Australian Government
National Mental Health Commission

NATIONAL MENTAL HEALTH RESEARCH STRATEGY

BACKGROUND PAPER: Lived experience research (Session 3B)

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Introduction

People with lived experience of mental health issues, including people with personal experience (consumers) and people who live with, care for or support these individuals (carers) bring critical, unique knowledge to health systems and research.[1,2,3,4,5,6] Collaborative research, particularly in the health services space, improves the relevance and quality of research, and develops relationships that aid translation into programs, policies and practice.[3,7] Conducting research that actively involves people with lived experience in the process moves research from being done *for* people with health conditions to being done *with* or *by* these groups.

One of the strongest health consumer movements internationally has been in mental health.[5,8] Due to a history of human rights abuses and power struggles, mental health consumers are change leaders, and in many countries, the promotion of active involvement in research, policy and services is most prominent in the mental health sector.[9,10,11] However, the active involvement of people with lived experience (consumers, carers and families) and incorporation of their knowledge into research and the health system remains fragmented and deprioritised, hampering effective implementation.[4,5,12,13] Despite a long history of the consumer health movement,[14,15,16] and policy requirements for active involvement across the research and health sector,[17] work to actively embed experiential knowledge within our health research and system remains siloed.

Research that is lived experience-*led* is particularly fragmented and marginalised. This paper introduces some of the key challenges faced by lived experience researchers and presents opportunities to improve the incorporation of this unique workforce in the mental health research landscape.

Background

Internationally, there are many different conceptualisations of active involvement of health consumers and carers in research.[6,18,19,20] Although each presents a slightly different model, central to each is that involvement in research exists on a scale from no involvement of consumers and the community through to full control and leadership by these groups. Figure 1 is an illustration of one such model of partnership with people with lived experience in research using the contemporary language of co-creation, which outlines five levels of lived experience involvement.

As the focus of the current paper is on lived experience-led research, it is beyond the scope to engage in a detailed discussion of the lower levels of this model, except to say that there is rarely justification for not engaging with people at all, or involving them only to "tick the box." However, effective involvement is appropriate for the purpose and skills of researchers and people they seek to involve, and this is frequently

at the middle levels of the model.[20] Resources such as the National Mental Health Commission's practical guide to engagement[21] and the LifeSpan lived experience framework[20] provide key principles and practical examples of activities that apply to involvement across the service and research sectors for those seeking to establish activities such as advisory groups, co-design and co-evaluation. However, it is important when working in the involvement space to be mindful of the accuracy of language chosen to describe the involvement opportunity. The policy push for co-design and co-production[22] has in some instances led to a simple re-badging of traditional low level consultations as co-design, rather than a true change of practice to equal lived experience and researcher or policymaker voices. This has resulted in rapid disillusionment amongst people with lived experience, who are yet to see their hopes for greater partnership in research and reform realised.[23]
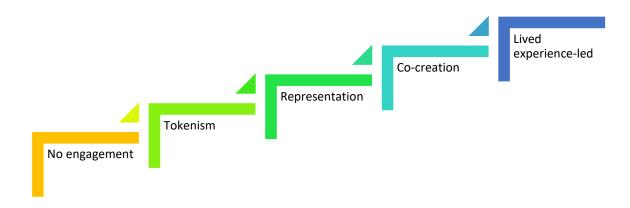

Figure 1: Levels of involvement

Level 1	No engagement	People have things done to them
Level 2	Tokenism	Enough engagement to tick the box
Level 3	Representation	At the table for advice, sometimes decision-making
Level 4	Co-creation	Equal partnership at all research stages
Level 5	Lived experience-led	Lived experience leadership of entire process

Lived experience-led research sits at the top of models of involvement. This level places control of all aspects of the research, from design through to implementation, in the hands of consumers and carers. From the perspective of ensuring experiential knowledge guides the topic, process, outcomes and uptake of the research, lived experience-led research is often viewed as the "best" form of involvement. There are many instances where this is indeed the case: lived experience researchers frequently succeed in sensitive areas where others may struggle (see for example Rose[24]). However, there are a number of challenges faced by lived experience researchers, and the remainder of this paper focuses on some of the key issues hampering progress.

Key issues

One of the core principles of lived experience involvement is that people who use or have used the health system are the best placed people to understand the problems and create solutions.[3,4,25,26] However, our conceptualisation of knowledge privileges professional expertise over the expertise gained by experience of health, illness and the health system.[27,28,29]

This leads to two key overarching issues for lived experience-led research: authenticity and recognition. Unlike the more practical challenges described in the next section, these issues are ideological and difficult to overcome. Progress on genuine lived experience leadership will require attention to these issues by constant, conscious resistance to the criticisms.

Authenticity

In order for lived experience researchers to fulfil the "expert by experience" role, it is critical that they not only have their own lived experience, including as a carer or family member, but they have connections to the broader mental health sector and an awareness of shared issues. There is significant risk of lived experience roles losing their authenticity for other people with lived experience if there is a perception that someone has been co-opted into the role who may not have these qualities. However, who judges this authenticity is also highly charged: as described in the next section regarding recognition, lived experience researchers can find themselves outsiders in both the lived experience and research communities.[1]

Recognition

The second major issue facing lived experience researchers is that of recognition of their expertise and research quality within the research and knowledge-user communities. This struggle for recognition is fuelled by two factors. By its nature, much lived experience research tends to be qualitative, as people with lived experience describe survey fatigue, and express a preference for telling their stories and identifying issues in their own words.[1] Qualitative research is often criticised for a "lack of objectivity" that stems from its interpretive nature. Compounding this, lived experience researchers are viewed as lacking objectivity by virtue of their experiential expertise. Whilst qualitative inquiry that focuses on experiential knowledge through a genuine connection is the strength of lived experience-led research, it can be difficult to publish and less attractive to knowledge-users, who find the simplicity of numbers more persuasive. Lived experience research that is conducted outside academia, for example through community organisations, is also rarely recognised.[1]

Challenges

Whilst the ideological issues represent concerns to address over the long-term, there are also some practical challenges that fall out of these key issues, which are more easily addressed. These challenges, listed below, are a useful place to focus early efforts to facilitate lived experience-led research as a part of the National Mental Health Research Strategy.

Lived experience-led research is an emerging area

Although the mental health consumer movement has a very long history, lived experience-led research is still in its infancy, particularly in academic research spaces. There are pockets of excellent lived experience practice in Australia, particularly in mental health, but all tend to be very small and subject to unstable funding. This creates the following challenges:

1. Lived experience researchers are still establishing our own research culture, including how to ensure authenticity;

2. Limited capacity means lived experience researchers tend to operate in isolation from one another, missing opportunities for collaboration and economies of scale;

3. Lived experience-led research has to establish credibility to compete with other types of research for funding and dissemination;

4. People who would like to get involved in the research process have limited opportunities, and they are difficult to find; and

5. There is a substantial amount of voluntary input, especially to early processes such as research design and funding applications, which reaps little reward due to low success rates.

Although some of these challenges are not unique to lived experience-led research, the connection that lived experience researchers have with other people with lived experience brings a higher level of expectation that the emerging workforce can find it difficult to meet.

Research and academic structures do not currently reward lived experience activities

Some structural challenges within the research and academic environments underpin the issue of recognition. Whilst the objectivity/subjectivity debate is likely to be ongoing whilst ever there are researchers with different ideological beliefs, the processes in place that reward research practice are able to addressed.

1. Peer review processes, particularly for competitive funding, favour particular research methodologies and definitions of scientific rigour, many of which are not compatible with lived experience-led research. The lack of substantial funding severely limits the scope and scale of research, particularly with the siloed workforce; and

2. Academic procedures such as promotions tend to focus on traditional metrics such as peer-reviewed papers, placing less weight on community engagement and implementation.

Opportunities

Several opportunities exist to support and enhance lived experience-led research, both from within the lived experience research effort and from the broader mental health research sector. Associated with these opportunities are goals to consider.

Within lived experience research, there is a need to improve evaluation and evidence of impact. Although consumer and community research involvement has become more common in health research, the evidence to demonstrate effects is still largely lacking. With a few exceptions,[12,30] there have been limited attempts to use rigorous research methods to test the impact of research involvement and to gather evidence from people involved to improve future practice. There is considerable experiential knowledge developing in this space, but even champions of the importance of active consumer involvement across all parts of research call for greater rigour in evaluation.[12,13] Embedding high quality evaluation of involvement processes across all projects is one possible goal for lived experience-led research.

A second opportunity for lived experience researchers to boost recognition of their work is by the development of quality ratings, both for the relevance of all mental health research to people with lived experience, and for the attributes of lived experience-led research and researchers specifically. These tools would be similar to those for rating quality and bias used in systematic reviews, but be developed by a broad group of people with lived experience, who identify the elements and attributes of research and researchers that signal quality and impact from a lived experience perspective. A short-term goal to address this opportunity is to create a collaborative, national research project amongst lived experience researchers to develop quality criteria and refine them by consensus. Longer-term goals may include evaluation of the guidelines, incorporation into catalogues of rating materials, such as with the Johanna Briggs Institute, and use in peer review processes.

More broadly, there are some obvious ways in which the mental health research sector could enable the development of lived experience-led research, particularly within the academic sector. Resourcing in the form of dedicated scholarships and fellowships for lived experience researchers at all career stages are one possibility, drawing on the lived experience quality guides for peer review criteria to complement traditional peer review metrics. These funds would still be to reward excellence and intended to enable competitiveness in mainstream funding opportunities by a "foot in the door." A goal for the near future could be the creation of a scholarship or fellowship within a philanthropic organisation, with a longer-term goal of such funding available through the National Health and Medical Research Council.

Likewise, centralised funding and/or in-kind support from a well-established research institute or university to support the creation of a lived experience network would enable collaboration between lived experience researchers, creation of a national or perhaps international register of people with lived experience interested in assisting with the research process, and thus generate the capacity necessary to conduct quality research on a large scale. Such a network may also provide a platform to identify and address structural issues that are common to all lived experience researchers in academic environments, such as reliance on metrics that don't allow for or reward innovation and investment in lived experience engagement. A short-term goal is the identification of a university or other institution willing to take leadership and provide basic support for the establishment of the network, such as some research or administrative assistant time. Longer-term goals may include a formal organisation or community of practice that works together to advance lived experience-led research as a unique research discipline.

Conclusion

Lived experience-led research is a crucial component of a National Mental Health Strategy. Lived experience researchers bring a unique perspective to mental health research, and represent a critical connection to the broader lived experience community. However, lived experience-led research faces some ideological and practical challenges, some shared with mental health research more broadly, and some specific to the nature of lived experience research and researchers. Establishing lived experience-led research as a unique discipline, preserving its authenticity whilst improving recognition will require focused development both within and outside lived experience research groups.

However, it is also important to recognise that the principles and goals outlined for lived experience-led research apply to mental health research more broadly. Mental health research tends to be underfunded and struggle for recognition,[31] presenting competitive challenges for early and mid-career mental health researchers to establish their careers and progress to leadership positions. Encouraging all mental health researchers to evaluate their processes, including active involvement of people with lived experience, by tracking and seeking to constantly improve their methods will both increase rigour and create a body of evidence to demonstrate that rigour. Similarly, encouraging dedicated mental health funding and active networks are good practice for mental health researchers in general. Investing, financially and practically, in lived experience-led research as a key part of a national strategy will both grow this emerging area and provide a blueprint for similar efforts across the broader discipline.

Acknowledgements

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