



ACACIA's Mental Health Research Newsletter

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

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## Understanding Ethics in Research



Bethany Jones

Ethics in research is of crucial importance. We need to be sure that we are doing meaningful research, but we also need to be sure that we are not causing harm. There are times though, when research participation may be uncomfortable or distressing to participants, but the outcomes from the research are very important. How then do we balance the needs of the wider population (benefits from research) with the needs of the individual (participating in research)?

Typically, any human research that is publicly funded or published in scientific journals has to be approved by an ethics committee. In Australia, these are called 'Human Research Ethics Committees' or HRECs. HRECs are made up of a range of researchers, clinicians and community members (sometimes including certain religious groups), and their job is to review all human research to ensure that it is ethical. All universities and most hospitals will have an HREC to review research undertaken within their institution.

The standards that guide their decision-making were created by the National Health and Medical Research Council (NHMRC). When balancing the benefits of the research with the costs to participants there are a number of key principles guiding members of an HREC.

One thing they consider is the concept of undue pressure. For example, it is often considered poor form for

researchers to directly contact people to participate in research. Most people would agree that it would likely result in some people feeling pressured into participating. We all know how it feels when we are approached by people selling things in the street! It is very uncomfortable! It is therefore also the case if a consumer had agreed to participate in research, and they then asked a family member to participate as a carer. Is there a chance of undue pressure on the carer to participate? What if the roles were reversed? What if the family member declined; would there then be the possibility of damage to the relationship?

Other key concepts are privacy and confidentiality. Like health services, research in mental health often involves collecting information of a very personal or sensitive nature. How we handle this information is of crucial importance. We need to ensure that people's personal information is not available to anyone outside the research team. Often data is 'de-identified'. This is a process where the responses from a participant have all personal information removed. That information is then either deleted or stored separately so researchers may have a list of participants and their contact details and, separately, a bunch of completed questionnaires. However, only one person knows how to match them up. (...continued on page 2)

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## Understanding Ethics in Research (...continued)

With consumer and carer involvement, breach of privacy may be an issue. For example, is a carer breaching the privacy of a consumer if they talk about that person's illness? How can the carer talk about their own experience without breaching the privacy of the person they care for? If they talk about that person's illness? How can the carer talk about their own experience without breaching the privacy of the person they care for?

Ethics committees are also very concerned with the wellbeing of people who may be unable to consent. For example, people who have an intellectual disability may need a modified information sheet to be able to fully participate, consent from a carer, and/or support to participate. As defined by the NHMRC, people with lived experience of mental illness are also in this category. Some people find this to be offensive as people who have experienced mental illness do not necessarily have 'diminished capability'. However, what of people who are current inpatients and acutely unwell? Should they have different rules than people who are currently well and in the community? And what of people who are unwell, but not inpatients? How can ethics committees protect people who may be vulnerable while still respecting that people with lived experience of mental illness are people, just like anyone else, who may not need special treatment?

Lastly, I will discuss the concept of informed consent. In order to participate in research, people must 'consent'. However, in order to do so they must understand what the research is for; what participation will look like for them; what the possible risks are; what information will be collected; where it will go in the future; and how their wellbeing will be supported. This is called 'informed consent'. Researchers generally write a brief document called an 'Information Sheet' to tell potential participants about the research.

However, unclear information sheets can result in participants not understanding the research at all. Therefore their participation is not truly 'informed'. At ACACIA we have sought consumer and carer feedback on participation sheets and found that the university's standard form is hard to understand and does not present useful information to the reader. When you participate in research, what kind of things do you want to know? Have you ever had difficulty with information sheets in your research participation experiences?

I hope these ideas have sparked some interesting thoughts for you. The ACACIA team will be conducting in-depth interviews about ethics in research in the New Year, we look forward to hearing your views.

## TheMHS 2015: Partners in research workshop

Bethany Jones

TheMHS Annual Conference was held in Canberra in August this year. It was a great opportunity for our community to hear from leaders in mental health research and practice from across the globe. The ACACIA group was very active at the conference, and we were delighted to hear many speakers talk about the importance of including consumer and carer perspectives in all aspects of research and service delivery.

Michelle and I presented a workshop for delegates on methods for including consumers and carers in research. We had a very enthusiastic group of attendees from a range of backgrounds, including service delivery and an early-stage PhD scholar. It was a fantastic opportunity for us to help people to understand the different ways in which consumers and carers can be involved in research. For many people it seems to be a question of either the researchers do everything, or the consumers and carers do everything. This kind of black and white thinking confuses people and they become unsure how to progress.

We were able to explain that consumer and carer voices can be involved at any or all stages of research. For example, consulting with consumers and carers about the questions of interest (WHAT to research), or whether the methods are suitable (HOW to research it). Consumers and carers can also have a crucial role in the monitoring of research through reference groups, or as direct research members. Lastly, consumer and carer involvement is essential to helping us get our results out to the community.

Attendees were then invited to form small groups to discuss a project and ways in which they could meaningfully incorporate consumer and carer perspectives to strengthen the research project. One group chose to discuss a project that is being developed by the ACACIA team. This project will investigate the usefulness of the term 'recovery' to ACT consumers and carers with regard to the NDIS. Another group used a project in development by one of the attendees. She was able to workshop her research plan to increase consumer and carer involvement, and thereby strengthen the program of research. Attendees were very happy with the workshop and commented that it had changed the way they think about conducting research.

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## TheMHS 2015: Carers Workshop Summary

Doris Kordes, Carers ACT

Carers ACT hosted The Mental Health Services pre-Conference Carer/Family Forum at the National Convention Centre on 25 August 2015. About 60 participants engaged with a variety of local and interstate speakers, including carers, on the broad topic of Holistic Approaches to Health and Wellbeing. This topic was agreed upon by members of the Carer Reference Group who were involved in designing the program format.

The audience heard about some of the key factors for enabling family involvement in mental health services. Professor Kim Foster, University of Canberra, shared her findings of an international literature review project she was closely involved in. It was interesting to hear Professor Foster talk about evidence that suggests family involvement reduces the intergenerational impact of mental illness.

Dr Brendan O'Hanlan, Bouverie Centre, talked about the Centre's commitment to and valuing of family inclusive practices in mental health services as well as the challenges of family involvement. Dr O'Hanlan was a recipient in this year's TheMHS Learning Network Awards for Exceptional Contribution to Mental Health Service in Australia.

Presenters also talked about the importance of physical as well as mental health. Professor Brenda Happell, University of Canberra, outlined the major inequities in life expectancy and physical health care for people diagnosed with a mental illness.

Professor Happell described a Canberra-based research project she is leading on the physical health care needs of people with mental illness. Carers ACT and ACT Health supported the extension of her project to include focus groups with carers. Catriona Bastian from SANE Australia shared information and resources about the Mind + Body Initiative. SANE and Neami National were recipients in this year's TheMHS Learning Network Awards, in the category of Physical Health and/or Primary Care, for their work in Peer Health Coaching.

Tara Smark and Noeleen Braddock from MI Fellowship shared their experiences of carers and consumers working closely together with Gippsland community mental health services to develop a physical health screening tool in 2012-13. Key to their success was the commitment by services to robust consumer and carer participation methods for the duration of this project. The Forum's focus on holistic approaches to health and wellbeing inspired the Carer Reference Group members to engage with researchers involved in a social and emotional wellbeing program originally developed and delivered by

and for Aboriginal and Torres Strait Islander peoples. Dr Roxanne Bainbridge from James Cook University and Dr Mary Whiteside, La Trobe University, described the key features and great outcomes of the Family Wellbeing program, and explored the relevance of the program for mental health carers and for mainstream health service delivery. The carer wellbeing session, run by Dr Florian Wertenaue from ACT Health, examined the value of Dialectical Behavioural Therapy techniques.

The new Carers ACT position statement - Working with Carers, Families and Support People - was also launched at the Forum. To download a copy, visit <http://carersact.org.au>

Carers ACT would like to thank the Carer Reference Group members who contributed their time and insights into designing the Forum's program, ensuring its relevance for caring families, and the speakers who generously shared their knowledge, experience and resources with the audience.



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## Meet Advisory Group Member: Professor Brenda Happell

Professor of Nursing and Executive Director, SYNERGY, Nursing and Midwifery Research Centre, University of Canberra and ACT Health

Mine has been an interesting and colourful career. I worked as a youth officer, a secondary school teacher, a general nurse and ultimately a mental health nurse. This is where I finally found my niche. It also provided a fantastic opportunity to combine my love of all things mental health with my passion for academia. Now in my 26th year as an academic I have held many challenging

and exciting roles, including the establishment of the Centre for Psychiatric Nursing Research and Practice at the University of Melbourne, Director of the Institute for Health and Social Science Research at Central Queensland University and of course my current role as Executive Director of SYNERGY, Nursing and Midwifery Research Centre, University of Canberra and ACT Health

Without a doubt the most rewarding aspect of my role has been the (... continued on page 4)



implementation of roles for consumer academics at the University of Melbourne, Central Queensland University and now at SYNERGY. I am a firm believer in “nothing about us without us” and because I am not a consumer of mental health services myself, I am very clear about my role and my boundaries. I refer to myself as an ally, which means I do what I can to facilitate consumer roles, defend them, support them, advocate for them and

contribute to research, evaluation and disseminate outcomes to show their importance and value. I look for opportunities and seize them. At the same time I don't speak on behalf of consumers (although I have often been asked to) and I don't define the structure or content of consumer roles.

I moved to Canberra in January this year to take on my new role. Since arriving I have been very impressed with the

strength of the mental health consumer movement and the strong sense of collegiality. The support of the ACT Mental Health Consumer Network and Carers ACT for my research agenda has been exceptional. Being invited to be a member of the ACACIA Advisory Group is an honour; and I look forward to being actively involved

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## Demystifying Research - what is translational research?

Professor Kathy Griffiths

Translational research is concerned with applying research findings for the benefit of the public. For example, there little point in finding the best method for treating depression if nobody ever receives the treatment in practice. There is little point in a researcher discovering the best approach to reducing stigma about mental illness if the organisations funding and running stigma campaigns fail to adopt the approach. Many health treatments and services are not based on the best evidence. We need to change that. However, it can be a challenge. According to one report, it takes an average of 17 years to translate research findings into clinical practice.

If we are to ‘translate’ research into practice it is important that policy makers, practitioners, consumers and carers and others know about the research. This means finding ways to best communicate the findings to different groups. However, simply sending out information does not necessarily change what governments or clinicians or we as consumers or carers do. For this reason, translational research is also concerned with undertaking studies to test which methods work best to change practice and policies.

For example, one German researcher wanted to know how best to attract high school students to use an effective online mental health self help resource. She compared the effect of sending posters about the program to schools with visiting the school and presenting a talk about the resource.



Personally visiting the schools was more expensive than sending posters. However, many more students signed onto the program after the personal visits and the cost per student using the program was actually less. In other words, what seemed like the most expensive method was in reality the most cost effective method for changing practice.

Ironically given its aims, ‘translational research’ is not a very consumer or carer friendly phrase. In addition, there has been little discussion about the role of consumers and carers in research translation. However, we at ACACIA are

confident that consumers and carers will play a critical role in research translation in the future. By working with academic researchers or by leading research, consumers and carers can make sure that mental health research is relevant to the real world problems they face. Consumers and carers can also use their networks to communicate important research discoveries to other consumers and carers who in turn can educate their practitioners. In these ways important mental health research will be freed from the confines of the ‘ivory tower’ of academia for the benefit of all.



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# Service Users in Academia Symposium, Auckland

Professor Brenda Happell

Since 2011, the Service User Academia symposium has been run annually to advance the discipline of service user academia. This discipline is the meaningful involvement of service users in mental health and addiction research and teaching. The 5th Service User Academia symposium will be held in Auckland, New Zealand on the 30th November/1st December 2015 with the theme - 'Creating Connections and Building Bridges Together: One Step Closer'.

This symposium is for service users who hold academic, education or professional development positions, or who think they might like to do so, and those (usually non-service users) who promote, support and advocate for these roles in academia and service settings. The main speakers at this event are Dr Jackie Liggins (University of Auckland and Counties Manukau Health) and Professor Brenda Happell (University of Canberra and ACT Health).

The event will provide an opportunity for service user academics to talk about

- The work of service user academics;
- Developing research and teaching skills; and
- The barriers and challenges to progressing service user academia.

For mental health researchers and educators, it will provide an opportunity to discuss

- Service user leadership and collaborations in mental health research and teaching;
- Supporting capacity building among service users; and
- Establishing links and networks with others already working with or as service user academics;

and for those who fund mental health research and workforce development it will provide an opportunity to discuss

- Assessing end-user engagement in mental health research proposals;

- Considering mental health service users' research priorities; and
- Re-orienting or developing training programmes with a recovery foundation and focus.

If you would like to look at the program and see exactly what will be discussed in the various sessions please visit: <http://www.otago.ac.nz/wellington/>

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## Whose story is it? Perspectives on Participation in Research Forum

Bethany Jones

The second ACACIA Consumer and Carer Forum was held on June 11th this year. It was a half-day event with about 12 attendees.

The purpose of the forum was to discuss ethical issues around the inclusion of consumers and carers in research. We were interested in such questions as:

- Can consumers and carers participate in research if the other declines?
- How can carers of people who disagree with their diagnosis participate in research?
- Can consumers and carers participate without the knowledge of the other?

We had fantastic support from the ACT Mental Health Consumer Network and Carers ACT to run the event, and Ben Matthews from MI Fellowship as our wonderful facilitator.

The participants on the day were very enthusiastic and discussed some of the complex and delicate issues with respect and openness. This allowed us to get great insight into the different perspectives we must take into account when designing research.

Some of the concerns and issues brought up by participants were:

- Who 'owns' the story of the consumer?
- How are carers able to tell their story and still respect the privacy of the consumer?
- Is it fair to include people with lived experience of mental illness in the same category as those with intellectual disability (classification from the National Health and Medical Research Council)

Participants were very happy with the forum. All participants said that the forum was 'good' or 'great'. They also enjoyed the "open discussion incorporating all perspectives" and "hearing other peoples' views and experiences".

So where to now? We are going to use the information from the forum to develop interview questions that will be coming your way next year. Do keep an eye out for the invitation to participate!



# 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:

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