

# CONNECT

## NEWSLETTER



A recap of activities and work in CONNECT and consumer engagement in the ANZIC-RC, in the most wonderful time of the year!

**EDITION #3, 2025**

**THIS NEWSLETTER CONTAINS:**

CONNECT Updates  
ANZIC-RC Updates  
Insights from Fiona Clay  
Spotlight - Our CONNECT Consumers  
CONNECT Contact Information



## **ACKNOWLEDGEMENT OF LIVED EXPERIENCE**

“The ANZIC-RC acknowledges the individual and collective expertise of those with a lived experience of critical illness, and those who love and care for them. We value the contribution of those that share their perspectives to improve research outcomes and we are committed to listening, learning and continuously improving.”



# CONNECT

## MEMBER REGISTRY



The CONNECT Family is growing ❤️

*More consumers join the Registry!*

First CONNECT Consumer  
CONNECT consumers  
today (November 2025)

*February 2024*  
*27 consumers*

We are pleased to share that the CONNECT Member Registry has grown over the past year, with consumers receiving word about our registry through professional consumer engagement organisations, ICU waiting areas as well as our own CONNECT consumers recommending our initiative to other fellow consumers.

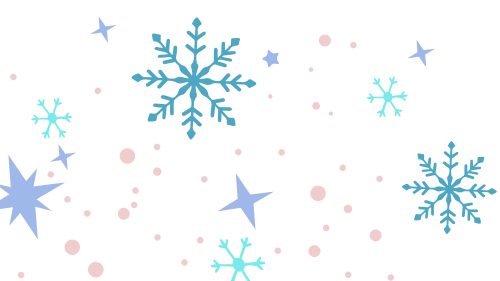
### Consumer Advisory Committee

*Advisory group comprising seven consumers with lived experience of intensive care who oversee the CONNECT consumer engagement process in a consumer lens.*



### Consumer Member Registry

*An additional twenty consumers with lived experience of intensive care, who are involved and engaged in consumer activities across projects at the ANZIC-RC.*



# CONNECT

## MEMBER REGISTRY

Consumer Engagement at the ANZIC-RC Wordcloud

REVOLUTION Public Feedback Survey

**BONE ZONE**    **REVOLUTION**

**NUTRITION**

Revision of ICU Memory tool and validation in patients with Post Intensive Care Syndrome

**SHAPING SEPSIS CARE**

JLA Survey on Swallowing and

Communication

ANZICS PFE

Guidelines

**GUARDS RCT**



# ANZIC-RC

## CONSUMER ENGAGEMENT

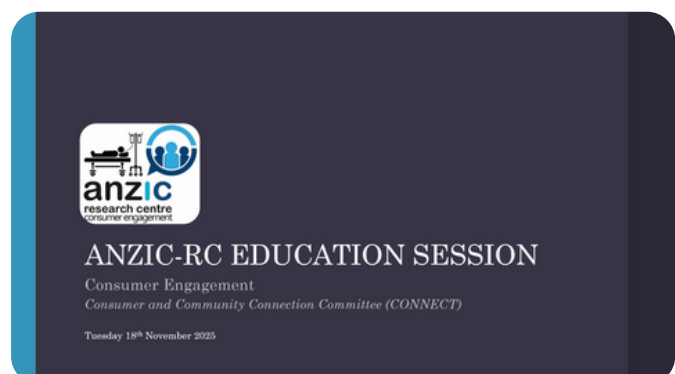
### ANZIC-RC EDUCATION SESSION ON CONSUMER ENGAGEMENT

**The ANZIC-RC held a 2-hour education session in November 2025 on how to conduct meaningful, effective consumer engagement.**

Focus areas include:

- Levels of Consumer Engagement and how to engage the consumer across all levels.
- Steps for onboarding the consumer and ensuring consistent communication as well as continual questions.
- Checking in with the consumer periodically to make sure they are not overwhelmed and experiencing burnout.
- Meeting specific needs of the consumer, from accessibility (to meetings, the building location, documentation and other research material), to approaching them with cultural sensitivity (Indigenous Australians, Cultural and Linguistically Diverse People).

CONNECT was also honoured to have the Advisory Consumer Members, John Asgari and Jacob Dye, participate in the session and share their experiences and insights on how to improve the consumer engagement process for both researchers and consumers.



# ANZIC-RC

## CONSUMER ENGAGEMENT



### NUTRIENT CONSUMER AND COMMUNITY ADVISORY COMMITTEE (CCAC)

#### **NUTRIENT Research and Education Meeting 2025**

The NUTRIENT Research and Education Meeting was held in October 2025. It brought together stakeholders including consumers, clinicians, industry and hospital leadership.

Day-01 comprised updates about the ANZIC-RC and the NUTRIENT program, educational talks and presentations as well as discussions on co-design.



Day-02 was a workshop opportunity in the concept of a World Café, where everyone came together in groups to work on re-designing nutrition care in the critically ill, through co-design. Central thoughts and ideas were based on what is “optimal” nutrient care.

For more information about the NUTRIENT program, please visit

<https://www.monash.edu/medicine/sphpm/anzicrc/research/anzic-rc-nutrition-program/nutrient>.



# ANZIC-RC

## CONSUMER ENGAGEMENT



### ECMO PATIENT ADVISORY GROUP

#### ECMO Patient Support Group Meeting September 2025

ECMO patients, friends and family members came together to share their lived experiences and discuss the recovery process following ECMO. The following aims of this meeting were to:

- Share stories about ECMO
- Be with people who had also been through ECMO.
- Accept, learn and understand the ECMO experience.
- Emotional Support
- Create time for vulnerability and to honour the experience.
- Inspire others and give back.

*'Many survivors are crying out for somewhere to sit with others who have been through and who are going through similar to them. It's the first time we've ever met other survivors face to face. Hearing others stories and feeling the raw emotion in the room was quite something to experience. I wanted to thank everyone involved with the ECMO group that I attended. How wonderful it was.'*

*'from my experience the 1st question that I needed was, "Did you understand what was happening to you?"'*

*'Nothing helped me more than knowing staff heard me and tried their hardest to attend to my needs.'*

**Scan the QR code to view more survivor stories →**



To learn more about the insights of ECMO survivors involved within the EXCEL Registry, please visit <https://www.monash.edu/medicine/sphpm/excel/survivor-stories>



# ANZIC-RC

## CONSUMER ENGAGEMENT



### SHAPING SEPSIS CARE: JLA-PSP

**Survey 2 is now open! Help us to identify Australia's Top 10 Research Questions for Sepsis.**

All Survey 1 responses were grouped into summary questions, and any deemed outside the scope of this project have been saved for future purposes. After checking these questions against current research, only the unanswered questions have been included in Survey 2.



To find out more information about the Shaping Sepsis Care Initiative, visit <https://www.nccr.au/shaping-sepsis-care>.

To access Survey 2, click [here](#).

# ANZIC-RC

## CONSUMER ENGAGEMENT



### HAVE YOUR SAY: JLA SURVEY ON COMMUNICATION AND SWALLOWING DIFFICULTY AFTER CRITICAL ILLNESS

**Help us identify the top 10 questions to guide future research on communication and swallowing following critical illness!**

Who can take part?

- People who have been critically unwell in an adult ICU and experienced communication or swallowing difficulty during or after their hospital admission
- Family members, carers or supporters of people who have been critically unwell in an adult ICU and experienced communication or swallowing difficulty during or after their hospital admission
- Health and social care professionals with experience with or providing care for critically unwell adults who experienced communication or swallowing difficulty during or after their hospital admission

Priority Setting  
Communication and  
Swallowing Difficulties  
in Critical Illness

PCCO:

What would your top question  
about communication and  
swallowing in critical illness be?

Help us identify the top 10  
questions to guide future research.  
**Survey One now open**



To access the survey, please click [here](#).

*The survey is available in 10 different languages (English, Arabic, Chinese, French, German, Hindi, Japanese, Portuguese, Spanish, and Russian).*

# INSIGHTS

## FROM FIONA CLAY

CONNECT CONSUMER STEERING ADVISORY MEMBER



### **PARTNERING WITH PURPOSE: PATHWAYS TO MEANINGFUL CONSUMER ENGAGEMENT**

Recently, I was fortunate to attend the workshop “Partnering with Purpose: Pathways to Meaningful Consumer Engagement” at the Adelaide Convention Centre.

This was a workshop attended by consumers, researchers and clinical providers. I have done a lot of consumer training, this was the first time I have done anything in person. Consumer involvement was defined as informing the things unknown to you as a researcher or clinician.

The value and importance of getting to know consumers via periodic check-ins and regular touchpoints was raised by many. It’s the same model as forming a friendship. Seen as a way of helping consumers feel more comfortable and confident; online meetings are unable to properly provide the interpersonal connections that build strong relationships. As one person put it “with digital, we are losing the power of small talk”.

One senior researcher described her approach. The last Friday of every month, her consumer advisors and study participants (based in Adelaide) met with members of her research team for a Friday “Walk and talk” along the Torrens river in Adelaide. While the option was there to raise any issues with the research, Walk & Talk very quickly morphed to chatting about life and families and what everyone was up to. Over time strong friendships formed and meaningful and rewarding collaborations between participants were built.

*Please turn over to the next page of quotes and interpretive drawings shared by Fiona on the day*

# INSIGHTS

## FROM FIONA CLAY

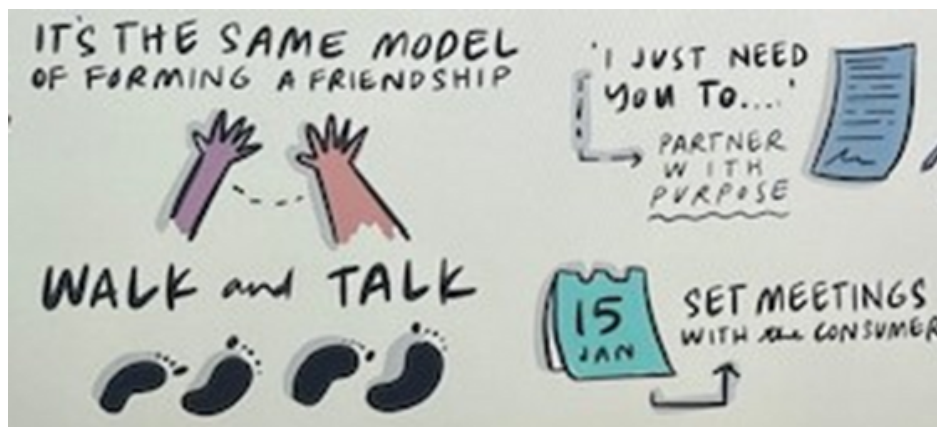
CONNECT CONSUMER STEERING ADVISORY MEMBER



### PARTNERING WITH PURPOSE: PATHWAYS TO MEANINGFUL CONSUMER ENGAGEMENT

"Consumer engagement is about relationships, not just engaging for specific projects or short time periods but ongoing collaboration and engagement."

- 'From Patient to Partners' BCNA workshop participant (March 2025)



"Look back at the journey, it's not a straight line - twists and turns, something you can't predict, the people you meet help you to elevate to the next position."

- PxP ('For Patients, By Patients') Conference 2025 presenter

# INSIGHTS

## FROM FIONA CLAY

CONNECT CONSUMER STEERING ADVISORY MEMBER



### ACTA 2025: CLINICAL TRIALS AND REGISTRIES SYMPOSIUM

#### **Clinical Trials Funding: Making Consumer contributions matter**

##### Perspectives of a consumer advisor involved in the review of MRFF applications:

- Some applications do not embed consumer engagement into the project proposal, and only rely on the consumer involvement statement.
- Some consumer engagement statements read like textbooks, i.e. they do not seem authentic.
- Budget allocations can be unclear or lacking in terms of consumer engagement support.
- Some projects rely on generic/institutional consumer reference groups rather than consumers with lived experience.
- Funders recognise the benefits of consumer engagement in achieving better quality research and health outcomes.

##### Advice to researchers from a consumer advisor involved in the review of MRFF applications

- Be authentic and make consumer engagement an integral part of the project.
- Don't regard consumer engagement as a burden but as a benefit to the research participants and improved, better outcomes
- Consumer engagement should be business as usual – the major cost is time.
- Engage early and make connections, develop relationships with the cohort of people who understand the condition/disease
- Don't be afraid to engage with consumers. Most are interested in improving health outcomes for others, even if they have had a difficult experience

# SPOTLIGHT

## CONNECT CONSUMERS



*Eileen Lam*



CONNECT CONSUMER  
ADVISORY MEMBER

Consumer engagement is making sure there is genuine and meaningful partnerships and leadership by consumers, patients and carers. This is important as the motto "Nothing about us without us" rings true. The research impact and outcomes need to come back to the community and ensure all aspects of the research are informed (and where possible, led) by lived and living experience. Consumers are the experts of their own lives and have rich experiences and perspectives to share. Diverse voices also need to be brought to the table, particularly the voices typically not a part of these discussions. Diversity and inclusion can ensure the engagement is productive and can apply to many in the community.

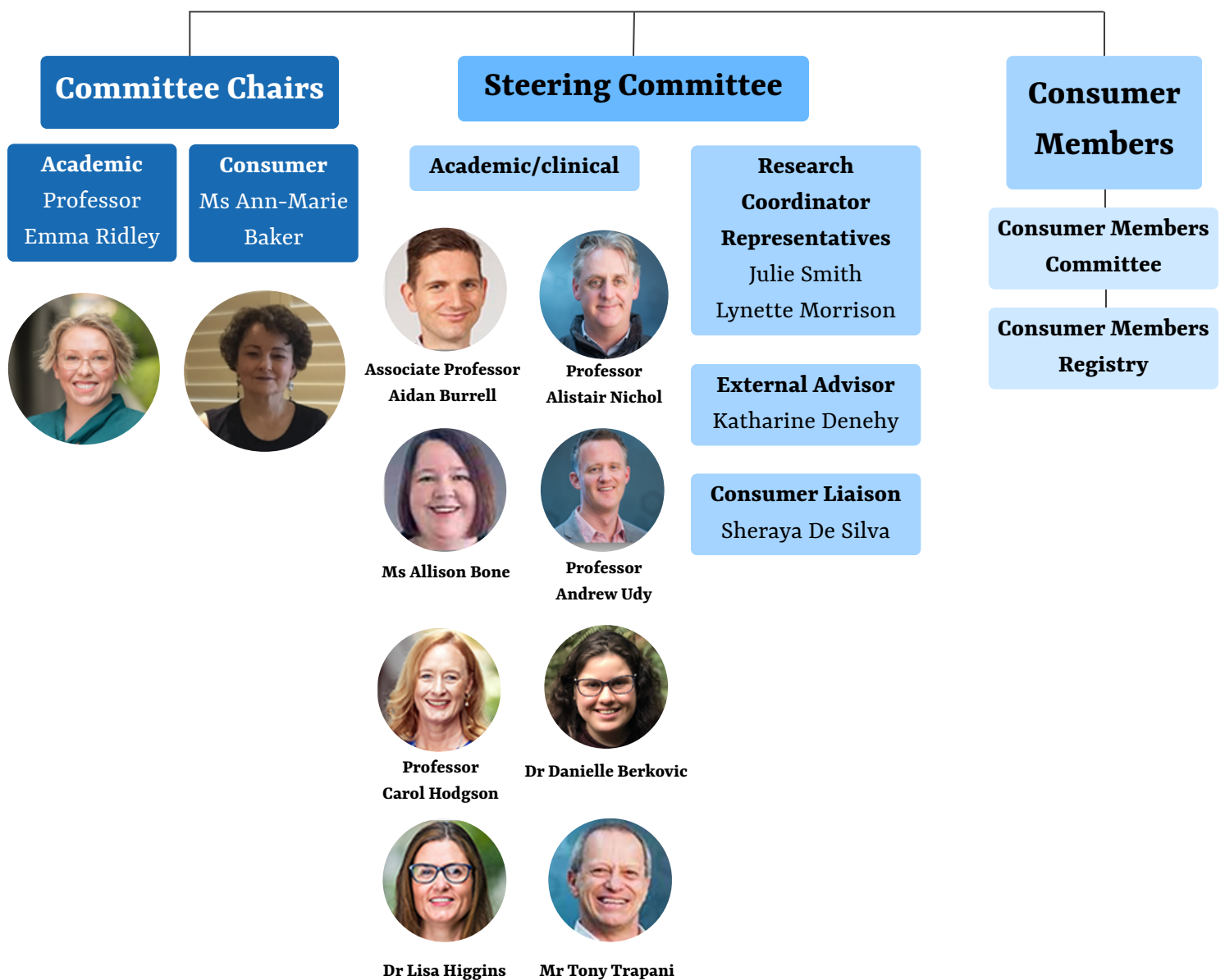
My experience working with the CONNECT team has been quite positive. I believe the engagement and involvement we have as consumers is meaningful and genuine. There have been many opportunities both in and out of meetings to contribute and provide feedback. It was a lovely surprise when I got a birthday message on my birthday and also certificates of appreciation and participation for events and the committee. It was great to contribute to the acknowledgement of lived experience statement as well. It is also a privilege of mine to be involved with writing and providing feedback on the ANZICS Patient and Family Engagement Guideline, which we hope will provide better engagements with patients and families to improve research and quality of care. I also got to be a part of the NUTRIENT Research & Education Meeting and ReDesign Workshop and experienced a World Cafe style meeting for the first time.

Being able to be a part of a community has broadened my perspectives and enabled me to share my experiences. I look forward to more meaningful engagement with the CONNECT team now and in the future.



# CONNECT

## GOVERNANCE AND STRUCTURE



# ABOUT CONNECT



The ANZIC-RC CONNECT is a member registry of keen, interested patients, family members or care givers with lived experience of intensive care who wish to contribute to any aspects of our research activities.

Led by co-chairs Ms Ann-Marie Baker and Associate Professor Emma Ridley, CONNECT intends to facilitate research of the highest quality that is patient-centred, accessible and meaningful to consumers.

## CONTACT INFORMATION

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### WEBSITE

<https://www.monash.edu/medicine/sphpm/anzicrc/community-and-consumers>



*We would to thank the Centre of Research Excellence-ICU (CRE-ICU) for generously supporting the CONNECT initiative through provision of funds.*