Insight

Message from the Head of ACACIA

Welcome to the first issue of Insight for 2019. It has been a busy few months for ACACIA, including conferences and new consumer-led papers published. Keep an eye on our web page and join us on Facebook (details on page 8) to keep up-to-date with what we're up to. We've also added a new electronic form to make it easier to join our register, so encourage other consumers and carers to get involved.

One of the exciting things we've been working on behind the scenes is plans to teach courses at the ACT Recovery College (www.recoverycollegeact.org). For those who haven't seen it yet, the Recovery College is a safe space to learn about mental health recovery and wellbeing. Courses are free and are co-facilitated by peers and professionals. As described on page 3, ACACIA will be running some research skills courses. The first is a two-session workshop about research basics and what active involvement in research processes means for people with lived experience. The second one will be co-developed with a working group of consumers and carers. It will teach people how to search for good quality health information, assess its quality and bring it all together.

To introduce you to this process, in this issue we have an update on where our consumer and carer research agenda is up to and what we need to do next. We also have an article on the "gold standard" of literature reviews, the systematic review.
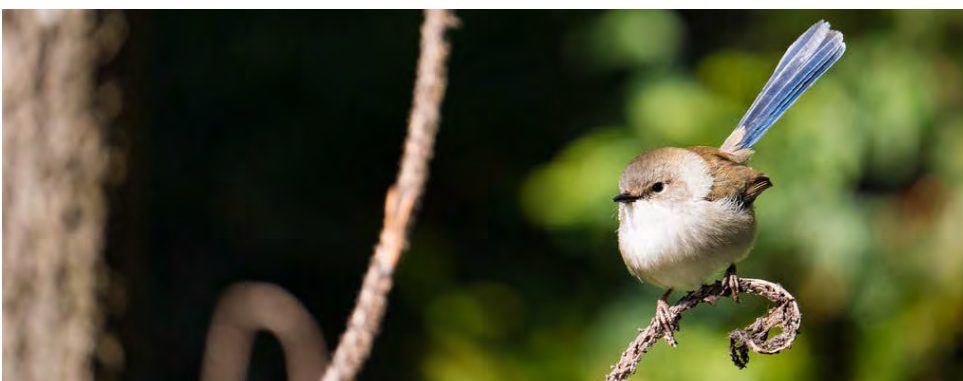
I look forward to seeing lots of you getting involved in the Recovery College. Hopefully, that will be in ACACIA's courses.

Inside this issue

Meet the ACACIA Advisory Group Member: Jane Grace

Jane Grace is a consumer representative on the ACACIA Advisory Group. She has been a long-term consumer advocate in the ACT.

She was a member of the Lived Experience Advisory Forum for Children of Parents with a Mental Illness (COPMI, the predecessor of Emerging Minds) and has been an ACT representative to the National Mental Health Consumer Carer Forum. Jane is an active member of the ACT Mental Health Consumer Network and a Board member of the Mental Health Community Coalition. She has a strong commitment to advocacy and consumer participation. She has a keen interest in developing the peer work force in Australia.

Jane currently works as a Team Manager at the Australian Communications and Media Authority. She has a Bachelor of Laws and Social Work from the University of NSW and a Master of Laws from The Australian National University.

Jane has recently co-convened a grassroots advocacy organisation called Red Flag Canberra which is directed at mental health action and runs speaker's forums, a support group called "Safe Harbour" and provides commentary on emerging mental health issues through a blog and website.

Jane is very pleased to be part of the ACACIA Advisory Group. It will be a great opportunity to learn from others' experiences and contribute to the important research ACACIA undertakes. Having a consumer and carer focus and leadership of mental health research lays the foundation for transformation in the research literature.

New Opportunities at ACACIA!

ACT Recovery College Workshop
Partners in Research: Methods for high quality collaborative mental health research

ACACIA will be running a two-day workshop at the new ACT Recovery College in Term 2 this year. Students who attend this workshop will gain an understanding of some of the key issues for conducting high quality research in mental health services. The two-day workshop is designed to be an introduction to rigorous research that is conducted with active involvement of consumers, carers and other mental health stakeholders.

Dates: Part 1: Wednesday 22nd May and Part 2: Wednesday 29 May

Time: 10am-12pm

For more information, or to enrol in the workshop, head to the ACT Recovery College Website: https://www.recoverycollegeact.org/

Coming Later this Year
Rapid Review Voluntary Internships

ACACIA's research is guided by a list of research priorities developed by Australian mental health consumers and carers (see page 4 to find out more). There are 87 individual topics on this list, grouped into 14 subject areas. To choose the best topics to work on, we need to know what research has already been done and whether that research is of good quality.

To tackle this challenge, ACACIA is currently developing a voluntary internship program. Interns will be trained and supported to conduct rapid systematic reviews of literature on research areas from our priorities list.

What's a systematic review? Head to page 6 to find out!

Anticipated outcomes of a voluntary internship:

♦ Learn how to conduct a systematic literature search and work with databases and search engines

♦ Develop skills to identify good quality health information

♦ Gather knowledge on a topic of high importance for Australian consumers and carers

♦ Produce a report or academic publication

Keep an eye out for more information about the internships later this year!

Stay in Touch!

There are a few different ways you can stay up-to-date with new opportunities at ACACIA.

Follow us on Facebook: @acacia.cmhr

Check out the website:

http://cmhr.anu.edu.au/acacia

Join the ACACIA Register:

Sign-up on the website or email acacia@anu.edu.au

Mental health research priorities in Australia: A consumer and carer agenda

Consumers and carers bring valuable experience and ideas to developing questions for research. They can identify new issues in the mental health sector or draw attention to areas that might have been missed in the past. Unfortunately, consumer and carer voices are not often included when priorities for mental health research are chosen.

One of ACACIA's key goals is to develop a research agenda focused on the issues that are most important to consumers and carers in the ACT and across Australia. ACACIA has worked with consumers and carers in the community to develop a set of research topics. We use these topics to help us choose and design research projects that are important to the community. Our research agenda was also recently published in an academic journal article where it can influence the work of other researchers.

The topics in our research agenda were created by consumers and carers in the ACT who attended a discussion forum in 2013. Forum participants came up with 87 research topics, which were then grouped into 14 broad subject areas. The broad range of topics discussed at the forum reflect the large number of gaps that people are experiencing in the Australia mental health sector.

A vote was held at the forum to try and find the most important research topics. Votes were spread widely across the different options and no clear winners were found. Out of the 120 possible votes, the most popular topics only received between 5 and 7 votes each. In 2013, the highest priorities for mental health research in the ACT were:

Research subject areas:

- Services
- Treatment
- Medication
- Health Professionals
- Comorbidity & Physical Health
- Justice System
- Consumer & Carer Involvement
- Stigma
- Experiences of Care
- Carers, Family & Friends
- National Disability Insurance Scheme (NDIS)
- Language & Communication
- Peer to Peer
- Legislation
- Other

◆ The integration of trauma informed care into service delivery

◆ Is care traumatising?

◆ Peer-led services

◆ Recovery and fulfilling potential

In 2017, ACACIA ran a national survey to update our research topics and priority levels. The survey asked consumers and carers to rate the priority level of each of the 87 topics from the forum. People could also add comments and suggest new research questions. Seventy people across Australia participated in the survey but we still couldn't identify any top priorities for mental health research. Most of the research topics were rated as high priority or very high priority by at least 50% of consumers, carers, and people who identify as both. Participants who commented on the survey said that they felt that everything seemed equally important.

I hate to say this but the list [of research priorities] touches directly on most of our carers and consumers involved in the mental health system. Your list shows just how far we have to go to have a first class mental health system… (Carer, Survey Participant)

The results of our forum and survey, and our discussions with our Advisory Group tell us that there are a large number of equally important issues in mental health. Research looking at any of these topics could help fill an important gap in the system.

A place to start

To find some key areas for researchers to begin working on, we focused on the topics that were rated as high priority or very high priority by at least 80% of consumers, carers or people who identify as both. Then we looked for the common ideas that linked those topics together. Survey participants' comments helped us to find the issues that were most important to people in 2017.

Many important topics were about the delivery of services. They included the quality of services, problems with services, and how services can affect consumers and carers. The National Disability Insurance Scheme (NDIS) was often highlighted in survey answers and comments. Participants were concerned about supporting people who were not eligible for an NDIS package and they worried about the service gaps the scheme was creating. Participants also wanted to find out how the NDIS definition of "psychosocial disability" would affect consumers and carers.

Another key research area was consumer and carer involvement. The highest priority topics in this area included: how participation works in practice, how to expand who is involved, and how lived experience voices are valued. Other high priority research topics included the over-representation of mental illness in the justice system, social inclusion, and employment.

There were some group differences in how the research topics were prioritised. Consumers tended to rate topics about peer services, peer workers and peer support as the highest priority. Carers focused on topics related to carer support services, the reach of services and continuous support and care for suicide. People with experience as both a consumer and a carer gave importance to topics about the organisation of care and carer recovery. "Organisation of care" included topics like care planning, care coordination and the transparency of services.

Work so far

ACACIA's research projects aim to look at one or more of the topics that were developed at the forum. In the table on page 5 you can see some of the progress we've made so far and what we're working on right now. If you'd like to know more about any of our projects, head to the "Our Research" page on the ACACIA website (http://cmhr.anu.edu.au/acacia).

Where to next

ACACIA's upcoming literature review internships (see page 3) will begin the task of finding out what kind of research has already been conducted on the 87 topics in the research agenda. Where would you start your investigation?

You can check out the full list of research topics in our freely accessible journal article. You can find a link to the article on our website – http://cmhr.anu.edu.au/acacia – just head to the "Our Research" page.

Topics we're investigating	ACACIA Project
♦ Consumers' experiences of peer-to-peer ♦ How to recruit and train peer workers. ♦ How are they being supported? ♦ What are clinician views on peer support? ♦ How to implement internationally recognised models of peer support	Implementation of a peer worker-led mental health recovery program Stay Strong: Peer-led e-mental health feasibility study
♦ How participation works in practice (tokenism vs. real involvement) ♦ How 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?	Understanding participation in the ACT Whose story is it? Consumer and carer perspectives on mental health research ethics
♦ Alternative treatments ♦ Impacts on specific age groups	Music Engagement Program evaluation
♦ Service pathways - First access, how do they go about it, what is the access to information, benefit of hindsight? ♦ Care planning: what makes a good mental health plan? ♦ Disconnection of services ♦ Monitoring and evaluation - to what extent is it built into program: pre-, post-, during evaluation from participants	Finding the Path: Service access and navigation for serious mental illness in a complex Australian policy landscape Partners in Recovery Evaluation

Demystifying Research: Systematic Review

What is a systematic review?

A systematic review is a review that follows a specific method to answer a research question. To do one, you need to try to collect and summarise the evidence that fits certain criteria you choose.

Figure 1. Level of Evidence hierarchy. See www.thelogicofscience.com

How does it differ from a literature review?

Systematic reviews follow empirical methods for collecting data. The aim is to create a review that answers a specific research question, and that follows pre-defined criteria. It also means the review could be re-done by another researcher ("replicated") and it should produce the same results—they are at the top level of the evidence hierarchy. This means they are one of the most important sources of evidence we have. **Figure 1** shows how studies with the weakest evidence are at the bottom. The strongest types of studies are at the top, including systematic reviews. On the other hand, literature (or narrative) reviews are very broad in scope. They report on any articles the author chooses to summarise. This means that different authors could produce very different reviews on the same topic, depending on which articles the author chose to include.

Why do a systematic review?

It is difficult to keep up with the findings from many articles about any topic. So, it is important to review the evidence regularly to find out what has been done before and what was found. Systematic reviews are most helpful when there have been at least a few scientific studies conducted on the research topic. They are also helpful for when we are not sure overall about the results of these studies. This includes the study quality, which shows us how much we can trust the results of the study.

What topics can you do a systematic review on?

Almost anything you want! Often systematic reviews will be of intervention (i.e. randomised controlled trials) or observation studies (i.e. case control or cohort studies). The type of study to be included will depend on your research question. For example, you may wish to know "Does **pet therapy** improve **depression** for **adults**?" So you would search for trials of pet therapy that measure depressive symptoms.

How do you do a systematic review?

There are many steps involved in a systematic review (see **Figure 2**). They are important to follow carefully, as this shows other researchers how good your review is, and that it can be replicated. The main steps are:

1. Deciding on a systematic review question.

Sometimes this is the hardest step! You need to find a question that has not been reviewed before. It is also important to find a topic for which at least a few studies have been conducted.

2. Performing the searches.

Usually you need to search multiple databases (e.g., Pubmed, PsycINFO, Cochrane). You brainstorm a list of search terms (e.g., "pet" OR "cat" OR "dog" AND "therapy" OR "intervention" AND "depression" OR "depressive symptoms"). It's also important to look through journal papers' reference lists by hand, to find

Demystifying Research: Systematic Review

anything that might be missed by the databases. It can help to brainstorm terms that mean the same thing and use all of these in your searches. After finding the articles, you can download them into a reference manager such as Endnote.

3. Selecting the journal articles that meet your criteria.

Write down inclusion criteria that aim to find relevant articles before starting your searches. This makes it easier and clearer to either include or exclude journal articles that meet or don't meet your criteria.

4. Extracting data from each journal article.

Usually this step involves creating a "coding sheet" in a word document. This is just a table that helps you write down important data from the article. For example, you might want to record the mean depression score for the pet therapy participants before and after the pet therapy program. If there is a control group, you could also record their depression scores. That way you can compare them, and you can also look across studies to see if the pet therapy programs are all helpful for depression or not.

5. Assessing journal article quality.

This involves assessing how well the research was conducted according to scientific standards of conducting research. Checklists such as the *Cochrane Risk of Bias* tool can be used, but there are many others.

Figure 2. A systematic review (Cochrane Consumers and Communication, step # added. See https://cccrg.cochrane.org/infographics

6. Summarising your data.

This is where you try to pull together what you have found into the final review. Summarising the studies based on key criteria such as the country of study, the number of participants, and the different types of interventions used (e.g., dog, cat, bird therapies) is useful starting point. Then it is important to summarise what the studies found. Did the pet therapy improve participants' depression? What can we say about the quality of the studies – were they based on sound scientific methods? Can we trust their results? At this point, some researchers also conduct a "meta-analysis". This is a statistical way of pulling the results of all of the similar studies together to be able to say with more certainty whether the intervention works or not.

7. Writing up the review.

The final step, is writing up the review for publication. Systematic reviews are very important pieces of research. They are very helpful for quickly identifying what the evidence is for a particular topic.
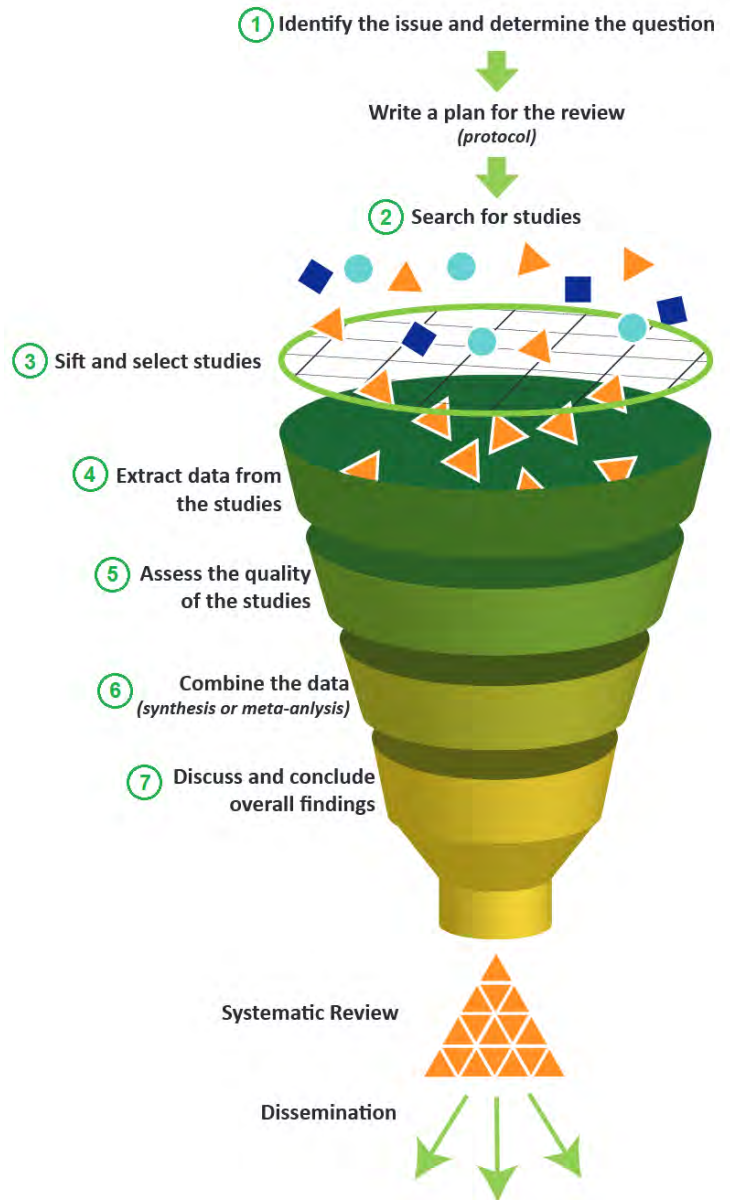
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- Access summaries of our research findings
- Find links to our published journal articles and other resources
- Learn more about the ACACIA team
- Download past issues of *Insight*

Contact Us

Email:
acacia@anu.edu.au

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

For more information about ACACIA, please visit http://cmhr.anu.edu.au/acacia