



## Exciting updates and plans for community engagement in medical research

We've been working really hard so far this year to embed community perspectives into medical research.

This year we've had a strong internal focus to **empower our research teams** to create more meaningful and impactful partnerships with you. A key part of this has been **designing and developing tools and resources** to help build the capacity and confidence of our researchers to effectively collaborate with community members. This includes **standardising community remuneration processes** across the School.

We've also been actively **investigating various community advisory panel models of engagement**. Our goal is to find the most effective ways to ensure your valuable insights are integrated throughout the research process, allowing for **broader reach and more diversity of voices**.

## Farewell and Thank You, Ange

I'd like to begin this message by sincerely thanking each of you for your continued contributions to our program. I'm incredibly proud of what we've achieved together — even when the path hasn't always been easy. The speed and quality of our work speaks volumes about the strength of this team.

Today, however, I'm writing with mixed emotions, as we say goodbye to someone who has been truly central to our success — Ange, our community engagement superstar.

It's hard to imagine the program without her. From day one, Ange has been the one laying the groundwork, building strong foundations, and setting the standard for excellence in everything from public communication to program development. She's not only helped build up an exceptional community engagement program,



but also created lasting relationships with researchers, stakeholders, and the wider public — always with clarity, care, and dedication.

Ange, your attention to detail, your passion for the work, and your ability to make things run smoothly behind the scenes have not gone unnoticed. Your presence, your leadership, and yes — even your familiar voice in our recordings — will be deeply missed.

Thank you for everything, Ange. You've left a lasting legacy, and we're all better for having worked alongside you. While we'll miss you, we're also so excited for the next chapter in your journey — your new permanent role is incredibly lucky to have you.

Wishing you every success and happiness in what's ahead!



- The PERSONAL Trial is a randomised controlled trial designed to examine the effectiveness of an artificial intelligence (AI) tool compared to usual clinical practice in selecting first anti-seizure medication (ASM).
- With participants' consent, the trial takes various pieces of information such as age, sex, epilepsy type, and EEG findings, and uses this through the AI program to predict the participant's most effective first-time epilepsy medication.

***"It's a fantastic experience that gives you the chance to contribute to important research and learn new skills and information."***

## **PERSONAL Trial: Artificial Intelligence informed Epilepsy treatments**

For the first time, Australian patients are being prescribed AI-informed epilepsy medication as part of a multi-centre randomised control trial led by neurologist Professor Patrick Kwan at Melbourne's Alfred Hospital and multiple sites nationwide.

***"Epilepsy is notoriously tricky to prescribe for"***  
***Professor Kwan.***

The PERSONAL Trial will continue the development and accuracy of a potential tool that can predict a patient's response to ASM and how well the ASM will work, so physicians can prescribe the most effective first-time treatment to optimise patient outcomes.

Participants who enrol in the trial will be assigned to one of two groups with different procedures that are compared to each other after the trial. Neither the participant nor the doctor reviewing them during follow-up for 12 months are aware of what group the participant is allocated to.

### **PERSONAL Trial Community Advisory Panel**

The community advisory panel assists the researchers in the design and ongoing improvement of the PERSONAL Trial. It is made up of people who are experiencing their own epilepsy journey, and can therefore contribute through lived experience. Additionally, they will bring numerous skill sets to ensure the trial will always be viewed with a community lens.

**Chris Ewert**, lived  
experience community  
advisor to the  
**PERSONAL Trial**.

Visit the trial  
website here

## We are currently looking for new members to join the Community Advisory Panel!

If you are a person with epilepsy, a carer or family member of a person with epilepsy and you are interested in joining the community advisory panel, please email the PERSONAL Trial team:

- **Emma Foster**, [Emma.foster@monash.edu](mailto:Emma.foster@monash.edu)
- **Daniel Thom**, [Daniel.thom@monash.edu](mailto:Daniel.thom@monash.edu)

## Legacy Resources

The health issues centre legacy resources are now available on the Health Consumers Centre website!

It was a big shock and huge loss when the Health Issues Centre announced their doors and services would cease. It's been lovely to follow the journey and development of the Health Consumers Centre, picking up right where the Health Issues Centre had to suddenly stop.

Luckily for all of us, we can now find all the Health Issues Centre's resources in the [Resources](#) section on the Health Consumers Centre website. These resources were created over many years to help healthcare organisations and community representatives build effective partnerships. Many can also be adapted for partnerships outside the health sector.



## Have your say!

Your feedback is needed for the revised Statement on Consumer and Community Involvement in Health and Medical Research.

The **National Health and Medical Research Council** are reviewing the 2016 Statement and have created a new draft based on initial feedback. Now, it's your turn to have a say.

This is a **critical opportunity** to have an impact. As one of the key funding bodies for medical research in Australia, this statement will determine how community engagement in research needs to look, feel and operate for all future awarded grants and research projects.

### You can provide your feedback by:

- Attending an in-person or online roundtable in July 2025.
- Completing the online survey on the NHMRC's Consultation Hub.
- Making a submission (coming soon).

To learn more and register for a roundtable, visit the [Consultation activities webpage](#).

For future updates, subscribe to the **Consumer Statement contact list:**  
[priorities@nhmrc.gov.au](mailto:priorities@nhmrc.gov.au)

[Refer a friend](#)

[Help Us](#)

We encourage participation by all community members impacted by the medical conditions we study.

[Express Interest Here](#)

Expressions of interest to join us, from community members are always welcomed.

Additionally, we are **currently** seeking community representatives to join specific research projects including:

- **Diabetes (T1 & 2) (advisory panel members)**
- **Autoimmune Encephalitis (advisory panel members)**
- **Progressive Supranuclear Palsy and other movement disorders**

[Know someone? Please share!](#)

Our research goals are to work with the community to develop better ways to diagnose, treat, care for and ultimately cure serious health conditions.

[Donate to our CaRE Program!](#)

Some of today's modern research discoveries were only made possible by the support and generosity of donors. Every donation helps our research to progress and create discoveries.

#### **How will my donation be used?**

You can choose how we use your valuable contribution, by either supporting a disease or condition themed area, individual research projects or individual researchers.

All donations of \$2 or more are tax deductible.

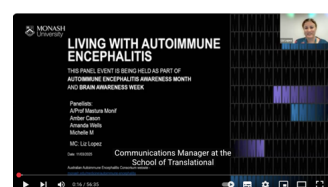
## **Understanding Autoimmune Encephalitis**

### **A webinar exploring personal stories and medical insights.**

For many, it takes a visit to the emergency department suffering from hallucinations or seizures, to discover that they have Autoimmune Encephalitis. This little known autoimmune condition is often mistaken by both clinicians and patients for others which show similar symptoms. A correct diagnosis often happens months or years later, if at all, requiring a specialist neuro-immunology and multidisciplinary input.

In an effort to boost awareness, in March 2025 Assoc/Prof Mastura Monif hosted a free panel event featuring members of the Australian Autoimmune Encephalitis Consortium, including researchers and people with lived experience. Mastura was delighted to invite people living with Autoimmune Encephalitis,

**The webinar was recorded, and you can share it with someone who might be interested or watch it any time here:**



family, friends and carers, health professionals, and researchers across Australia to this free online event which finished with a Q&A.

Follow us on our social channels!

Keep up to date with our latest news, interesting information and engagement opportunities!



### Noteworthy items from the sector...



**We need to engage representative patients' community rather than 'expert patients' to increase impact of research in the era of personalized medicine: Commentary**

In patient engagement, understanding the distinct yet equally crucial roles of **expert patients** and **representative patients** is vital. Paola Zaratin highlights why we need both.

[Read the article](#)



**Before you call it co-design, take the "Co-word fast check"**

In people-centred work, the language we use to describe collaboration often **doesn't match the reality** of how much people are truly involved.

Sue Muller and Morgan Cataldo created this tool to help teams quickly verify the actual level of participation possible in a project before over-committing.

[Try the tool](#)



**Squiggles and spirals: a model linking co-design and improvement science**

Jo Szczepanska and team have developed this visual model of engagement to explain how **co-design and improvement science** (two powerful methodologies) can be combined to offer a robust approach to developing and refining solutions.

[Read the web article](#)

Together we can work towards improved medical outcomes.

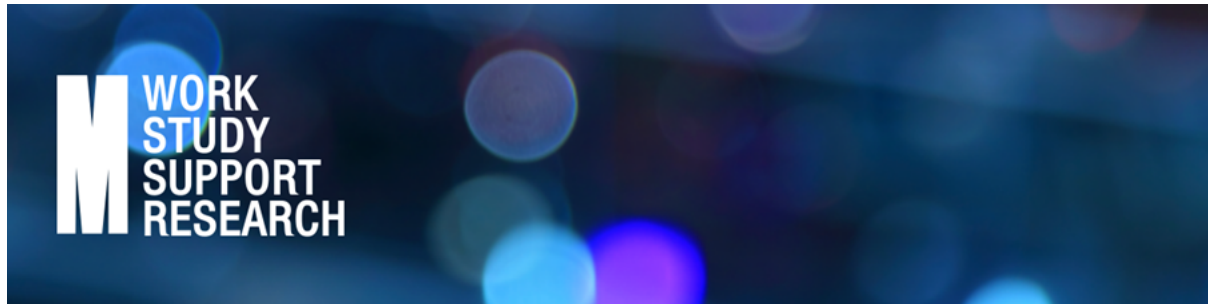
**Associate Professor Karen Alt**

On behalf of the CaRE Committee

Community and Researcher Engagement

School of Translational Medicine

Faculty of Medicine, Nursing and Health Sciences



Copyright © 2020 Monash University ABN 12 377 614 012

Monash University values the privacy of every individual's personal information and is committed to the protection of that information from unauthorised use and disclosure except where permitted by law. For more about Data Protection and Privacy at Monash see our [Data Protection and Privacy Procedure](#). Since the introduction of the General Data Protection Regulation (GDPR), Monash University is committed to improving its processes and systems to support a privacy framework that is consistent with the GDPR approach, and steps towards this transition are well underway. If you have any questions about how Monash University is collecting and handling your personal information, please contact our Data Protection Officer at [dataprotectionofficer@monash.edu](mailto:dataprotectionofficer@monash.edu). To unsubscribe to this mailing list please email [stm.care@monash.edu](mailto:stm.care@monash.edu).