

Insight



Inside this issue

The ACACIA Team.....	2
Meet Advisory Group.....	2
ACACIA Publication	3
SMHR Report	4
Conference Review.....	5
Demystifying Research	6
Research Bites.....	7
Get Involved.....	8
Contact Details	8

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

Edited by Alyssa Morse



Meet the ACACIA Advisory Group Member: James Eastburn

ACACIA Staff

Dr Michelle Banfield, Head

Dr Amelia Gulliver, Research
Fellow

Alyssa Morse, Research Officer

ACACIA Advisory Board

Dalane Drexler, ACT Mental
Health Consumer Network

Robert Pedlow, ACTMHCN
Consumer Representative

Jodie Fisher, Carers ACT

James Eastburn, Independent
Consumer Representative

Rebecca Randall, Independent
Consumer Representative

Janet Milford, Independent
Carer Representative

Sophie Hope, Independent
Carer Representative

Matthew Wafer, ACT Mental
Health Policy Unit

David Lovegrove, Invited
Member

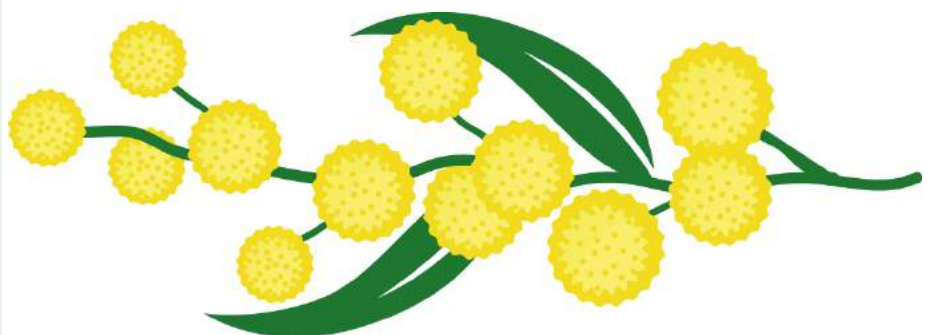


James Eastburn is an independent consumer representative in the ACACIA Advisory Group.

James has personal experience as a mental health consumer, having experienced major depressive disorder and generalised anxiety disorder. Through this experience he has become interested and passionate about mental health. He is particularly interested in improving the wellbeing of young Australians through reducing mental health stigma, improving mental health literacy, and improving awareness and access to services.

In addition to his personal experiences with mental health, James has a Bachelor of Science (Psychology) from the Australian National University, and has participated in various mental health advisory and consumer groups in addition to the ACACIA Advisory Group, including the headspace Canberra Youth Reference Group and the uniVirtual Clinic Student Leadership Program.

James currently works as a Policy Officer at the Department of Social Services. In this role he aims to improve the wellbeing of Australians, particularly those that are vulnerable. He has contributed to policy aimed at improving long-term outcomes for individuals on income support, as well as improving consumer protections for individuals who participate in online gambling.



ACACIA Publication: A Peer-Led Electronic Mental Health Recovery App in an Adult Mental Health Service: Study Protocol for a Pilot Trial

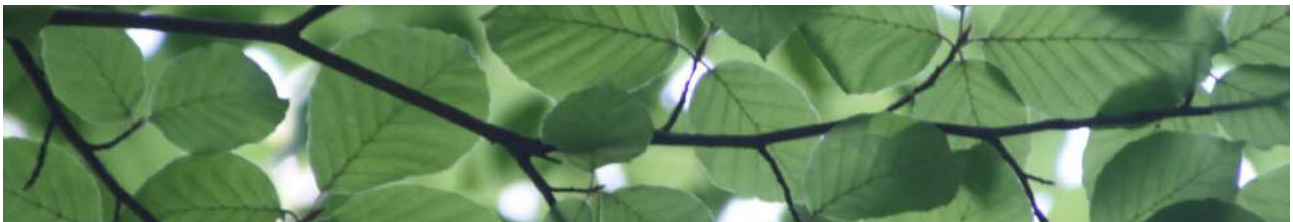
ACACIA recently partnered with ACT Health to develop a brief peer-led program. The program aims to help people in their recovery journey in a mental health service. This article is a summary of the study protocol. A study protocol is a published paper that describes how we intended to conduct the project.

Background information: Peer workers are people with lived experience of mental health problems who are able to support others in their recovery. They provide a unique perspective in a health care team. There has been a lot of recent interest in having peer workers work alongside consumers to improve outcomes and recovery. Peer work can also be helpful for the peer worker themselves. In Australia, peer work is beginning to be used more often in health care services. Current evidence suggests that peer work can make a positive difference in mental health services. However, the way peer work is delivered varies across different settings. We also still do not know how positive outcomes for consumers are best achieved.

Technology-based electronic mental (e-mental) health is rapidly growing. Programs for mental health are being delivered more often on new types of technology, like tablet (e.g. iPad) and mobile phone apps. This is because they can make services more engaging and innovative. Many studies of e-mental health are not conducted in existing health care environments. So we do not know how best to use these tools in routine health care.

Peer workers may be able to help people use and complete e-mental health programs. Supporting peer workers to help with mental health care is important for enhancing mental health and recovery.

Aim: The aim of this project is to find out if a peer-worker led e-mental health recovery program would be possible, acceptable, and effective for people with moderate to severe mental illness.



Methods: The recovery program will be delivered on an iPad by a peer worker. The peer worker will help individual consumers with the program at an adult mental health service. After the program is complete, the participants will complete a survey about their own recovery. They will also record what they thought of the program and the peer worker. Consumers will be invited to participate in a focus group to discuss the program. Interviews will be conducted with the peer worker, peer supervisor and other staff at the mental health service. This will help tell us how well the peer worker and the program fit in within the health service. The program will be delivered over a period of about 4 months starting in June 2017.

Results: Results will be published in a report to ACT Health. A plain language summary will be provided to participants, to the consumer and carer organizations involved with ACACIA, and in Insight newsletter. A published paper and conference presentations will also be sought.

Discussion: The protocol describes an exploratory proof-of-concept study. The results will tell us how feasible it is to carry out the program in the mental health service. It is also important to listen to consumers' thoughts about the program. Key strengths of the study include the consumer input into the design, and the inclusion of staff, peer worker, and consumer viewpoints in assessing the program.

Society for Mental Health Research Conference 2017

From Discovery to Translation



The Society for Mental Health Research (SMHR) annual conference was held in Canberra in December 2017. The theme for the 2017 conference was “From Discovery to Translation”. The event featured a strong focus on physical health in mental health and on youth mental health. Across three days, talks and posters were presented on a wide variety of topics, from biological traits to online interventions.

The ACACIA research team was involved in SMHR in a variety of ways. The conference was a great opportunity to share ACACIA’s work with the academic community. It was also a chance to educate other researchers about working collaboratively with consumers and carers.

Partners in Research: Collaborating with people with lived experience for high quality mental health research.

Dr Michelle Banfield presented a pre-conference workshop about designing research that actively involves consumers, carers and service providers. The workshop was attended by participants from many different work backgrounds. The ACACIA research team helped run the discussions.

It was wonderful to talk to a group of people keen on involving consumers, carers and other stakeholders in their work in a meaningful way. The workshop inspired some thought-provoking discussions about research design and what involvement really means.

Priorities for Research

Owen Forbes gave his debut conference presentation. The talk was part of a Mental Health Services presentation session chaired by Michelle. Owen talked about the early findings of the Priorities Update survey. The survey was collected in October and November 2017. The presentation was well received by the audience, and prompted some interesting questions.

Thank you to all the Insight readers who took part in the Priorities Update survey!

Peer-led E-mental Health

Dr Amelia Gulliver presented a poster about a recent peer work project. The project looked at the use of a peer-led recovery app in an adult mental health service. The app is called Stay Strong and was first made for Aboriginal and Torres Strait Islander consumers.

If you’d like to find out more, you can view the poster on our website (<http://cmhr.anu.edu.au/acacia>). An article about how this project was done can also be found on page 3 of this issue of Insight.

Personal Projects

Alyssa Morse also gave her debut conference presentation. She talked about the results of a study from her PhD thesis, which focused on genes, social behaviour and mental health. Alyssa gave a second talk about a school-based project being done at the Centre for Mental Health Research, ANU. The project looks at the effects of the Menslink Silence is Deadly program in schools.

ACACIA Sponsored Community Members

ACACIA sponsored three members of the community, who identified as a consumer or carer, to attend one day of the conference. The community members were selected through an application process. They were chosen based on how the conference could benefit them and how they would share that benefit with their community. We hope that this experience was valuable for the three people and the communities they are part of.

Health Services Research Association of Australia & New Zealand (HSRAANZ) Conference Review

The Health Services Research Association of Australia & New Zealand (HSRAANZ) conference was held at the Gold Coast, Australia during November 1-3, 2017. This conference aims to support practical research. Research that can have a real impact on improving the delivery and organisation of health care in Australia and New Zealand. The people who attended were from a wide range of groups. This included universities, research units, government departments, agencies and consumer groups. The conference has a focus on bridging the gap between research and policy. It also aims to give a voice to consumer issues.

The conference theme for 2017 was “Shifting priorities: balancing acute and primary care services”. The idea behind this theme was to identify the priorities for what is needed to create a sustainable and patient focused healthcare system.



Two ACACIA members (Michelle Banfield and Amelia Gulliver) were selected to present research at the HSRAANZ conference. Michelle spoke about the role of general practice in managing serious mental illness. Amelia presented the findings from the Partners in Recovery (PIR) evaluation.

The conference had a solid focus on co-production and collaboration between researchers, practitioners, and consumers. This was to ensure that the research makes a difference in the real world. Several of the keynote speakers presented on this topic; they were mostly from overseas including Canada and the UK.

Dr Roman Kislov is a Senior Research Fellow from The University of Manchester. He spoke about “The art of compromise: Cooperation between researchers and practitioners to support integrated care”. His talk focused on how to work together to make a difference to healthcare. Dr Kislov spoke about the challenges of this approach. He included some ways that these challenges might be overcome through discussion and compromise. For example, practitioners often value researchers having a good understanding of health services. They also think it is important to take details about the context of the research setting into account. He suggested that researchers could work with this idea by using the local intelligence of the setting. They also need to make sure they focus on practical research rather than “ideal” research designs.

Professor Ian Graham is a Professor at the University of Ottawa, and a Senior Scientist at the Ottawa Hospital Research Institute. He spoke about current evidence for using participatory or co-production approaches to improve our ability to put research into practice. Professor Graham highlighted the increasing interest in co-production or participatory approaches to research. This increased interest means that funding organisations are seeing the value in this type of research. This is because it is more able to be translated into practice. Integrated knowledge translation (IKT) refers to this type of co-production research. IKT aims to create projects that support decision-making in health care practice. IKT refers to the relationship between the researchers and healthcare decision-makers (e.g., practitioners, policy-makers) in working towards these goals.

These speakers and others, highlighted the importance of co-production including consumers to work towards effective health care solutions in Australia and New Zealand.



Demystifying Research: Information sheets and informed consent

Information sheets, most research studies you participate in will have one. You've probably read a fair few yourself! What's the point of making you read through pages of information before you can start participating? Let's take a look at why information sheets are so important and how you can help us improve them in the future.



What is informed consent?

Modern codes of ethics require informed consent as a central part of ethical research. In Australia, researchers follow the guidelines set out in the National Statement on Ethical Conduct in Human Research. This document is freely available online.

According to the National Statement, consent must be **voluntary**. **Voluntary consent** is free from pressure and not influenced too much by rewards. Consent also has to be **informed**. People who are **informed** understand the purpose, methods, demands, risks and potential benefits of a research study. **Informed consent** happens when people make a decision that takes this information into account.

Why is informed consent important?

It isn't fair to ask a person to make a decision when they don't have all the information they need. Without enough information, you can't decide whether a study is safe for you to take part in. You also may not know if the research is relevant to you or worth your time.

People have not always been given the right to choose whether they wanted participate in medical research. In fact, for much of the early 20th century, unethical and sometimes cruel research was carried out using human participants. In many cases, people would not have chosen to be involved in these studies if they had been given enough information about their true purpose and consequences. People who were institutionalised, disadvantaged or very unwell were at the most risk of being mistreated.

Modern human research ethics protect the right of participants to choose whether or not to participate in research. Having truthful information about the nature of a research study gives you the power to make an informed decision about whether to get involved.

What is the information sheet for?

The goal of the information sheet is to describe the most important information about a research study to you.

A written information sheet has its good points. Participants can keep their own copy of a written sheet. Then if any questions or problems come up later, it is easy to read the information again. An information sheet should also include the contact details of the research team. You can contact them if you have more questions.

Written information sheets can have bad points too. Sometimes they can be too long or they might use words that are technical or complicated. It is important that you have all the information you need before you make a decision about participating. If you have trouble understanding something, you can ask the researcher to explain it to you. You can also ask for more details if you need them.

How can we improve information sheets?

At ACACIA, we try to improve our information sheets by listening to our participants' feedback. You are always welcome to let us know what you think about our research materials – good or bad. We value honest and constructive comments. In the past, we have used participant feedback to improve to the look and content of our information sheets. It's important to us that the informed consent process works as well as possible for you.

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 back page.

Consumer views on youth friendly mental health services in South Australia.

Loughhead et al., *Advances in Mental Health*, 2017

A recent study from South Australia explored the views of young people on mental health services. The goal was to find out what young people think a youth-friendly mental health service would look like. Thirty-two young people from a variety of backgrounds participated in group interviews. Questions focussed on what had helped or stopped people from seeking help. A diverse group of people were interviewed, including people who were Aboriginal, came from different cultures, identified as LGBTI+, or had experienced being a refugee or being under the Guardianship of the Minister. The study found that the young people's experiences of help-seeking had a lot of things in common. Help-seeking and getting access to services were complex processes. It was important for young people that these processes were transparent. They wanted information about what would happen at the service and during treatment. Services also needed to be delivered in a flexible way. Otherwise it was difficult for young people to

fit them into their schedule and transport limitations. A good therapeutic relationship was also important to young people. They needed warmth, acceptance and privacy from their clinician. Teachers, family and friends could all help young people to access services. But they could also be unhelpful if they were not well educated about mental health issues. The information collected in this study can help contribute to the design of future mental health services.



Addressing the mental health needs of looked after children in foster care: the experiences of foster carers.

York & Jones, *Journal of Psychiatric and Mental Health Nursing*, 2017

A study from the UK explored the experiences of foster carers who had accessed mental health services for a young person in their care. Young people in foster care have usually experienced trauma and disruption. They are also more likely to experience mental health issues than their peers but their uptake of mental health services is still low. Ten foster carers were interviewed to find out what helped and hindered them from accessing care. The study found that foster carers had good mental health literacy and were aware of what services were available. They also had a lot of empathy for young people's experiences. Foster carers had actively sought mental health services for the young people in their care. They found it easy to get a referral to mental health services from a social worker, but hard to actually access those

services. There were long wait times for specialist and long term services. This made foster carers feel anxious and powerless. It could also result in a young person's placement becoming unmanageable before help was received. When receiving treatment, young people who disengaged from services were not followed up. Foster carers also felt that services did not listen to or value their input and their knowledge about the young person in their care. Peer support for foster carers was important for their wellbeing and their ability to carry out the caring role. To improve the uptake of mental health services for young people in foster care the access pathways to treatment need to be improved. It is also important for services to work in partnership with foster carers, valuing their input and expertise.

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://
cmhr.anu.edu.au/acacia](http://cmhr.anu.edu.au/acacia)

