Insight

ACACIA 10th Anniversary—Special Edition

Message from the Head of ACACIA

Welcome to our special 10-year anniversary edition of Insight. It has been a few years between newsletters due to so many global and local events. All of the ACACIA team members have done our best to keep things going despite the disruptions, and as Head, I would like to thank everyone for their hard work and persistence.

There have been some major changes to our team over the past few years. Amelia and Alyssa have moved into new roles at the Centre for Mental Health Research, but still contribute to ACACIA projects as accomplished lived experience researchers. New Research Fellows Julia and Grenville introduce themselves in this newsletter, and we also have Research Officer Anna Foxcroft in the current team. Along with Craig Allen, Anna was one of our ACACIA interns in 2023, and liked us enough to stay. I also acknowledge the work of Bridget Berry, who was our Program Manager during 2022-23.

This year marks 10 years of continuous lived experience research work in ACACIA. Our first forum was held in November 2013, and we still use the agenda developed to guide our work, with regular priorities updates as described on pages 8-9. You can see some photos and posters from our celebration in this bumper issue.

It is fitting that this year, the ACACIA team won the ACT Mental Health Month Research Evaluation Award for our long-term commitment to lived experience-led mental health research. This is a real team effort and I'm very proud of our work and pleased to see it recognised.

The other major development in the past few years is our connection with the ALIVE National Centre for Mental Health Research Translation. You can read about this unique, large-scale initiative on page 7.

I wish everyone a safe and peaceful holiday season, and hope you enjoy catching up on ACACIA news.



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Seasons Greetings!

The team at ACACIA wishes you a safe and merry holiday season, and a happy new year!







ACACIA 10-year anniversary Celebrating our achievements

ACACIA celebrated our 10-year anniversary in September

It was wonderful to see so many people who have been connected with the work of ACACIA over the last 10 years at our celebration on 8th September 2023. It was an opportunity to showcase many of ACACIA's achievements and acknowledge the success of lived experience research.

The event was held in The Gallery at Kambri ANU, with fantastic catering by Bella's Feast, including a green and yellow donut wall!

The gallery space was filled with a poster exhibition presenting the timeline trail of the unit from its establishment in 2013 through the work completed to date. Some of ACACIA's current projects are highlighted in this edition of Insight.

Guests enthusiastically took part in a trivia quiz designed to encourage engagement with the work on display, with the winner receiving a giant jar of ACACIA themed lollies. Congratulations to Calo Huang for being the first correct entry drawn. Congratulations also to Anna Foxcroft, who had the closest guess for the number of lollies and chocolate frogs in the other giant jar. I hope you both enjoyed your treasures.

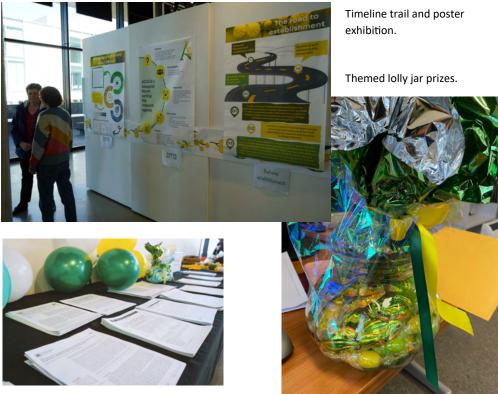


Publications, project summaries, past newsletters and jelly beans!

Among the guests enjoying the event were members of the ACACIA Advisory Group, lived experience participants who have contributed their time and insights to our research, ACACIA staff and students, staff and students from NCEPH, CMHR and elsewhere from the ANU, and representatives from ACT Health, Office of Mental Health and Wellbeing and Carers ACT.



A/Prof Michelle Banfield with Dr Amelia Gulliver and Dr Alyssa Morse.





10 years and counting

Summary statistics on ACACIA's objectives

Research in partnership

36 peer-reviewed papers



5 keynote presentations



31 conference presentations

Research translation

11 project reports to sector



12 public lectures

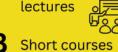


5 panel discussions



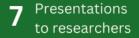
Capacitybuilding

24 Specialist lectures



Advice to research bodies

8 Researcher workshops









Delicious food and donut wall.

Dr Amelia Gulliver, Prof Alison

Calear and Dr Lou Farrer.



ACACIA Advisory Group

Dalane Drexler, ACT Mental Health Consumer Network

Dia Andrews, ACTMHCN

Consumer Representative

Caroline Davidson, Independent Consumer Representative

Adele Lewin, Independent Consumer Representative

Heather Lamb, Independent Carer Representative

Bianca Rossetti, Independent Carer Representative

Johannah Collins, Mental Health Policy Unit, ACT Health

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

Catherine Joseph, Mental Health Carers Voice, Carers ACT

David Lovegrove, Invited Member

Jane Grace, Invited Member

Meet the ACACIA team: Julia Dray



Julia, or Dr Dray as she humorously is happy to be called, is new to the team in 2023. Julia is a Lived Experience Research Fellow with both ACACIA and the ALIVE National Centre. Her current focus is exploring the who, where, what and how of mental health lived experience research in Australia, lived experience perspectives of use of language

in mental health, and capacity building of lived experience mental health researchers. Julia completed her PhD, with the University of Newcastle (2018). Her postgraduate work focused on resilience and mental health problems in children and adolescents.

Julia is passionate about enabling people to recognise their strengths and wider community protective factors; to develop and maintain positive mental health, development, and life trajectories; and breaking disadvantage. She has research and teaching experience in resilience, mental health, suicide prevention, health psychology, health promotion, and evaluation of change initiatives and complex health interventions. Julia sees her current and future roles developing collaboration with government, nongovernment and community partners; including communication and translation of evidence-based research; advocacy for youth involvement and lived experience recognition in research and service design; and a positive influence on related policy.

Julia is based on Awabakal Land in Newcastle, New South Wales where she lives with her young family. Julia has lived experience of postnatal anxiety and depression since the arrival of her two tiny humans who are now 1 and 3 years old, which added further fuel to her fire for mental health research. She enjoys a good toastie, lives for good coffee (and her beautiful tiny humans), wine, dancing, and beach days.



Meet the ACACIA team: Grenville Rose

The longer I've been involved with mental health work the more benefits I think that lived experience and peer work have to give to the community, so I'm really happy to be working here at ACACIA.

My B.A. is in psychology and after a temporary detour into food science due to an interest



in perception and the availability of a PhD scholarship, I've become a registered psychologist and have been working in the area of mental health since 2007. For most of that time I've been working in research, but I have done a small amount of counselling. Most of the research I've done has been in the NGO mental health area and, because life almost never takes a straight path, community pharmacy.

Lived experience is such a broad term that I think it can be useful, for those who are in a position to do so, to clearly define their lived experience. I identify as someone who is a survivor of suicide with a lived experience of mental health and substance use issues, including injecting drug use. My current wellbeing is the product of what I like to think of as 40 years of recovery.

I first became involved in consumer led health in 2002 when I became a hepatitis C lived experience speaker, work that I still occasionally do, but now I can happily talk about being cured. I am currently a member of; the Master of Professional Psychology course advisory committee at Macquarie University, the Lived Experience Panel of Suicide Prevention Australia, the Academic Advisory Board of the College of Professional Psychology and the Hepatitis C advisory committee of the Australasian Society for HIV Medicine, as well as being a brand-new board member of Being-Mental Health Consumers. Retirement isn't what it used to be.

Currently at ACACIA I'm working on a couple of projects that came into being as a result of the need to make sense of the Covid Pandemic for people with various forms of disability and/or pets. The work has been challenging as well as rewarding, so far. I've also been involved with a research education program for people with lived experience of mental health issues but who have little or no research experience. I think this is an exciting initiative since, to provide the most significant benefit to the community, 'nothing about us without us' must also include research.

ACACIA Staff

A/Prof Michelle Banfield, Head
Dr Julia Dray, Research Fellow
Dr Grenville Rose, Research Fellow
Anna Foxcroft, Research Officer

ACACIA PhD Students

As part of our capacity-building in participatory research, ACACIA academics supervise postgraduate research students conducting lived experience research consistent with the ACACIA consumer and carer agenda (see page 8-9).

The current PhD students are:

Dianna Smith - Recovery College
Outcomes

Chérie McGregor - Peer support values and practice

Capacity-building in participatory research

ACACIA Pilot Internship Program

An intro to the ACACIA Pilot Internship Program

The pilot internship program is a major new initiative for 2023 encompassing an innovative program conceptualised by A/Prof Banfield, and designed by the ACACIA team with input from the Advisory Group.

The program consisting of short courses, mentoring and a small research project aligns with our four objectives as follows:

Research in partnership

 An embedded research project addressing two of our 92 research priorities developed by consumers and carers in 2013 and 2017.



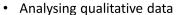
Capacity-building

 Two Research Support Officers with lived experience as a consumer or carer were recruited into the 2023 pilot.



- Mentoring of ACACIA interns by other ACACIA researchers.
- A suite of short courses designed and delivered to the interns by ACACIA staff on the following aspects of conducting mental health research:
 - Introduction to research methodologies
 - · Ethics and integrity
 - Lived experience involvement in mental health research





- Literature reviewing, and
- · Writing an academic paper



Advice to research bodies

 Generating knowledge on structures and requirements for how to embed lived experience training within academic contexts.



Research Translation

 Using learnings from the embedded research project to inform ACT Health commissioning and policy processes.



Our embedded research project: What we call ourselves? A qualitative investigation of language in mental health

The 'What we call ourselves?' study is embedded within the ACACIA Internship Program. The study addresses the two main language topics from the ACACIA priority agenda, investigating how language can be used to include and exclude, and the influence of labels.



15 interviews

conducted with consumers and carers from around Australia.



Our ACACIA interns are currently working hard to analyse what





The data is rich with early **findings** relating to:

- Labels and language as double-edged swords (positives and negatives; inclusion and exclusion).
- When we are just not enough for a label.
- Identity in language.
- Hearing lived experience voices.
- The power of words to help or harm.
- Guides through the language maze.



The whole ACACIA team is collaborating on a peer-reviewed paper from the study, for submission in late 2023 at the completion of the 2023 pilot internship program.



ALIVE National Centre for Mental Health Research Translation

The ALIVE National Centre

ACACIA and the ANU are proud to be partners in The ALIVE National Centre for Mental Health Research Translation, coordinated by the University of Melbourne and funded by the NHMRC Special Initiative in Mental Health. Associate Professor Michelle Banfield, Head of ACACIA, is also the Co-Director and Lived Experience Research Lead of the ALIVE National Centre. The focus of ALIVE is to embed lived experience perspectives into mental health research and translation. More information about The ALIVE National Centre, its networks and research can be found on the website https://alivenetwork.com.au/.



The ALIVE National Centre Annual Symposium 2024 — Canberra

The ANU is the host partner for the ALIVE National Centre Annual Symposium 2024 – Holistic Formations, to be held in Canberra on 14-15 March 2024, more information about this event is available on the website https://alivenetwork.com.au/the-alive-national-centre-annual-symposium-2024/.

Lived-Experience Research Collective

The Lived-Experience Research Collective is a dedicated group for lived experience mental health researchers and carer/family researchers. The collective aims to integrate lived experience knowledge and expertise into mental health research and strengthen lived experience-led research. The group offers mentorship, training, and opportunities to develop expertise and career pathways. For more information about the collective and membership see the website https://livedexperience.alivenetwork.com.au/.

The Long Conversation

Members of the Lived-Experience Research Collective are currently contributing The Conversation. This flagship project is experience lived mapping contributions to research in mental health, looking at the who, what, where and how lived experience research is conducted and the capabilities that might be needed to grow and integrate lived experience research. The project is using crowdsourcing to gather information. If you are interested in more information about this project or to take part, please visit the website



https://alivenetwork.com.au/our-research/lived-experience-research-collective/.

Mental health research priorities in Australia

A consumer and carer agenda

Priorities Progress

Creating a research agenda that included the views of people with lived experience as consumers and/or carers was a priority for ACACIA when it was originally established in 2013. The original ACACIA forum participants developed 87 research topics that were grouped into 14 broad subject areas. In 2017 a follow-up online survey was conducted to rate and rank the topics generated at the forum. The findings from both these studies showed that there were many equally important issues in mental health, and research in any of the identified areas could help to fill a gap in the system.



Keeping the agenda current

To ensure that the research projects that ACACIA undertakes continue to align with the priorities of people with lived experience, it is important to regularly update the priorities. In 2021 ACACIA ran two virtual world cafes to generate, discuss and rank new priorities. As with earlier studies people with lived experience created large numbers of important research ideas and reaching a consensus on priorities was not achieved. However, rather than describing issues at the individual service delivery level, the latest study showed a greater focus on mental health systems and issues around service funding, accessibility, and equity of access.

What next?

In 2022 ACACIA's consumer and carer research agenda formed the basis for The ALIVE National Centre (see page 7) massive online public co-design for research translation. The priorities from the 2022 ALIVE National survey and co-design project have been highlighted in a consensus statement available on the website https://alivenetwork.com.au/our-massive-online-public-co-design-project/. The ALIVE National Lived Experience priorities survey will be conducted again in 2024, with a focus on elevating the voices of people in regional, rural, and remote communities.

Want to know more?

To find out more about the consumer and carer research agenda you can read the original open access research articles using the QR code or visiting the ACACIA website

https://nceph.anu.edu.au/acacia. Or contact the ACACIA team for assistance. You can find our contact details on page 14.



The table below shows where the research undertaken by ACACIA over the last 10 years has addressed the established research priorities developed by lived experience consumers and carers.

Care planning - What makes a good mental health plan? (e.g. individualised, including perspectives of consumers, carers and clinicians) Alternative treatments - What are they, and how can they contribute to evaluation recovery? Holistic approaches, meditation, exercise evaluation Pet therapy COVID-19 mental health study COVID-19 mental health study COVID-19 mental health study Understanding Participation which is the consumer and carer voice integrated into policy and services? How are their contributions valued, and what indicators exist to demonstrate how their voice is used? Reach - Are services reaching the people that need them? Consumer and carer journey through service pathways - What works and what doesn't? What do clinicians think? Monitoring and evaluation - to what extent is it built into programs: pre-, post- and during evaluation from participants Disconnection of services Service pathways - first access, how do they go about it, what is the access to information, benefit of hindsight? How to implement internationally recognised models of peer support in Australia How to recruit and train peer workers - What is going on, and where? Where is it embedded? How are they being supported? Consumers' experiences of peer to peer services Peer-led services - What are the gaps? (e.g., support groups) Peer support in public mental health system What are clinician views on peer support? What is a peer? How is psychosocial disability defined in the NDIS, and how will it impact consumers and carers in Australia? How does the use of language include/exclude individuals? Consumer perspectives on use of labels - Which terms are useful/helpful, which are not? How participation works in practice (tokenism vs. real involvement) Consumer and carer voice integrated into policy Carers & bereavement - Are we offering enough counselling? is it timely evaluation Mental health in LGBTIQ+ populations Mental health in LGBTIQ+ populations Mental health in culturally and linguistically diverse populations Mental healt	Research Topic	ACACIA projects
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Research InFocus - current ACACIA research projects

COVID-19 mental health survey

This project aims to improve the understanding of COVID-19's impact on the mental health and behaviors of the Australian community. A team of researchers from the Research School of Psychology and National Centre for Epidemiology and Population Health at the ANU are collaborating on the project. The study was conducted in eight waves from March 2020 to February 2021. An additional follow-up survey was conducted in March 2022. Information was collected from over 1,400 people and ACACIA is working on three studies using this rich data set.

Exploring personal experience of the COVID-19 pandemic in Australia

Survey data showed that overall people were more depressed and anxious in the early period of COVID than pre-COVID. This applied to both people with a mental health diagnosis and people who had no diagnosis. The main drivers of this increase were pandemic induced changes in work and social functioning. Financial distress, rather than job loss, was also a key driver of a decrease in psychological wellbeing.

Ableism and the COVID-19 pandemic

As the pandemic evolved, public messaging changed to encourage individuals to be responsible for their own safety and health. The focus on restarting the economy and the relaxing of restrictions had worrying consequences for people with significant mental and physical health problems, disability, or other risks. These people are forced to restrict their own activities to minimise risk. The 2022 follow-up survey included questions exploring people's attitudes towards risks and responsibility for public health, to investigate ableism.

Pet ownership and mental health during the COVID-19 pandemic

As lockdowns began across the world pet shelters emptied as people rushed to get pets. There could be many reasons for this spike in pet ownership, companionship, boredom or taking a decision that has been put off in the past. This study includes drawing together the results of the more than 20 articles published in the last 3 years on the relationship between pets and mental health. Both our data and the wider literature suggest that the effect of having a pet on mental health is complex and depends very much on the person's whole of life situation. Having a pet, particularly a pet that needs a large amount of care and attention such as a dog or a horse, may add to a person's psychological burden, or conversely may reduce anxiety and stress in the household if the pet is not perceived as an added burden.





Want to know more?

To find out more about the ACACIA research projects mentioned in this newsletter you can read the original open access research articles using the QR code or visiting the ACACIA website https://nceph.anu.edu.au/acacia. Or contact the ACACIA team for assistance. You can find our contact details on page 14.

Research InFocus - current ACACIA research projects

Co-creating Safe Spaces

What are Safe Spaces?

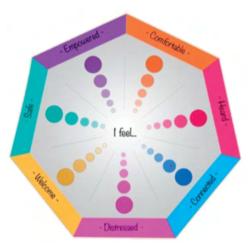
Safe spaces are an alternative to emergency departments, which are often unable to provide optimum care for people experiencing emotional distress and/or suicidal crisis. There are several different types of safe spaces being trialed in Australia but there is not much research on how effective they are.

New research

The project aims to evaluate the implementation and outcomes of six safe spaces in three Australian states: ACT, NSW and SA and has been funded by Suicide Prevention Australia. The project has a strong focus on meaningful outcomes for safe space guests (beyond reduction of distress), the implementation of suicide prevention peer worker roles, and the integration of non-clinical services into mental health and suicide prevention services.

A secondary aim of the project is to develop and publish research co-creation methods. A co-creation project requires recognition of equal and shared knowledge across all groups involved in the service, particularly people accessing the service and peer workers. All stakeholders are involved in data collection, analysis, and dissemination of results.

Co-creation with safe space guests, peer workers and service providers enables the development of novel co-created data collection tools for use in these spaces. Shown here is our evaluation wheel, which can be accessed from a tablet at the safe space. Safe space guests are given a range of ways to provide feedback, if they wish to, so that they can contribute to the research in a way that suits them.





Community survey open now

Whether you have personal experience, have supported someone in distress, or simply wish to contribute, we value your perspective and welcome your input.

Access the survey via the QR Code or this link: http://quicklink.anu.edu.au/eepr

All questions optional, the survey will take around 10-30 minutes depending on your choice.

Co-creation with Roses in the Ocean

As a result of the successful ongoing partnership, Roses in the Ocean asked ACACIA to lead an evaluation of the community-led safe spaces being trialed by the organisation. The project will draw on the cocreation work undertaken for the Co-Creating Safe Spaces project and will focus on the implementation and sustainability issues unique to the volunteer-led model.

Research Bites:

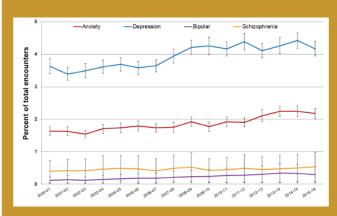
Finding the Path

Service access and navigation for serious mental illness

Aim: To explore access to services and support for navigation, and develop recommendations to improve the system for people with serious mental illness

Access

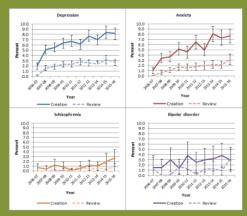
- Compared GP access for four different mental health conditions
- Rates of access to GPs about as expected for depression and schizophrenia
- Access to general practice was low for people with bipolar disorder and anxiety



Percent of GP encounters for mental health conditions

Navigation

- Compared the use of GP care plans for four mental health conditions
- Development of care plans for depression and anxiety increased significantly over time, but rates of review were much lower
- Rates of creation and review were both very low for schizophrenia and bipolar disorder



Percent of GP encounters involving development and review of care plans

[The care plan] is instrumentally useful in enabling me to access cheaper psychology services.
Otherwise it has never really helped. They are one off items. What people need are high quality ongoing medical and allied services. The plans do not enable adequate, let alone high quality, mental health services to arise from the ether. Until such services are created the plans remain a bureaucratic exercise for many, probably for most with significant mental illness.

Thought leaders recommended the system needs...

- Co-design more than consultation
- Sufficient sustainable funding
- Evidence-based government policy & strategy
- The right type, timing & intensity of services
- Consumer ownership of their mental health care plan
- Whole service system and workforce development supporting mental health
- Technology for mental health care

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Quantitative data were drawn from the Bettering the Evaluation and Care of Health (BEACH) study

Research Bites:



Experiences of families, carers, and community members impacted by suicide in the ACT

Scott J. Fitzpatrick¹, Kerrie Gallagher², Michelle Banfield¹, Amelia Gulliver¹, Alison L. Calear¹, Stella Conroy², Philip J. Batterham¹

¹Centre for Mental Health Research, The Australian National University ²Relationships Australia Canberra & Region

Background

Little attention has been paid to the experiences of families and carers supporting and accessing support for individuals in the period preceding and following their death by suicide.

For many families and carers who have experienced loss and been subjected to a series of unhelpful or harmful encounters with health and emergency services, there is a desire to share their stories so that their experiences might contribute to the improvement of practices and policies.



Results

The findings were organised around three interconnected key themes that were developed from analyses: i) Disconnected spaces, ii) Fragmented, episodic, and reactive care, and iii) Exclusion and marginalisation of families and carers.

Disconnected spaces

Highlights the sense of isolation, disconnection, and disempowerment experienced by those seeking services before their death as well as those providing care for them that resulted from their interactions with health and emergency services.

"From the first suicide attempt up until that second suicide attempt, and then obviously his death six months later... [We] didn't know where to turn, [we] didn't get any support...We felt lonely. We started feeling isolated... Even our close friends didn't get it. ...It was...very stressful."

Conclusions

The health system, including primary care services and hospitals in the ACT, have significant gaps in supporting people who experience suicidal distress and their families

Understanding the family context and appropriately including family members when providing support, with consent, can contribute to better outcomes and provide opportunities for more effective and efficient care.

Identifying the support needs of families and carers will help empower and support them as partners in care, as well as to address their own health and wellbeing needs.

Method

Qualitative interviews with 17 participants supporting and accessing support for individuals who died by suicide in the Australian Capital Territory, Australia.

Interviews and thematic analysis were guided by the theoretical frameworks of trauma-informed and restorative practice.

"It was very difficult understanding what all these things are [psychiatrist, psychologist, general practitioner] and what the pathways were. Some of the pathways weren't around the [person], they were more around the admin and the Medicare."

Fragmented, episodic, and reactive care

Describes a mental health system that focused primarily on crisis management and the alleviation of symptoms rather than on the provision of trauma-informed, holistic, and coordinated care. essment time points



"We weren't given clear information and were balked at any time that we tried to even get information...because of his age. Even just general information about what was available...You know, no one came and said, 'Look, OK, we can't talk to you about [name] because he's over 18, but here's the system and here's what you can do'...People would throw us, you know, a brochure or whatever."

Exclusion and marginalisation of families and carers

Shows how power dynamics, ineffective communication strategies, and insufficient procedures for sharing information were a barrier to effectively engaging and supporting families and carers.

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Email: acacia@anu.edu.au

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

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