



Looking back to move forward

"Since we began the program has been continually developing. With the help of an amazing and inspirational team, we have gone over and above all our original expectations. I am very proud to lead this program and I can not wait for what comes next."

Dr. Karen Alt, Chair and Co-Founder of CaRE

We have been measuring and evaluating the impact of the CaRE program, and we wanted to share our findings with you!

CCS Community and Research Engagement

Recruited and screened 44 consumers



3 community members listed as Associate Investigators



Representation of 17 unique illnesses



Established 12 Research Partnerships



Interest from 22 CCS research projects



Community contribution to at least 6 grant applications



Completing our first evaluation was a long and challenging exercise. However the effort was all worth it as we can follow the blue print for future years, AND it has given us a lot of useful information we will use to set the plan for the coming year.



100% of researchers would recommend the CaRE program to other researchers



83% of community members reported an increase in knowledge about their medical condition since being paired with a research team.



86% of researchers reported a positive change in their own perception to consumer engagement in research since joining the program

The **program wide evaluation** reviewed the period from 31 March 2021 until 31 March 2022 and showed us that the CaRE program achieved and surpassed its original objective - to establish a mechanism to pair and support researcher-consumer partnerships, so that researchers could take in account consumer experiences. Originally founded in the [Australian Centre for Blood Diseases \(ACBD\)](#), the program is now available to all researchers at the [Central Clinical School \(CCS\)](#).

The reputation and excitement of the program has spread to the extent that we have even received requests for consumer engagement support from beyond the CCS! We look forward to a time when the program will be able to service our entire faculty.

The CaRE program has moved from an establishment phase into a consolidation and improvement phase, which is why this evaluation is critical to the future success of consumer engagement at the CCS. We learned that the program is certainly creating a positive impact at CCS, and is meeting its purpose; however, as the evaluation indicates, with more resources CaRE can be more effective and impactful by providing even more support and guidance to both our researchers and community members.

A final note, thank you to all of you who completed the surveys we circulated earlier this year. Your

personal responses were very insightful and we can not continue to grow and improve without your input!



**Understanding the genetic lesions in
Myeloproliferative neoplasms (MPNs) can transform
diagnosis, prognosis and treatment**

Date: Thursday 13 October

Time: 6 - 7.30 pm

Venue: The Betty & John Laidlaw AO Alfred Innovation & Education
Hub, The Alfred Hospital, 75-85 Commercial Road, Melbourne

FREE EVENT

**Myeloproliferative Neoplasms –
Towards Precision Medicine**

The Community and Researcher Engagement Committee at the Central Clinical School in the Faculty of Medicine, Nursing and Health Sciences, Monash University is delighted to invite you to this public Hybrid meeting.

Please join us as Prof Perkins and Mr Young discuss the role of genetics and new therapeutic options in MPNs, and how medical staff, researchers and the MPN community can work together towards precision diagnostics for MPN patients.

Prof Jane, Foundation Dean, Sub-Faculty of Translational Medicine & Public Health, Director of Research, Alfred Hospital will host this engaging event.

Register to attend in person or the webinar.



Have you, or a loved one, experienced Bowel (Colorectal) Cancer?

Are you interested in research into Bowel Cancer?

We are currently taking expressions of interest for people to work in a research partnership with [Dr. Joseph Kong](#), who have personal experience (patient or carer) with bowel cancer.

Express Your Interest

Please note this is not an invitation to join a clinical trial

Help us connect lived experience of bowel cancer with research

Bowel cancer (colorectal cancer) is the 4th most diagnosed cancer and the 2nd most common cause of cancer-related death in Australia. Surgery remains the cornerstone of curative treatment for bowel cancer. But despite removing all visible cancer tissue during surgery, bowel cancer can return in every 4th patient. The recurring bowel cancer is commonly resistant to further treatment and consequently patients are unlikely to survive.

The Colorectal Cancer Immunology Laboratory has just commenced at the Central Clinical School and is aiming to develop a test to identify patients whose bowel cancers are likely to come back and to explore new therapies to reduce their risk of recurrence.

This is a **volunteer opportunity**, however out of pocket costs related to the research partnership may be reimbursed.

You will **attend a 2 hour meeting every 3 months (in person or online)** to hear updates and provide your feedback, share your experiences and opinions. You will also be asked to review project plain language documentation and contribute to Human Ethics applications. There may be further opportunities for you to work with the research team. **This project is just starting, so it is great opportunity to get involved and help define the research project from the outset!**



A team from our Department of Neuroscience, including one of our CaRE Researchers A/Prof Bridgette Semple, recently published a study in the scientific journal *Epilepsia*:

"Incidence and risk factors of post traumatic epilepsy following paediatric traumatic brain injury: A systematic review and meta-analysis."

[Read the article](#)

New Paper Alert!

Post-traumatic epilepsy is a disabling chronic complication following traumatic brain injury (TBI).

Despite some evidence that age at the time of injury may influence the likelihood of post-traumatic epilepsy, the incidence of this condition in paediatric populations remains unclear.

In this systematic review, the researchers evaluated the available published literature from around the world (almost 5000 patients from 19 studies) to determine that the overall reported incidence of post-traumatic epilepsy after paediatric TBI is 10%.

Additional analyses revealed potential risk factors associated with the development of epilepsy in this population - the occurrence of early post-injury seizures, sustaining a severe TBI, and intracranial hemorrhage were all factors that increased the risk of post-traumatic epilepsy. This study demonstrates that post-traumatic epilepsy is a significant chronic complication after childhood TBI, similar to in adults, and highlights the need for further investigation into the condition.

We're on Twitter!

Keep up to date with our latest news, interesting information & meet the team!

[Tweet with Us!](#)



The complimentary memberships will provide access to upcoming workshops, new research and training tools, such as our Healthy Ageing Data Platform, news and events.

[Visit the National Centre for Healthy Ageing](#)

Monash University is thrilled to launch our Australian-first residential aged care research network, RACReN!

Become a network member!

Bringing together expert researchers and key residential aged care stakeholders, RACReN will work collaboratively with industry to identify quality improvement gaps and priorities to inform research that will help address some of the greatest challenges facing our ageing communities.

You can become a member if you are involved in residential aged care as a resident, friend or carer of a current or former resident, provider, nurse, PCA, support staff, clinician, GP, allied health professional, funder or policy maker, or anyone interested in aged care research.

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

We are currently seeking community representatives to join specific research projects.

[Sign Up Here](#)

Your ideas really matter

Your ideas and feedback are the best way for us to improve. They will tell us how we can continue to build the best possible consumer engagement program.

[You can give feedback at any time!](#)

Together we can work towards improved medical outcomes.

Ange and the CaRE Committee

CaRE Program, Central Clinical School

Faculty of Medicine, Nursing and Health Sciences



MONASH
University

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YEARS OF
MAKING
CHANGE

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