Australian National University

Priorities for mental health research in the ACT

ACT consumer and carer mental health research forum final report

Dr Michelle Banfield

Professor Kathleen Griffiths

National Institute for Mental Health Research

January 2015

National Institute for Mental Health Research

+61 2 6125 2741

acacia@anu.edu.au

The Australian National University

Canberra ACT 0200 Australia

www.anu.edu.au

CRICOS Provider No. 00120C

Acknowledgements

Thanks is due to many people whose assistance ensured the day ran smoothly.

Special thanks to Keith Mahar whose facilitation skills and good humour kept the forum on track.

Forum preparations, small group facilitation and note-taking were ably provided by the ACACIA Advisory Group: Dalane Drexler, David Lovegrove, Colleen Sheen, Sharon Leigh-Hazell, Mariana Oppermann, Maureen Bell, Julia Bocking and Jane Pepper; and National Institute for Mental Health Research staff: Bradley Carron-Arthur, Mearon O'Brien, Ãine Tierney, Rebecca Randall, Bregje van Spijker, Phil Batterham, Edwina Wright, Angeline Tjhin, Lou Farrer and Julia Reynolds.

The work of ACACIA: The ACT Consumer and Carer Mental Health Research Unit, including the 2013 Consumer and Carer Mental Health Research Forum, is funded by ACT Health.

Message from the researchers

As researchers with personal experience of mental health issues, our aim for ACACIA is for consumers and carers in the community to take an active role in leading and contributing to high quality research that is relevant to consumers and carers.

The forum described in this report was our first major event and we found it both an exciting and inspiring day. The people who attended the forum were very generous with their ideas. This is reflected in the number and variety of research areas developed. It's always a pleasant problem as a researcher to have more data than expected.

We would like to thank everyone who attended the forum for making our first event so successful. Your thoughtful contributions have given us a good idea of both the breadth and depth of issues that ACT mental health consumers and carers face. We look forward to working with everyone on research projects to address these issues.

Dr Michelle Banfield

Professor Kathy Griffiths

January 2015

Contents

Acknowledgements 3

Message from the researchers 4

Section 1: Background 7

- Background to the report 7
- Methods 7
  - Participants 8
  - Group activities 8
  - Analysis 10

Section 2: “Dot”-mocracy - identifying and prioritising research topics 11

- Topics of interest to each group 15
- Summary 16

Section 3: Methods for involving consumers and carers in the research process 17

- Summary 17

Section 4: Forum evaluation 18

- Forum feedback 18
- Suggested improvements 18

Section 5: Future directions 20

Glossary of terms 21

Appendix A - Agenda 23

Appendix B – Presentation introducing ACACIA: Professor Kathy Griffiths 24

Appendix C – Presentation on research involvement: Dr Michelle Banfield 42

Appendix D – Prompt list of previous consumer-developed topics for research 49

Appendix E – Forum evaluation 50

Appendix F – Notes from group discussions (session 2) 52

Appendix G – Flip chart summaries (session 3) 59

Appendix H – Notes on methods of involvement (session 6) 66

Section 1: Background

Background to the report

The importance of consumer and carer participation in all areas of mental health, including research, has been recognised in Australian mental health policy for more than 20 years. However, implementation has been slow and patchy. Many consumers and carers report that involvement practices are tokenistic and are not meaningful.

At the National Institute for Mental Health Research (NIMHR), consumer participation is built into the organisational structure through the Depression and Anxiety Consumer Research Unit. Established in 2003, the Consumer Research Unit works to embed consumer participation in mental health research. Staff and students in the Unit have personal experience of mental health issues and conduct research with a strong consumer focus.

In 2013, NIMHR established a consumer and carer mental health research unit funded by ACT Health and focused on issues within the ACT. This new unit, ACACIA, sits alongside the Depression and Anxiety Consumer Research Unit, extending participation to include carers. Researchers work closely with the ACT Mental Health Consumer Network (ACTMHCN) and Carers ACT as well as consumer and carer representatives from the community. ACACIA is intended to combine the expertise of qualified researchers with those who are experts by virtue of their lived experience. This will ensure that the research is both of high scientific quality and meaningful for consumers and carers.

To ensure consumer and carer priorities and preferences for involvement were embedded early, ACACIA held a one day discussion forum for ACT mental health consumers and carers in November 2013. The forum had two main purposes: (i) to introduce ACACIA and its objectives to ACT consumers and carers; and (ii) to develop and prioritise consumer and carer ideas for research in the ACT. A session brainstorming ways to engage with consumers and carers was also included.

This report summarises the day's activities and outcomes.

Methods

The forum consisted of three main parts, split into six sessions (see Appendix A). The first session was an introductory presentation by Professor Kathy Griffiths on the development of ACACIA and our plans for its activities (see Appendix B). The second part consisted of small group discussions on topics for research, ending with a large group exercise to prioritise these topics. The final part of the day focused on research methods. This included a presentation from Dr Michelle Banfield on models of consumer and carer involvement

(see Appendix C) and an open discussion on ways to engage people with research. Participants completed an evaluation of the day at the close of the forum.

Participants

A flyer was developed to advertise the event through ACT consumer and carer networks. Members of ACACIA's Consumer and Carer Advisory Group sent this flyer out to the ACTMHCN, Carers ACT, ACT Health and the Mental Health Community Coalition with a request to forward it to other relevant networks. The flyer was also emailed to ACT members of the Depression and Anxiety Consumer Research Unit Register, a database of people who have expressed an interest in NIMHR research.

A total of 25 people with a lived experience as a consumer or carer participated in the forum, the majority (17) of whom were women. Fifteen participants identified as consumers, five as carers and five indicated they were both a consumer and a carer.

The forum was chaired by long-time, well known consumer advocate Keith Mahar, who also facilitated the large group discussions. Small group discussions were facilitated by NIMHR staff or ACACIA Advisory Group members with lived experience as a consumer, carer or both. Facilitators were also contributors to the discussions.

Group activities

Participants were seated at tables of between six and eight, including facilitators. People were free to choose their own table, which allowed mixed tables of consumers and carers. However, participants stayed at the same table throughout the day. The lead members of the research team moved about the room and joined tables for short periods to listen to discussions.

The purpose of the first group activity was to identify areas that consumers and carers believed needed research. Participants were provided with the following discussion question:

> *What are the topics/areas/services that you think should be the focus of research within the ACT?*

Table facilitators chaired the discussions, with note takers recording topics as they arose. Participants were also provided with a list of priority areas developed in a previous consumer priorities study as prompts for further discussion (see Appendix D).

In the second group activity, participants were asked to start refining the ideas generated during the first activity. Their guiding brief was:

> *Building on the topics raised before the break, how might we start to put our ideas together into research questions?*

This activity helped to focus the earlier open discussions and allowed consumers and carers to participate in the early stages of qualitative analysis. As topics were refined, they were written on flip charts and whiteboards.

During lunch, the research team worked to collate the topics from the flip charts into broad thematic areas as a second stage of analysis. Fresh flip charts with topics organised in the thematic areas were prepared for the third group activity, the “dot”-mocracy. Participants were provided with five coloured dots each: blue for consumers, yellow for carers and green for consumer/carers. Each dot was a “vote” for a topic or area. Participants were free to distribute their dots across as many or few topics as they wished by placing one or more dots against the topics on the flip charts.

The final group activity was a facilitated large group discussion on methods to engage mental health consumers and carers in the research process. The forum facilitator invited participants to suggest ways of ensuring that consumers and carers actively participated in the research process across the five stages of research introduced in the presentation on models of involvement, as illustrated below.[1]

Figure 1. The research cycle (NHMRC & CHF, 2005)

[1] NHMRC & CHF (2005) A Model Framework for Consumer and Community Participation in Health and Medical Research. Commonwealth of Australia: Canberra.

Participants were also asked about their preferred ways to gain research skills through training.

The day concluded with participants filling out anonymous feedback forms (see Appendix E). These forms invited consumers and carers to identify what worked well and what did not and to provide suggestions for future ACACIA activities.

Analysis

As described above, to encourage consumer and carer involvement in the collation and analysis of findings, the beginning of the analysis process was built into the forum. Participants discussed and agreed on how to present ideas in topics that could be developed into research questions. Notes and flip chart contents are provided in Appendix F and G. One group table developed a list of suggested research questions (see Appendix G).

The research team also organised topics into basic themes for the priority-setting exercise during the forum and took notes on the final session on methods of involvement (Appendix H).

The research team collated all of these materials and conducted further thematic analyses to produce the summary findings in the remainder of this report.

The draft report was circulated to forum participants for feedback before this final version was produced.

Section 2: “Dot”-mocracy - identifying and prioritising research topics

During the morning sessions of the forum the four tables developed a total of more than 85 topics. Many of these topics also had sub-topics and specific questions. Topics were kept as they were written and only exact repeats were removed, leaving 79 topics on which people could vote. The research team organised these into the following 14 broad areas:

- *Services*
- *Treatment*
- *Medication*
- *Health professionals*
- *Comorbidity/physical health*
- *Justice system*
- *Consumer and carer involvement*
- *Stigma*
- *Experiences of care*
- *Carers/families and friends*
- *NDIS*
- *Language and communication*
- *Peer to peer*
- *Legislation*

Sixteen topics did not fit into any of these areas and were listed together as “other topics”.

Twenty-four of the 25 forum participants took part in the “dot”-mocracy: 14 consumers, five carers and five consumer/carers. This meant there was a total of 120 votes available (70 from consumers, 25 from carers and 25 from consumer/carers). 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. Some votes were for general areas rather than specific topics. A full list of topics and the votes they received is contained in Table 1.

The top three individual topics overall were:

- *the integration of trauma-informed care into service delivery* (7 votes);
- *peer-led services* (6 votes); and
- *recovery and fulfilling potential* (6 votes).

The integration of trauma-informed care received votes from all three groups – carers, consumers and consumers/carers. A fourth topic, *Is care traumatising?*, received five votes including three from consumers and two from carers. This suggests that issues of trauma, care and how they are related are considered important by consumers and carers alike.

The votes prioritising research on *peer-led services* and *recovery* were mostly from consumers. There was one consumer/carer vote for *peer-led services* and two consumer/carer votes for *recovery.* Nobody in the carer group voted for these topics.

Table 1. Topics for research

Topic	Consumer votes	Carer votes	Consumer/carer votes
Services			
Disconnection of services	2	1	
Do the public and private sectors work together? Consumer and carer experiences			1
Awareness and role of GPs. E.g., engagement with carers, language and communication skills with consumers and carers			1
Service pathways: first access, how do they go about it, what is the access to information, benefit of hindsight?	3	1	
Trauma informed care: how is it integrated into service delivery?	3	1	3
Impact of service delivery on individual: Consumer and carer views on recovery Consumer and carer journey What works and what doesn't What do clinicians think?			
Consumer and carer voice integrated into services/policy: Feedback on effectiveness, how contribution is valued, what are indicators to demonstrate feedback use			
Monitoring and evaluation: to what extent is it built into program/pre-post-during evaluation from participants	2	1	
Reach – are services reaching the people that need them?	1		
How are Partners in Recovery, PHAMS, support and clinical management working together			
Treatment			
Alternative treatments: what are they? Holistic approaches, meditation, exercise	1	2	
ECT: what information is given, does it follow best practice, what are consumers' experiences	2		
Pet therapy			

Topic	Consumer votes	Carer votes	Consumer/carer votes
Care planning: what makes a good MH plan e.g. individualised, including perspectives of consumers, carers and clinicians		1	1
Transparency of clinical management			1
Implementation of clinical practice guidelines (why the disconnect)			1
How do current protocols support consumer and carer recovery?			
Medication (2 carer votes for area)			
How people are supported to come off	2		
Gender specific effects of medication	1		
How medications are tailored to the individual			
Criteria for prescribing	2		
How do individual adapt to change e.g. in meds that impact lifestyle and quality of life			
Is it what we want? Side effects, health impacts, alternatives, efficacy, cost-effectiveness			
Health professionals			
Burnout of mental health professionals: impact on service support and delivery			
Getting health professionals working together			
How can consumer perspectives be incorporated into psychology training?	2		
How is privacy interpreted by health professionals and does it differ from consumer and carer interpretation?		1	
Comorbidity/physical health			
Effects of drug and alcohol use early in life		2	
Support when pain is comorbid and how people experience that			
Physical health concerns			
Trial of primary health care nurse with mental health teams			
Evidence base for linking mental illness with alcohol and other drugs			
Justice system			
Overrepresentation of mental illness in the justice system	1	1	
Discrimination	1		1
Consumer and carer involvement			
Who is involved?			
How do we expand who is involved? E.g. young people			
How participation works in the ACT (tokenism vs real involvement)	1	1	

Topic	Consumer votes	Carer votes	Consumer/carer votes
Stigma (1 carer vote for area)			
By health providers (mental health and others): what do they believe and how does it impact?	1		2
Comorbidities and stigma			
Does the stigma in the mental health system worsen outcomes?	1		
Borderline personality disorder			
Analysis by disorder			
Stereotype formation			
What changes do people make in their own lives as a result of stigma?	3		
Experiences of care			
Is care traumatising?	3	2	
How have people who have experienced trauma been cared for?	1		
What is helpful in recovery oriented services? Are consumers being consulted? Do people know services exist/the pathways into them?		1	
Carers/families and friends (1 consumer vote, 1 consumer/carer vote)			
Who are the carers and what are they doing?			
What kind of support would they like?			
Bereavement – are we offering enough counselling? Is it timely enough? Should it be offered in prisons?			
NDIS			
Impact of NDIS – longitudinal study. Scope: who is included? How is it defined? What are the effects on consumers and carers and on service funding?	1	2	1
People out of NDIS scope: what can be done to reach them?	2	1	1
Language and communication			
How does language include/exclude?	2		
Consumer perspectives on use of labels	1		
What forms of communication work for consumers and carers?			1
Peer to peer			
How to implement internationally recognised models of peer support	1		
What are clinician views on peer support?			
Peer-led services	5		1
What are the gaps? E.g., support groups	2	1	
How to recruit and train workers. What is going where? Where is it embedded? How are they being supported?	3		

Topic	Consumer votes	Carer votes	Consumer/carer votes
What is a peer?			
Consumers' experiences of peer to peer			
Legislation			
Capacity for decision making/change in the Act and its application; consumer and carer experiences of this. What information is provided about the Act? What support is provided e.g. legal?	1		
To what extent do we follow human rights legislation on mental illness?	3		
Ungrouped/other			
Impacts on specific age groups (young people, older people)	2	1	1
Accommodation	2	1	
Employment		1	1
Children of people with mental illness	1		
Smoking cessation			
Support in education settings	1		1
Culturally and linguistically diverse people	1		1
Risk factors for mental illness	1		
Social inclusion			
Recovery and fulfilling potential	4		2
Learned helplessness (experience with services)	3		
LGBTI			
Insurance			1
Bullying			1
Bereavement			
Suicide: continuous care and support			1

Topics of interest to each group

Several topics received votes from people in only one group. Since there were many more consumer votes available, quite a number of topics received one or two consumer votes (see Table 1). The topics with three or more votes chosen only by consumers were:

- *What changes do people make in their own lives as a result of stigma?*
- *How to recruit, train, embed and support peer-to-peer workers*
- *To what extent do we follow human rights legislation on mental illness?*
- *Learned helplessness (experience with services)*

Topics chosen only by carers were:

- *How is privacy interpreted by health professionals and does it differ from consumer and carer interpretation?*

- *Effects of drug and alcohol use early in life*
- *Recovery-oriented services: consultation with consumers and knowledge of pathways into them*

Carers also voted for the medication and stigma general areas.

The 25 votes from people who identified as both consumers and carers were quite widely spread, covering 20 topics and one broad area. Eight of these topics received votes only from this group:

- *Consumer and carer experiences of whether the public and private systems work together*
- *Awareness and role of GPs such as engagement with carers, language and communication skills*
- *Transparency of clinical management*
- *Implementation of clinical practice guidelines (why the disconnect)*
- *What forms of communication work for consumers and carers?*
- *Insurance*
- *Bullying*
- *Suicide: continuous care and support*

Summary

The striking feature of the morning sessions was the large number and scope of topics that were raised and that received votes. A small number of topics received more votes than the average, but even these received a relatively small proportion of the available votes. There was also some suggestion of differences between topics of interest to consumers, carers and consumer/carers. It is clear that further work is needed to settle on initial topics of focus for ACACIA work. This is discussed further in Section 5.

Section 3: Methods for involving consumers and carers in the research process

The final sessions of the day were conducted as a single large group and focused on methods of actively involving non-academic researchers in the research process. This section of the day started with a presentation by Dr Michelle Banfield that introduced the research process and some of the ways people may be involved in it (see Appendix C). The focus was on simple but effective ways of getting started with involvement. Some of the key challenges for academic researchers such as balancing the timely sharing of results with the community with the constraints imposed by academic publishing (a job requirement) were also mentioned. Medical journals only permit publication of research findings that have not been previously published via other means. This can result in substantial delays in sharing full research findings with participants and the community more broadly.

The day finished with an open discussion of ways to engage with consumers and carers in research. Forum participants raised a number of possible ways to connect with consumers and carers, both to encourage people to become actively involved in the process of research and to recruit participants as the focus of the research. A full list of points raised is contained in Appendix I. Some of the suggestions for engaging people in the research process were:

- *Working with community organisations that conduct their own research to improve methods and increase recognition of this work as research*
- *Using training workshops and forums to help people gain skills to contribute*
- *Asking for consumer and carer input on information sheets to make sure they can be read and understood.*

Other points of discussion for engaging people in research more generally included:

- *Using a variety of communication methods e.g., social media, Skype and face-to-face*
- *Focusing on in-person methods (e.g., interviews) rather than online surveys*
- *Being creative for hard-to-reach groups – e.g., taking the research to them*
- *Using consumer-led processes such as peer-to-peer interviews, especially to engage with vulnerable populations*
- *Making sure that there is feedback of the study findings to the community, using a variety of methods e.g., organisations' newsletters, public seminars and online.*

Summary

The main message from the discussion on methods of involvement was that no one size fits all. Throughout the process of a research project, using a variety of online and face-to-face methods and looking for opportunities to partner with consumers, carers and organisations will give the best chance of good results.

Section 4: Forum evaluation

At the close of the forum, participants were asked to complete a short evaluation form (see Appendix E). The evaluation was intended to serve two purposes: 1) to hear participants' views on the inaugural forum; and 2) to give people the opportunity to suggest improvements for future events.

Forum feedback

Twenty-one people completed the evaluation form. On the five -point rating scale from "very poor" to "great", 13 people rated the forum as "great" and the remaining eight said it was "good". Everyone said that the forum met their expectations; some commented that it actually exceeded them.

When asked to identify the "best thing" about the forum, most people said that they liked the discussion sessions. People enjoyed the freedom to brainstorm their ideas, share their experiences and work together to shape these into research topics. Further, many people also commented that they felt the atmosphere was respectful and encouraged good discussion.

> *"Not being patronised as consumers – acknowledging our capacity to <u>be</u> researchers, not just <u>be</u> researched…Freedom to brainstorm."*

Responses to the "worst thing" question were more varied. Six participants either left this question blank or said there was no worst thing. A small number of people noted problems with the catering and venue, particularly sound. A small number also commented that occasionally the group size made it difficult for everyone to have a fair say, and it was challenging to identify priorities.

> *"8 people around a table, sometimes difficult to get your ideas heard/understood"*

Suggested improvements

Several participants suggested trialling different methods for the group discussions. These included comments that the group sizes needed to be smaller (four or five) and suggestions to mix things up by having people move between tables or spend more time on reflection with the whole forum.

Two people suggested that targeting specific groups such as CALD and gender diverse groups for future forums may be useful. Others made broader comment that an expanded recruitment and advertising campaign for future events may help to attract harder to reach groups.

"'Pollinate'. Find as many ways to get your message out. Obviously it's up to you to control where is appropriate. Hard to balance but the people that don't know can be suffering the most."

Other suggestions included a shorter day and a variety of time options to attract people with work, school or caring responsibilities. A few people also said they hoped that results would be shared.

Eighteen participants offered further suggestions in the final open-ended question, "anything to add". These ranged from a simple "thank you" to excellent summaries of what was positive about the day and their hopes for the future.

"Very well organised, especially in tight timeframe. Ideas just flowed and there were enough for multiple sessions. Leave one optimistic about future projects. I love the idea of going outside usual research constraints by having consumer and carer involvement."

Section 5: Future directions

The forum generated a large amount of high quality information about topics consumers and carers view as priorities for research. Although this report has only summarised the findings, the individual ideas contributed by consumers and carers will not be lost. All the collected information will serve as a guide not only for ACACIA but also for other researchers in the future. The forum was the first of many opportunities for consumers and carers to contribute to ACACIA's work. The main priority now is to finalise the topics on which ACACIA's research will focus first. This will involve further consultation with ACACIA's Advisory Group as well as further consultation with consumers and carers on the topics raised at the forum. It will also include scoping the research and evaluation work that is already being conducted in services throughout the ACT. This will ensure the research fills the gaps that are important to consumers and carers. Meanwhile we will ensure that the findings from this research reach a wide audience of researchers around the world by preparing a paper for publication in a medical/scientific journal.

Finally, work on methods of involving consumers and carers in the research process will be ongoing. One workshop on research processes and effective involvement for consumers, carers and organisations has already been held. Further mentoring and training opportunities such as partnering with organisations to develop research skills are also being developed.

Glossary of terms

Comorbidity

A person with co-morbidities has more than one disease or condition at the same time (e.g. diabetes and coronary heart disease). The conditions may or may not be causally connected to each other.[2]

Consumer advocate

Consumer advocacy involves supporting and promoting the rights and interests of individuals, assisting individuals to achieve or maintain their rights and empowering and representing their needs. [3]

Learned helplessness

A condition in which someone has learned to behave helplessly and feels powerless to alter her/his situation or condition, even if the opportunity presents itself.[4]

NDIS

National Disability Insurance Scheme

Partners in Recovery (PIR)

PIR is an initiative of the Australian Government Department of Health. It aims to better support people with severe and persistent mental illness with complex needs and their carers and families by facilitating the collaboration, coordination and integrated operation of relevant multiple sectors, services and supports. [5]

Peer-to-peer research

A type of consumer-driven research where peers from the same community conduct qualitative research interviews with others from the community.

[2] ACT Health: (2014), Australian Capital Territory Chief Health Officer's Report 2014, ACT Government, Canberra, ACT.
[3] Disability Services Queensland and Federal Department of Families, Community Services and Indigenous Affairs, Strategic Reporting Framework for Advocacy (2007) 3
[4] Harris, J., & White, V. (2013). learned helplessness. In A Dictionary of Social Work and Social Care. : Oxford University Press.
[5] Australian Government Department of Health (2014): About Partners in Recovery http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pir-about

Peer worker

Peer workers provide positive relatable role models for other consumers and carers and can apply the expertise they have derived from living with their own mental illness to support others dealing with similar issues.[6]

Personal Helpers and Mentors Service (PHaMS)

PHaMs is an initiative of the Australian Government Department of Health. It provides increased opportunities for recovery for people aged 16 years and over whose lives are severely affected by mental illness, by helping them to overcome social isolation and increase their connections to the community.[7]

Recovery-oriented services

Recovery-oriented services reflect a consumer-centred approach to designing and providing mental health services that are framed by the principles of hope, optimism and self-determination.[8]

Social inclusion

A socially inclusive society is defined as one where all people feel valued, their differences are respected, and their basic needs are met so they can live in dignity.[9]

Trauma-informed care

A trauma-informed care model engages the system or organisation in a culture change. It emphasises the core values of safety, trustworthiness, choice, collaboration, and empowerment in every facet of program activities, physical settings, and relationships. Service systems are designed in a way that allows services to be delivered in a way that avoids inadvertent retraumatisation and facilitates consumer participation in treatment.[10]

---

[6] Franke, Carmen C. D.; Gassner, Lee-Anne J. and Paton, Barbara C. Implementing mental health peer support: a South Australian experience [online]. Australian Journal of Primary Health, Vol. 16, No. 2, 2010: 179-186.
[7] Australian Government Department of Health (2014): Mental Health - Personal Helpers and Mentors (PHaMs) https://www.dss.gov.au/our-responsibilities/mental-health/programs-services/personal-helpers-and-mentors-phams
[8] Hungerford, C., & Fox, C. (2014). Consumer's perceptions of Recovery-oriented mental health services: An Australian case-study analysis. *Nursing and Health Sciences*, *16*, 209–215
[9] Cappo, D Monsignor, 2002, Quoted in VicHealth Research Summary 2 - Social inclusion as a determinant of mental health & wellbeing (January 2005) accessed at: http://www.health.vic.gov.au/agedcare/maintaining/countusin/inclusion.htm
[10] Jennings, A. (2008), Models for Developing Trauma-Informed Behavioural Health Systems and Trauma-Specific Services, NCTIC, Rockville, MD.

Appendix A - Agenda

ACT Consumer & Carer Mental Health Research Forum

27th November 2013

9:30AM-4PM

Agenda

Session 1. Introduction to ACACIA (9:30AM)

Presentation by ACACIA team: *Welcome and overview of ACACIA*

Session 2. Developing areas for research (10AM)

Small group discussions: *What are the topics/areas/services that you think should be the focus of research within the ACT?*

Morning tea break (11-11:30AM)

Session 3. Refining areas for research (11:30AM)

Small group discussions: *Building on the topics raised before the break, how might we start to put our ideas together into research questions?*

Lunch break (12:45-1:45PM)

Session 4. Priority setting (1:45PM)

Whole group activity: C*hoose which areas you think should be the priorities for research*

Session 5. Models of involvement (2:15PM)

Presentation by ACACIA team: *Models for active involvement of consumers and carers in mental health research*

Afternoon tea break (2:45-3PM)

Session 6. Methods of involvement (3PM)

Large group discussion: *Methods of active involvement of consumers and carers in mental health research*

Wrap up (3:45PM)

Final remarks from MC and ACACIA team. Completion of feedback forms.

Forum close 4PM

Appendix B – Presentation introducing ACACIA: Professor Kathy Griffiths

The following slides provide an overview of Professor Kathy Griffiths' introductory presentation on ACACIA.

Australian National University

From CRU to ACACIA:
The ACT Consumer and Carer Research Unit

Professor Kathy Griffiths
Director, Centre for Mental Health Research
1st ACACIA Mental Health Research Forum
26 November 2013, ANU Commons

Australian National University

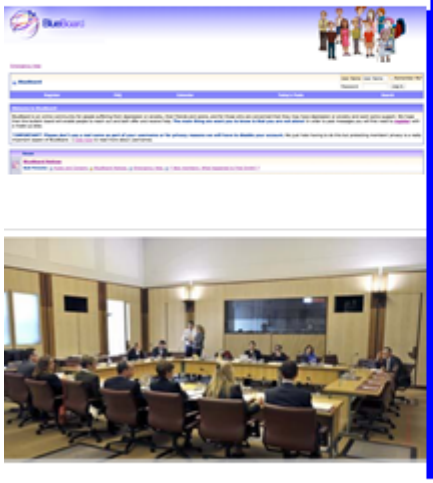
Aim of this forum and ACACIA:
Consumers and carers participating actively in research

Consumers and carers participating in research.

- **But why is this important?**

Current research effort is not necessarily the most important to consumers and carers or what will make the most difference to them

Consumers and carers participating in research. Why?



"Putting on weight drags you down, you get down, they put you on more meds, you get fatter, etc the vicious cycle never ends. There has to be SOMEONE who can help us??" (FM)

Consumers and carers participating in research.

Consumers and carers generate critically important new knowledge as part of their lived experience but there are not always the channels for it to be translated into mainstream knowledge and practice.

http://www.healthboards.com/boards/depression/38022-head-shocks-dizziness-effexor-venlafaxine.html

'. . the reason I know I have forgotten a dose . . . is because I get really dizzy and these horrible head shocks...that's when I think 'oops, I forgot to take it yesterday' or whatever. Its not that I think, oh no I forgot to take it, then get these 'imaginary' head shocks! Has anyone else experienced the same on this medication??'

June 7, 2003

a

http://www.peoplespharmacy.com/2008/05/26/stopping-antide/

http://www.healthboards.com/boards/depression/38022-head-shocks-dizziness-effexor-venlafaxine.html

'It's refreshing to know t
company. I w
beli ... of that my
's ... caused by something
els

Consumers coined the term 'brain shivers' to describe the problem

The Psychiatrist

HOME | CURRENT | ARCHIVE | FEEDBACK | SUBSCRIBE | HELP

SPECIAL ARTICLES

'Brain shivers': from chat room to clinic

David M. B. Christmas, Lecturer in Psychiatry

The Psychiatrist (2005) 29: 219-221

"While the medical literature is silent, online there is active discussion about 'brain shivers'. In contrast to this online community of people discussing a particular side-effect, psychiatrists appear to be unfamiliar with these patient-led terms. Of a small sample of psychiatrists sampled by the author, none had come across the term 'brain shivers' before."

But, 7 years later in 2012 has much changed?

HELP ME, MY BRAIN IS SHIVERING.

APRIL 15, 2012

12 COMMENTS

0 Tweet 0 Like

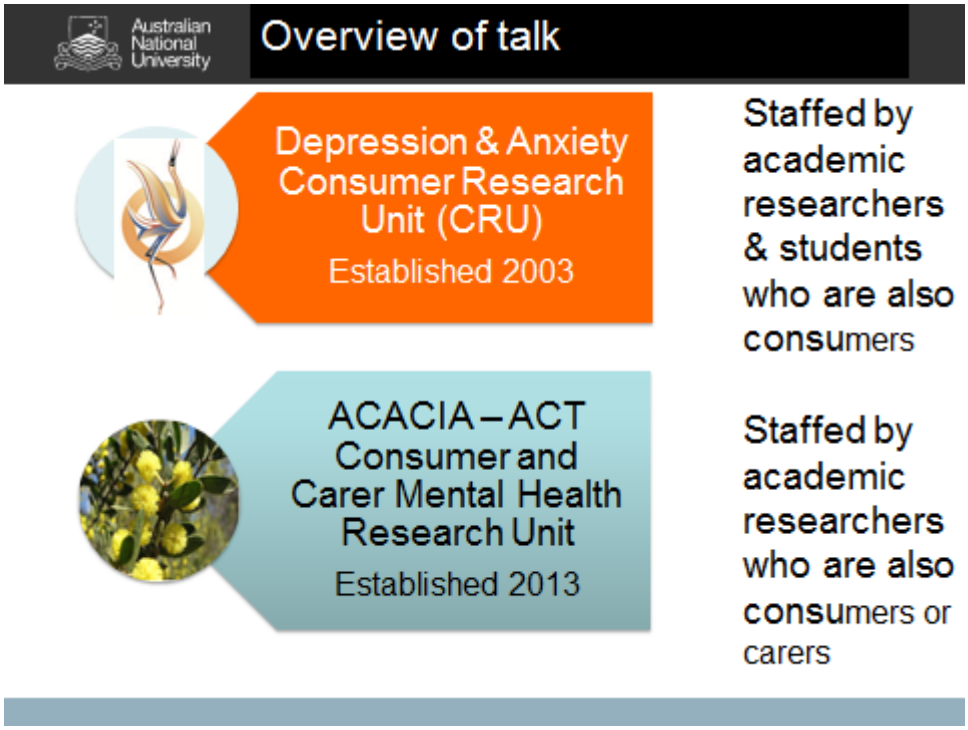
I have found a seemingly endless number of forum posts from people who've felt the exact same symptoms as me on Effexor. My "shudders" are known as "Brain shivers" online, but they are definitely the same thing.

Australian National University

What we need

- We need to **hear** what consumers and carers have to say
- We need a formal systematic means for collecting consumer and carer voices
- We need to systematically disseminate the results to consumers, carers, practitioners, policy makers

Papers
Involving consumers in designing, conducting, and interpreting randomised controlled trials: questionnaire
Editorials
Involving patients in clinical research
Improves the quality of research
Education and debate
What do I want from health research and researchers when I am a patient?
Participatory research maximises community and lay involvement
the NHS research and development programme?
Handbook of Service User Involvement in Mental Health Research


Australian National University
Overview of talk
Depression & Anxiety Consumer Research Unit (CRU)
Established 2003
Staffed by academic researchers & students who are also consumers
ACACIA – ACT Consumer and Carer Mental Health Research Unit
Established 2013
Staffed by academic researchers who are also consumers or carers

Overview of talk

Depression & Anxiety Consumer Research Unit (CRU)

Established 2003

Staffed by academic researchers & students who are also consumers

ACACIA – ACT Consumer and Carer Mental Health Research Unit

Established 2

Depression & Anxiety Consumer Research Unit (CRU)

Staffed by academics and students with lived experience of depression, bipolar or anxiety disorder

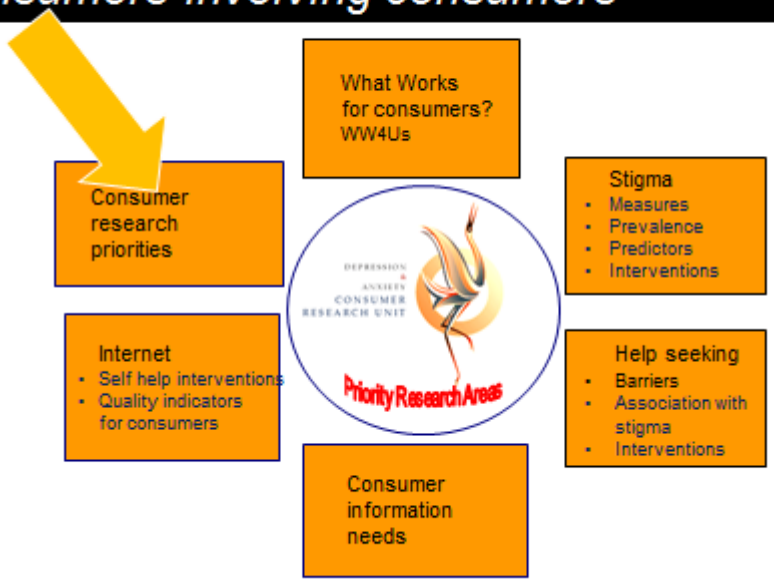
Aims

- Undertake high quality depression & anxiety research from a consumer perspective
- Provide post graduate training to qualified consumers
- Influence mental health research priorities and practice.

Depression & Anxiety Consumer Research Unit (CRU)

- Develop strategies to disseminate finding consumers/ researchers/policy makers/he professionals
- Contribute to MH policy
- Facilitate active participation of lay consumers in MH research
- Reduce stigma by breaking down distinction between consumer/researcher

CRU: Research for consumers by consumers involving consumers



Consumer research priorities study:

SCOPE FOR RESEARCH

Michelle Banfield

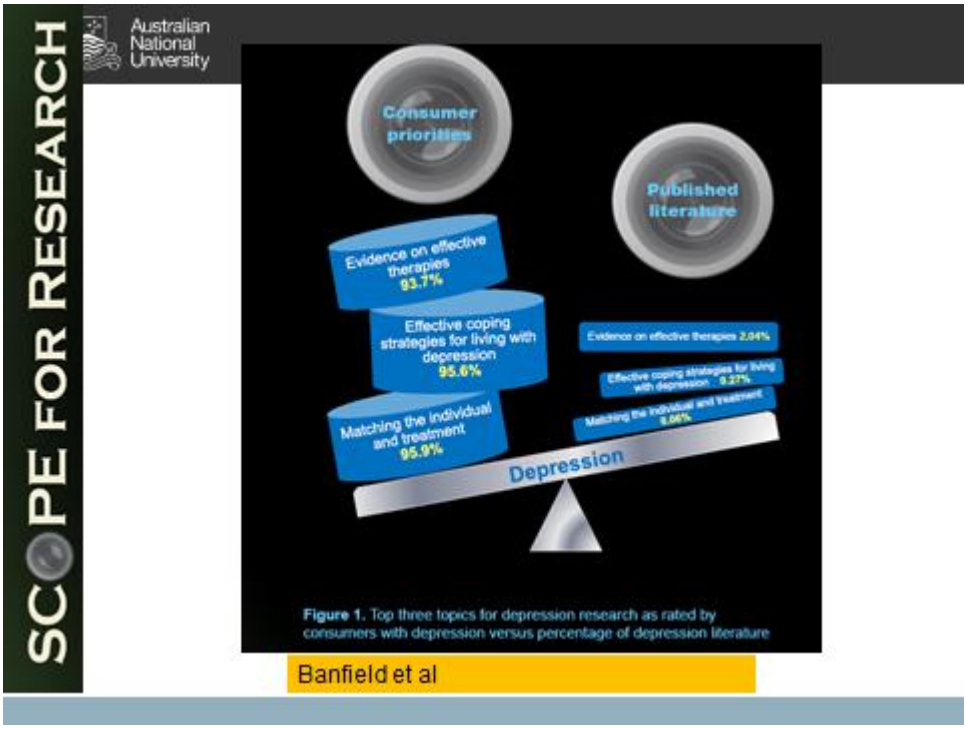
CTimes 17 Sept 2007

What are the the right questions?

Australian National University

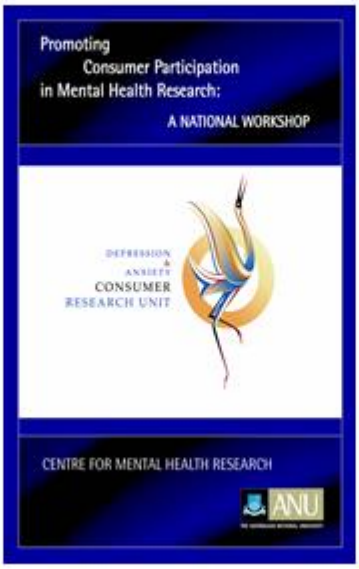
Consumer-developed broad topics

- Management of mental health issues (including self-management)
- Treatment
- Effects of mental health issues (eg on carers and families)
- Causes and risk factors for mental health issues
- Medication
- Diagnosis
- Education and awareness
- Services
- Psychological therapies
- Aspects of everyday life that affect mental health (eg diet, sleep)
- Employment
- Government policy and funding for mental health
- Health professional issues
- Description and characteristics
- Alternative therapies
- Research issues (eg methods)


SCOPE FOR RESEARCH
Australian National University
Consumer priorities
Published literature
Evidence on effective therapies 93.7%
Effective coping strategies for living with depression 95.6%
Matching the individual and treatment 95.9%
Evidence on effective therapies 2.04%
Effective coping strategies for living with depression 9.27%
Matching the individual and treatment 8.66%
Depression
Figure 1. Top three topics for depression research as rated by consumers with depression versus percentage of depression literature
Banfield et al

SCOPE FOR RESEARCH
Australian National University
Consumer priorities
Published literature
Long-term effects of medication 95.4%
Matching the individual and treatment 95.4%
Effective coping strategies for living with bipolar disorder 95.9%
Long-term effects of medication 1.83%
Matching the individual and treatment 8%
Effective coping strategies for living with bipolar disorder 9.61%
Bipolar disorder
Figure 2. Top three topics for bipolar disorder research as rated by consumers with bipolar disorder versus percentage of bipolar disorder literature
Banfield et al

Australian National University



Australian National University

Overview of talk

Depression & Anxiety Consumer Research Unit (CRU)

Established 2003

ACACIA – ACT Consumer and Carer Mental Health Research Unit

Established 2013

Staffed by academic researchers who are also consumers or carers

Australian National University

2010 ACT Community Mental Health Sector Review by independent consultant (Sebastian Rosenberg, Connetica)

There is a need to identify the 'views of service users to inform quality improvement. Consumers and carers need to report on their entire experience ... " (p. 15)

...'so that the growing ACT Community mental health sector can continue to deliver quality care to the community' (p. 16).

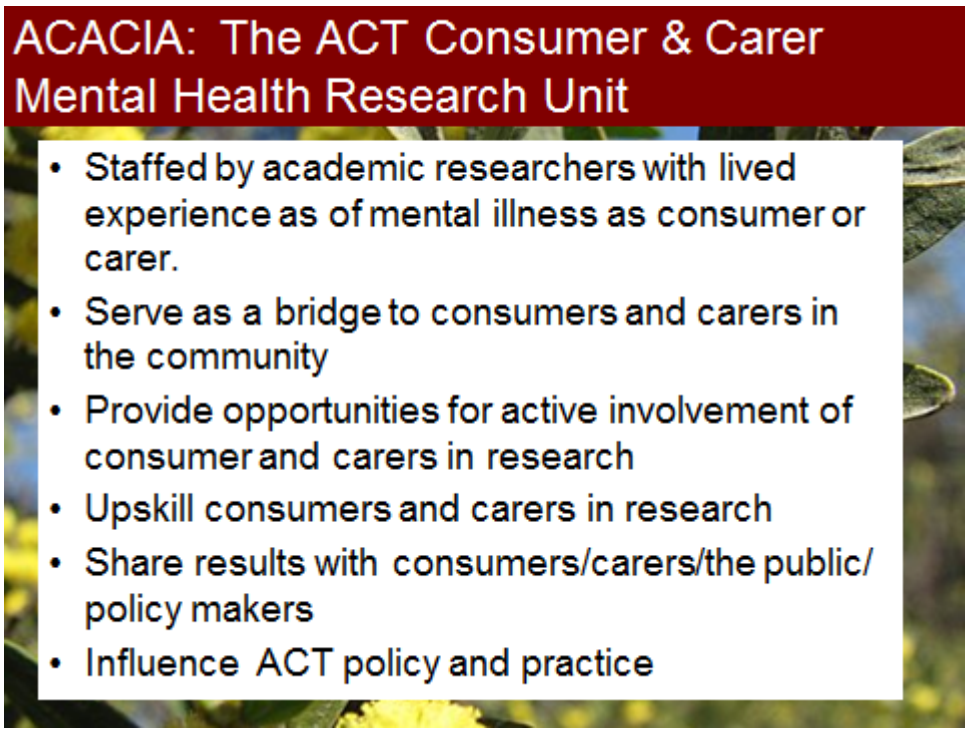
ACT Government Health

REVIEW OF THE ACT COMMUNITY SECTOR OF MENTAL HEALTH SERVICES

MAY 2011

Recommendation 7:
Establish a new Consumer Carer Mental Health Research Unit in the ACT 'to bring the voice of consumers and carers to bear in systemic quality improvement'.

Australian National University
Australian Capital Territory
Budget
2011-2012
ACT
Tender May 2012
ACT
Fundi t aside in
201 T
B velop an
umer &
esearch Unit
ANU Centre for Mental Health Research was the successful tenderer
tablish ACT-based consumer and carer research unit within a university;
- Research to benefit the lives of ACT mental health consumers and carers


ACACIA: The ACT Consumer & Carer Mental Health Research Unit
• Staffed by academic researchers with lived experience as of mental illness as consumer or carer.
• Serve as a bridge to consumers and carers in the community
• Provide opportunities for active involvement of consumer and carers in research
• Upskill consumers and carers in research
• Share results with consumers/carers/the public/ policy makers
• Influence ACT policy and practice

ACACIA: The ACT Consumer & Carer Mental Health Research Unit
Personnel
• Griffiths (Director, Centre for Mental Health Research)
• Dr Michelle Banfield – ½-time academic consumer researcher; ACACIA Project Manager
• Ms Aine Tierney - 1/2-time carer research assistant

ACACIA Advisory Group members
David Lovegrove, Consumer Rep - ACT Consumer Mental Health Network
Sharon Leigh-Hazell, Carer Rep - Carers ACT
Mariana Oppermann, Independent Consumer Rep
Maureen Bell, Independent Carer Rep
Ms Dalane Drexler, Organisational Rep - ACT Consumer Mental Health Network
Colleen Sheen, Organisational Rep - Carers ACT
Julia Bocking, Consumer Consultant - ACT-Wide Mental Health Programs, ACT Health Directorate
Jane Pepper, Organisational Rep - ACT Mental Health Policy Unit, ACT Health Directorate

Today's forum

- Development of research areas
- The hard question:

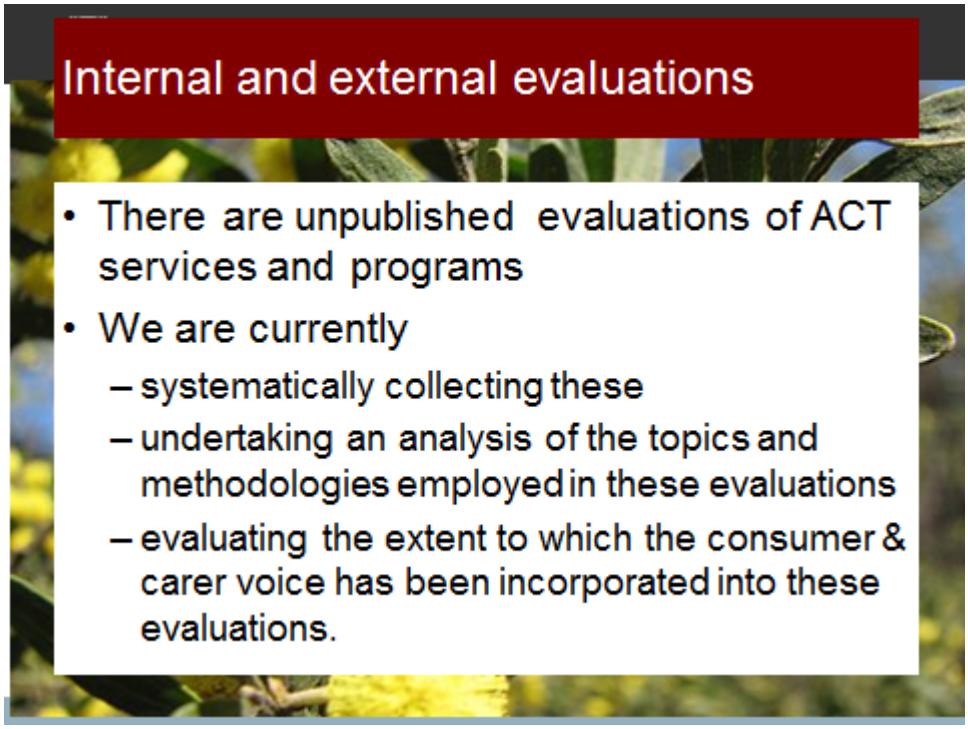
  Which are the most important?
- How would consumers and carers prefer to become involved in the work of the unit? Eg, Think tanks, reference groups, a register with different activities stating which they would be interested in

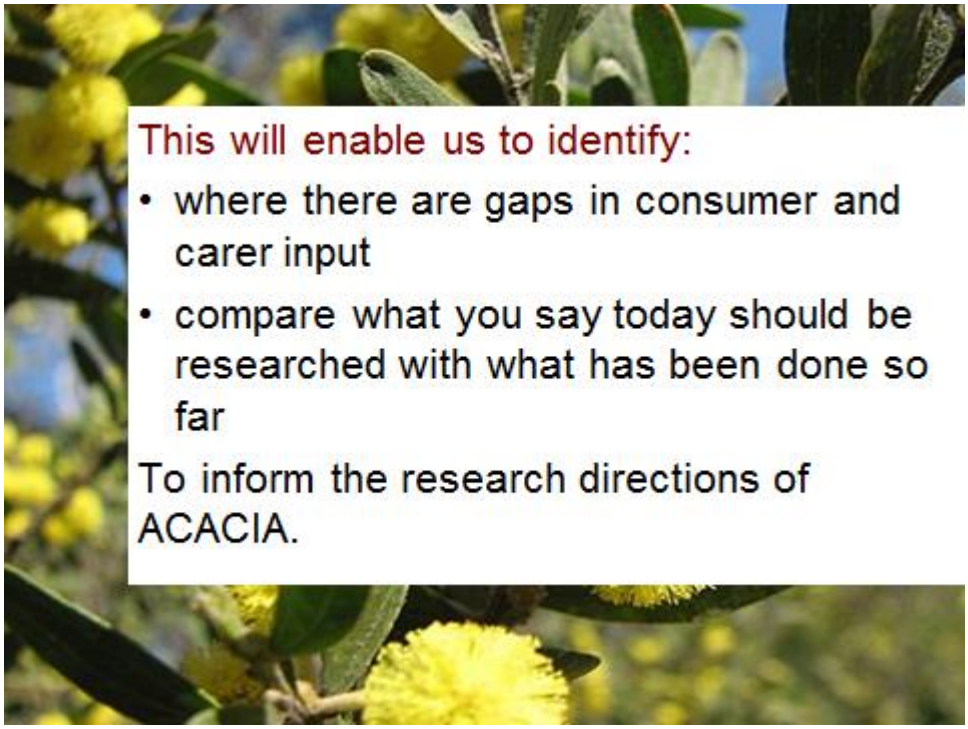
Today is part of ACACIA's research

ACT funded mental health programs

Program type	Number programs	Research
Consumer advocacy, training, representation	7	2
Carer support & advocacy	7	
Peak bodies	8	
Prevention, promotion & early intervention	23	3
Non-crisis early intervention	8	
Recovery-focused	14	
Indigenous health	16	
Gender specific	12	1
Drug & alcohol	4	9
Employment	2	
CALD & multicultural services, advocacy, info	6	
Services for children	3	
Recreational support	1	
Supported accommodation	2	

Research focus
• Focused on issues rather than services/programs
– Eating disorders
– Psychosis & antipsychotic use
– Drug & alcohol use
– Psychological therapies
– Human rights
– Service planning and use


Internal and external evaluations
• There are unpublished evaluations of ACT services and programs
• We are currently
– systematically collecting these
– undertaking an analysis of the topics and methodologies employed in these evaluations
– evaluating the extent to which the consumer & carer voice has been incorporated into these evaluations.


This will enable us to identify:
• where there are gaps in consumer and carer input
• compare what you say today should be researched with what has been done so far
To inform the research directions of ACACIA.

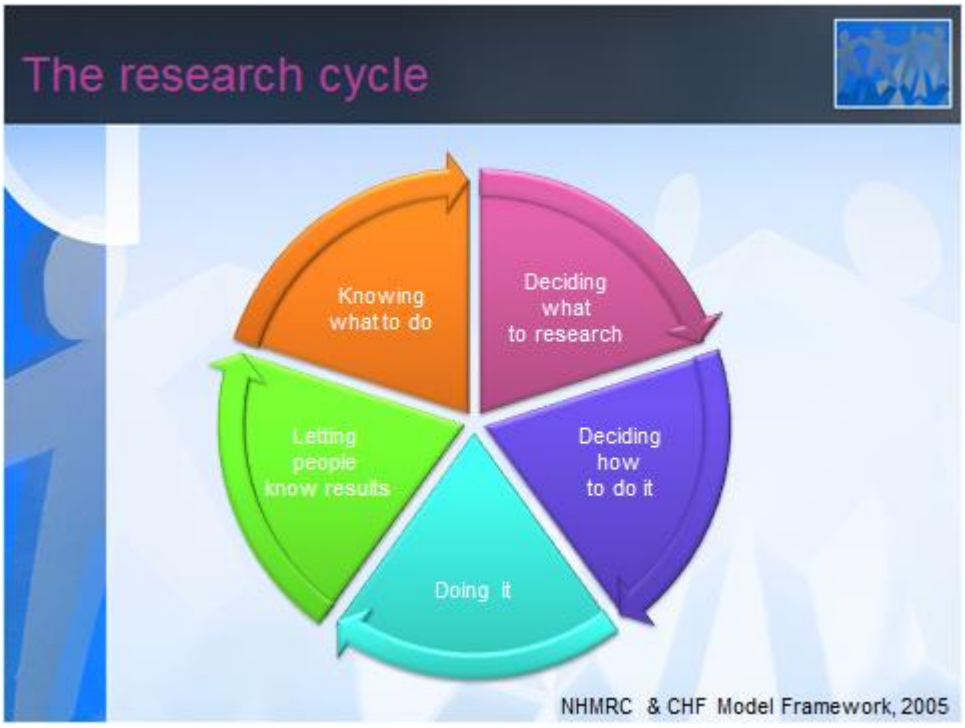
Thankyou and . . . Over to Keith

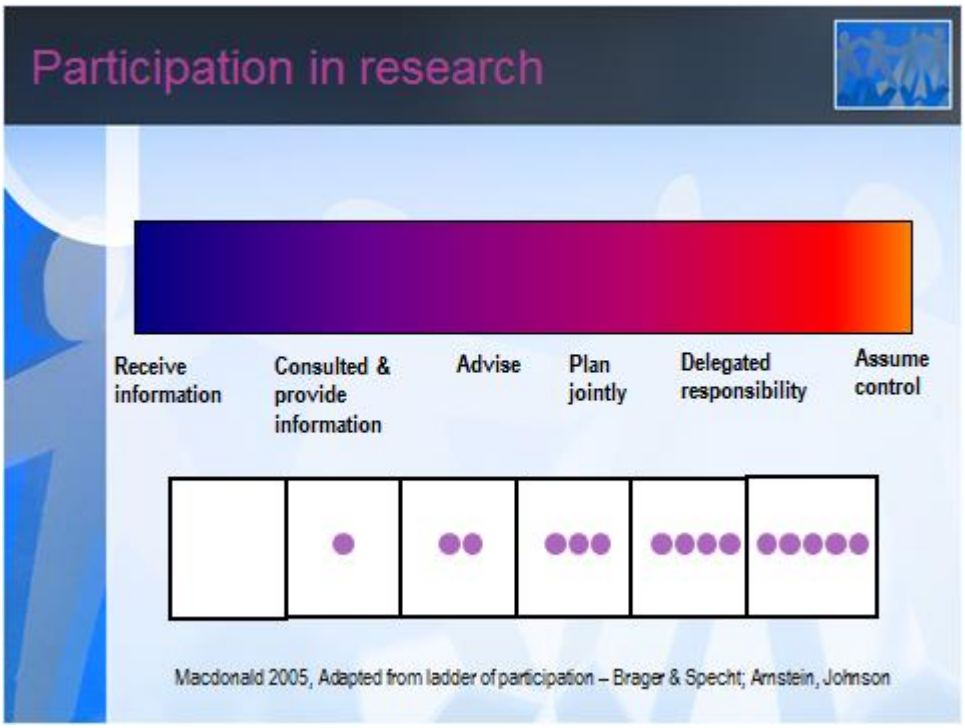
Thank You
• ACT Health
• ACTMHCN
• Carers ACT
• Woden Community Service
• Dr Michelle Banfield, Aine Tierney, Mearon O'Brien, Brad Carron-Arthur, Becca Randall, Julia Reynolds, Lou Farrer, Dalane Drexler, Colleen Sheen, Sharon Leigh Hazell.
• ACACIA Advisory Board members
• And last but not least Keith Mahar

Appendix C – Presentation on research involvement: Dr Michelle Banfield

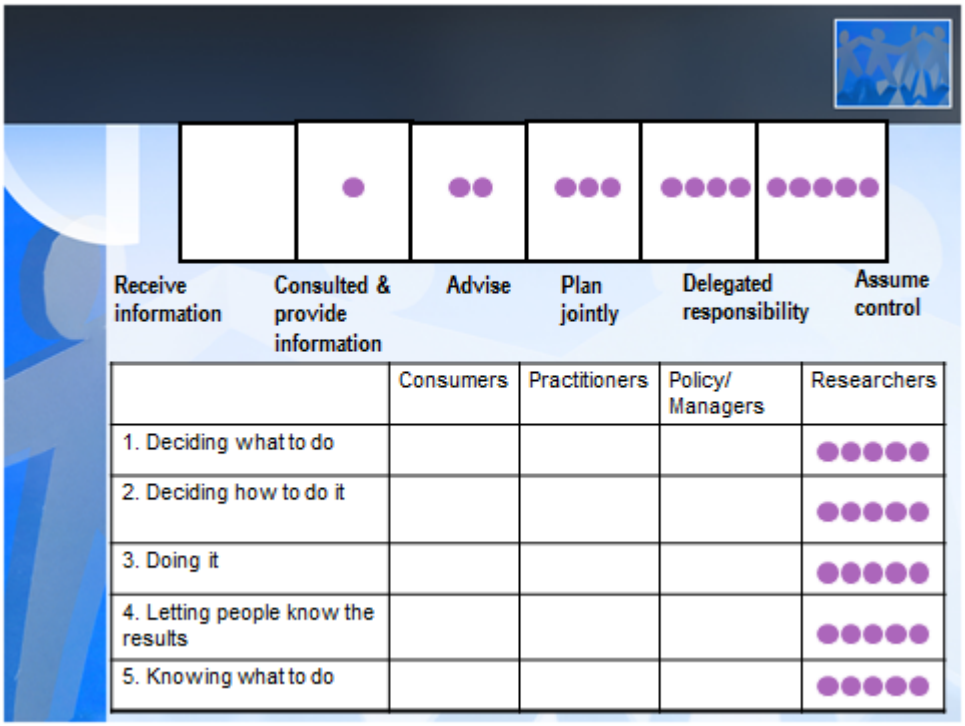
The following slides provide an overview of Dr Michelle Banfield's presentation on models and methods to involve consumers and carers in the research process.

Research stakeholders
Consumers
Carers
Health professionals
Policy advisers
Researchers

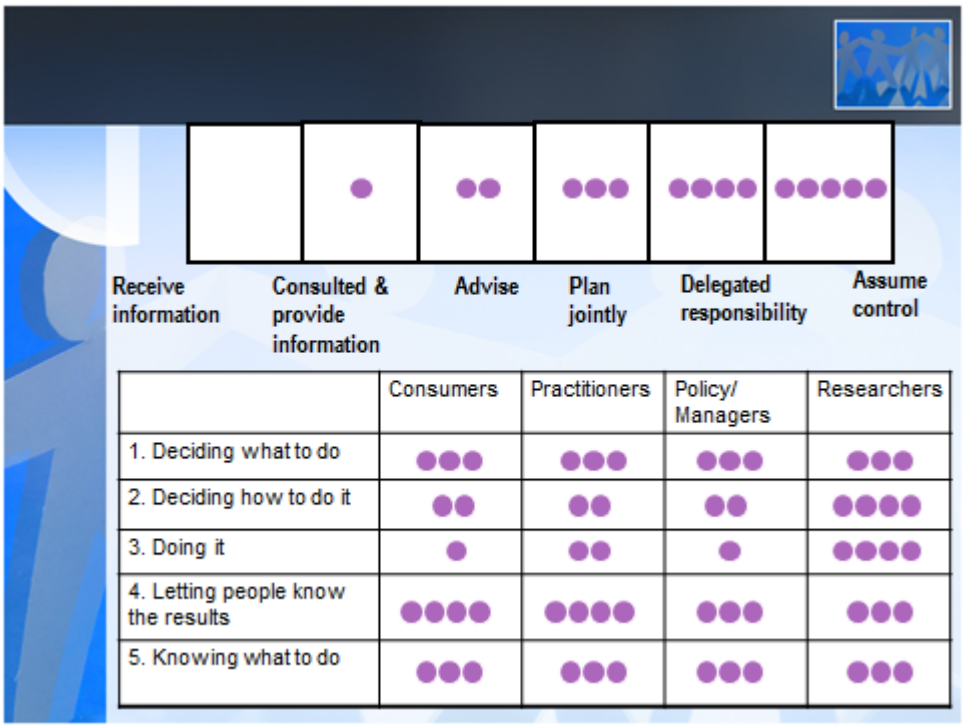

The research cycle
Knowing what to do
Deciding what to research
Deciding how to do it
Doing it
Letting people know results
NHMRC & CHF Model Framework, 2005



Appendix C: Presentation on research involvement: Dr Michelle Banfield



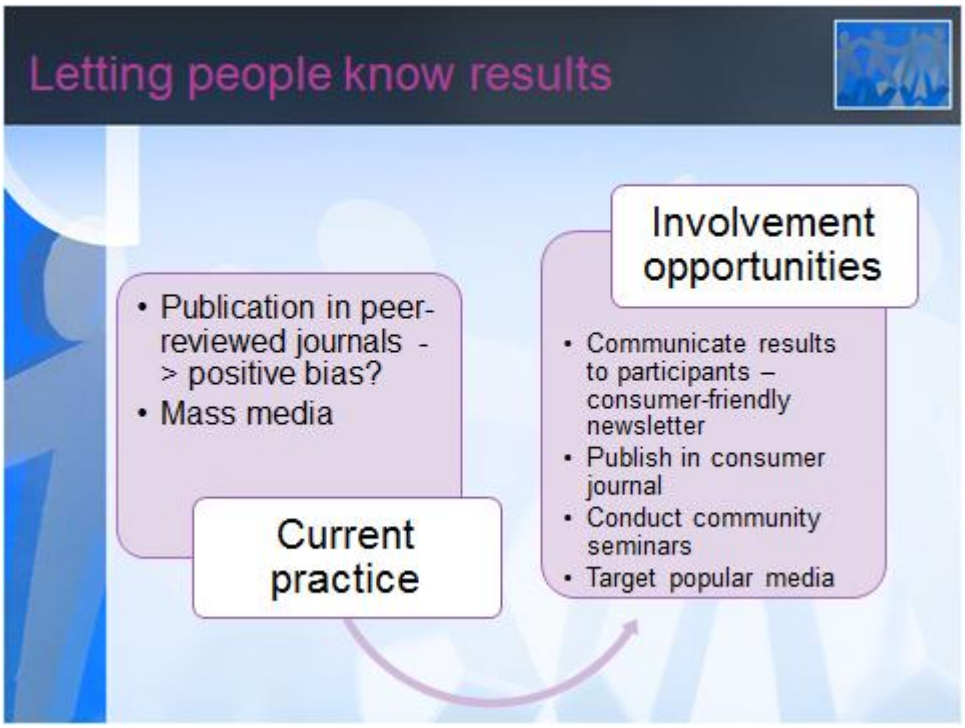
Appendix C: Presentation on research involvement: Dr Michelle Banfield



	Consumers	Practitioners	Policy/ Managers	Researchers
1. Deciding what to do	●●●	●●●	●●●	●●●
2. Deciding how to do it	●●	●●	●●	●●●●
3. Doing it	●	●●	●	●●●●
4. Letting people know the results	●●●●	●●●●	●●●	●●●
5. Knowing what to do	●●●	●●●	●●●	●●●

Deciding how to do it
Involvement opportunities
• Comment on burdens or insensitivities in methods
• Help write info sheets
• Suggest alternative recruitment strategies
• Ensure question provides answer relevant to consumers (practical)
• Assist with recruitment – sensitive populations
• Follow established methodologies for rigour
Current practice

Doing it
Involvement opportunities
• Consumer member of research team
• Reference group
• Guided by NHMRC Statements on ethics etc – little active partnership
Current practice


Letting people know results
• Publication in peer-reviewed journals -> positive bias?
• Mass media
Current practice
Involvement opportunities
• Communicate results to participants – consumer-friendly newsletter
• Publish in consumer journal
• Conduct community seminars
• Target popular media

What to research next
• As per deciding -> funding, researcher interests, track record
Current practice
Involvement opportunities
• Consumer perspective on outcomes
• Participant feedback on methods etc

Appendix D – Prompt list of previous consumer-developed topics for research

Management of mental health issues (including self-management)

Treatment

Effects of mental health issues (e.g. on carers and families)

Causes and risk factors for mental health issues

Medication

Diagnosis

Education and awareness

Services

Psychological therapies

Aspects of everyday life that affect mental health (e.g. diet, sleep)

Employment

Government policy and funding for mental health

Health professional issues

Description and characteristics

Alternative therapies

Research issues (e.g. methods)

Appendix E – Forum evaluation

ACACIA: The ACT Consumer & Carer Mental Health Research Unit

ACT Mental Health Research Forum

27th November 2013

Evaluation

1. What was your overall impression of the forum? (please circle one)

Very poor	Poor	Okay	Good	Great

2. Did the forum meet your expectations?

Yes	No

If "No" please tell us what we could have done better:

3. The <u>best</u> thing about the forum was:

4. The <u>worst</u> thing about the forum was:

5. **Do you have any suggestions about how we might improve future events?**

6. **Is there anything else you would like to add?**

Thank you for your feedback.

Appendix F – Notes from group discussions (session 2)

NB: Each source of notes is separated by a solid line. Some groups (tables) submitted more than one set of notes.

- Meds
- Multi-cultural perspectives and mental health within mainstream system (CALD and refugees)
- Education and awareness
- Progress of mental health over 10-20 years to address dependence on supply and access to services
    - Emphasis on mental health support and services
    - Not wanting people to be over dependent (learned helplessness)
- Employment – personal challenge
    - Access to employment and support structures within the workplace
    - Encouragement and support to engage in workforce
    - Nature of illness within specific work environments (ebb and flow of illness)
    - Disconnection of services and navigating pathways through system
    - Psychosocial disability, limited functional recovery but need to do something meaningful and be being paid to do it
    - Availability of relevant employment opportunities – nowhere for people at end of courses to work
- Awareness for individual – information dissemination
    - Post diagnosis what services are available through crisis point or diagnosis through other means
    - Awareness around what support services can be accessed before progressing to crisis point
- Siloed systems and departments that people access
    - Police, justice, health, housing
- Support available at university
    - Transition from home to uni and pressures
    - What support exists in institutions to support and recognise students with warning signs
    - How to support students within universities before students reach crisis point
    - How do students perceive the support environment and if people have accessed how has that been or what do people think they need
- Education in high schools as preventative for other pathways later in life (e.g. leaving school to work) – no awareness at a young age
- Labels
    - Investigating with consumers how terms are useful/helpful or not (pick it apart and explore components)
- MIEACT, Headspace, MoodGYM, SANE, Partners in Recovery
    - Longitudinal research on long term impacts, especially from promotional activities

    - Indicators of what's effective or an influence on someone's help seeking behaviour
- Where do physical health concerns fit into health services when you have mental health problems as main focus
    - What role labels play in affecting physical health due to mental health labels
- Support for people with chronic mental illness with limitations and goals
- Research into project planning and how outcomes are related to type of planning
- Step up, Step Down and Mental Illness Fellowship (post hospitalisation residential environment) talking to people in recovery stages about what they are hoping for and negative aspects
    - Before leaving residential environment, what is negative experience around different influences
- 35-50 residential program?
- Ongoing care for people with long-term conditions (life time care for life time conditions)
- Accommodation
- Coping with transition points – processes
- Inclusions and support around <u>whole</u> family and carers
- Carers are not included in treatment team
- Move from recovery focus to family focus as in NZ
- Financial aspects of mental health
- Employment issues
- Empower consumers to be independent – safe, secure living environment
- Shop front for mental health – never send anyone away
- What is the difference for people accessing the same service but having different recovery pathways (e.g. someone recovering well and moving forward while their peers keep going back through a service or system and staying there for months and years, specifically for youth services)

- How can we ensure that all people who are affected by mental illness fulfil their potential without being inhibited by external sources?
- What could be considered to be something that could potentially aid your recovery?
- What gives you hope and belief that things will improve in the future? Why?

- Stigma
    - By illness
    - Self-stigma
    - Experiences of it in daily life
- Borderline personality
- Carers
    - Who they are
    - How they are supported

    - What support is missing
- Human rights and the mental health Act: experiences of this. (ACT Civil and Administrative Tribunal, qual research)
- Peer workers: how/if they can be implemented
- Education of psychologists – what students learn
- Borderline personality disorder
    - Diagnosis and how people are care for
    - Trajectories after diagnosis
- Human rights and mental health treatment
    - Respect and dignity
    - Safety
    - Seclusion and restraint
    - Explanation of treatments
- Care coordination between mental health and physical health
- Attitudes toward recovery focused practice by practitioners
- Gaps in the carers system
    - Types of carers
    - Spectrum of carers and supports they need
- Forensic mental health consumers
    - People rarely talking about it
    - Criminalisation of mental health
- Stigma and knowledge in police
- Crisis services
- Peer support in public mental health system
- Pet therapy – hasn't been implemented in the ACT, particularly for people who are institutionalised
- Support for coming off medications
    - Research into how to do it
    - Long term research about it
- Looking into what works overseas and alternatives to medicalised options – ACT trials
- How intensely suicidal people are looked after
- Mental Health Act and level of capacity of those detained under the Act
- Mental health stigma
    - How people have experienced stigma
    - From where
    - How does it affect your life?
- How people are being treated and stigma associated with this
- Borderline personality disorder – how people are being treated
- ECT
    - How often is it used?
    - Info provided appalling
    - Denial of adverse effects
    - Lived experience of people who have gone through it

- Use of supported accommodation: more of it and more varied supports

---

1. Longitudinal study: Impact of the new NDIS scheme on people with mental illness
    - Who's included in NDIS?
    - Effects on clients, effects on service funding?
2. Bullying (preventative) – how the non-violent therapeutic programs, strategies address + bridge the gaps in support services for children and youth?
3. What makes a good mental health plan (individualised)?
    - Perspectives of mental health consumers, carers, psychologist, clinicians & service providers.
4. Social inclusion for both consumers and carers
    - Models of success
    - What do we want from it?
        i. Work
        ii. Employment
        iii. Education
    - What makes a good life for consumers + carers?
5. Issues of Carer Recovery / Living grief – what is the effect of caring? And is there such a thing as carer recovery?
6. ACACIA task – provide link on website
    - clearinghouse / collation of evidence-based research on consumer and carer issues/topics available online
    - events and activities that are going on that consumers and carers might be interested in & can contribute to
7. How mental health-aware are ACT's GPs? What is their role (perceived and actual) as part of the therapeutic alliance in care of mental health consumers?
    - Engagement with carers
    - Language & communication with consumers
    - What do consumers and carers want?
8. Suicide – longitudinal – continuums of care and support over the life span?
9. Impact of aging on the economic, social, emotional health and well-being of women over 55 years old
    - Consumers and carers perspective
    - Broader community perspective
10. Mental health services and care: Do the public and private sectors work together to respond to consumers' and carers' needs?
    - What is the consumer and carer experience?
11. Medication and Alternative Treatments:
    - Is medication what we want?
    - Side effects, impacts mental and physical health
    - Are there alternative pathways to treatment? – Efficacy & Cost effectiveness
    - Creating evidence base towards medication design
12. Transparency of clinical management
    - How does it respond, interact with carers and consumers?

13. PIR, PHaMs supports + clinical management – How are these two services working together?
14. What is peer support?
15. How is 'privacy' interpreted by GPs, clinicians + hospitals? Does it differ from consumers and carers' interpretation?
16. How does participation works in the ACT?
    - Tokenism vs Real Engagement
17. Mental health workers + non-clinical staff – worker exhaustion + burnout: How does this impact service support and delivery to consumers and carers
18. How well are the standards (of carers) being applied? Are they being implemented or ignored?
19. Diverse voices and perspectives: Public lectures and community education from independent and well informed speakers for consumers and carers
    - Issues of access
    - Choice
    - Equity
20. Psychiatry, care & mental health and wellbeing:
    - Are psychiatrists there to medicate and get people out the door?
    - Or are they providing holistic treatment?
21. Insurance & Recovery: How does the current insurance system affect people living with mental illness?

Session 2

Medication:

- Lack of recognition of impact of long term medication on people. Is there enough research on this?
- Transition period from one medication to another often not well managed.
- Often no explanation is provided to carers about the different medications that are prescribed (e.g. what each medicine does).

Medical model and psychosocial issues:

- More research should focus on psychosocial issues (e.g. how people can be supported living in their own homes) and we should break out of the medical model.
- GP's often just give a script for depression, and subsequent treatment also often focuses on medication. It would be better to have treatment that looks into factors contributing to the depression than be given medication.
- What are the journeys for people when they leave the GP or the hospital? What happens next?
- Discharge planning often inadequate – more research into this is needed.
- Research into what triggered people to get admitted (e.g. interpersonal conflict, bullying, finances, etc.) and how this can be dealt with? Hospitals generally don't treat these triggers and this needs to change.
- Psychiatrists should spend more time with person and not jump to diagnosis and medication.

- Research into what psychiatrists think consumers need, what the barriers are to provide this, and how this aligns with consumer views.
- Research into what works for people who don't take medication. How do they manage crises? What kept them out of the system? (E.g. did they change their lifestyle after being diagnosed [quit job for example]).
- When being treated in a hospital for a physical condition (that may or may not have anything to do with the mental illness), the mental condition is often not taken into account / ignored. These 'silos' in medicine need attention. Similarly, physical condition are often not taken seriously but seen as part of the mental illness and therefore not adequately treated.

Self-management:

- There are no therapies available on how to help control energy (to prevent manic episode).
- It would be useful to know what works for other people in a more systematic way. How are they managing their depression, bipolar, anxiety, etc.? What prevents them from being admitted (e.g. financial support, support at work).
- Research into what people need to recover.

Communication:

- What communication methods work for consumers and carers? Ranging from elderly who don't use the Internet and young people who use smartphones and tablets all day.
- When looking for information on the internet, you can often find someone with similar problems, but also with opposite problems. This is not very helpful and it is hard to tell how to use this information.

Peer-worker roles / peer support:

- Research into the role of people with lived experiences in supporting others with a mental illness.

Other:

- Research into bullying (this was mentioned but not discussed further).
- When people first seek support, it is important to determine what they need.

<u>Session 3</u>

- How does service delivery impact on the individual?
- Pathways to recovery in the ACT using different services. Map different pathways and see where it disconnects.
- Research into different models (i.e. other than medical model).
    - Including what the place is for e.g. alternative medicine and exercise in treatment in the ACT.
- Survey clinicians and consumers and carers to investigate what helps people recover and identify disparities.
- How to tailor drug-treatment to individuals?
- Peer-workers:
    - What are people's roles and responsibilities?
    - How is it supported in the ACT?
    - How do mental health care providers view peer-workers?
    - What is it? (it's not well defined at the moment)

    - How does it relate to other services (such as case-management) and how can they work together.
    - How do consumers and carers view peer-workers?
- NDIS
    - Research into psychosocial disability. What is it? Not clear /well understood at the moment.
- How do consumers and carers communicate?
    - Who do they trust / take advice from (e.g. Internet, health care providers, family, friends).
    - Which opinion holds strongest weight when making decisions about treatment (e.g. Internet, health care providers, family, friends).
    - How is the consumer voice treated / how is feedback to services used? And how is this incorporated in future policies?
- How are services measuring their effectiveness?
    - Based on monetary outcomes? Or based on consumer and carer outcomes?
- What led people to first seek support? What was happening in their life? Where did they go and where did they find the information?
    - Analyse patterns of subsequent support. (E.g. if people first go to the GP and are given a script, do they tend to keep following the path of medication? And if they first go to a counsellor, do they follow this path, or will they go on to take medication?)
- What are the gaps in support groups.
    - There is a variety of support groups available (e.g. for woman, young people, etc.), but it was mentioned that not everyone fits in these categories while they would like to be part of a support group, so it would be good to identify these gaps in the ACT.
    - What works for consumers and carers in support groups?
- Notion of trauma informed care.
    - Why is trauma informed care important and how to make it part of the services/training in the ACT.

Appendix G – Flip chart summaries (session 3)

Collation of butcher paper notes

- New legislation and tribunal
    - How are consumer and carers experiencing the process? Specifically orders? (Note this could be done using archival research)
    - What information is provided?
    - What support is provided including legal support?
- How do current protocols and their implementation support a consumer and carer journey to recovery?
- What services/pathways do people access when they first seek support in the ACT?
    - How?
    - Access to info
    - Benefit of hindsight
- Trauma informed care
    - Why is trauma informed care important and is it/how is it integrated in service delivery in the ACT (Note: not happening in the ACT!)
- Mental health services and care: do the public and private sectors work together to respond to consumer and carer needs?
    - What is the consumer and carer experience?
- Medication:
    - Is it what we want?
    - Side effects
    - Impact on mental and physical health
    - Are there alternative pathways to treatment
    - Efficacy and cost effectiveness
    - Creating evidence base towards medication design
- Transparency of clinical management: how does it respond/interact with carers and consumers?
- Justice system and intersection with mental health
    - More discrimination?
- Seclusion and restraint and human rights
    - Consumer perspectives of seclusion and restraint
    - Experiences of human rights
- Peer support
    - Where has it happened?
    - What have people experienced?
    - How are they integrated into services?
- How can internationally recognised models of crisis peer support be modelled in the ACT? E.g. N2
- NDIS
    - Who does it reach versus what will it reach?
    - What conditions will be supported?

    - Quantify number of people in the ACT who have mental illness/disability versus how many access NDIS support
- NDIS
    - How is psychosocial disability defined and how will it impact consumers and carers in the ACT?
    - What are consumers' experiences of the impact of mental illness on coping, function, day to day activities?
- Medication
    - Addressed in service delivery?
    - Tailoring drugs for individual
    - Criteria for prescribing
- Consumer and carer involvement
    - Who is involved?
    - How do we expand who gets involved?
    - Specifically young people
- Partners in Recovery, PHAMS and clinical management: how are these services working together?
- What is a peer?
- How is 'privacy' interpreted by GPs, clinicians and hospitals? Does it differ from consumers and carers in interpretation?
- How does participation work in the ACT?
    - Tokenism versus real engagement
- Mental health workers and non-clinical staff
    - Worker exhaustion and burnout – how does this impact service support and delivery to consumers and carers?
- Service delivery and impact on the individual
    - What do consumers and carers consider contribute to recovery?
    - What is the consumer and carer journey in the ACT?
    - What works? What doesn't work?
    - What do clinicians think works compared with consumer and carers?
- What are the "alternative" treatments in the ACT that have contributed to recovery?
    - Holistic approaches
    - Meditation
    - Physical exercise
- What is the value of peer workers in the ACT?
- Peer work:
    - What roles does it encompass?
    - How is it supported (or not)?
    - Consumer and carer views
    - Clinicians' views
    - Support by the sector
    - What is happening across Australia and internationally as evidence?
    - Advocacy roles of carers
    - Peer led services
    - Support groups

    - What are the gaps?
- Mental health Act
    - How many people lose capacity to make their own decisions?
    - How does new ACT Act change this?
    - Is it always applied correctly?
    - What do consumers think of this process?
- Training of psychologists: how can consumer perspectives be incorporated into psychology training?
- Physical health: trial of having a primary health care nurse with a mental health team – does it improve physical health outcomes?
- Communication
    - What forms of communication work for consumers and carers?
    - What sources of information do consumers and carers have faith in?
- How is the consumer and carer voice integrated into policy and services?
    - Feedback effectiveness – is it part of co-design? (note: project would feedback to sector)
    - How is contribution valued?
    - Indicators- how they demonstrate voice is used
- Comorbidity: experiences of drug and alcohol
- NDIS longitudinal study
    - Impact of the new NDIS scheme on people with mental illness
    - Who's included in NDIS?
    - Effects on clients, effects on service funding
- Preventative
- Bullying – how the non-violent therapeutic programs, strategies address and bridge the care of children and youth
- What makes a good mental health plan (individualised)?
    - Perspectives of MH consumers, carers, psychologists, clinicians and service providers
- How mental health aware are ACT GPs?
    - What is their role as part of the therapeutic alliance in care of mental health consumers? Perceived and actual
    - Engagement with carers
    - Language and communication with consumers
    - What do consumers and carers want?
- Suicide – longitudinal – continuum of care and support over the life span?
- Impact of ageing on the economic, social, emotional health and wellbeing of women over 55 years
    - Consumers and carers perspective
    - Broader community perspective
- Treatment research
    - Smoking cessation for those with mental health issues e.g. after being in a smoke free mental health unit: what might be helpful for those in this demographic, tailored treatments/interventions

    - What are the gender specific effects of medication? E.g. physical, self-esteem (Note: longitudinal study?)
    - How many people under 18 are being diagnosed and how are we supporting their families? How are families experiencing support?
    - What support is available when pain is a comorbid condition? How are people experiencing that?
- ECT
    - What info given?
    - Does it follow best practice/clinical literature?
    - How do consumers experience it?
    - Do these match up?
- Supported accommodation
    - What is available versus who needs it?
    - What levels are available?
- Peer support
    - How to recruit and train peer support workers
    - What is going on? Where is it embedded?
    - How are people being supported?
- Pet therapy
- What are the experiences of and needs of people coming off medication?
    - How are they being supported?
- How many service providers believe in recovery and what do they do to support it?
- ECT
- Eating disorders day program
- Outpatient support
- Experiences of care
    - Is care traumatising?
    - How have people who have experiences trauma been cared for?
    - What is helpful in recovery oriented/wellbeing/health services?
    - Are consumers being consulted?
    - Do people know services exist/the pathways into them?
- How are people from CALD backgrounds experiencing the mental health system?
- Borderline personality disorder
    - What percentage of people diagnosed?
    - What are the trajectories after?
    - Look at this from a symptom-focused point-of-view
- Review of training and implementation in trauma-informed care
    - Who is doing it?
    - How are they being trained?
    - Are consumer voices being heard?
- Translation of frameworks and guidelines into practice
    - Why is there a disconnect?
    - What is people's experience?
- Trauma
- Human rights

- Peer work
- Families and children
    - Attitudes towards parents with mental illness, specifically guardianship orders
    - How many disclose? Why/why not?
    - How is status as parents considered in treatment?
    - How many people have been told not to have children and what is their diagnosis?
- How well are the standards being applied? Are they being implemented or ignored?
- Diverse voices and perspectives: public lectures and community education from independent and well-informed speakers for consumers and carers
    - Issues of access
    - Choice
    - Equity
- Psychiatry care and mental health and well-being: are they there to medicate and get people out the door? Or are they providing holistic treatment?
- Insurance and recovery: how does the current insurance system affect people living with mental illness?
- Social inclusion for consumers and carers
    - Models of success
    - What do we want from it?
    - Work, employment, education
    - What makes a good life for consumers and carers?
- Living grief
    - What is the effect of caring?
    - Is there such a thing as carer recovery?
- Acacia task
    - Clearinghouse link on website
    - Collation of evidence-based research on consumer and carer issues/topics available online
    - Events and activities that are going on that consumers and carers might be interested and can contribute to
- Stigma
    - By health providers, mental health and other: what do they believe? How does it impact?
    - Comorbidities and stigma
    - Does the stigma in the mental health system worsen outcomes?
    - Borderline
    - Analysis by disorder
    - Stereotype formation
    - What changes do people make in their own lives as a result of stigma?
- Medication
- Project planning evaluation re outcomes and planning characteristics
- Learned helplessness with changes in last 10-20 years with access to support and services – employment, socialising, participation

- Employment
    - Access to relevant opportunities
    - Understanding of mental health support and services
- Disconnection of services
- Awareness for the individual around services and support post diagnosis, depending on acute care/crisis point
- University
- Labels
- Physical health concerns

Research questions developed by consumers and carers

How can we ensure that all people who are affected by mental illness fulfil their potential without being inhibited by external sources?

To what extent do we follow HR legislation on mental illness?

How are students supported in education settings to achieve mental wellbeing?

What are the current understandings surrounding mental health in the high school/primary school/college age groups?

To what extent is robust monitoring and evaluation planning integrated into project and program planning and design? Evaluation from participants during/after/1 year after

To what extent is program planning and design related to outcomes?

How does the use of language include/exclude individuals?

What gives you hope and belief that there will be improvement in the future and why? (post hospitalisation/treatment)

How can the voices of consumers and families guide programs and services from planning through implementation and evaluation/review?
What are consumer perspectives around the benefits and detriments of label use?

How does early incidence of alcohol and other drug use impact on life?

How can quality of life be maintained during/after treatment for mental illness?

What groups are at highest risk of mental illness and why?

What are the influences, experiences and attitudes of CALD populations towards mental health and mental illness and how does this impact on access to supports? – individuals/families ostracised, community taboos etc.

How can we get mental health and other health professionals to work together more efficiently? E.g. psychiatrists and neurologists

How do systemic problems impact on access for Aboriginal and Torres Strait Islander peoples?

How does mental illness impact on the whole family? I.e. how can we be more inclusive to ensure the individual, the family and both together are well supported?

NDIS does not adequately support the mental health community – what programs/supports can be devised for reaching individuals that are out of scope?

What is the evidence base for linking mental illness to alcohol and drugs?

Are the services reaching the people who need them?

Review the precedence of consumers in the justice system inappropriately

How do individuals adapt to changes (e.g. in medications) that impact their lifestyle and quality of life?

Appendix H – Notes on methods of involvement (session 6)

- Talking rather than surveys
- Face-to-face forums
- Bounce off ideas
- Prefer one-on-one
- Prefer collective forum
- Mentoring – consumer investigator in NGO for consumer-researcher mentoring
- In person rather than online
- Would online archive help?
- How to structure and run research?
- Tailored advice for specific projects
- Building capacity for NGOs, pooling resources
- Timing
    - Difficult to get a group together
    - One-to-one and computer –based, Skype etc. in own time
    - Archive online of resources
    - Different markets, not one size fits all
- Cater for people who don't want to be identified/show up for a forum
- Marginalised people with severe mental illness
    - Go to where they are, opportunistic methods, discussion face-to-face
    - Peer-led research
- Timing difficulty – getting the bus at a particular time etc.
- Feedback – keeping stakeholders in the loop
    - Forums like these
    - Partnering with existing consumer and carer organisations (Carers ACT etc.)
    - Feeding back to organisations – constituencies with networks
- Information sheets
    - Ensure info is understandable to masses, contact for more info
    - Accessible, brief, short, simple and to the point
    - Quality over quantity
    - CALD translation etc., economic
- Using social media
    - Making it engaging, easy to feedback/interact
- Using existing resources in local community e.g. media (Chronicle, noticeboards)
- Splitting research from change processes
    - Disconnect
    - Knowledge is formalised but no change happens
    - Linking advocacy/activism to research (difficult to integrate but important)
    - Translational research
- Need to engage with clinical profession – behind the times (+ politicians and policy makers)

- Researcher involved/linked to politicians, policy makers, clinicians in a feedback system
- Academic review process driving research – limits the scope and is slow process
- Dissemination of results – using arts to communicate (art, theatre); community development approach
- Involvement in consumer-led projects
    - Different dynamic, methods/processes
    - Integrate inputs into research
    - Reaching more people, especially young
- Engaging through Facebook – engage young people where they are, ongoing engagement
- Engaging through schools – going to young people rather than asking them to come to us
- Newsletters, invite a friend

Training

- Forums like this useful
- Consumers talk to each other differently than with researchers: consumer to consumer = richer data
- Training in developing and delivering questionnaires: volunteers instead of RAs

Recruitment methods

- Diverse group – different needs e.g. statistical methods
- Professional development, upskilling in a range of research methodologies

Other barriers

- Feeling targeted, equality
- Non-threatening activity
    - Stay together within public housing settings
    - Come to the people e.g. BBQ
- Stigma, self- stigma
    - Not wanting to associate/self-disclose; intimidated
    - ? Online, mail back?
- Making research methods useful for other purposes
- Regional/service-based linkage to research workshops