or of going back – often to an institution or back to being unable to cope. There was a strong theme of perseverance though, of acceptance that life may always be a struggle but that having dreams, setting goals and accepting help were beneficial and contributed to people moving forward: *Yeah and I'm getting used to now that I realise people do care but I'm still finding it hard to accept that (P3)*. While this was strengths based research where we were seeking stories of recovery and 'what works', numerous people spoke about being victims of sexual assault, child abuse, domestic violence, physical violence, institutionalisation, suicidality, systems abuse, and the impact of extreme poverty. People also struggled to find a meaningful place in

the world and struggled for freedom.

For some the struggle to be heard and taken seriously was the hardest struggle of all: *'Cos everywhere else I go even if I go the police station or somethin' they just don't want to listen to me. They just keep on tellin' me to get out the door. Like last night they told me to get the F out the door. 'You can't speak to me like this. I'm talkin' to you nicely'. They didn't want to listen to me... Even like I got raped three times...Like three times last Thursday night but I never went and told the police. They won't believe me so I never told anyone (P14)*. This speaks strongly to people's experiences of stigma. Being stigmatised at the very least means people don't speak to you and at the worst leaves you open to abuse and neglect from the very services which are supposed to keep you safe: *society doesn't know enough either. They hear that word, 'mental health' or 'depression' or whatever. I lost a lot of friends that didn't wait around for me to get better (P19)*. People also spoke about financial stressors associated with unemployment and underemployment which results in limited access and choice in terms of services. People are unable to supplement additional private psychology services, for example, or trauma informed counselling outside the scope of the limited publically funded services.



Although these disturbing stories of stigma and struggle were present in the data, most of the participants demonstrated resilience in the face of adversity: *So I get spat on, kicked at, bashed up. Me house gets destroyed. Town treats me like dirt and they wonder why I want to move... I never want to go there in the first place. I went there to try and start a life. They destroyed it, ripped out me heart, soul, mind and body and I'm still here (P12)*. Much of this resilience was supported by people's acceptance. On the whole, participants accepted their past; they did not deny the difficult things and their part in them: *I kind of diminished my light through drugs and alcohol and cigarettes and stuff like that and I've let my confidence go down from what I used to be before I started to take drugs to being this withering mess (P18)*. Some recognised that their experiences of mental illness had given them something: *I've become a better storyteller the older I've got and I think that probably stands to reason a bit... That experience that gives you more authenticity... It gives you that emotional weight or something of what you've been through and that (P2)*. Hearing people's stories of struggle and stigma was distressing and confronting. Sometimes what was confronting was the level of acceptance when people were no longer shocked by their own stories of abuse which had become normalised or expected: the stigma was internalised.

Pivotal moments

Gaby is the person that saved me... She talked to me and tried to make me understand and just unloading the whole thing, my whole problem I think it helped and made me realise too that just to withdraw and that wasn't the answer... Gaby's been a lifesaver to me (P22).

There was a strong theme throughout the interviews of pivotal moments. A pivotal moment is one where the person recognises that a major change took place: one that may have been unexpected. These moments are powerful and life changing. Pivotal moments are different to the more enduring and persistent things which enabled people to

continue life and gave them hope and joy, such as animals, nature, studying. Many people spoke of a moment, an encounter, a realisation when their life changed. They often spoke about this 'saving them' either saving them from their illness; from further abuse or from death. For participant P16, a neighbour literally saved her life. Unable to see a GP to help with her back pain she decided: *that was it. So I took everything I had in the house...He must have known something was wrong and he came straight in. He called an ambulance (P16)*. For others, they were shocked into action to help themselves: participant P4 realised her partner had spent most of her money so she learnt to drive which for her was freedom and she: *went to TAFE which changed my life (P4)*. It may have been having a crisis which meant they had to seek help or having a service provider just come and talk to them, or really feeling the sunshine for the first time. It could have been that a service provider helped them get a house and so escape homelessness for the first time in many years. The actual moments were many and varied. What was common was that nearly everyone had a pivotal moment.

Identity and building a positive sense of self

I'm moving forward and achieving goals and I'm going to keep going forward until I get my boys back. I'm not gonna take any steps back. I'm just going to keep going (P6).



People spoke about their achievements in this context as a way of showing themselves and us that they could achieve their goals and that their future focus was realistic. They were actively planning what to do; they knew what steps were involved in meeting their goals; and they knew where to get help. They accepted that they needed help in life skills, in building relationships in concrete matters like negotiating with Centrelink or the rental market, in treating and managing their illness. Overall people were self-determined and they demonstrated that they could also juggle competing goals. One participant, for example, missed his research interview as he had booked himself into a residential facility to get the help he needed at that time and was able to re-schedule his interview despite the complexity of the situation.

Nearly all participants told stories of active caring, for other people or for animals and pets and in some instances for gardens. It seems important to people that they are needed, that they have responsibilities and that they can make a difference in another creature's life. There were many stories of animals being rescued either in the moment: *His mum got hit by a car and she had four little ones so I ended up takin' him (P14)*; or as part of a deliberate 'animal rescuer' role by both women and men in the study despite the usually gendered nature of caring. Four of the 24 interviewees were, or had been, animal rescuers. People spoke with tenderness and with pride about their ability to care: *He was skinnier than that. You could see his ribs when I got him... The day I got him for three weeks straight seven days I was walking him. Come home take him for a walk. Turned him into a ... strong dog (P5).*

While pets and animals were the overwhelming examples of people caring and loving another creature there were also numerous examples of people caring for their partner, children, other family members and/or friends. In some instances this was what we call a 'stance of caring': *I could say I love you and mean it... it's the compassion you get back from everyone else and outweighs anything. I want to say too to everyone*

here I love them but mean it... Why not? (P23). People demonstrated a wide range of caring skills: being organised and understanding another's needs; putting an animal's or person's needs before their own when necessary; as well as empathy, trust and reciprocity. The following quote shows many of these qualities: *That's Grandma's...when her first husband – my pop – died of cancer as well, she had to go with Spot (the dog) as a partner so they both recovered each other. So when Spot died of cancer as well, she couldn't cope. So I found a look-alike dog which is him and we named him Spot...it cost me a mint but it was totally worth it (P20)*. What is important here is that being a caring capable person was necessary to the person's identity, sense of being useful, responsible and needed.

Learning and creativity

How I changed my life (P4).



Learning and involvement in creative activities were also common threads across the participant cohort. Many people have a creative outlet such as gardening, home making, knitting, craft, furniture or car restoration, photography, painting, music, writing and, at times, contributing to other people by making them gifts. These activities provide a means of self-expression and self-care, helping at distressing times: *last night when the police took me partner, locked him up and I was at home in tears and, 'What should I do? I can't go the cop shop every five minutes'. So I stayed home and when I bought those canvas I ended up sittin' there and done one big writin' right across it for Carol..., she's like a mum to me. So I put on the canvas, 'Home Sweet Home' (P14); that painting there – that was drawn by someone that was deep down in depression, couldn't really concentrate, hardly sleep, so she'd stay up till four o'clock in the morning, drawing it, designing it, painting it (P5)*. Another participant explained the therapeutic impact of her detailed stitch work: *I was unwell every stitch of that bedspread and then when I was anxious, particularly after I left my husband, I used to get up and get it on my legs and watch TV and every little tiny one is by hand and that's all felted up of course. So that was the therapy for my anxiety (P10).*

However, during periods of wellness, participant P10 takes creativity to another level, travelling, painting and exhibiting her work. Similarly, another participant spoke of the centrality of music to his life: *I absolutely love it... Look, I think at the end of the day it's about the pleasure and satisfaction we get from doing things regardless of whether somebody else judges them as good or bad...That's what song-writing is for me – when I song-write and that – first and foremost it's like therapy really and then if a lot of people like it, that's great (P2)*. For such participants, there is an evident engagement with the public domain and confidence in their personal expertise and knowledge. This is congruent with the growing 'arts-based' recovery literature demonstrating that participation in the arts contributes to increased social engagement and empowerment of people with mental health needs (Secker et al 2007). Creative activity here is more than a private pleasure; it is a means for relationship building, social connection and identity beyond mental illness.

Additionally, many participants embraced self-discovery and learning, be that in formal or informal settings: *TAFE changed my life... now I finish Certificate Two, I finish Certificate Three and 'I'll finish Certificate*

Four'... under TAFE I make the knowledge. I learn more and more and I know more how to use [a computer]– that's amazing. I couldn't tell you how happy I was every day – like I discovered something, 'Oh I didn't know to use that!' It was making my life easier (P4). There is an acceptance that life is a continual learning journey. People understand that they need to learn and that they need help to learn either in terms of formal education at TAFE or peer support: *incredible what they are here and what I learned from here – you get a taste – I take it somewhere else. Centrelink or anything – you know I just take it there (P23)*. There was optimism and excitement about the fact they could learn and change and again this demonstrates how learning is a tool for social connection and relationships as well as engendering feelings of hope.

THEME 3: CONTRIBUTING TO THE SOCIAL FABRIC

The main story in the literature about people living with a mental illness is one of their needs: their need for services, for medication, for programs and for help and support and/or the financial cost to society (see NMHC 2014) While this is undoubtedly true there is less said about how and what people contribute. The participants in this research were very clear about what it is they have to offer and how they contribute in many ways. They position themselves as active and contributing members of networks of relationships: *There's a fair few people at home who need to be introduced to each other and are interested in music and I'm hoping to help get them together and maybe even join myself (P2)*. Reciprocity was important to people: they believed that they had something to offer that was useful.



The collective and individual benefits of participation in, and engagement with, the local community or society in general are well accepted and range from increased health and well-being to decreased crime rates. Indeed, social relationships are as vital to our well-being as food, shelter and cleanliness. Social capital is the most commonly used term to reflect these collective benefits (Putman 2000). However, when talking about people living with mental illness it is generally assumed the relationship goes one way: that social capital is a resource to be used. The data challenges us to move away from this deficit approach as people provided many examples of their contribution to social capital in their communities and families through the ups and downs of their illness.

Sharing knowledge

No matter what you've gone through or done the next person listening to you can get through what they're going through... I had so many people commit suicide and it's too confronting and to tell the story it'd save somebody else... just talking on the phone, doing the shopping at Coles I come across someone. Someone wants to talk and I've had people saying, 'Oh it's been a pleasure talking to you,' and 'Thank you very much for talking to me'. So it makes a difference in their world... And that's a lot for me (P23).

Many people spoke about helping other people through sharing their own experiences and knowledge about life. This is linked to the development of a positive identity and being useful. For some this was passing on family knowledge and family history to the younger generation (P8). For others it was about building relationships and helping others with

a shared interest (P2). Many of our participants had a depth of insight into both their illness and the recovery process seeing it as a *bumpy road... it takes time. It's not something that can happen overnight and I understand that (P19)*. They have a desire to use this insight to help others, *I've been trying to help other people and I've started a support group (P9)* or to address societal ignorance and associated stigma, *I was trying to show people who don't live with mental illness how opposite it is and even when you are well you can't explain it to anyone 'cos it's lost its sting and you can't get that (P10)*. Many people also understood that helping others was beneficial for others and themselves.

The following quote demonstrates insight, a clear goal, and a desire to be a useful member of the community no matter how difficult that can be: *this was a way I suppose to then support others during these stages because it doesn't really end – it's an on-going – it's up and down – it does fluctuate – and getting that to manage better and help others to do so – to stay out of hospital – that's basically it. To live a meaningful life and be part of the community even though it might be frightening. And that's OK to do and to model and to mentor all that (P11)*. People did this sharing through volunteer work, paid employment, talking to their friends, setting up groups, talking to people on the streets and through deliberate actions like talking with the media and contributing to research such as this. These examples demonstrate that people held the belief that they have knowledge that is useful and that passing this on gives meaning and purpose to their lives.

Caring for others

I'm going to work two days a week as a waitress or something like that and then ... I'm going to work a day or two at Baptist Community Services which is aged and disabled care and then for two or three hours at Westhaven which is for mentally challenged people and children. And then every second Saturday I'll work at the Japanese Gardens, volunteering at the Japanese Gardens, cleaning that up and weeding and everything and then on a Sunday I'll go to church (P18).



We have already spoken about caring in terms of helping people to develop a positive sense of self (in Theme 2). Here we talk of caring as a contribution to others and society more broadly. There were numerous examples of how participants cared for others: this could be members of their own family, their partner, friends or other people who are also living with a mental illness or it could include doing volunteer work. This caring was underpinned by a strongly developed sense of empathy and insight which appeared to be drawn from their own experiences and struggles: *And this photo here – she's happy but she's got depression – yeah – she's got a lot of hurt in her heart from the kids taken away from her... Like I can describe that. She's happy but deep inside she's sad, emotional and every time she goes to the parks and swings that there's always something missing (P5)*.

It can be easy for us to forget that the people in this project are already a part of networks of relationships – they are sons and daughters, mothers and fathers, friends and relatives, co-workers and classmates and they often do the work needed to build and maintain these relationships. The data shows they were essential in providing the glue that holds communities and families together: *it's very hard to keep a relationship going with him. Especially with distance – he lives away from me and he's*

really hard to talk to on the phone. So I've got to really struggle with that and try my hardest to make time to go and visit him (P21).

THEME 4: SERVICE PROVISION - WHAT WORKS AND WHAT DOESN'T?

They're fantastic. They've been really, really good to me. I didn't mention it before but like outside of family and friends and that so many people have been responsible along my path. Like I've had mental health issues now for just on 20 years so it's been a long journey and I've that many people – I'm sure I've forgotten half of them – have helped me along the way (P2).

But to me it just symbolises getting across the valley that's hard to get across – an area that's hard to get across...Rough terrain, there's a bridge there to help you to get across (P9).



According to Glover (2012:8), services “should provide opportunities that enable and not hinder a person’s capacity to negotiate” their path of personal recovery. Overwhelmingly it was clear that the services people spoke positively about were operating from a recovery oriented practice framework (for example, as outlined in the National Standards for Mental Health Services, DoH c 2010). Indeed, the findings reflect many of these standards: hope; social inclusion; person centred practice; choice; quality of life; a holistic approach to the person rather than a health focussed one; empowerment; and a strengths-based focus (Bird et al. 2014; CoA 2013; Glover 2012). This is not surprising as the project participants were all clients of the Partners in Recovery (PIR) program which was specifically designed and funded to implement the recovery model of mental health service provision. The PIR initiative is part of a system reform of re-orientation toward person centred services called for by the Mental Health Commission (NMHC 2014). So, it is good to know that participants did indeed report that PIR was helpful and valued. A further element of the recovery model is that service provision evaluation should also be client centred (DoH c 2010). That is, the people receiving the service are seen as major stakeholders whose opinions matter. This research is an example of this type of evaluation and knowledge building from a client-centric position.



Table 3 on page 13 details the services participants in this project were accessing. In this research, we sought detail about what services and their employees did that was helpful; what was it that people valued

and what did they want us to know about the services funded to support them? During interviews we asked people to be specific, or tell us what they meant by ‘these are good people’, for example. We aimed to drill down and get underneath more generalised comments. This was often quite difficult for people to express: *If it was something and I was really, really bad they'd work towards getting a solution for me, some way to help myself. Just talk to me – I don't know how to explain it (P22).* Nevertheless participants worked hard to provide information and feedback that would be useful to services, and they were mindful that this could then be of further benefit to others living with mental illness. Overall the data showed that it was important that clients and providers worked together towards goals; respectfully discussed options and choices, even the hard choices; and that clients were seen and listened to as whole people – not illnesses or health problems – without judgement.

Qualities of ‘good enough’ services

They gave me security and I've never been left alone and they've been with me all the way in good times and bad times (P19).



The research participants did not expect services to solve their problems or make their illness go away. They did though have an expectation that services would walk beside them through the ups and, sometimes severe, downs of living with mental illness: *the support that I got so far helps me along the way (P13); PHaMs and they basically took my hand and guided me to get to where I am today (P19).* Overall they wanted company that was companionable, competent, reliable and trustworthy from people who recognised them as individuals and who had some understanding of their experiences: *She's my inspiration...She understands where I'm coming from. She listens and she knows where I'm coming from (P3).* People valued support workers who understood them: *you work with people with mental illness. You know what's like (P17).* The photos people took often included a support person who had been important to them. The participants spoke easily and often about these individuals who they trusted and valued, which included people from community mental health, pharmacists and psychologists, for example.

It was interesting that while we struggled for specifics, participants were determined to tell us that being made to feel comfortable, included and cared for, was essential: *the people are beautiful here. And they make you feel like part of the family when you walk in (P1).* It is often the little things that count, or demonstrate to people that they are cared for: *When I can I just pop in and they'll make me a cup of tea! That's lovely (P23),* or an act of kindness that is enduring: *one of the nurses brought me that little – guardian angel or something – and it had a little card that goes with it. So I always have that on now so when I'm not well I stroke that (P19).* This is not frivolous, or a nice add-on to service provision. People were clear that these qualities were often lifesaving: *If they didn't have a heart they wouldn't be in their jobs that have kept people like me alive (P19).* This participant also adds continuity and persistence to the qualities that are necessary for effective provision of services. People appreciated stable but flexible community based services which are available over time so they can dip in and out according to the sporadic nature of their illness.

Just listening

Come in for a cup of tea' and there's someone I can talk to about...just being here is enough (P 23).

Previously we have noted that support people and being listened to were pivotal moments for participants. We also noted that not being

heard, listened to or taken seriously were often everyday experiences of continued stigmatisation and possible abuse for people. Being listened to was a very strong theme in the data: *He's been comin' around and seein' me and pickin' me up when I'm feelin' down and just by bein' there and talkin' to me – yeah – but he's been a great help (P17)*. Just the seemingly simple act of being able to tell their story to someone who takes the time to listen, to not judge and who shows empathy and skill in listening, is life changing for people: *I was tellin' 'em how I was feelin' and how I been drinkin' that much and ended up goin' there and see if I can speak to Louise or Sue and they just sat down and listened to me, what's happenin'?* (P14). People want to feel safe in telling 'what's happenin': the listener has to suspend judgement and provide the opportunity and space for people to speak, in this example, about drinking too much.

It was also important that people felt the listeners had the skills to offer concrete suggestions and advice if they wanted it: *Talking to someone and realising that I'm not the only one that gets in these downers and things like that and I think the biggest thing is knowing I've got that backup there if I get really down I can ring Gaby or Karen and they will help me in some way. They'll work out something (P22)*. All of this requires well developed communication skills, staff with good mental health literacy and, according to our participants, preferably with some personal experience.



Material help and skills development

They took us to places like that. Took us down the street – to places to get over our anxiety ...and stuff. To help us with stuff like that...when people fund these sort of places they help us as well to go places... To get out even if it's to go down the street or to go to the shops or wherever (P15).

It was clear from the data that services had taught people specific skills and strategies to look after themselves and to do what they can to manage their illness, *when I'm mad I get a piece of paper and write down what's the best thing to do when you're stressed (P14)*, including rituals and processes for working with grief, financial planning, setting goals and learning life skills: *The help they gave me – their support – like when I come here – the programs...The programs that they did with me. ... Like your goals and what you sort of want to look forward to in life... I probably wasn't the nicest person and I had a lot of regrets and they really helped me out and really gave me a lot of directions and I owe a lot to them (P15)*. This was done either individually or in specific groups, such as life skills, wellness and other psycho-educational groups. Skills development that was tailored to the individual by helping them work against patterns of behaviour that are anti-social and limiting were appreciated: *Yeah they've helped me become the person I am now... I was pretty upset and angry – I was very angry. I had an anger problem which I was trying to control and they've helped me work it out. (P13)*.

The data shows that within a trusting relationship people are willing to confront and change behaviour and to address painful and difficult histories in order to work towards a hopeful future. Participants voiced that service providers need to be able to address these difficult issues with respect and a willingness to support a client's dignity of risk. At the same time providers need to express and sometimes hold the hope that difficulties such as drinking too much or anger can be overcome. Other examples of everyday support that people found helpful included: being

taken to different coffee shops, or into town; being told about courses at the local TAFE; having an advocate for them in negotiations with Centrelink; help in understanding their medication/s; support in getting more stable housing; and being given information about what is available in the community: *She's been good. She told me that I can join the library for free and use the internet and computers down there (P16)*.

Services working together

That's where we have our super clinic that I like to call it and I meet with a psychiatrist, a counsellor, dietician, a health nurse – all on the same day and it's really been very helpful to my mental health improvement (P 21).



No one actually said 'yes it's good that services work together'; but we had numerous examples of people talking about being referred, or of a service provider telling them about a counsellor, or a life skills course. People were articulate about having a team to rely on when they needed it. Word of mouth and being told about another service by someone they were already in relationship with and who they trusted, was effective: *that's our counsellor – was helping me – sending me to the right people (P4)*. Using a collective impact framework (Kania and Kramer 2011) is successful. It foregrounds collaborative work between clinical and non-clinical services and key support people, with the person at the centre, and provides supportive and individually tailored services which people appreciated and used.

The pros and cons of living regionally

Just being able to get out and have nothing but trees and things around me – it calms me. When I'm in crowds the anxiety just goes sky-high. At the same time it's very lonely so it's kind of a double-edged sword a bit (P 21).

Our research of service provision in regional and rural living gave rise to mixed data. There were differences across participants with some feeling that they had access to all they needed with *just enough services (P6)* and others being quiet clear that their town did not have adequate services. There were also differences depending upon which regional centre people were accessing. Participants lived in multiple towns and surrounding areas within Western NSW including; Orange, Mudgee, Dubbo, Wellington, Narromine and Baradine. Dubbo and Wellington were seen as lacking services, by various participants *No, it's very bad, especially in Wellington... It's very, very limited and that's why I have to travel to either Dubbo or Orange to get professional help (P9)*. Data also showed that Regional centres have their advantages, everything is so close... *You go five minutes this way, a minute that way you're somewhere else and you can do your shopping (P23)* and disadvantages, *in the country a person with depression can easily fall through the cracks because of the tyranny of distance. The sheer volume of people, like we've only got one doctor here in town ... you know if you can't get in to see them – like I was when I took the overdose (P15)*.

The issue of access to services and travel distances was raised by two of the three consumer reference group participants whose role it is to advocate for people in the region living with mental illness: *And with the*

drug and alcohol problem there it's just a place – and because there's people who don't have transport – how are they supposed to travel to Dubbo or Orange to get help? (P9). Interestingly, an analysis of service availability within the region showed that Dubbo, for example, has more services available than Mudgee. Yet, overall, participants within Mudgee spoke more positively about service access and availability than those in Dubbo. What this finding potentially highlights is the importance to participants of community and community based services working collaboratively to fill possible gaps. It also highlights the importance of natural and mainstream supports (such as a pharmacist) working together to create safe and inclusive places for people with complex mental illness.

During the course of the research, two participants travelled three hours each way to take part in the workshops and interviews. Others travelled, on average, between thirty minutes and one hour. Very few participants drove and had access to a vehicle (10%). The participants who did not walk to their interviews were driven by peer support workers or taxis funded by the research project. Public transport is almost non-existent between towns and this is compounded by unemployment/ underemployment and limited finances which impacts ability to purchase other means of travel for the three hours it might take to access the nearest adequate service.

Loss of power and control

The very first time when I was put in hospital it felt like a jail ... that's exactly what it felt like. Jail (P19).



Powerlessness and loss of control over themselves and their bodies was a strong theme in terms of what does not work for people. The research participants were grandmothers, fathers, workers, volunteers, pet owners, artists, musicians, furniture restorers, students. They were people who, when well, were self-determined and sometimes, jet setters. They demonstrated insight into their illness, their need for support and their ability to ask for and receive help. They understood that sometimes people need a whole range of services and at other times they are fully self-determined. It is against this context that participants spoke about experiences where control was lost, or taken away.

Loss of control could be due to medications which many participants stated made them tired, affected their motivation and had significant health effects *it's the medication that makes you suicidal and anxious and shaking. It's changed my mood and makes you worse (P7)*, and often affected their weight resulting in many previously sporting people no longer being active. This can have a direct impact on social isolation. The data clearly shows that participants accepted the need for clinical services for medications, treatments such as ECT, periodic hospitalisation, or as safe places to ensure they stayed alive, *Well I can go and self-admit, and that was very hard for me to do but I needed to because I wasn't safe. I knew if I stayed out I'd for some reason... I'd pretty well die (P11).*

At the same time there was a strong theme of mistrust and scepticism of the clinical environment and the way people were often treated. There

were many references to jail, bars, and losing their freedom, *so yeah I went into hospital and then they wouldn't let me out when I wanted (P11)*. Many people spoke about the lack of green spaces or the ability to go outside, even when they may be in hospital for many days, even months. The same was true of medication, most people did not question that they needed it but they were sceptical about the types, the amounts, the side effects, *I was on medication but I was O/D-ing on it and I didn't know... So now it's good but I still go back and think about that and think, 'Oh my God! How overwhelmed I was on that medication!' (P1)*. People had insight and knew they often needed help. But how and where that help was provided was often lacking: *lock you up in closed wards and courtyards. Used to be able to wander in the grounds not now, big high fences in there with shocking people. Everything high security like being in goal padlocked in, forced medication. Tablets, needles 'don't tell her we've upped her dose'... Turn the attitude around get rid of people that don't care. The mental health system ruined my life and it's worse than my original problems... Being locked up is not helping (P7)*. As we can see, people are clear that they need clinical support and interventions and they are also clear that they need them to be person-centred.

Culture clash

People are more than a chemical imbalance (P7).



The data shows that one of the difficulties for people is the contrasting approaches between services. Non-clinical services are supporting people to be self-determined and make choices, to take some control of their lives and get the help they need. However clinical services have not fully embraced a client/person centred culture where people are seen as being able to make choices, with support, and where there is a model of negotiated care. This leads to a clash of cultures which clients have to move between, often to their detriment: *I know they were trying their best – from their perspective, I understand that but I had a bit of a falling out with them because we were trying a new medication for me and that and well, it just didn't work and I wanted to go back on my old medication and I think from that point on really my relationship with them deteriorated quite rapidly to the point where one day I thought I was just going in for a meeting and I got told that was it, I was out of the service. Yeah, they actually kicked me out. I wasn't aggressive to them or nothing but I did take umbridge at a couple of things that the psychiatrist said to me but I didn't like go bezerk or anything. Yeah but I got kicked out of their service (P2)*. A difficult or challenging history with a service remains with people impacting their relationships and future choices, perhaps putting them at risk. The PIR model recognised that people living with mental illness should not be expected to negotiate between these two cultures, or do culture change work. It therefore implemented a collective impact approach (Kania and Kramer (2011) to bridge the two cultures. The data indicates there is still room for further improvement.

CONCLUSION

This one year research project operationalised an innovative methodology informed by the principles of recovery, trauma-informed practice and collective impact to further develop knowledge and understanding of mental health recovery from the perspective of people living with mental illness. The aim was to inform policies and funding models that shape community options for people with lived experience of mental illness in regional and rural NSW. Those living with severe and persistent mental illness are among the most disadvantaged and stigmatised in society (Henderson, Evans-Lacko and Thornicroft 2013). The Partners in Recovery (PIR) initiative aims to better support people living with severe and persistent mental illness by providing a coordinated system response to their mental health needs (DoH a). However, community-managed mental health organisations are 'not well described in current data collections' (AIHW 2014:386) which implies that what they do and how effective they are may not be well understood.

For this reason, the qualitative methodology used in this research placed the voices of research participants at the centre of knowledge production. The findings demonstrate that people with severe and persistent mental illness have the capacity to communicate not only their stories of recovery, but also clear suggestions for improving the services that impact their everyday lives. People with lived experience of severe and persistent mental illness and complex needs were asked about how their lived experience of mental illness shaped their identity, relationships and social inclusion; what effect living in regional and rural NSW has on this lived experience; and, finally, what they have found helpful and supportive in their recovery journeys. The participant's self-generated stories, photographs, insights and aspirations provided rich data that was distilled into four main themes: connection and belonging; learning to dance in the rain – survival; contributing to the social fabric; and service provision- what works and what doesn't?

The themes showed that being connected is as fundamental to successful recovery as clinical and non-clinical services and supports. However, connections to nature and wild places, animals, personal histories, family and spirituality were shown to be just as important to recovery, identity and wellbeing as social connections. The research also revealed powerful stories of loss, grief, struggle and stigma, which was often internalised such that people were no longer shocked by their own stories of abuse. At the same time, there were stories of hope, renewal, acceptance and perseverance with people actively developing their identities in positive and self-determined ways. Furthermore, the research participants positioned themselves as active members of networks of relationships, contributing to the social fabric through working, caring, volunteering, and sharing their knowledge and experience. The need

to be heard and have their knowledge and experience respected was clearly conveyed in the data through the importance given to service providers seeing clients as whole people and working with them toward goals in a collaborative and respectful way.

The findings of this research are congruent with the philosophy and practice promoted by the recovery movement and they give rise to a number of key recommendations. First, that the core principles of the Partners in Recovery (PIR) model be maintained and expanded to include trauma informed practice across all service settings; second, that service impact and outcomes can be increased through broadening definitions of 'connection' in policy and practice to include nature and wild places, animals, spirituality, personal and family history and memorabilia; third, that regional communities should take a greater responsibility for their role in developing tolerance, acceptance and belonging for people living with mental illness, in this way being part of the solution to reducing stigma and discrimination towards their citizens; and, fourth, further develop and prioritise systems, procedures and opportunities for service users to speak and be heard and to be treated with respect and dignity, no matter how complex their needs.

FUTURE DIRECTIONS

The findings and recommendations stemming from the service-users perspectives in this project prompt three clear areas of further investigation. The first emerges from the 'culture clash' evident between many of the non-clinical services and clinical services that have not fully embraced the client-centred recovery model. Workers in the respective systems are the point of departure for uncovering what works well in the space between the different logics of service systems on the one hand and service-users on the other. The perspectives of the clinical and non-clinical workforce constitute a potentially significant voice for mapping the 'missing middle' in mental health service provision with a view to more adequately working with people across intensive clinical support and social support. Second, the current research needs to be expanded to include a comparative study in other regions and states with a focus on remote and urban areas to explore if and how the findings of this study resonate nationally. A third, related, area for further inquiry is developing the recovery informed research methodology piloted in this study to further explore sense of place and the centrality of companion animals in the recovery journey. This combination of methodology and a focus on place and animal led recovery practices is potentially ground-breaking.



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APPENDICES

1: PARTICIPANT INFORMATION SHEET

Participant Information Sheet

School of Social Sciences and Psychology
University of Western Sydney
Locked Bag 1797
Penrith NSW 2751
Australia
Telephone: 02 4736 0093



You are invited to participate in the following project: *“Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place”*. Your participation is completely voluntary and you can withdraw at any time. If you don't want to participate that is perfectly fine and your decision will not affect your ongoing involvement with Partners in Recovery. Participation in the project may reveal your identity to others.

We are looking for 26 ongoing clients, including up to 10 consumer advocates, with Partners in Recovery (PIR) in mid-Western NSW who wish to share their stories of recovery from mental illness through photos and voice narratives. The project will use photos and voice recordings of clients to capture stories of recovery. The project will result in a regional exhibition of the photos and accompanying stories as part of a community awareness campaign. To participate in this project it is important that you already have a support network in place that you can use if you need to, this could include a support worker from PIR.

The project is a partnership between The Benevolent Society (TBS) and the University of Western Sydney (UWS) School of Social Sciences and Psychology and is funded by Western Medicare Local. The project is being conducted by Professor Debbie Horsfall (UWS School of Social Sciences and Psychology) and Amie Carrington (Community Programs Manager, Mudgee, and The Benevolent Society).

What will I be asked to do?

There are 3 things we will ask you to do if you chose to be part of this research project:

1. **Attend a 2 hour photography workshop which will be audio recorded.** The workshop will be about using cameras and taking photos to capture your recovery story. The workshop will be audio taped and transcribed. We will also discuss 'how to tell your story'. There will be about 8-10 other people at this workshop. We will provide you with a camera and develop all the photos you take with that camera. You will be given a copy of the photos you take. The workshops will be held at the most convenient location for everyone attending. We will pay your travel expenses to attend the workshop. If you like, you can bring a support person with you to the workshop.
2. **Take photos and participate in follow up via email / phone in the following two weeks.** In the two weeks after the workshop you will take photos which illustrate your recovery journey. These photos may be of a place or item or something that represents an activity (e.g. a park; a cup of tea; looking out of a window). Sometimes the subject will be people. No images of people will be used unless with specific consent. The Senior Research Officer, Joy Paton, will ring or email you, 2-3 times during these two weeks to see how you are progressing. She will also support you with this project if you need it. She will take notes about the conversations you have. These notes will be about the research and how it is going.
3. **Participate in a follow up face-to-face interview to discuss the photos and your narrative.** Roughly two weeks after the workshop we will organise an interview with you and either Joy Paton or Debbie Horsfall. We will meet at a time and place that suits you. At this interview we will discuss the photos you have taken and talk about your recovery story. Together we will decide if you want to write your own story or if you would like us to write it based on what you tell us. We will also choose the photos that you would like to have put in an exhibition with the other people in this research. This interview will be audio recorded and transcribed. We will show you a copy of the transcript and you will be able to delete anything you do not want included. If you like, you can bring a support person with you to the interview.

You can also choose to be a part of the following optional extra activities:

1. Be part of a group of people who will organise and curate the exhibition of photos and stories from the project.

2. Attend a 2-3 hour celebration of this exhibition with other people from the community, the research participants and the people who funded the research.

The details for these two activities will be worked out with all the research participants during the project.

How much of my time will I need to give?

- 2 hours for the initial workshop;
- 15-20 minutes for each follow up phone call or emails;
- 2 hours for the interview; and
- It's up to you how long you want to spend taking photos to illustrate your recovery journey and how long to want to spend writing the narrative that is included with your photos

Total: 4 hours and 40 minutes plus however long you want to spend writing your narrative and taking your photos

What specific benefits will I receive for participating?

There are no specific concrete benefits for you. However, you will receive copies of the photos you take and help with writing your recovery story. Your work will also be part of an exhibition in your local area. You will get the chance to tell your story in the way you want to and make that story public. You will have your travel expenses paid for attending the workshops and interviews.

Will the study involve any discomfort for me? If so, what will you do to rectify it?

Telling your story and thinking about mental illness and recovery may be upsetting. If at any time during the workshop or interviews you become distressed you can tell us (or we may notice) and we will stop what we are doing and talk with you about your distress. You are also encouraged to bring a support person to the workshop and interview. You can also decide to stop being part of the research at any time. As we are interested in stories of recovery though you may find that it is helpful for you to talk about what has helped you and what you have found useful and supportive in your journey. If you find you are distressed after the workshop or interview, please contact your usual supports (e.g. support person, GP, counsellor etc.) and/or contact:

- Lifeline 13 11 14 (24 hours)
- Suicide Call Back Service 1300 659 467 (24 hours – call and leave a message, they'll call you back)
- Mental Health Line 1800 011 511 (24 hours)
- Beyondblue 1300 22 4636 (24 hours)
- Mental Health Association (9 am to 5 pm Monday to Friday)
 - Mental health support and referral 1300 794 991
 - Support for people with anxiety disorders 1300 794 992

Please also tell us if there is a particular person you would like us to contact during the research if you become distressed.

How do you intend to publish the results?

Please be assured that only the researchers named above will have access to the raw data you provide. The findings of the research will be published as: an exhibition; a report to the Benevolent Society and the funding body; as conference papers and journal articles. We will not use your name or any identifying material in any publications. UWS and TBS will work hard to maintain your privacy. However if you include a photo of yourself in the exhibition then people will know who you are. We will discuss this in the workshop and interviews.

Please note that the minimum retention period for data collection is five years.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do participate, you can withdraw at any time without giving a reason.

If you do choose to withdraw, any information that you have supplied will be returned to you and/or deleted.

In the case of the workshop which is a group activity, we cannot erase your material but we will make sure we do not refer to anything you said in the workshop.

Can I tell other people about the study?

Yes, you can tell other people about the study by providing them with the contact details of Joy Paton or Debbie Horsfall. They can contact Joy or Debbie to discuss their participation in the research project and obtain an information sheet.

Data storage The information you supply will be stored securely and it will be de-identified before it is made to available to any other researcher.

What if I require further information?

Please contact Joy Paton or Debbie Horsfall should you wish to discuss the research further before deciding whether or not to participate:

Joy Paton, Senior Research Officer, School of Social Sciences and Psychology.

Email: joy.paton@uws.edu.au

Phone: 02 4736 0998 or 0497 304 276

Debbie Horsfall, Professor, School of Social Sciences and Psychology.

Email: d.horsfall@uws.edu.au

Phone: 02 4736 0093

How is the study being paid for?

The study is being sponsored by Western Medicare Local, Partners in Recovery Program.

What if I have a complaint?

This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is: H11225

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form.

2: RECRUITMENT FLYER



Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place

*Would you like to tell us your story using photos and narratives?
Would you like to have your work exhibited locally so that people have
the chance to understand your story?
If so we would like to hear from you.*



This research is a partnership project with the University of Western Sydney and the Benevolent Society. It will use photo voice to tell stories of recovery from regional and rural NSW. There will be a regional exhibition of the photos and stories as part of a community awareness campaign.

To participate you must be:

- over 18 years of age
- have been a participant of Partners in Recovery in mid-Western NSW
- be able to provide consent to participate and
- have a wellness plan already in place

The first workshop will be held **10.30-12.30pm Wednesday 30th September at the Uniting Church, Mortimer Street Mudgee** (across the road from Woolworths) - refreshments and all materials provided

If you would like some more information about the project, or you would like to participate, please contact the researchers:

Joy Paton - Email joy.paton@uws.edu.au

Phone **0497 304 276** or 02 47360998 (Tues & Wed, or leave message); or
Debbie Horsfall – Email d.horsfall@uws.edu.au Phone 02 4736-0093



Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place

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To participate you must be:

- over 18 years of age
- have been a participant of Partners in Recovery in mid-Western NSW
- be able to provide consent to participate and
- have a wellness plan already in place

The consumer reference group workshop will be held **11.00-1.00pm Thursday 8 October at the Benevolent Society, 160 Church Street, Mudgee** - refreshments and all materials provided

If you would like some more information about the project, or you would like to participate, please contact the researchers:

Joy Paton - Email joy.paton@uws.edu.au

Phone **0497 304 276** or 02 47360998 (Tues & Wed, or leave message); or
Debbie Horsfall – Email d.horsfall@uws.edu.au Phone 02 4736-0093



Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place

*Would you like to tell us your story using photos and narratives?
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the chance to understand your story?
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This research is a partnership project with the University of Western Sydney and the Benevolent Society. It will use photo voice to tell stories of recovery from regional and rural NSW. There will be a regional exhibition of the photos and stories as part of a community awareness campaign.

To participate you must be:

- over 18 years of age
- have been a participant of Partners in Recovery in mid-Western NSW
- be able to provide consent to participate and
- have a wellness plan already in place

The next workshop will be held **10.00-12.00 noon Tuesday 10 November** at the **Dubbo Western Plains Cultural Centre** (Coolabah Meeting Room) - refreshments and all materials provided

If you would like some more information about the project, or you would like to participate, please contact the researchers:

Joy Paton - Email joy.paton@uws.edu.au

Phone **0497 304 276** or 02 47360998 (Tues & Wed, or leave message); or
Debbie Horsfall – Email d.horsfall@uws.edu.au Phone 02 4736-0093



Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place

*Would you like to tell us your story using photos and narratives?
Would you like to have your work exhibited locally so that people have
the chance to understand your story?
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This research is a partnership project with the University of Western Sydney and the Benevolent Society. It will use photo voice to tell stories of recovery from regional and rural NSW. There will be a regional exhibition of the photos and stories as part of a community awareness campaign.

To participate you must be:

- over 18 years of age
- have been a participant of Partners in Recovery in mid-Western NSW
- be able to provide consent to participate and
- have a wellness plan already in place

The next workshop will be held 2:00 – 4:00pm, Monday 8 February at Wellington Neighbourhood Centre (27 Swift Street, Wellington) - refreshments and all materials provided

If you would like some more information about the project, or you would like to participate, please contact the researchers:

Joy Paton - Email joy.paton@uws.edu.au

Phone **0497 304 276** or 02 47360998 (Tues & Wed, or leave message); or
Debbie Horsfall – Email d.horsfall@uws.edu.au Phone 02 4736-0093

3: WORKSHOP SCHEDULE

Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place.

Photovoice workshop schedule

The workshops will run for 2 hours and will be co-facilitated by the SRA and CI. The purpose of the workshop is for people to learn about photography and decide on the parameters for their photo assignment (e.g., how many pictures each person would take; whether or not to include people in the pictures; the focus of the exercise which is stories of recovery). The workshop will be audio taped and transcribed.

1. Welcomes and introductions including signing of consent forms. 10 minutes.
2. Overview of the Photovoice technique including some examples. 15 minutes
3. Distribution of cameras and Q&A. 15 minutes.
4. Brainstorming/discussion of the sort of photos people could take with reference to hard copy examples provided by researchers. Remind people that it is entirely up to them which photos they take and why. There is no right or wrong photo. 15 minutes.
5. Practical where people will take photos of items and the environment at hand with a supplied digital camera. These will then be discussed in terms of the quality of the photo; if the person captured the image they wanted to, what the image meant to them. Techniques and tips will be shared and exchanged. 45 minutes.
6. Conclusion Q&A and reminder of the focus of the photo assignment over the next two weeks. i.e. to take photographs of things that illustrate your story of recovery. 20 minutes.

4: INTERVIEW SCHEDULES

Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place.

Telephone/email follow up schedule

The participants will have indicated at time of original consent whether they wish the follow up to be via telephone or email. Either way the questions will be the same. This stage will be in a conversational style. The RA will take field notes of the conversations.

1. Hellos and check in. How is it going?
2. Have you managed to take any photos? If yes: can you tell me what of and what that has been like? If no: have you some ideas about how you might start? Is there something you want to take a photo of but feel you can't? What needs to happen for you to get started?
3. Has it been easy for you/difficult? Tell me a bit more about that.
4. Do you think you have finished/nearly/soon? (Remind people of the process for returning the cameras and set date and place for interview).

1:1 Interview schedule

The interviews will be conducted at a mutually convenient place. If in the persons home we will follow the already existing Benevolent Society protocols for home visiting which included a risk assessment having been complete (see attachment). Interviews will last 2 hours and will be audio taped and transcribed. They will be conducted by either the RA or CI.

1. Introductions. Renegotiating consent. Remind people it is a research project, check that they are still happy for the interview to be audio recorded. Remind them about how the photos could be used. Signing of 'use of photos' consent form. Brief description of the purpose of the interview: to discuss the photos; to choose photos for the exhibition and to begin to develop the person's narrative/story.
2. Looking at the photos together over light refreshments. This stage also includes the throwing away of any photos people do not wish to be used in future.
3. Prompt questions for discussion:
 - What is your overall impression of the photos?
 - What stood out to you/interested you?
 - Do you think there are any connections/similarities between some of the photos?
 - What do you think the photos 'say' overall, about you, about community and/or belonging?
 - What do they say about recovery and about what is supportive and helpful?
 - Do they say anything about 'place' or living in the bush/regional/rural NSW?
 - What do they tell us about this experience and how we help each other?
 - Are there themes or an overall message?
4. Which photos do you think you would like to use for the exhibition? Which speak most clearly and powerfully about what you want to say/tell others?
5. Now we need to think about writing a page or so which captures the things you want to say/your story. Shall we start doing this now? Do you want to think about it and get back to us with some ideas? Would you like us to write a draft and then send it to you?
6. To finish agree on time frame for writing the story/narrative and clarify roles.

5: CONSENT FORMS



Human Research Ethics Committee, Office of Research Services

Participant Consent Form

This is a project specific consent form. It restricts the use of the data collected to the named project by the named investigators.

Project Title: *Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place.*

I, _____ [name of participant] consent to participate in the research project titled *Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place.*

I acknowledge that:

I have read the participant information sheet [or where appropriate, 'have had read to me'] and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I consent to (please tick the box next to things you agree to do)

1. Attending a 2 hour workshop on Photovoice and narrative. The workshop being audio recorded. I understand that I can bring my support person with me to this workshop.
2. The Senior Research Officer contacting me 2-3 times after the workshop to support me in taking the photos for the project. I would like this to be via the telephone/email (cross out the one which you don't want). This will take about 15 minutes and notes will be taken about the research process.
3. A 2 hour interview at a mutually convenient place to discuss the photos I have taken and to begin to write my story. I consent to this interview being audio recorded and transcribed. I understand I will see a copy of the transcript and can delete anything I want to. I understand my support person can attend the interview with me if I want them to.
4. Having the photos I select and my written narrative exhibited locally at the end of this project.
5. Being part of the group which plans and curates the exhibition.
6. Attending the celebration at the end of the project.
7. Please contact _____ if I become distressed at any time (but check with me first if possible).

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity unless I have given consent to be identified.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s and /or Partners in Recovery now or in the future.

Signed:

Name:

Date:

Return Address: Dr Joy Paton or Professor Debbie Horsfall

School of Social Sciences and Psychology | Penrith (Kingswood campus) | University of Western Sydney Locked

Bag 1797 | Penrith NSW 2751

Ph: 02 4736 0998 or 02 4736 0093

This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is: H11225

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229

Fax +61 2 4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Participant Consent Form – Use of Photos.

This is a project specific consent form. It restricts the use of the data collected to the named project by the named investigators.

Project Title: *Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place.*

I, _____ [name of participant] consent to the photos I have given the researcher being used in research project titled *Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place.*

I acknowledge that:

I have read the participant information sheet [or where appropriate, 'have had read to me'] and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I consent to my photos being used in the project. This may include them being used in conference presentations, reports about the project and journal articles.

I also realise that this may mean that they become visible on the internet.

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future.

Signed:

Name:

Date:

Return Address: Dr Joy Paton or Professor Debbie Horsfall

School of Social Sciences and Psychology | Penrith (Kingswood campus) | University of Western Sydney Locked Bag 1797 | Penrith NSW 2751

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Ethics Committee, Office of Research Services

Participant Consent Form – Use of Photos with an identifiable person in them

This is a project specific consent form. It restricts the use of the data collected to the named project by the named investigators.

Project Title: *Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place.*

I, _____ [name of participant] consent to the photo of me being used in research project titled *Stories of Recovery from the Bush: unravelling the experience of mental illness, self and place.*

I acknowledge that:

I have read the participant information sheet [or where appropriate, 'have had read to me'] and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I consent to my photo being used in the project. This may include them being used in conference presentations, reports about the project and journal articles.

I also realise that this may mean that they become visible on the internet.

I understand that if these photos are used then my involvement is not confidential and people will know who I am.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future.

Signed:

Name:

Date:

Return Address: Dr Joy Paton or Professor Debbie Horsfall

School of Social Sciences and Psychology | Penrith (Kingswood campus) | University of Western Sydney Locked Bag 1797 | Penrith NSW 2751

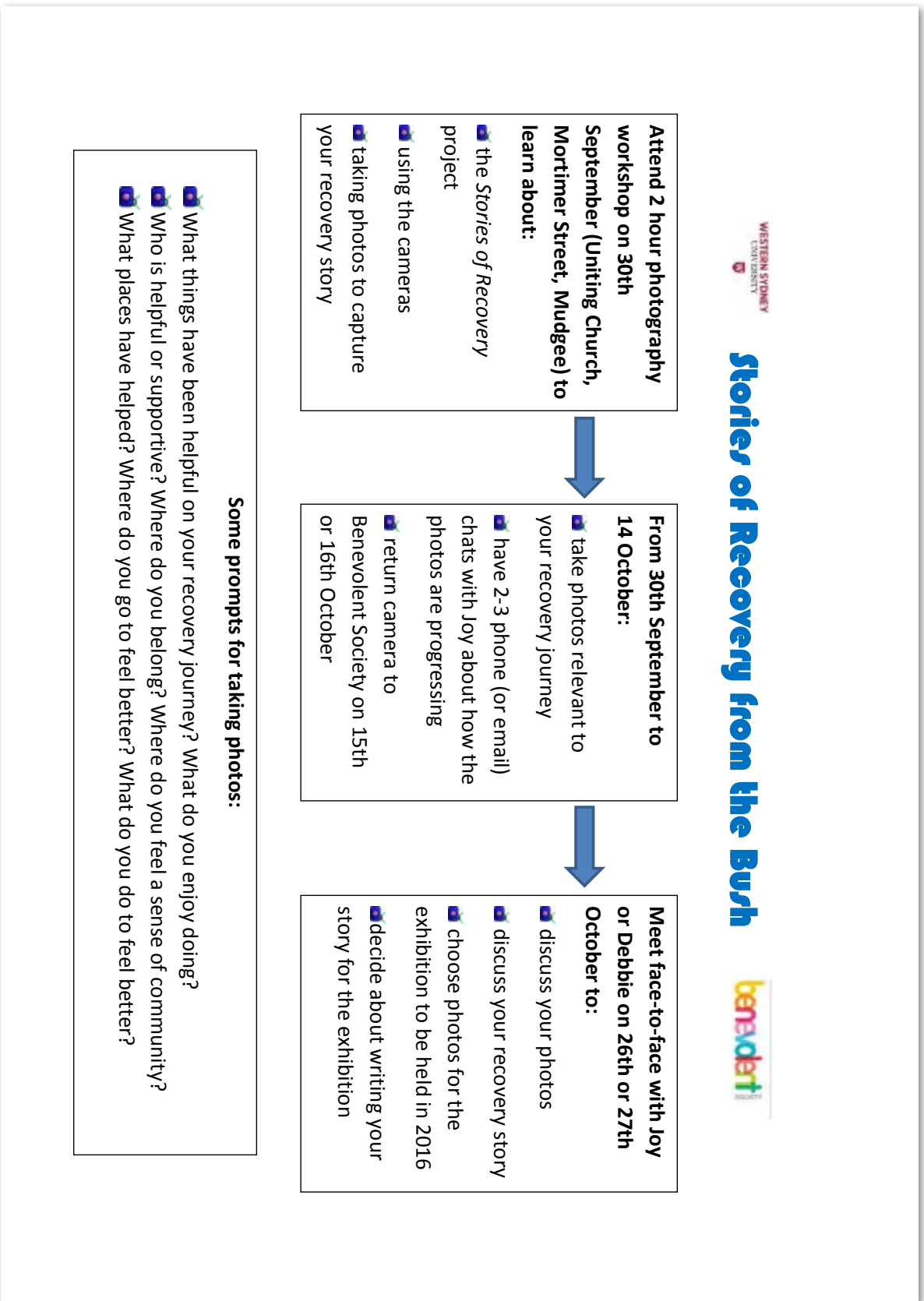
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Fax +61 2 4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

6: FLOW CHART FOR PARTICIPANTS





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