



# Insight

## Mental Health Month Edition

October 2019



[WWW.MENTALHEALTHMONTH.ORG.AU](http://WWW.MENTALHEALTHMONTH.ORG.AU)

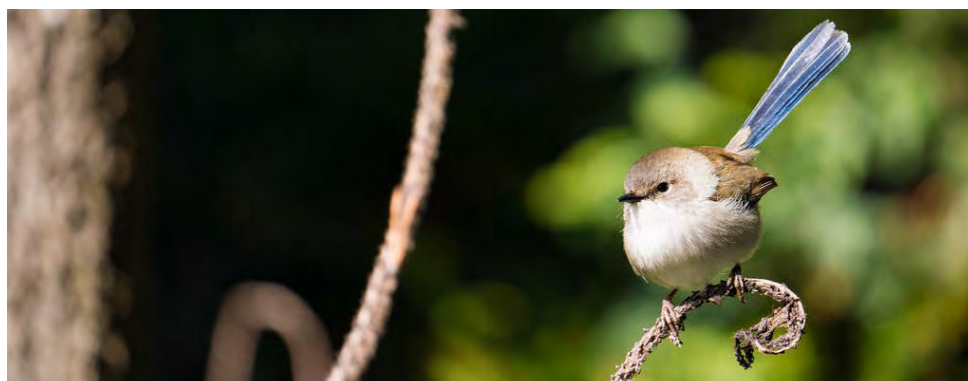
Join the ACACIA team at the **2019 Mental Health and Wellbeing Expo**.

**When:** Thursday 10th October

**Where:** Petrie Plaza and City Walk, Civic

**Time:** 11am-2pm

We'd love to see you there!



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

Edited by Alyssa Morse



## ACACIA Advisory Group

Dalane Drexler, ACT Mental Health Consumer Network

Jane Grace, ACTMHCN Consumer Representative

Caroline Davidson, Independent Consumer Representative

Adele Lewin, Independent Consumer Representative

Heather Lamb, Independent Carer Representative

Bianca Rossetti, Independent Carer Representative

Matthew Wafer, ACT Mental Health Policy Unit

Suzan Thomas, Mental Health, Justice Health, Alcohol and Drug Services

David Lovegrove, Invited Member

## Meet the ACACIA PhD Student: Chérie McGregor



I am very excited to be accepted to begin my PhD with Michelle Banfield. I'll be studying externally, identifying the values that underpin different approaches to psychosocial peer support. Life-changing experiences of altered states, being compliantly (but unwillingly) detained in a mental health unit, and supporting a

family member (who straddles multiple realities) informs my work as a Lived Experience (LE) systems change advocate.

It was great to come down to Canberra recently for induction, to spend time with Michelle and meet Bianca Calabria (who will be on my panel) and fellow PhD-ers. At 50++ years old, I could be the oldest and newest on the team.

I've been a LE practitioner since 2010, working in a variety of roles in regional public mental health, Primary Health Network and academic settings in regional Queensland. I have delivered training in Intentional Peer Support and Certificate IV in Mental Health Peer Support. Currently I am working from home part-time to establish the Queensland Lived Experience Workers Network (Q-LEWN) as a state level, independent peak body representing the LE workforce across Queensland.

I started my career in community services in the early 90's in youth work. I've also worked in homelessness, domestic violence, community and sector development programs across regional Queensland & northern NSW. I've worked for a variety of non-government organisations (including peak bodies) and local and state government agencies. My work demonstrates a strong commitment to values based practice; experiential learning; person driven support and collective action/community development approaches for systems change.

On a personal level, I have a deep respect and love for Aboriginal culture born out of close family ties with Jagera (south-east Qld) and Bundjalung (northern NSW) mobs. I live on 10 acres of eucalypt scrub in a "renovator's delight" 25km from Maryborough, Queensland with my partner and the youngest three of our six children (five boys and one very tough girl). I am also a grandmother to four amazing kids. Outside of time with family, my favourite happy place is riding my Tiger 800 on a deserted stretch of good, twisty road, doodling and mucking around on my guitar or ukulele. That's me.

## Meet the ACACIA Staff Member: Kate Gregory

Kate Gregory is the administration support officer for the ACACIA team and secretariat for the ACACIA Advisory Group. She also works part-time for the Research School of Population Health, supporting the Department of Global Health and the Centre for Research on Ageing, Health and Wellbeing.



Kate started professional life in the Building and Design Industry on the Far South Coast, before moving into Sales, and then in 2016, managed a boutique family owned GP Clinic in the Weston Creek area.

Volunteering is a large part of Kate's life, and in 2014, she began her studies of Mandarin Chinese language to offer support to the local Chinese congregation of Jehovah's Witnesses, located in Dickson, ACT. Kate's study of mandarin equipped her to assist mandarin speaking people study the bible and apply principles that can benefit themselves practically.

Kate's passions include alternative healthcare, entertaining friends and travelling. In June 2019, Kate was invited to be one of 5,300 international delegates from over 40 countries, at the "Love Never Fails!" International Convention held in Lisbon, Portugal. With over 63,000 attendees, it was a life-changing opportunity for Kate and she has made some lasting connections with other members of her worldwide organisation. The convention program highlighted how to strengthen your love despite problems such as a troubled upbringing, chronic illness or poverty as well as how to strengthen the family unit under stressful circumstances.

Kate is looking forward to being able to 'give back' the hospitality shown to her at the international convention with the same program, held in Melbourne this November, which will also have an estimated 60,000 + attendees and delegates from all over the world.

Kate enjoys working with the ACACIA team and values the opportunity to be part of such important mental health carer and consumer research.



### ACACIA Staff

Dr Michelle Banfield, Head

Dr Amelia Gulliver, Research Fellow

Alyssa Morse, Postdoctoral Fellow

Natasha Katruss, Research Assistant

Kate Gregory, Support Officer

### ACACIA Students

Petra Hill, PhD Student

Chérie McGregor, PhD Student

### Visitors

Dr Georgia Pike, Visiting Fellow

## Awards and Prizes

### Celebrating our team members' achievements

#### The John James Foundation Tony Ayers Prize for Excellence in Research in Translational Medicine

Dr Michelle Banfield has been awarded the 2019 John James Foundation Tony Ayers Prize for Excellence in Research in Translational Medicine.

The annual award recognises a scientist who has made a significant contribution to translational research, moving from 'bench to bedside' to transform science breakthroughs into clinical application. Her prize included \$5000, and an invitation to present a public lecture about the research that has led to the award, at the award ceremony.

Dr Banfield presented the lecture: *Better Together at Finding the Path: A story of collaborative mental health research*. She described her lecture as being her "story of conducting mental health research in partnership with non-researchers. It's a story of surprising successes, tangled research designs, and what happens when things don't quite go to plan."

The award is named in honour of long-time John James Hospital and Foundation Board Member Mr Tony Ayers AC. It was presented on 29th July 2019 at The Finkel Lecture Theatre, ANU.



Tony Ayers Prize for Excellence in Research in Translational Medicine (Image – A. Gulliver)

#### National Health and Medical Research Council Consumer Engagement Award

Dr Michelle Banfield has received the inaugural and prestigious 2019 Consumer Engagement Award from the National Health and Medical Research Council.

NHMRC CEO, Professor Anne Kelso AO, said the award recognises "long-term contribution and commitment to representing consumer and community needs in health and medical research".

Dr Banfield said of the award: "People who have experienced or cared for someone with mental illness help our team to better understand the issues and bridge the gap between consumers and health service providers. By conducting research as a consumer researcher, I help to break down the stigma of living with a mental illness. I'm very excited that the NHMRC has created an award for consumer engagement, and am delighted to have received it."

The award was presented at the NHMRC annual Research Excellence Awards dinner in Canberra on 13th March 2019.



NHMRC Consumer Engagement Award – 2019, Dr Michelle Banfield (Image – ANU).

## Australian Institute of Policy & Science Young Tall Poppy Science Award

Dr Amelia Gulliver, a part-time research fellow with ACACIA, has won a Young Tall Poppy Science Award for 2019.

The Tall Poppy awards recognise the achievements of young scientific researchers. The Tall Poppies are awarded by the Australian Institute of Policy & Science (AIPS). AIPS is an independent and not-for-profit organisation established in 1932.

Dr Gulliver was recognised for her work in both lived experience research, and the evaluation of e-mental health interventions. She is currently working on a trial of the Music Engagement Program for improving mental health in people living with Alzheimer's disease and Dementia in residential care homes. Dr Gulliver is also working on a randomised controlled trial (RCT) of an intervention designed to increase uptake and engagement with e-mental health programs.

Dr Gulliver's major previous projects include the evaluation of a peer-led recovery program delivered in a community-based public mental health service. She has also worked on a collaborative project with the Young and Well Collaborative Research Centre, to build and evaluate an online virtual clinic for improving the mental health of university students.

Dr Gulliver has also worked on the creation and evaluation of an online intervention designed with the Australian Institute of Sport to improve help-seeking for mental health problems in young elite athletes.

The award was presented at the Australian Academy of Science's Shine Dome in Canberra on 3rd September 2019.



Prof Russell Gruen (Dean, ANU College of Health and Medicine), Dr Amelia Gulliver (ANU) (Image - M. Banfield).



The Hon Judith Moylan (Chair of NHMRC Consumer and Community Advisory Group), Dr Michelle Banfield (ANU), Prof Anne Kelso (NHMRC CEO) (Image – NHMRC).



Dr Michelle Banfield (ANU), Prof Paul Smith (Chair, John James Foundation) (Image – ANU)

## Whose story is it?

### Mental health consumer and carer views on carer participation in mental health research

Conducting research about mental health carers, or the relationship between consumers and carers, can raise some interesting ethical questions. Carers contribute unique lived experiences, perspectives and agendas to research, and it is important to facilitate their safe and ethical participation in research projects. Australia's National Statement on Ethical Conduct in Human Research includes special guidelines for doing research with people who have a mental illness. But there aren't any specific guidelines for research involving mental health carers. Instead, researchers must apply general ethical principles to design their research. These principles alone aren't always enough to answer the questions and dilemmas that we can encounter in mental health carer research.

The *Whose story is it?* project grew out of some tricky ethical questions. While developing a research project about carers of older people with mental health issues, questions were raised about risks to participants' relationships. Could the study pose risks to the relationship between a carer and the person they cared for? Should researchers collect informed consent from both the carer and consumer, even if only one person was participating? The research team consulted the National Statement and previous research, but found little help that was specific to their situation.

We turned these questions into an opportunity to talk to consumers and carers about their views on the ethics of mental health research. We were particularly interested in exploring how to do safe and ethical research with mental health carers and on the topic of consumer and carer relationships. The goal of this research project was to develop recommendations for research practice. We started our investigation with four questions:

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

Mental health consumers, carers and lived experience researchers discussed these questions at a public forum. The research team then explored the ideas developed at the forum in more detail using one-on-one interviews. From the information gathered, we developed two themes related to research involving carers and consumer-carer relationships: *ownership of story* and *communication and education*.

#### Ownership of story

Consumers and carers both have lived experience stories to tell, and these stories can have separate and shared elements. The ownership of a story depends on the story being told. A personal story includes a person's own thoughts, feelings and experiences. It does not include speaking on behalf of another person, particularly without their consent. Conflict between people may occur when there is disagreement or uncertainty about the boundaries of story ownership, making it important to understand what can and can't be safely shared.



*... his story's his story, my story's my story and our story's our story. (Interview Carer)*

*...you have to know within your own relationships -- that confidence that "You have a story, I have a story" and maybe they're separate. But you have to know that the other person is comfortable with that, or you might cause friction. (Forum Consumer)*

## Communication and education

Potential conflict between people could be managed by talking about information sharing boundaries. Participants who were mental health advocates or educators had negotiated information sharing boundaries within their own relationships, but other participants had not. When conducting a research project, researchers should be responsible for informing participants about privacy issues that could affect the consumer-carer relationship. When relevant, researchers should also educate participants about information sharing boundaries and how to discuss them with friends and family.



*There's also shared aspects of it [the lived experience story], and I think it's important to negotiate that where the other person's mentioned, and negotiate whether the other person should be de-identified...*  
(Interview Carer)

*I think it [would be] nice that it's in the information sheet to be aware or to be knowledgeable to the fact that... your participation in research can impact on others, your family or friends and you may want to consider those relationships* (Forum Carer)

## What does this mean for research?

Consumers and carers have their own lived experiences and stories to tell. The shared elements of stories can pose risks to the privacy of people involved in the story. Storytelling can also carry a risk of creating conflict within personal relationships. In a research context, these risks can be managed through communication and education. Both between researchers and participants, and between consumers and carers.

When research is focused on the individual experience of a consumer or carer, we suggest it may be helpful to provide participants with information about safe storytelling, and about how to discuss information sharing boundaries with family and friends. This makes sure that participants are fully informed of potential risks, and gives them the tools to discuss the research project with other people if they choose to.

When research is focused on a shared experience or the consumer-carer relationship a more formal communication process may be required. In these situations, it might be helpful to collect informed consent from both the consumer and the carer, even when only one person will be participating. This allows the researcher to make sure that both people understand and agree with the research project.

The findings of this study are a starting point for improving mental health research practices. In the future, the ACACIA research team would like to begin a broader co-creation process with carers, consumers, researchers and other relevant stakeholders to develop guidelines for mental health carer research. Guidelines for good research practice can help to support the growing role of carers in mental health research.

## Find out more

To find out more about this project, you can read the original open access research article. Just search for:

Morse A.R., Forbes O, Jones B, Gulliver A & Banfield M. (in press). Whose story is it? Mental health consumer and carer views on carer participation in research. *Health Expectations*. doi: 10.1111/hex.12954

Or contact the ACACIA team for assistance! You can find our contact details on page 10.

## Conference Report: The Mental Health Services Conference, 2019

Dr Amelia Gulliver and Ms Alyssa Morse, both academic researchers with ACACIA, travelled to the Brisbane Convention & Exhibition Centre for The Mental Health Services (TheMHS) Conference, 27-30th August, 2019.

TheMHS is the largest multidisciplinary mental health conference in Australia and New Zealand. It welcomes abstracts from anyone who feels they have something valuable to contribute to the conversation about mental health.

Both researchers received Research School of Population Health, ANU: Excellence in Population Health Research Awards to assist in funding the research they presented at TheMHS.

### Understanding Participation Project

Ms Alyssa Morse presented her work on the protocol for the Understanding Participation project.

This project aims to understand the nature of consumer and carer participation in the ACT, including changes in the participatory environment and responses to those changes. Another key aim of the project is to investigate how lived experience is valued, and how consumer and carer voices are used in services and policy. The project also broadly aims to explore the concept and meaning of 'value' in the representation/participation space from multiple perspectives.

Ms Morse conducted a Roundtable discussion at TheMHS to provide an opportunity for conference delegates to contribute to the discussion for the project around the concept of "value". Questions for discussion were:

- ◇ What does "value" mean to you?
- ◇ How are lived experience voices valued in the health sector?
- ◇ How can value be demonstrated?

The Roundtable was very well received, with 10 people attending (despite the late timeslot!) and providing valuable input for the project.



Miss Alyssa Morse (Image - A. Gulliver)



Brisbane Convention Centre (Image - A. Morse)



Southbank Brisbane (Image - A. Morse)



## The Music Engagement Program



Dr Amelia Gulliver (Image - A. Morse)

Dr Gulliver presented her work on the Music Engagement Program (MEP) pilot trial. The MEP was developed by Professor Susan West at the Australian National University School of Music.

The MEP has been conducting outreach sessions for many years in Canberra with multiple groups of people including both children and adults. However, it has not yet been formally evaluated in this population.

The former convenor of the MEP, Dr Georgia Pike, delivered the program for the trial. Preliminary findings have indicated that the residents' mental health improved after the 8-week program.

Dr Gulliver and Dr Pike are very excited by this research, as it supports previous observations of the MEP in this population.

The presentation was well received, and generated several discussion questions from the engaged audience at TheMHS.

### Research Bite:

#### Management or missed opportunity? Mental health care planning in Australian general practice.

Banfield, M., Farrer L. M., & Harrison, C. (2019) *Australian Journal of Primary Health*

General practice (GP) care plans are designed to improve the management of chronic illness by making it easier to access teams of different health professionals. They are also designed to help general practitioners and their patients work together to decide on health care needs and what to do about them. The aim of this study was to compare how often GP care plans were created and reviewed for mental disorders and type II diabetes. The study also aimed to examine patient experiences with care plans.

To look at care plan creation and review, the study used ten years of data from the Bettering the Evaluation and Care of Health (BEACH) study. The creation of care plans for depression and anxiety had increased between 2006 and 2016. Care plans were made more often for these high prevalence (common) mental disorders than for type II diabetes, bipolar disorder, and schizophrenia. This suggests that people with serious, low prevalence (uncommon) mental disorders are not receiving the potential benefits of care planning as often as people with depression or anxiety. This is a critical missed opportunity. People with a complex health care needs could benefit from a coordinated care approach. GP care plans could support access to specialist and allied health care, and encourage proactive health care management.

To be good health care management tools, it is important that care plans are regularly reviewed.

Diabetes care plans were reviewed about as often as they were created. This suggests that diabetes plans are working the way they should. In comparison, mental health care plans for depression and anxiety were reviewed much less often than they were created. Mental health care plans might mainly be used to help people access allied health care, but not to support ongoing care.

To understand people's experiences of care planning, people with a GP care plan were invited to complete an online survey. All 18 participants reported that the main purpose of their care plan was to help them with the costs of seeing allied health professionals. Care that they might not have been able to afford without a plan. Most people viewed this as one of the best things about the care planning process, but the process also had many problems. Participants commented that their care plans were simplistic, bureaucratic, 'tick box' exercises that, at times, made them feel judged or incompetent. Participants' experiences of care planning also rarely included shared decision-making. Care plan reviews were seen by people as a barrier to treatment rather than a chance to assess progress and make any necessary changes to overall care.

Mental health care plans work well as a way to increase access to mental health care. However, they do not appear to support shared decision-making and improved quality of care over time.

# Stay in Touch

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- Access summaries of our research findings
- Find links to our published journal articles and other resources
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