



# CONNECT

## NEWSLETTER

**EDITION #2, 2025**

*Transforming ICU Research,  
together.*

An incredible timeline of events so far this year with the Australian and New Zealand Intensive Care Research Centre Consumer and Community Connection Committee (ANZIC-RC CONNECT) Group.

**THIS NEWSLETTER CONTAINS:**

- CONNECT Updates
- Streamlining the CONNECT Process
- Updates on consumer engagement across ANZIC-RC
- CONNECT Consumers Spotlight
- 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

## UPDATES



### **CONNECT Acknowledgement of Lived Experience Statement**

CONNECT developed an Acknowledgement of Lived Experiences Statement, which all ANZIC-RC projects (involving consumer engagement) will incorporate this Statement for presentations, guidelines and more.

### **Consumer Member Committee Meeting APRIL 2025**

We held the first Consumer Member Committee Meeting of this year in April. We were joined by the ANZIC-RC Project Team, who were interested in learning more about the consumer engagement process..



### **ANZICS Patient and Family Engagement Guideline**

The CONNECT Consumer Members are involved in reviewing and writing the ANZICS PFE Guideline for Consumer Engagement, which outlines ways to engage better with patients and families to improve research and quality of care.

### **Updating CONNECT Preliminary Documentation**

CONNECT is currently updating the Terms of Reference and Remuneration Guidelines in alignment with advice and recommendations from our consumers.



### **Updating CONNECT Webpage**

The CONNECT Webpage is currently being updated to include more information and resources. You may visit the webpage at

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

# STREAMLINING CONSUMER ENGAGEMENT

*CONNECT is reaching many researchers across the ANZIC-RC, and requests for working with our consumers is increasing.*

*That's great! But...*

We acknowledge the considerable contribution by consumers in projects across the ANZIC-RC. As we receive more traffic to engage the CONNECT Consumers, we realise that our procedure to link researchers and consumers must be structured in a more streamlined, effective manner so that the consumers do not feel overwhelmed and are well-supported throughout.

Therefore, in alignment with the updated Terms of Reference, CONNECT will introduce guidelines for Grant Writing with Consumers and Undertaking Research Projects with Consumers. These guidelines, which will be reviewed by the CONNECT Consumer Members and the Steering Committee, will detail a step-by-step procedure on how to meaningfully engage with the consumer with consistent communication.

Stay tuned for more updates!



# ANZIC-RC

## CONSUMER ENGAGEMENT

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

The NUTRIENT CCAC is the first dedicated CCAC for critical care nutrition in Australia. It comprises 9 members (among which two members are committee co-chairs), and meetings are held every 3 months (around 4 times annually).

Focus areas include:

- Development and review on the Aftercare Protocol.
- Discussions which have shaped the database for Stream 2 Clinical Data Collection, including areas and gaps that were missed.
- Members providing patient and support persons' experience of nutrition in the ICU and in the Ward.
- Members giving insight on preferences for future studies (such as preferences for primary outcomes and possible research designs).
- How CCAC feedback has shaped the NUTRIENT project so far.



**Stream 1 Nutrition Consumer Aftercare Protocol**

**Background:** The intensive care hospital environment can be a sensitive topic to discuss. It is possible that when reflecting back on their time or experience in these environments, the person with lived experience may feel some distress afterwards.

**Aim:** This protocol has been designed to provide guidance to researchers in the provision of aftercare to consumers. The aim is to minimise the risk of distress and discomfort during sessions, and to ensure that care and follow up are provided to participants after meetings.

#### THE MEAL EXPERIENCE

**Meal Timing:** Meal timing is important, having set meal times can be grounding in the ICU, while more flexible schedules on the ward support recovery. Receiving food on time, particularly with respect to medication (e.g. insulin timing for diabetics), is critical for patient health.

**Receiving what is requested:** Ensuring that patients receive what they've asked for

**Presentation:** Meals that are visually appealing, warm and served in non-plastic dishes improve the dining experience, making meals more appetising and pleasant.

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

The ECMO Patient Advisory Group comprises nine members (of whom eight have been an ECMO patient and one is the wife of someone who has been an ECMO patient). This year has been a busy one, as the group has been highly engaged with the work and oversight of ECMO research at the ANZIC-RC.



The ECMO Survivor Peer Support Group at the EXCEL Registry 2025 Symposium



Two ECMO Patient Advisory Group members shared their lived experience at the EXCEL Registry 2025 Symposium.

- Two members advocated for ECMO in the [EXCEL Registry: The Australian and New Zealand Extracorporeal Membrane Oxygenation \(ECMO\) Registry](#) video.
- One member co-designed the ECMO Survivor Peer Group which was attended by 31 ECMO survivors and their loved ones.
- Two New Zealand ECMO survivors were welcomed into the ECMO Patient Advisory Group.
- All nine members have generously shared their thoughts on the research undertaken at the EXCEL Registry, nutrition studies and rehabilitation studies.

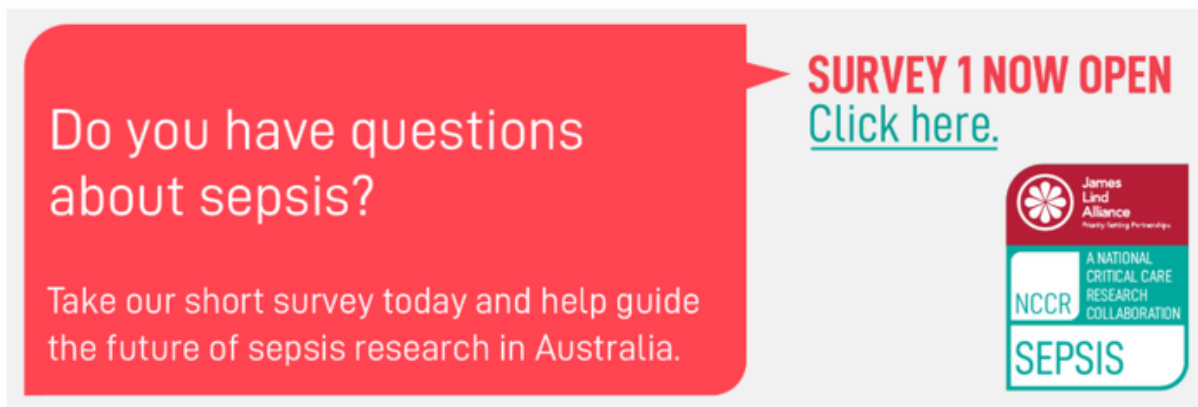
To learn more about the insights of ECMO survivors involved within the EXCEL Registry, please visit <https://www.monash.edu/medicine/sphpm/excel/survivor-stories>

# ANZIC-RC

## CONSUMER ENGAGEMENT

### SHAPING SEPSIS CARE: JLA-PSP

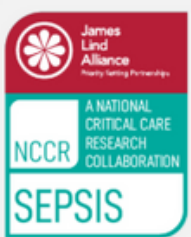
The Shaping Sepsis Care Initiative brings together patients, carers and healthcare professionals to identify and rank the most important unanswered questions about sepsis.



Do you have questions about sepsis?

Take our short survey today and help guide the future of sepsis research in Australia.

**SURVEY 1 NOW OPEN**  
[Click here.](#)



James Lind Alliance  
Priority Setting Partnerships

A NATIONAL CRITICAL CARE RESEARCH COLLABORATION

NCCR

SEPSIS

On the 27<sup>th</sup> May 2025, [Survey 1](#) was launched in collaboration with sepsis survivor AFL Star Sam Taylor from the GWS Giants. The survey can be taken by:

- Adults who have been diagnosed with sepsis
- Family members or carers of someone who has had sepsis
- Healthcare professionals with experience in caring for patients with sepsis

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

To access Survey 1, click [here](#).

# SPOTLIGHT

## CONNECT CONSUMERS



*Fiona Clay*

CONNECT CONSUMER  
COMMITTEE MEMBER

I joined CONNECT when it was first established primarily as a carer to my brother and mother both of whom had extended ICU stays. I am so impressed by the work that was done behind the scenes to establish CONNECT as well as the governance and administration processes. That both Emma and Sheraya are caring, knowledgeable and easy to interact with makes a big difference as my involvement feels seamless and easy.

I am an active consumer representative and aside from CONNECT, I also contribute to the Monash Partners Adult Emergency Care consumer group. I have recently been appointed to the Victorian Government Low Volume, Highly Complex Care Committee.

I have a background in academic research and have been involved in grant development for several years. As a consumer I have participated on grant assessment panels. When I joined CONNECT, I was offered opportunities to help ANZIC-RC researchers (Ary, Aidan, Emma and Ashwini) with their funding applications. The researchers were very receptive to my suggestions for the grant. I was very pleased when the MRFF grant that Ary led was funded and I look forward to contributing to the management steering committee.

To me, consumer engagement is when consumers, carers and the community are not just the subjects of research but active partners at every step of the research journey. Developing meaningful relationships and a shared focus between researchers, clinicians and those with lived experience will I am sure lead to a better understanding of the health condition that led to their ICU stay and improve health outcomes for other patients needing critical care.

# SPOTLIGHT

## CONNECT CONSUMERS



*Jacob Dye*

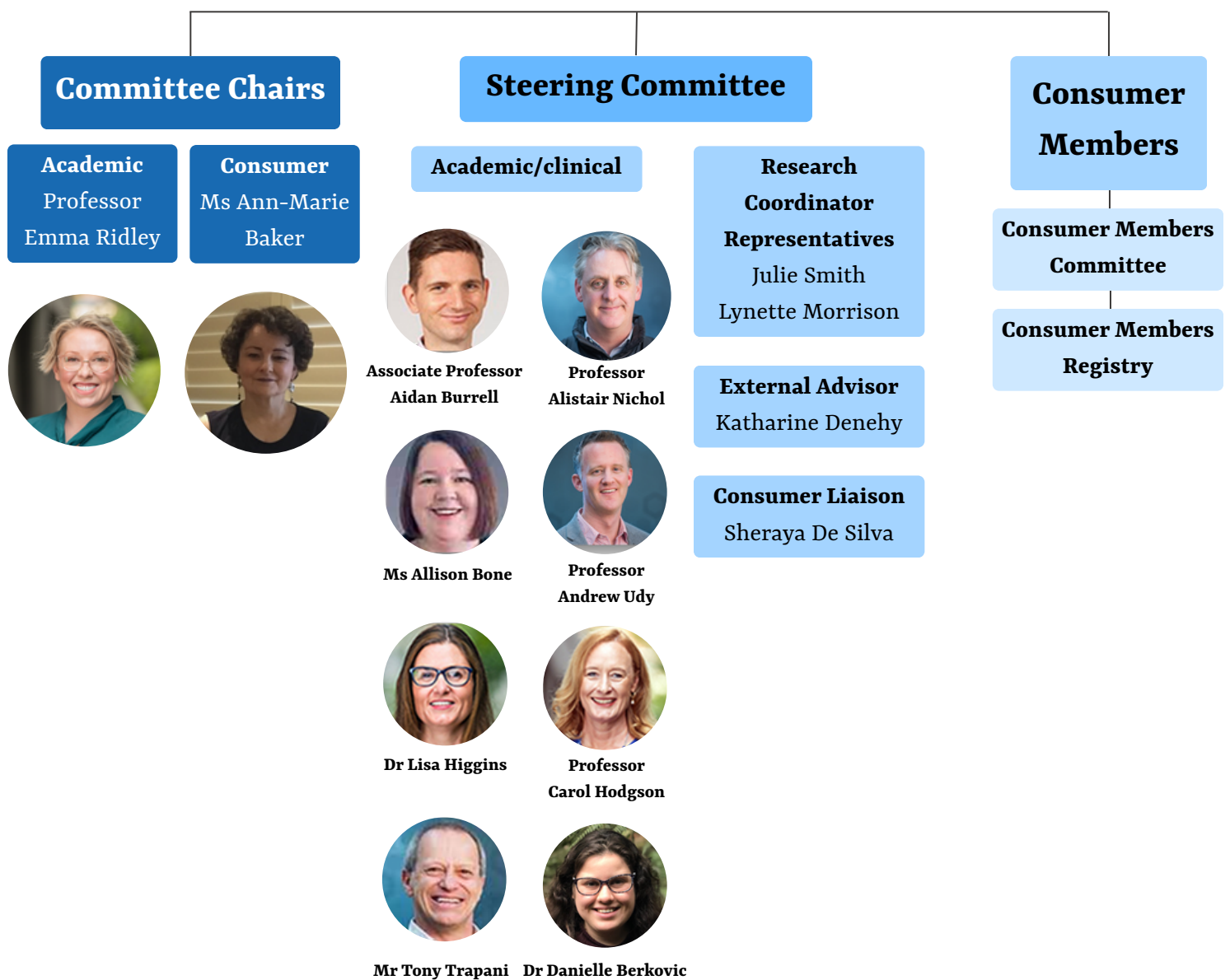
CONNECT CONSUMER  
COMMITTEE MEMBER

Consumer engagement, to me, means building respectful, genuine partnerships with people who have lived experience relevant to the research or healthcare context. As someone who occupies the dual role of both a researcher and a consumer, this approach holds substantial meaning. Experiencing healthcare trauma firsthand has given me a deep, personal understanding of the gaps in care and communication that data alone can't capture. At the same time, my professional background allows me to translate those insights into methodologically sound, impactful research. Bridging these two perspectives has been both challenging and rewarding—it highlights the contrast between traditional academic priorities and the urgent, lived realities of patients and families. Meaningful engagement helps close that gap, ensuring research is not only rigorous but also responsive, accessible, and truly patient-centred.

Working with the CONNECT team has been a collaborative and enriching experience. They create a space where consumer voices are genuinely valued and embedded from the outset, which has strengthened both our research and stakeholder relationships. Similarly, being part of the James Lind Alliance Shaping Sepsis Priority Setting Partnership is a powerful experience. It brings together survivors, families, clinicians, and researchers to identify critical unanswered questions in sepsis care. Hearing these diverse perspectives in real time reinforces my commitment to embedding lived experience into trauma and critical care research in meaningful, ongoing ways.

# 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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AUSTRALIA

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### E-MAIL ADDRESS

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### WEBSITE

[https://www.monash.edu/medicine/sphpm/anzicrc/community\\_and-consumers](https://www.monash.edu/medicine/sphpm/anzicrc/community_and-consumers)