

Insight

Message from Head of ACACIA

It's hard to believe that another year is drawing to a close. It feels like only a few weeks ago that members of the ACACIA Advisory Group joined me in interviewing all the great candidates for the research assistant and intern positions on a couple of very hot days, but that was in February! Alyssa and Owen have been a dynamic duo throughout the year. With the addition of Dr Amelia Gulliver who is introduced in this edition of *Insight*, ACACIA has had a tremendous surge in activities this year. We have completed data collection for the "Whose story is it?" project on ethics, carers and mental health research. We hope to complete analysis and write up early in the new year. We will also launch a new project in the first quarter of the new year, talking to consumers and carers about their perceptions of recovery and "recovery-oriented services." Watch out for the chance to take part.

To extend our work beyond what we can do with existing staff, we have a number of proposals for external funding in progress. These cover topics suggested at the 2013 priorities forum including:

- ◆ Examining models of service delivery with a focus on innovative models, including trauma-informed care, peer-led services and embedding peer workers within existing models
- ◆ Further work on service pathways and consumer/carers experiences, particularly in the context of the development of stepped mental health care
- ◆ Trialling an intervention to improve the physical health of people with serious mental health issues within their usual mental health care (externally led by Prof Brenda Happell, Synergy)

Amelia and I are also working with Ms Julia Reynolds (lead of the e-mental health in practice team at the Centre) and ACT Health staff to trial a recovery-oriented e-mental health program delivered by a peer worker in the Adult Mental Health Day Service.

I want to take this chance to thank the great ACACIA staff team for all their hard work this year. They are all fabulous individuals and work brilliantly together. I am sorry to say that Owen's term as our intern comes to an end at Christmas, but we are working on a few options to keep his skills and talent at the Centre so we hope he won't be going far.

Thanks also to the ACACIA Advisory Group, especially the members who have completed their terms and are leaving us.

Best wishes to all for the holiday season.



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This issue of *Insight* was written and produced by members of ACACIA.



Demystifying Research: Research Project Recipe



Research projects come in many shapes and sizes. Just within mental health research, projects can range from a short survey, to an experiment investigating the effect of stress on heart rate, to in-depth interviews about people's life experiences. These may seem to have little in common but there are some basic steps shared by almost every research project. This is the basic recipe for designing and conducting research.

Step 1: Following curiosity

The first thing we need is an idea that sparks our curiosity. This could be a topic we find interesting or a problem we would like to solve. How a researcher chooses or finds their topic depends on their field of study and their workplace. At ACACIA, our ideas for research projects come from stakeholder input including the 2013 Priorities Forum. The research team develops these ideas into potential projects with input from our Advisory Group of consumer and carer representatives. This helps us to choose research topics that are relevant and important to consumers and carers in the ACT.

Step 2: Reviewing existing information

Once we have selected a topic, we need to find out what people already know about it. To do this, a researcher needs to search for published information about the issue they want to research. Sources of information can include academic journal articles, government reports, books and conference presentations. Next, the researcher needs to read the information they find and critically analyse it. This process is called reviewing the literature.

Step 3: Finding the gap

When we review the literature, we are looking for a

gap in the knowledge — something we do not know, or need to know more about. The research project design will aim to fill the gap we have found. This gap will shape our research question and hypotheses (what we think we will find).

Step 4: Designing the methods

In turn, our research question and hypotheses will shape the methods we use to investigate them. It is important to select the best available methods to answer our research question. The methods we choose need to be possible with the resources we have and must treat our participants with respect.

Step 5: Ethical considerations

Ethical behaviour is especially important for research involving human participants. An ethical researcher recognises that every human is valuable and respects this value in the way they think and act towards people. Usually, researchers will complete an ethical review process to make sure participants are treated ethically. Typically, a research project needs ethical approval from a review board to publish results in academic journals.

Step 6: Collecting data

Now we can start to conduct our research. This step can be broken into two main stages: recruiting participants and collecting data.

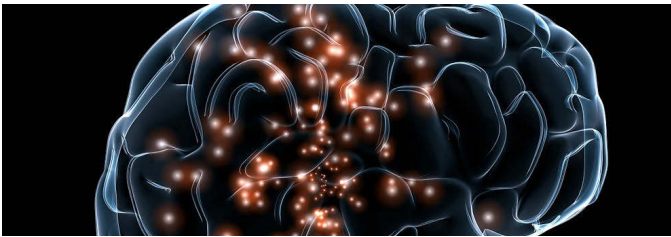
To recruit participants, a researcher needs to think about the best strategy to get in touch with people. Common methods include advertising through posters, newspapers and social media. If a researcher is interested in a very specific group of people, they may recruit through services or companies who work with that group.

Collecting data involves gathering information using the method we designed in Step 4. A researcher could interview participants or ask them to fill in a survey or complete an activity. The information collected at this stage makes up our data. These data are securely stored until we are ready to move on to analysis.

Demystifying Research: Research Project Recipe

Step 7: Analysing data

To find out the answer to our research question, we analyse the data we have collected. How we do this will depend on the question we asked and the method we used to collect our data. If we have quantitative data (recording information as numbers), we can use statistical methods to answer our research question. If we have qualitative data (describing information in words), we can analyse the meaning of the text, finding themes that link different sources of information together.



Step 8: Communication

“Remember kids, the only difference between screwing around and science is writing it down.” – Adam Savage, Myth Busters.

When we have our results, we need to tell people what we have found. This is what research is all about! There are many ways to do this. Often results are published in academic journals but they can also be shared at conferences, recorded in official reports or included in media stories. It is also important to communicate your results to your participants and to the community you hope to benefit with your research.

Meet the ACACIA Advisory Group Member: John Franklin



When I formally retired from paid employment about 3 years ago I contemplated a future of relaxed enjoyment, engaging with family and friends, hobbies and interests. In a short while boredom and frustration set in and the prospect of many years ahead repeating the same routines was not so attractive.

Then I discovered opportunities to serve as a volunteer representative of consumers and carers on committees and boards in the health sector. My interest in the impact of health policies and practices on our lives has grown from the personal experiences of myself and my family and through engagement in the community sector for over 30 years.

Prior to retirement I had spent 8 years working as a counsellor at the Canberra Men’s Centre. I saw there the interweaving of mental health issues with socio-economic disadvantage, physical disabilities, dysfunctional families and broad community prejudices.

I am a carer for a family member with complex mental health conditions and I have been closely associated,

through family, friendships and my work, with others who have served as carers. The mental health of carers and recognition of the diversity of those undertaking a caring role (especially the ‘hidden’ carers) are issues that particularly concern me.

While I have managed to maintain my own mental health (mostly) within functional bounds, I am aware of the impact that mental illness can have on a person and their support network. I believe there is much to be improved in our mental health services before they can be considered acceptable for a modern affluent society.

My work and tertiary studies have taken me into diverse and interesting fields. A large part has been in the federal Public Service and specialist government agencies. I worked in a CSIRO laboratory and as an industrial chemist while studying for an Applied Science degree. Later I had administrative roles in astronomy and chemical safety agencies. I was a senior archivist with responsibility for reference and access services at the National Archives. During that time I completed a BA degree in history and politics at ANU. For about 8 years I managed security and emergency services in various government agencies. In conjunction with my counselling studies I have explored psychology and human biology subjects.

Participating in the ACACIA Advisory Group and in other representative roles gives me the challenges and satisfaction that I cannot get from a relaxed retirement.

ACACIA is Blooming

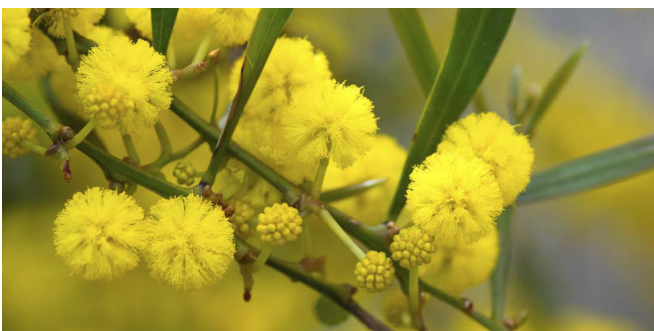
The last six months have been busy here at ACACIA. We have been involved in a range of different events. These have been great opportunities to make connections, share knowledge and let people know about ACACIA, who we are and what we do.

International Mental Health Conference

In August this year an ACACIA team member attended the 17th International Mental Health Conference, "Guiding the Change". The conference had a strong focus on services and service evaluation and was a chance to find out about current work happening around Australia and abroad. The value of lived experience was recognised and featured as the topic of many presentations, including two of the keynote addresses. Presentation sessions were also held on the importance of mental health carers and Indigenous wellbeing. The conference was an inspiring opportunity to hear from lots of different researchers from around the country.

Lived Experience Employment Forum 2016

In October, the ACACIA team gave a talk at the Lived Experience Employment Forum. This event is held each year during mental health week. It aims to showcase opportunities for people with a lived experience of mental illness to become involved in paid and volunteer work. Several organisations gave talks at the forum, including MIEACT, Wellways (formerly MI Fellowship) and the ACTMHCN. ACACIA's talk described the work we do and the volunteer opportunities currently available at ACACIA. These included research participation, new positions on the ACACIA Advisory Group (applications now closed) and chances to volunteer or work on small research projects in the future.



Service User Academia Symposium

The sixth Service User Academia Symposium was held at the ANU Commons on the 21st and 22nd of November this year. The symposium began in 2011 with the goal of advancing the meaningful involvement of service users (consumers) in mental health and addiction research and teaching. This year's event included presentations on a wide variety of topics, a workshop on co-production and plenty of chances for people to meet each other and exchange ideas. This year's theme was "Creating Connections & Building Bridges Together: The Journey Continues". The event featured our own Dr Michelle Banfield as a keynote speaker. The other keynote speakers were Professor Diana Rose (co-director of the Service User Research Enterprise, King's College London) and Professor Pete Ellis (Head of the Department of Psychological Medicine, University of Otago). Dr Banfield and Professor Rose shared stories of their own journeys as consumer researchers. Professor Ellis presented a fascinating history of asylums and psychiatric treatment.

Many of the presenters identified as having a lived experience of mental illness and some were working as consumer researchers. All of the presented work included some kind of consumer involvement. The symposium brought together a wide range of perspectives from people with diverse backgrounds and experiences.

The Australian National University co-hosted the symposium with Synergy (University of Canberra and ACT Health), Central Queensland University, the University of Otago and the Auckland University of Technology. ACACIA provided materials for the conference bag and display tables (including some delicious jellybeans in the ACACIA colours!). This was a valuable opportunity to spread the word about the work we do and to make new connections with consumers and researchers.



Masterclass with Professor Diana Rose

On November 28th, ACACIA hosted a masterclass with Professor Diana Rose, titled "User-led and collaborative research: beginnings, development and where we are going now".

Professor Rose is a world leader and pioneer in the field of user-led research in mental health. She is currently a co-director of the Service User Research Enterprise (SURE) at King's College in London. Professor Rose conducts user-led research in mental health, having experience both as a researcher and a service user. In her own words, she has a passion for "putting the service user voice into research that is done in the field of mental health". She is keen to better define consumer involvement in research, measure its impact and determine if it should be ethically essential in conducting future studies.

The masterclass was very interactive and was a fantastic chance to share ideas and learn from the expertise of Professor Rose and from fellow participants. Professor Rose shared her experiences and insights from being a consumer researcher and doing involvement research. The group discussed research methods, ethics and values and shared personal experiences. The class reaffirmed the value of consumer researchers and research that actively involves consumers. It also emphasised the importance of community and support when working as an identified consumer. We hope that every participant came away inspired

and enthusiastic about doing user-led and collaborative research.

Future events

Keep an eye out early next year for information about a Research Forum co-hosted by ACACIA and the Mental Health Community Coalition. The forum will aim to help connect research to practice, with a focus on opportunities in the ACT.

The best way to stay up to date with ACACIA's activities is to join our register. Members of the register receive the *Insight* newsletter and get to hear about upcoming opportunities and events. To join the register, or update your details, just fill out the form at the back of *Insight* and submit it to ACACIA via email or post.

You can also find out more about ACACIA by visiting our website: <http://cmhr.anu.edu.au/acacia>



Australian
National
University

ACACIA: THE ACT CONSUMER AND CARER MENTAL HEALTH RESEARCH UNIT

cmhr.anu.edu.au/acacia



Meet the ACACIA Research Team:

Dr Amelia Gulliver

ACACIA Staff

Dr Michelle Banfield, Head

Dr Amelia Gulliver, Research Fellow

Alyssa Morse, Research Officer

Owen Forbes, Research Support Officer

ACACIA Advisory Group

Dalane Drexler, ACT Mental Health Consumer Network

David Lovegrove, ACT Mental Health Consumer Network

Alexandra Scetine, Carers ACT

John Franklin, Carers ACT

Rebecca Dawson, Mental Health Policy Unit Representative

James Eastburn, Independent Consumer Representative

Rebecca Randall, Independent Consumer Representative

Janet Milford, Independent

Carer Representative

Sophie Hope, Independent Carer Representative

Julia Bocking, Invited Member

Prof Brenda Happell, Academic Advisor



Amelia is new to the team, having recently taken up a part-time Research Fellow role with ACACIA. Lived depression and anxiety, as well as being inspired by her mother's work as a mental health nurse as she was growing up, contributed to Amelia's keen interest in working in mental health research. She completed a psychology degree with honours in 2005 and went on to work as a Research

Assistant at the Centre for Mental Health Research (CMHR) at the Australian National University (ANU) until completing her PhD in 2013 on the topic of help-seeking for mental health problems in elite athletes. Since then, Amelia has been working as a postdoctoral fellow at CMHR on the development of a new online space for university students' mental health, the Uni Virtual Clinic.

Amelia's research interests are broad and include help-seeking in vulnerable populations, as well as the investigation of stigma and mental health literacy in different groups in the community. She has a particular interest in the delivery of treatment and information programs using new technologies, as well as young people's mental health. Amelia is passionate about eliminating the stigma around mental health problems.

Amelia has many and varied interests including playing football, catching up on quality TV shows, and hanging out with her 21 year old Burmese cat. Having lived in the ACT since she moved here from England in the early eighties, Amelia is excited by the opportunity or working with ACACIA to give back to the Canberra community she loves so much.



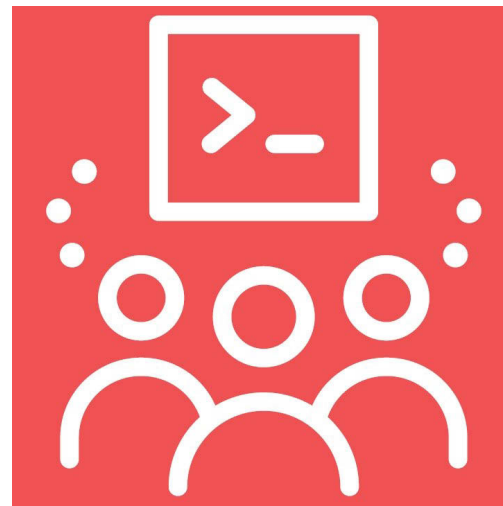
Research Bites

'Research Bites' provides short summaries of interesting recent mental health research. Please note that the inclusion of research in this section does not mean that it is associated with or endorsed by ACACIA. If you would like information about the research in this section, and don't know where to start to find it, please contact ACACIA using the details on the front page.

Stakeholder priorities for research in health communication and participation: Findings from the Cochrane consumers and communication priority setting project. Cochrane Consumers and Communication Group, La Trobe University

Cochrane is a not for profit group that conducts systematic reviews of research to make it easier for health services and the public to access and digest. Last year Cochrane worked with healthcare stakeholders to find priority topics for five new review projects. In an online survey, 151 health workers and service users proposed 191 topics around communication and participation in health care. These were grouped into 22 main themes, including: holistic care; patient centred care; communication skills and training for health workers; and supporting consumers to play a more informed and active role in their own care. Twenty-eight consumers, carers and others then took part in a workshop to pick the twelve best topics from this list. Finally, Cochrane staff and a consumer steering group looked at past and planned reviews to choose five review topics spanning one or more of these community priorities. These five reviews will target the following topics: Improving communication about end of life care; Patient, family and carer involvement in patient safety; Improving future doctors' communication skills; Consumer engagement strategies; and Promoting patient centred care. All five reviews are under way and

will begin to be published and promoted in late 2017. Cochrane reviews are widely used by health workers and services to guide best practice. This process will help to raise the profile of consumer and carer involvement in health care. These reviews will also help service users and carers gain more knowledge and power to play an active role in services, and have a greater say in their own care.



Evidence Check: The effectiveness of services led or run by consumers in mental health. Flick Grey & Mary O'Hagan (2015) Sax Institute Evidence Check for the Mental Health Commission of NSW

A growing body of research supports the merits of consumer operated services (COS) in mental health care. A recent report by the Sax Institute looks at studies since 2000 across many journals, to review COS around the world. This report finds that mental health COS with consumers in director, member or volunteer roles have many benefits. COS focus on consumer control, choice and decision-making. Their clients report having more power, hope and satisfaction in these services. Compared to other services, clients in COS report fewer days spent in hospitals and less use of emergency services. The review states that while a few COS had only token consumer involvement, most held strong values of mutual respect and shared power. Overall COS have better outcomes for users' welfare, employment and mental health stability – even when measured 3 years after exiting. COS can help both workers and service users by giving tailored support strengthened by lived

experience. This suggests the need for further work to promote services' commitment to the value of consumer workers and spread positive attitudes to consumer involvement.



Join the ACACIA Register

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

How do I get involved?

Join ACACIA's Consumer and Carer Research Register.

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

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

Name _____

Address _____

Phone _____

Email _____

I am a:

Consumer Carer Consumer & Carer

Preferred newsletter format:

Email Regular mail I don't want a newsletter

Mail To:

ACACIA at CMHR
Building 63
Eggleston Rd
The Australian National
University
Acton ACT 2601,
AUSTRALIA

Or email us at:

acacia@anu.edu.au

For more information about
ACACIA, please visit [http://
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