



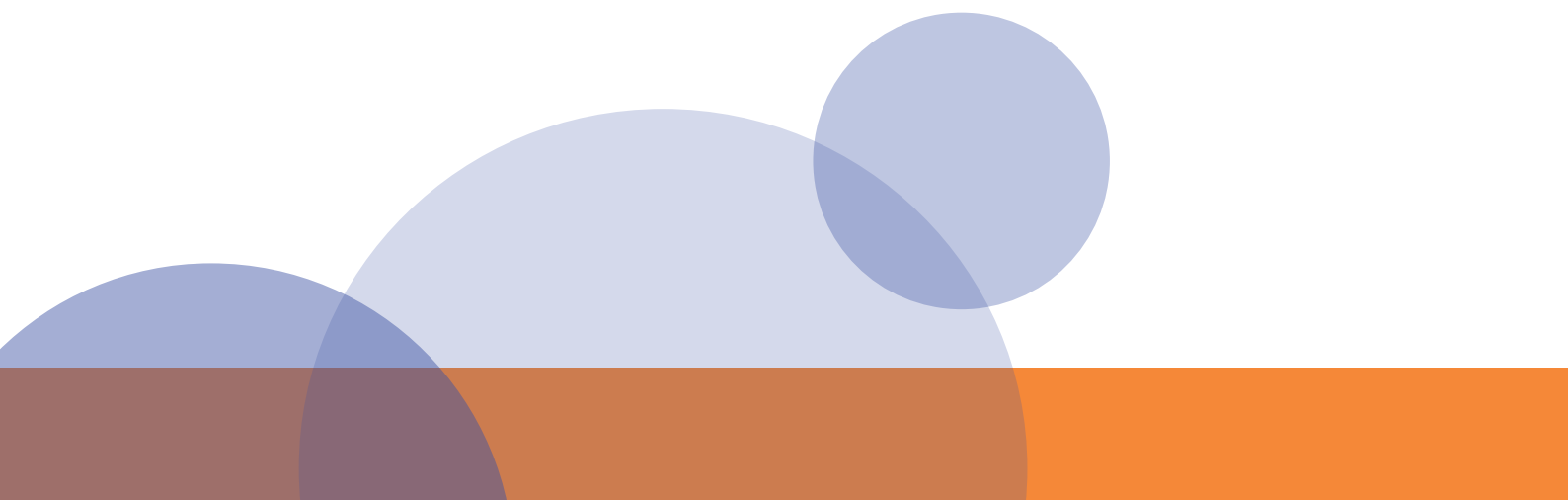
**Mental  
Health**  
Commission  
of New South Wales



Participant discussions from  
*Consumers or Service Users as Partners,  
Collaborators and Leaders in Mental Health  
Research: Exploring and Sharing ways to extend  
and sustain opportunities*

Hosted by  
**The University of Sydney's Brain and Mind  
Centre and Consumer Led Research Network**

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*This article includes the discussions and presentations of participants in this event but does not necessarily reflect the views or policies of the Mental Health Commission of NSW.*

## **Opportunity calls for consumer-led mental health research**

**A meeting of minds shines a light on the challenges, achievements and possibilities for consumer-led mental health research in Australia, writes Jodie McLeod.**

When a group of mental health researchers get together to discuss their field, there is one unwavering point of agreement: that people with lived experience of mental health issues – also referred to as consumers or service users – must be involved in all forms of mental health research; and ideally as collaborators or leaders.

It's this vision for the future of mental health research that fuelled discussion at the 2017 International Initiative for Mental Health Leadership (IIMHL) match in Sydney, hosted by the Mental Health Commission of NSW, and was the lynchpin for a legion of ideas on how to not only sustain research opportunities for consumers in Australia, but how to help the movement as a whole push boundaries.

### **Tackling tokenism**

It is globally acknowledged that consumer involvement in mental health research is beneficial to both the research itself and to the individuals engaged, to the point that in Australia, some major funding bodies even require consumer involvement as part of their project criteria. But not all 'involvement' is created equal.

Senior lecturer in occupational therapy at University of Sydney and facilitator of the IIMHL discussion, Nicola Hancock, says research projects in Australia and overseas more often than not still involve consumers at the most basic 'token' level of consultation.

"Can you tick a box and say you asked a consumer if it was a good idea? That is where most people are at," says Hancock. "On some projects, consultation might be the best involvement, but

opportunities where consumers can be involved in the whole spectrum of engagement would be ideal,” she adds.

Evidence shows that when consumers are partners or leaders of mental health research projects, more meaningful connections are made with participants – who find it easier to open up to someone who has experienced what they’re going through – which ultimately improves research results. Consumer researchers also create more effective research tools, such as surveys, since they have greater insight into the challenges facing participants, and they report personal and professional benefits of conducting research. The very act of going to work, gaining research skills and (in some cases) getting paid improves morale and increases employability, all of which contributes to their recovery.

Why then, when so much empirical evidence exists on the advantages of involving consumers at the upper levels of engagement, is tokenistic involvement still rife? The main reason, suggests Hancock, is stigma.

“The biggest barrier to consumer engagement is attitudinal – the attitudes of academia and research funding bodies,” says Hancock. “[Consumers] don’t get opportunities to research or work because people are fearful and misunderstand and have all of the attitudes that the general population have.”

The perception that consumers don’t have the necessary research skills, the perceived costs involved in building those skills and the impact this will have on research quality and budgets are all deterrents to engaging consumers above the level of participation.

Two key suggestions made at the IIMHL match to overcome these barriers included creating a designated research training facility for consumers, as well as creating alternative entry pathways into academic positions for consumer researchers. But as with many obstacles facing the consumer-led research movement, achieving each of these would require a major shift in long-entrenched attitudes towards service-users and their capacity as collaborators and leaders of academic research.

## Alternative pathways

Currently in Australia there are only six permanent consumer academic positions, along with a limited number of casual positions. The only entry pathway into consumer academic positions is by doing a PhD. For students and individuals living with mental illness who want to collaborate on and lead mental health research, this presents a difficult journey towards incredibly narrow goal posts.

Many in the consumer-led research community would like to see the creation of alternative pathways into research positions for consumers. Among them is Professor Ian Hickie, co-director of health and policy at the Brain and Mind Centre, University of Sydney.

“The most productive people in the world of mental health research are those who have real-world experience combined with academic certification,” says Hickie. “So we are interested in alternative pathways [for consumers into research roles] – not just through certification but also skill acquisition.”

Non-traditional pathways into academia for service users are not uncommon in the UK. Diana Rose, professor of user-led research and co-director of Service User Research Enterprise (SURE) in the UK, part of King’s College London, says activism in the user-led research movement counts for a lot.

“You can be influential without having academic certification,” says Rose. She gives the example of well-known UK independent survivor (user-led) researcher Alison Faulkner who, after 25 years of working in mental health research and having pivotal research published peer-reviewed journals, only recently attained her PhD by prior publication. This method of attaining a doctorate assesses the candidate’s past published work and accompanying thesis rather than a PhD-specific research project. It’s regarded as the ‘recognition by prior learning’ degree.

And while this pathway to a PhD is also available in Australian universities, there’s still the initial hurdle for consumers of being published in the first place, which is very difficult to do without studying for or having a PhD.

Why is it so difficult? One reason is, again, stigma.

“To get published as a lived experience user is much harder,” says Hancock, adding that there are some academics who don’t “out” themselves as consumers because their work as a non-consumer is much more respected.

Additional barriers to getting published, according to Hancock, include lack of access to ethics committees and the difficulty for non-government organisations – which make up a large part of the mental health sector in Australia – of gaining ethics approval for research.

This results in a lot of good consumer-led research going unnoticed, relegated to the limbo of ‘grey literature’ which is available but is not highly regarded since it’s missing that stamp of academic approval.

“So while you can find it online, it’s not valued by the scientific community because it hasn’t gone through this rigorous process of peer review,” says Hancock.

Rose believes consumer researchers can still get published in peer-reviewed journals and become influential in the consumer-led research world without a PhD – on one condition: as long as you’re not trying to do the research by yourself.

“I think it’s absolutely critical that there’s a group of you,” she says. And though Rose acknowledges not everyone would feel the same, she believes if groups are linked with established organisations – particularly universities – then all the better.

### **Recognition of lived experience as expertise**

One development many in the consumer-led research movement want to see, which would create more research opportunities, is for lived experience to be recognised as expertise in itself.

Cath Roper, consumer academic for the Centre of Psychiatric Nursing in Victoria, says acknowledging lived experience as expertise would help consumers build a stronger foundation for pursuing academic study.

“It’s about honouring and valuing a fundamental body of knowledge unique to consumers,” she says.

Consumer researchers would also like to see this expertise collated, put in one place, disseminated and made accessible to service users.

Hickie says the issue of what constitutes expertise in mental health research is divisive. “Some feel expertise derives from certification. Others feel lived experience should be recognised in the research world. It’s very difficult,” he says.

While debate ensues, Hickie says an important consideration right now is how lived experience is valued in individual research teams, which affects factors such as the level of participation and the payment of consumer researchers.

Alison Faulkner, whose PhD looked at valuing experiential knowledge in mental health research, found in her research that lived experience was valued more highly at the community research level as opposed to academia. She gave the example of the Hearing Voices Network, a global movement that has since the 1980s viewed experiential knowledge as equal to scientific or academic knowledge, and prioritises collaboration between ‘experts by experience’ and ‘experts by profession’.

“Often the involvement of service users in academic research does little to change the knowledge or the research paradigm,” says Faulkner.

“I hold on to the value of experiential knowledge at the community level where it is valued and hope that we can continue to find ways in which it can be validated and legitimised,” says Faulkner.

Faulkner adds there are many smaller ways in which individual strategies and local information is validated, and in her PhD draws a link between self-organising groups and peer support and the formation of experiential knowledge.

## **What lies ahead**

*“Let’s not start with ‘what are the problems’, but with ‘what are the possibilities?’”*

Adopting an attitude of innovation is crucial for propelling consumer led-research in Australia, and there were numerous ‘wouldn’t it be great if...?’ ideas explored at the IIMHL match. The priorities included:

- **Build awareness and create opportunities** by means of a journal article or proposal for a special edition of a journal focusing on consumer-led research and the benefits of consumers in academic positions.
- **Collate information** by developing a website for Australian and New Zealand mental health service-user researchers that details researchers and their projects.
- **Learn from other countries** by identifying and evaluating service-user-led research centres and initiatives that exist globally.
- **Make research accessible** by creating a grant proposal to translate knowledge gained from service-user research that is then made accessible to consumers.
- **Create a national consumer-led research centre** that will offer consumer research training, conduct consumer-led research projects, and generally be the go-to-hub for all things relating to consumer-led research.

Most attending the match agreed a national consumer-led research centre would be of significant value, but the details of what it might look like were hotly debated.

Internationally, possible models for such a centre include the Lived Experience Academy within Yale University and SURE (Service User Research Enterprise) in King's College London. Locally, and on a smaller scale, there is ACACIA: the ACT Consumer and Carer Mental Health Research Unit – part of Australian National University.

While many were in favour of a completely independent centre, not linked with a university, others pointed out the necessity of aligning with a university for both funding and credibility.

As co-director of SURE, Rose is in the latter camp.

“I think there are arguments for both,” she says. “There are advantages to being inside a place where legitimate knowledge is created. When you’re inside you can push the boundaries because you know exactly how they operate.”

“I think [SURE is] successful because we’re inside the university – we know the rules. But because we know the rules we know how push the limits of what’s possible. But I don’t think SURE would be what it is if it didn’t have a lot of contact with user groups,” says Rose.

“Also, if you have an established team inside a university you do tend to get invited to high-level stuff,” she adds.

So, is an Australian consumer-controlled mental health research centre with paid positions really possible? And are the funding dollars ready and waiting?

Louise Byrne, a lecturer in lived experience mental health at CQUniversity, believes it is, and they are.

“If we can nail the value of what [consumer researchers] do to the right people at the right time, then it can be done,” says Byrne. “It’s about influencing key decision makers to put money towards our movement.”

This brings to light one of the biggest hurdles in the academic and scientific worlds: Just how can the consumer-led research movement gain and maintain sway in academia? Byrne says it’s about playing the research ‘game’.

“You’ve got to make sure you’re delivering to the university’s main big priority at any given time,” says Byrne. “It might be grants, it might be the publish-or-perish model. The rules of the academic game shift all the time.”

Others at the match questioned: Why do we have to play the game? Why can’t we play our own game? Why can’t we challenge the thinking that we can’t get research in a peer-reviewed journal without a PhD?

And while the answers to these questions remain allusive, it’s precisely these questions that continue to challenge the status quo and to drive mental health research in Australia in the direction consumers want it to go.