

AUSTRALIAN REAL WORLD CANCER EVIDENCE NETWORK (PAN CANCER INITIATIVE)

MAY 2025 NEWSLETTER

CALL FOR LIVED EXPERIENCE CONTRIBUTORS

The overwhelming interest in our lived experience engagement as part of Work Package 1 has highlighted just how important this initiative is to patients, caregivers, and families. In response, we are establishing a network of lived experience voices who are interested in contributing to future aspects of the Pan Cancer initiative.

This is a valuable opportunity for individuals to shape meaningful change across cancer care in Australia. If you or someone you know would like to be involved, we encourage you to express your interest [here](#).

DELPHI RESEARCH TEAM ESTABLISHED

We're pleased to share that the research team supporting the Delphi process has now been established. This team brings together a diverse group of experts with deep experience in cancer care, outcomes measurement, and the use of patient-reported measures.

In forming the team, we carefully considered not only the relevant skillsets, but also geographical representation and inclusion of voices connected to priority populations – particularly those from rural and regional areas, and Aboriginal and Torres Strait Islander communities. This diversity is critical to ensuring that the resulting Core Outcome Set is both scientifically robust and grounded in real-world relevance.

This collaborative effort will help shape a nationally endorsed Core Outcome Set that elevates the voice of people affected by cancer and supports more responsive, equitable, and person-centred care.

The Research Team:

- **ACT:** Emily Symons, Kellie Browning
- **NSW:** Carolyn Mazariego, Haryana Dhillon, Claudia Rutherford
- **QLD:** Natasha Roberts
- **SA:** Imogen Ramsey, Bogda Koczwara, Michael Osborn, Hannah Freeman
- **TAS:** Jessica Roydhouse, Louise Nott
- **VIC:** Huw Rees, Sarah Weller, Sibilah Breen, Sandra Nolte, Julia Lai-Kwon
- **WA:** Christobel Saunders, Susan Hayes

LATEST UPDATES:

- We successfully launched our first Quarterly Virtual Update on 27 May. Attendance was strong with 48 attendees, and it provided an opportunity to share a more detailed update and respond to questions and comments from across the sector.
- Ethics approval has been granted by the Flinders University Human Research Ethics Committee, enabling further progress on key research components of the initiative.
- The most recent Steering Committee meeting focused on embedding lived experience across all aspects of the initiative to ensure that patients' voices are at the heart of our work. Discussions centred on recruitment of an advisory group, and the inclusion of lived experience representatives on the Steering Committee. Stay tuned for updates and upcoming opportunities to get involved.
- The PRM Advisory Group is currently reviewing the first draft of a literature review and a draft of the Round 1 Delphi survey that will be distributed to participants, both developed by Dr Imogen Ramsey and the Flinders University team.

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SECTOR AND LIVED EXPERIENCE ENGAGEMENTS – SUMMARY OF INSIGHTS

Who We Heard From

We were privileged to hear from over 97 people with lived experience (PWLE) of cancer, including:

- 24 participants in focus groups;
- 29 participants in one-on-one interviews; and
- 44 participants via survey.

This group included individuals from all states and territories, covering a range of demographics including First Nations (21%), LGBTQIA+ individuals (27%), and people from culturally and linguistically diverse backgrounds (8%).

In parallel, we also engaged with more than 120 sector stakeholders from across Australia, participating in 13 dedicated workshops. Attendees represented clinical trials, clinical quality registries, government agencies, peak bodies, allied health, First Nations organisations, private industry, and others.

What We Heard From People With Lived Experience

First Person Consulting have drafted their report on the engagement, titled *Just Ask: How Are You Feeling*. The report highlighted a clear message: PROMs have the potential to make a meaningful difference when they are done thoughtfully, respectfully, and holistically.

- Mental health and wellbeing must be a central part of any core outcome set.
- People want flexibility in how and when they complete PROMs and PREMs – for example, paper vs. online, verbal vs. written, early vs. later in treatment.
- Most had never heard of PROMs/PREMs, despite going through cancer care – highlighting a need for greater awareness and communication.

What We Heard From The Sector

Across 13 workshops, cancer sector experts provided deep insights into the domains of greatest importance and the systemic barriers to collecting and using patient-reported data effectively.

Key priorities for PROMs included:

- Quality of life (physical, psychological, social)
- Pain, fatigue, cognitive function, sexual health
- Financial toxicity and family/carer impact

For PREMs, the most valued areas were:

- Information, communication, coordination of care
- Cultural safety and responsiveness
- Support, inclusion, and person-centred care

However, challenges remain. Barriers such as digital literacy, language access, integration with clinical workflows, and data privacy were raised repeatedly. Encouragingly, the sector also pointed to enablers like education and training, strong clinical leadership, and the importance of embedding PROMs and PREMs into existing governance structures and IT systems.

Thank you to everyone who shared their time, stories, and expertise. Your voice is driving the direction of this work. The reports are being finalised and will be shared on the Pan Cancer website in the coming months.



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BUILDING A NATIONAL PLATFORM TO COLLECT PRMS

Work Package 2 continues to make strong progress in developing a secure, national digital platform that enables cancer patients to share information about their health, experiences, and outcomes in a simple, streamlined way. This involves collecting both PROMs and PREMs – critical information that helps the health system better understand how care is delivered and how it affects patients' lives.

At its core, the platform is designed to make it easier to collect electronic PROMs and PREMs from patients across Australia. Patients can complete questionnaires online in their own time, and their responses are sent directly – and securely – to the relevant clinical quality registry database. Importantly, the platform itself does not store any patient data but instead acts as a secure intermediary, helping to transfer information safely between the patient and the registry.

Originally built for prostate cancer, the platform is now being expanded to support multiple cancer types, allowing for customisation based on the needs of each registry. So far, we have hit a number of milestones, including a rebuild of the platform Application Programming Interface (API) and survey tools, ensuring Fast Healthcare Interoperability Resources (FHIR) compliance.

If your registry or organisation is interested in joining the platform or learning more about how it works, we encourage you to get in touch.

DISCOVERY WORK KICKING OFF FOR BENCHMARKING AND DATA AUTOMATION

Work will soon kick off on two foundational elements of the Initiative. These efforts represent vital steps in supporting sustainable, high-quality use of patient-reported measures in cancer care.

Work Package 3: National Benchmarking

We are currently preparing to go to market to commission a discovery phase to inform the development of a national benchmarking platform for patient-reported outcomes and experiences. This discovery work will explore governance models and current practices in Australia and internationally and identify the requirements needed to support meaningful benchmarking across regions and cancer types. It will also examine adoption barriers and enablers to ensure the platform's long-term relevance and impact.

Work Package 6: Data Automation

In parallel, we are progressing plans to initiate a discovery phase for Work Package 6, which focuses on identifying opportunities to streamline and automate data collection across the Pan Cancer CQRs. This work will map the current data environment, engage key stakeholders across the cancer and digital health ecosystem, and assess the feasibility of various automation technologies. The resulting roadmap will guide future implementation of more efficient and sustainable data capture strategies across cancer registries.

These will be led by external providers with deep expertise in stakeholder engagement, digital health systems, and strategic delivery. If you are aware of any vendors or organisations with the right expertise to undertake this type of work, please don't hesitate to reach out to us via email (pancancer@movember.com).

CONTACT US:

Got a question? Want to join the consortium? Visit our website at www.pancancer.movember.com or send us an email at pancancer@movember.com.