

# AUSTRALIAN REAL WORLD CANCER EVIDENCE NETWORK (PAN CANCER INITIATIVE)

MARCH 2025 NEWSLETTER

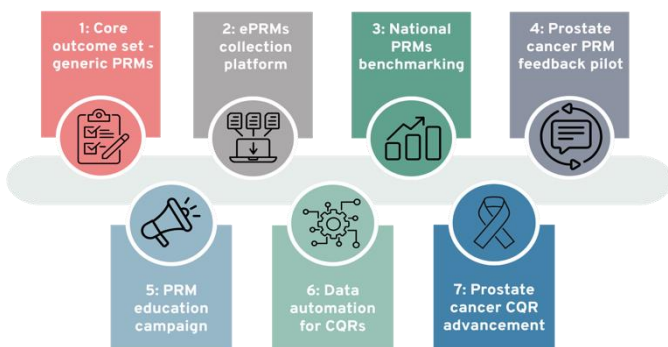
## OFFICIAL WEBSITE LAUNCH:

We are delighted to share that we have recently **launched a website** dedicated to the Pan Cancer Initiative.

The purpose of the website is to update visitors on the progress of the initiative, provide further information on initiative activities, engagements, and strategies, as well as offering a means for visitors to get involved in the initiative.

Check out [www.pancancer.movember.com](http://www.pancancer.movember.com) for further information.

## THE 7 WORK PACKAGES OF THE PAN CANCER INITIATIVE:



## LATEST UPDATES:

- We have made significant progress through February and March into our **lived experience and sector engagement** work, in turn setting great foundations for **Work Package 1**.

To advise on the activities of Work Package 1, we are very privileged to have an **expert advisory group**, consisting of:

- Dr Imogen Ramsey, Flinders University
  - Prof Bogda Koczwara, Flinders University
  - Prof Claire Snyder, Johns Hopkins University
  - A/Prof Sandra Nolte, Monash University
  - Dr Carolyn Mazariego, University of New South Wales
  - Emily Symons, Cancer Australia
  - Sarah Weller, Movember
- The Pan Cancer Initiative recently **stood up its Steering Committee**. Reporting to the initiative Executive Committee, the groups expertise will oversee and coordinate activities to drive innovation and impactful change in patient-centred cancer care.
- The first meeting, held on 6 February, focused on the purpose and implementation of national benchmarking for patient-reported measures (PRMs). The Committee is made up of representatives from across the cancer sector, including state and federal health departments, research, clinical practice, clinical quality registries and other experts.
- The development of **Work Package 2** is well underway, and we will soon start work with stakeholders around onboarding them.
  - Over the next few months we'll undertake sector engagement for **Work Package 3**, to work to identify the needs and priorities of a national benchmarking platform.

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- We will soon also be conducting a discovery piece for **Work Package 6** to help us understand the data automation requirements for CQRs. Detailed requirements are currently being explored by the Steering Committee.
- The Pan Cancer Initiative is hosting **workshops for Cancer Clinical Quality Registries (CQRs) to explore their role in the project**. Registry investigators and staff can attend either the 31 March or 9 April session.

The workshops will focus on CQR information needs, barriers, and enablers related to patient-reported measures (PRMs), the use of an ePRMs platform, and benchmarking practices. Attendees will gain a clearer understanding of how they can engage with the Pan Cancer Initiative work packages and contribute to improving cancer care outcomes. If you are part of a cancer CQR and would like to attend the workshop, get in touch.



## WORK PACKAGE 1:

### Developing a Core Outcome Set for Cancer Care

Patient-reported measures (PRMs) are essential for improving cancer care, but implementation remains inconsistent across Australia. The lack of a nationally coordinated approach and standardised guidance limits benchmark reporting and comparison of outcomes.

To address this, we will develop a Core Outcome Set (COS) – a consensus-driven list of essential outcomes and experiences for clinical cancer care. By standardising data collection, this initiative will enhance patient-centred care, support national benchmarking, and inform health service planning and policy decisions.

After the COS has been selected, a recommendation on a set of PRMs to be collected across cancer care in Australia will be published.

### Lived Experience Engagement

Between January and February, First Person Consulting (FPC) engaged 53 people with lived experience through focus groups and one-on-one interviews across metropolitan, regional, and rural areas in all states and territories. Participants included those who have been diagnosed with cancer, carers of those with cancer, and those who had lost a loved one to cancer.

Encouragingly, the team was able reach people from diverse backgrounds, with over half of those consulted coming from priority populations, including Aboriginal and Torres Strait Islander peoples, multicultural communities, and the LGBTIQ+ community, with a diverse mix of genders represented.

Further consultation with additional stakeholders will be undertaken with a short survey, further enriching insights to inform the development of a nationally agreed COS of PRMs.

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## Cancer Sector Engagement

Building off the insights gained from the pre-conference workshop held at the COSA ASM in November 2024, engagement with the cancer care sector is ongoing. Movember and Cancer Australia, together with Aspex Consulting, have convened 13 workshops with more than 150 healthcare practitioners, researchers, and policymakers.

Our aims are to identify the most important and relevant outcomes and experiences for cancer care, as well as exploring considerations for implementing PRMs nationwide. Emerging themes from the workshops include domains related to quality of life, symptoms, emotional wellbeing, financial distress, and being involved in the decision-making process.

These collaborative approaches are a significant step toward achieving the goals of the Australian Cancer Plan and embedding PRMs into cancer care nationwide. We look forward to continued engagement with the sector and lived experience community, to ensure that cancer care in Australia is informed by those it impacts most.

## COMING SOON:

### The Delphi consensus process

A Flinders University team, led by Dr Imogen Ramsey, will use a modified Delphi methodology to achieve consensus on a core set of outcomes and experiences, most important and relevant for collection across all cancer types in the Australian healthcare sector.

This process builds on foundational work conducted with lived experience and sector engagement, ensuring input from a diverse range of stakeholders. The ethics application will be submitted in March, with invitations for the first Delphi round expected to be circulated in May.

**Further information about our activities across the other Work Packages will follow in subsequent newsletters.**

## CONTACT US:

Got a question? Reach out to us via email at [pancancer@movember.com](mailto:pancancer@movember.com).

