Lived experience engagement in mental health research: Opportunities for UniSA’s Mental Health and Substance Use Research Group

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Introduction

Engagement with people with lived experience is at the heart of mental health research undertaken by the UniSA Mental Health and Substance Use Research Group. The last decade has seen increasing activity, writing and practice in lived experience engagement in health research. This has occurred alongside policy and practice initiatives in engagement in health service planning and delivery.

Within the mental health field, consumer and carer engagement has a long history, and there has been considerable activity in defining engagement in the research space (Rose, 2013). This includes involvement at different levels – from user lead research initiatives, partnership approaches, and examples where people with lived experience are engaged in specific roles e.g. as consumer/carer interviewers (Rose; 2013; Syrett, 2011).

The aim of this newsletter is to communicate our basis for building capacity of consumer and carer engagement in the research activities of the Mental Health and Substance Use Research Group. The first part will provide a brief context of the topic, highlighting key themes about effective engagement and linking to other Australian work in the area. Secondly, the newsletter will report on the consultation process undertaken with consumers, carers and clinicians associated with MHSURG. In late 2016 a group of members met to discuss their views on priority research topics, effective strategies and principles for involving people with lived experience, and various support and educational needs. The outcomes of this consultation will be used to establish the guidelines for how MHSURG can improve engagement in the future. The data contained in the section below in this newsletter are the early origins of what will eventually become guidelines. We invite your comments and feedback.

1 Throughout this paper ‘people with lived experience’ includes community members that have personal experience of illness and also carers. The terms consumer and carer are also used to align with national mental health policy and language. Readers should note that in general health policy, the term consumer is used to include both people with experience of illness and carers.
Key themes in the literature

Understanding successful engagement practice requires us to consider many factors in the organisational environment, and the various interests, skills, knowledge and experience of research leaders and people with lived experience. Strategies include activity in changing cultural expectations of involvement, work in defining the roles of lived experience researchers and partnership structures, educational programs to develop the skills of all researchers in engagement practice, and the need for leadership and involvement at the governance level. Support strategies and specific resourcing of engagement e.g. for sitting fees and administration are also commonly mentioned. Many of these aspects are detailed by the NHMRC’s (2016) recent ‘Statement on Consumer and Community participation in Health and Medical Research’. This statement also provides key rationales for the importance of engagement. These include the benefits of relevance, shared knowledge and social responsibility, improved priority setting, research questions, tools and project design, increased consumer and carer ownership of research, and better levels of information dissemination.

Saunders and Girgis (2011), in reviewing examples of good practice, have proposed that engagement strategies can be located across four organisational areas of activity. These are activities at the governance level, those that develop infrastructure, those that build capacity, and strategies which promote advocacy. Their review explored successful engagement work across Aboriginal health, cancer care, mental health, child health and primary health research activity.

These organisational areas have been utilised in a local engagement framework which has been developed via partnership between the Health Consumers Alliance of SA and the SA Health and Medical Research Institute. The ‘SAHMRI’ framework also noted the importance of considering lived experience engagement at the different stages of the research process. This occurred by using the phases and stages model of Shippee et al (2013). This approach helps us to apply well known strategies of engagement to the common practices of research planning and activity. Engagement can therefore be considered across the stages of preparation, execution and translation and within the phases of priority setting, funding application, project design and procedures, recruitment and participation, data collection and analysis, dissemination, implementation and evaluation.

A further ingredient of the SAHMRI framework was to consider the levels of involvement and engagement. This was enabled by using the International Association for Public Participation (IAP2) Public Participation Spectrum. Commonly used by policy makers and in health promotion, the IAP2 Spectrum details five key themes to depict involvement: to inform, consult, involve, collaborate, and empower. At each of these levels, different expectations and goals shape the level at which consumers and carers are invited to engage in decision making, project activity and information sharing. Key processes and tools to facilitate each level of engagement are also highlighted with the Spectrum.

Engagement in mental health research

The mental health literature on engagement in research also explores levels of involvement, where commentary reflects the varying levels of the IAP2 Spectrum. An evaluation of 374 studies funded through the NIHR Mental Health Research Network (UK) reported considerable differences in the nature and strategies used for consumer and carer engagement. The authors identified that engagement tends to fall into four categories of being 1) consumer/carer initiated or controlled, 2) joint consumer/carer–researcher initiated collaboration, 3) researcher initiated collaboration, and 4) consultation (Staley et al 2013). In exploring the use and success of

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2 The SAHMRI framework was also built upon a substantial basis of research and consultation with local consumers, carers and communities (see e.g. Johnson 2014; Miller et al 2017). We acknowledge the contribution of this work for our preparation.
methods or strategies of involvement, the authors explored 45 particular research projects in more depth. They found that engagement methods could be summarised under three key themes. These are summarised as follows:

**Consumers/carers as contributors of research design:** The authors reported lived experience reference groups, focus groups and advisor roles being opportunities where lived experience perspectives can shape preparation and design. This included work in shaping research questions, identifying priorities, identifying outcome measures, and feeding back on questionnaires, study information sheets and recruitment processes.

**Consumers/carers as members of steering committees:** In these roles consumers and carers can play effective roles in advising on design and implementation aspects of the project. This requires well informed and supportive committee leadership to ensure people are well supported in their experience.

**Consumers/carers as co-researchers:** The authors also note significant success where projects employ lived experience researchers for the life of the project. These researchers can play roles in recruitment, facilitating focus groups and interviewing (Staley et al, 2013 p 1122-23).

The themes in this evaluation connect well with the knowledge emerging from other writing and experience in health research engagement. Staley et al note common challenges as describes by authors such as Shippee et al (2013) and Syrett (2011). These include the need for adequate education and preparation of research leaders, support and education for lived experience partners, having clear expectations about the scope and purpose of partnerships, and achieving genuine, transparent engagement.

There are examples of significant lived experience engagement within mental health research centres in the UK and Australia. This includes approaches based on empowerment and collaboration. Centres such as the Service User Research Enterprise (SURE) and the ACT Consumer and Carer Mental Health Research Unit (ACACIA) are established as user led research teams, whilst other centres have established partnership and collaboration approaches which involve strong relationships with consumer and carer networks and employing lived experience academics and causal researchers. These examples achieve a deeper level of involvement and focus compared to consultation and information based activities, where lived experience partners are less involved in decision making or project operations. User led or collaborative approaches enable consumers and carers to be engaged with the preparation stages of research, and involved across the life of specific projects.

**Consumer engagement and the MHSURG**

This scan of literature and practice indicates that lived experience engagement in health research requires changes to organisational culture and practice. This is especially the case for moving towards collaborative approaches as envisaged under the IAP2 Spectrum or by writers such as Shippee et al (2013). The breath of this activity indicates the importance of having a framework, or a road map which outlines the new areas of practice and how they can apply to new research projects or to the broader planning of a research group. For the MHSURG this road map is extremely important as it sends a message about who we are as a group, what we stand for and how we work with others. There are also emerging examples such as the SAHMRI framework which can inform this and related work.

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3 Kings College, UK – Rose (2013).
4 Part of the Centre for Mental Health Research, Australian National University.
5 See for example the Centre for Psychiatric Nursing, University of Melbourne, as one of the first Australian universities to establish a consumer academic position and research focus.
Consultation outcomes

In December 2016, the MHSURG held a consultation process to discuss views about lived experience engagement and to raise ideas and expectations about what could be achieved. The process asked people to work in small groups and consider the following questions:

- What is your vision for lived experience engagement in MHSURG activities?
- What levels of engagement and partnership could be facilitated by the research group?
- What are some priorities areas for research from a lived experience perspective?
- What are the supports and areas of skill development which would enable meaningful partnerships between consumer and carer leaders and academic researchers?

Facilitators ensured there were a mix of clinicians and lived experience participants at each table. The resulting small group and large group discussions provided a rich range of principles, ideas and experience, pointing to aspects of engagement practice detailed above. These have been briefly summarised and are presented below. The group responses have been organised under key themes:

Principles and culture

- Consumer/carer engagement as standard practice for increasing knowledge of key issues
- Consumer/carer perspectives to be included at the very beginning of the research process
- Consumer/carer driven, led and informed research activities – lived experience people to ask the questions rather than to answer them!
- Shared power and authorship
- A culture where consumers and carers feel welcome and can tell a story of their contribution
- Consumers and carers understand the scope and limitations of research activities (boundaries)
- Look at different levels of involvement, and engagement at different stages of research activity – design, data generation (interviews/ focus groups), communication, outcomes, evaluation, shared authorship (verbal and written)
- Ensure value and meaningful engagement – shared lived experience as a benchmark of meaningful engagement and knowledge on service standards.

Supports and infrastructure

- Appropriate reimbursement for involvement of consumers and carers
- Making sure lived experience researchers are skilled and ready – provide orientation and education on research processes. Look for learning opportunities.
- Provide info and supports regarding ethics, privacy and confidentiality
- Provide engagement training for researchers by consumers and carers
- Consider adjunct status for lived experience researchers and leaders
- Ensure the team environment is safe and supportive for engaged lived experience researchers and partners.
Consumer and community partnerships

- Youth focus and inclusion – from 16 years
- Consumers – clinicians also with lived experience
- Do regular invitations – write formally to state-wide Lived Experience Workforce group to get feedback and involvement
- Development of formal relationships with SA Health, not just the Office of the Chief Psychiatrist
- Support and consultation with LHNs/NGO sector on research activities
- Working with other universities to follow a similar model to UniSA to make this a state-wide commitment.

Priority topics and approaches for research

- Community based research, not just ED and inpatient care
- Episodic care and better ways of responding
- Knowledge of substance use and staff awareness of information
- Talking therapeutic for hearing voices – self enabling/empowering for people to manage their own voices
- Normalising experience – how to talk to consumers in an open and honest way
- Understanding alternative treatments and therapies
- Shared decision making and involvement in care planning
- Analysis and critique of incidents and consumer/carer feedback
- Trauma informed practice for older people experiencing mental health conditions
- Research that is practical, applied and has value at the point of care
- Write formally to state-wide Lived Experience Workforce group to get feedback and involvement
- Exploring the peer worker role in the ED in a general hospital – rural and remote
- Consumer led care
- Carer involvement in care – to what extent are carers being involved and what role does information sharing context play with respect to involvement?

Research practice and translation

- Disseminate outcomes broadly
- Ensure research publications have plain language summaries
- People with lived experience need to know they are listened to – feedback loop and transparency of where input goes
- Ensure research translates to practice so consumer and carers benefit from it
- Advocate for specific groups
- Use the UniSA Mental Health Podcast Series to connect innovation, research, and practice.
Next steps

The MHSURG plans to continue to work with these themes and strategies and begin to draft a set of principles and guidelines for lived experience engagement in MHSURG activities.

We would like to invite consumers, carers, clinicians and policy makers to provide further input and share your views on the important principles and practices of engagement. This can be done via our online consultation process, or in discussion with Dr Mark Loughhead, Lived Experience Lecturer, School of Nursing and Midwifery on 08 8302 1267. The online process is a short Survey Monkey questionnaire. It is available here: https://www.surveymonkey.com/r/LEengagement.

Feedback will be used to inform our next process, which will be to work with MHSURG members to discuss specific guidelines, goals and priorities for our work.

The Shared Learning in Clinical Practice Philosophy

Shared Learning in Clinical Practice is a policy relevant and service delivery focussed collaboration to promote best practice in mental health and develop professional skills. The strategic purpose of the initiative is to demonstrate through research and practical example how much consumers, clinicians, policy makers and academic faculty can achieve working together. Deep discussion, deep connectivity and diffusion of the insights are central to its philosophy. Multidisciplinary in composition, the aim of each publication, podcast, film, social media communication and symposium is to capture and spread new ideas and know-how in mental health practice and challenge traditional ways of thinking.

Further information is available from:
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References


Johnson A., 2013. What strategies for consumer engagement in health and medical research have been effective for consumers and researchers? A review of the literature. Health Consumers Alliance of South Australia.


