



ACACIA's Mental Health Research Newsletter

National Institute for Mental Health Research, Research School of Population Health

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A message from the Director



What better way of ensuring this than engaging consumers and carers in the process of research. This is a primary aim of the new ACT Consumer and Carer Research Unit, ACACIA.

ACACIA involves consumers and carers in research in two ways. First, our staff are mental health consumers or carers with academic expertise and qualifications. They bring both research expertise and lived experience to the task of undertaking research that will make a difference to consumers. The second means by which ACACIA will involve consumers and carers is by building a bridge between the University and the community and engaging consumers in the process of research. For example, this issue of the newsletter describes a forum that ACACIA convened to determine the consumer and carer priorities for our future research agenda. We also describe a workshop for ACT consumers and carers who are interested in learning about becoming engaged in mental health research.

ACACIA's brief is to undertake research that will be of benefit consumers and carers in the ACT. We are looking forward to working with the ACT community to meet that challenge.

Last but not least, I would like to congratulate the ACT government and Mr Richard Bromhead, Director of the ACT Mental Health Policy Unit for their vision in initiating a mental health consumer research unit in the ACT and for making the funding available to turn that vision into reality.

Professor Kathy Griffiths,
Director, National Institute for Mental Health Research.

If I asked you to define a mental health expert, the chances are that you would explain this person as one with academic training and qualifications in mental health. Few people would think of describing mental health consumers or carers as mental health experts. And yet if you are mental health consumer or carer that is exactly what you are: an expert by lived experience. You may not have wrestled with text books and examinations but if you are a consumer you have lived 24 hours a day with a mental illness. As a consumer you understand what it feels like and how the illness and its treatments affect you. You also know about the importance of learning strategies for coping. Similarly if you are a carer you know first hand the challenges of mental illness, of caring for someone with an illness and of navigating the mental health system.

Research provides an opportunity to provide answers that will improve the mental health outcomes, wellbeing and quality of life of both consumers and carers. However, it is important that the research questions that we ask are relevant.

Inaugural Forum for ACT mental health consumers and carers

ACACIA, the new ACT consumer and carer mental health research unit at ANU, held its first forum for ACT mental health consumers and carers on the 27th November 2013 at the ANU Commons. The main aim of this one day forum was to find out what ACT consumers and carers believe should be the key research priorities for ACACIA.



The event was skilfully facilitated by Keith Mahar, a member of the National Mental Health Consumer Reference Group and a social worker with Woden Community Services. More than 30 people attended the forum including mental health consumers and carers ranging in age from their early 20's to their 60's, members of the ACACIA Research Advisory Group and staff from ACACIA.

Professor Kathy Griffiths, Director of the ANU National Institute for Mental Health Research (NIMHR) and ACACIA, welcomed everyone. To set the scene, Professor Griffiths and ACACIA Research Fellow Dr Michelle Banfield spoke about the new research unit, how it came about, why participation in research is important for consumers and carers in the ACT, the vision for ACACIA and the aims of the day's activities. All consumers and carers were then invited to join in and brainstorm ideas in small groups and later as a large collective. The atmosphere was convivial with lively round table and group discussions throughout the day.

One carer from the ACACIA Advisory Group who served as a facilitator in her group commented that she found it exciting and challenging to assist participants towards shared understandings.

"On our table not everyone had the same level of understanding of mental health terminology or they had different understandings of it. For some people it was their first forum so there were different levels of experience and knowledge. We found a common language not limited by mental health jargon so that the

diverse experiences and learnings of all contributors could be incorporated. Once we did that we were able to work really well together, learn from each other and reach consensus on ideas. I learnt a lot from the experience and was grateful for having an opportunity to have such an important role".

It was an extremely successful first event, with everyone contributing many ideas for potential research topics throughout the day. Participants were very positive about the forum saying that the discussions were dynamic and uplifting, that they liked the format and the feedback session at the end of the day, and were delighted with what they achieved and how that fed into the aims of the event. One consumer attendee remarked that "it was a good opportunity to meet others with lived experience. It was dynamic with a great sharing of ideas, a really brilliant experience".

The Staff at ACACIA are looking forward to organising more community events and forums and to seeing you there in the future.

Positive consumer and carer feedback about the Forum

We highly value the feedback of consumers and carers. To make sure we capture these views of those who attend our activities we will use evaluation strategies such as feedback evaluation forms and surveys. This information helps us to respond to your suggestions and to develop a research agenda and initiatives that truly reflect what you want.

At our recent forum we offered participants an opportunity to provide written feedback on what they thought of the event through a short open-ended survey. We received 21 completed evaluation forms. It was encouraging that everyone rated the forum as either "great" or "good". Everyone said that the forum met their expectations and some felt that it exceeded them. We were encouraged many commented that they felt the atmosphere was respectful and encouraged good discussion.

"Not being patronised as consumers – acknowledging our capacity to be researchers, not just be researched... Freedom to brainstorm."

We would like to thank all those who took the time and effort to fill in the feedback forms. It was much appreciated.



“Dot”-mocracy: What research topics are important to ACT Consumers and Carers

We are in the process of analysing the Forum findings and writing a full report on ACT consumer and carer priorities for mental health research in the future. Meanwhile, here is a brief summary of the outcomes of the Forum day.

Ideas for research topics were developed in small groups during the morning sessions of the first ACACIA Forum. Together the groups suggested a total of more than 85 research topics, with even more sub-topics and specific questions. During the lunch break, the ACACIA research team organised the topics into 14 broad areas. We kept topics as they were written and after taking out exact repeats we were left with 79 topics. After lunch, participants were each given five coloured dots to “vote” on their top priorities. To see if there were differences in priorities, each group had different coloured dots. The 14 consumers still present had blue dots, the five carers were given yellow dots and the five consumers and carers had green dots.

With so many important topics raised, people found it hard to choose where to put their dots. Votes were spread across 59 of the topics, with most receiving 1-3 votes. However, three topics attracted more dots:

- The integration of trauma-informed care into service delivery (7)
- Peer-led services (6)
- Recovery and fulfilling potential (6)

Trauma-informed care received votes from all three groups, but the other two topics received votes only from consumers and consumer/carers.

Where to now

The ‘dot’-mocracy exercise was just the first stage in deciding where ACACIA should focus its first research projects. We will be sending out a survey of the topics raised in the forum soon and may have more discussion sessions. Watch this space!



Meet ACACIA Advisory Group Member

Maureen Bell

I have been co-carer of a family member with mental illness since 1992, member of the Mental Health Carers Network since 1998 and Carer Representative on ACT government mental health committees (Clinical Practice and Quality Improvement, Clinical Review, and Publications) since 2005. I joined the ANU National Institute for Mental Health Research ACACIA advisory group as an independent carer representative in 2013.

My working background includes: teacher of adult English as a Second Language at CIT, ESL project officer at CIT Solutions, editor for the Department of Parliamentary Reporting (Hansard), editor for the National Centre for Social and Economic Modelling at University of Canberra and teacher of community classes for CIT Solutions and U3A.



Research in Brief

Engaging consumers to develop research studies that matter

The Patient-Centered Research Outcomes Institute (PCORI) in Baltimore is developing new ways of engaging consumers, carers and clinicians to make sure health research is relevant to their needs. The Institute compares different treatment and health care options with the aim of providing consumers and carers with the

scientifically-based information they need to best support their well-being.

Consumer researchers lead qualitative studies of psychosis

Consumer researchers from the Lived Experience Research Network (LERN) in the USA are in the process of studying the experience of psychosis using qualitative research methods. The researchers believe that this is the first study of psychosis and voices where all phases of the research have been led and undertaken by consumers.





Want to learn more about research?

We are running workshops on research methods and active participation

Research training for consumers and carers is a key priority for ACACIA. We started this process with a workshop at the Mental Health Community Coalition Conference on June 4, 2014.

The workshop was an introduction to research that includes active involvement of consumers, carers and other mental health stakeholders.

Dr Michelle Banfield talked about ways that non-researchers could be a part of the processes. She also outlined some of the problems researchers face. Participants then worked on designing a project that had active involvement.

These workshops are a chance for consumers and carers to learn about research and also to suggest ways they would like to be involved. We will be holding more in future, with topics and format evolving with your input. Please sign up for our register if you want to get involved in our work.

Meet Michelle Banfield

Dr Michelle Banfield is an academic consumer researcher managing ACACIA's work for the National Institute for Mental Health Research. She also leads the consumer perspectives team for the Australian Primary Health Care Research Institute.

Using her own experiences as both a mental health consumer and researcher, Michelle advocates for the involvement of consumers as equal partners in research. She gives lectures and workshops on collaborative research for health researchers and the community. Her work on establishing priorities for mental health research from a consumer perspective (SCOPE for Research) has been recognised by four awards and led to collaboration on a similar project in New Zealand.

Michelle is a member of the National Mental Health Consumer Reference Group advising the Mental Health Council of Australia on the establishment of a new national peak consumer body. She also sits on the board of the Health Care Consumers' Organisation of the ACT. Through these roles, she hopes to foster strong ties between the consumer and research communities.

Michelle believes that having a mental illness is not a life sentence and is committed to helping other mental health consumers and carers find their voice and break down the stereotypes.

Staff of ACACIA

Professor Kathy Griffiths, Director;
Dr Michelle Banfield Research Fellow
Ms Aine Tierney, Research Assistant

ACACIA Advisory Board

Maureen Bell, independent carer
Julia Bocking, ACT Health Mental Health Policy Unit (acting)
Dalane Drexler, ACT Mental Health Consumer Network
Sharon Leigh-Hazell, Carers ACT
David Lovegrove, ACT Mental Health Consumer Network
Mariana Oppermann, independent consumer
Colleen Sheen, Carers ACT





Australian
National
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Get involved

Would you like to get involved in ACACIA's research?

Why should I participate?

ACACIA values the perspectives of consumers and carers. We are committed to identifying and researching the issues that affect you. By participating in ACACIA's activities you can contribute to research that is relevant and designed to improve the mental health and wellbeing of ACT consumers and carers.

Benefits

By becoming involved in ACACIA's research activities you will have opportunities to:

- > Share your ideas (eg, for research topics) in forums, surveys or discussion groups
- > Contribute to research designed to make a difference to the lives of consumers and carers
- > Learn about research
- > Meet other consumers and carers

How do I get involved?

Join ACACIA's Consumer and Carer Research Register

If you are a consumer or carer and you would like to become involved in ACACIA's research or training opportunities please fill in the form below. Please then return the form to ACACIA. There is no obligation for members of the register to become involved in ACACIA's research. However, if you put your name on the register we will let you know of opportunities as they arise.

Yes, I would like to add my details to the ACACIA register!

Name _____

Address _____

Phone _____

Email _____

I am a:

Consumer Carer Consumer & Carer

Preferred newsletter format:

Email Regular mail (hard copy)

I don't want a newsletter

Mail to

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