

AUSTRALIAN REAL WORLD CANCER EVIDENCE NETWORK (PAN CANCER INITIATIVE)

APRIL 2025 NEWSLETTER

JOIN US FOR THE PAN CANCER INITIATIVE VIRTUAL UPDATE:

The Pan Cancer Initiative has made significant strides over the past few months, and we have been exploring ways to share key updates with you while also providing a forum for questions and key considerations about the project. We are delighted to share that we will be hosting a **Quarterly Virtual Update**. The first of these sessions will be held on **27 May 2025**.

From broad sector-wide engagement and valuable lived experience insights to progress on national data collection and benchmarking, these sessions will provide a **comprehensive look at how the initiative is shaping the future of cancer care in Australia**.

This is your opportunity to stay informed, ask questions, and ensure your voice is part of the conversation. Don't miss the chance to connect with key stakeholders and hear directly from those leading the work. **Register [here](#) to secure your spot and be part of this important update!**



LATEST UPDATES:

- An ethics application has been submitted for the Delphi process. Given the **low-risk nature** of the methodology, we do not anticipate significant hurdles in obtaining clearance. The team is preparing for the **first-round survey launch in late May or early June**.
- Our **lived experience and sector engagements** for WP1 (Core set of PROMs and PREMs) have now been completed and we are awaiting the outcome reports. These consultations provided **valuable insights** into the outcomes and experiences considered most important, as well as the **challenges of implementing PROMs and PREMs**.
- We have now concluded the first round of **workshops with the clinical quality registries** involved in the Pan Cancer initiative. These sessions focused on **PRM collection and use in CQRs**, as well as defining the **critical requirements for a national ePRM collection platform**.
- The Steering Committee have now agreed upon the **objectives, key activities, and deliverables** for the Discovery Phase of WP6: Data Automation. A **brief has been drafted and will be distributed to the market**, ensuring a competitive process for securing a vendor to complete this **vital discovery phase**.
- The **ePRMs collection platform**, being developed by Movember as part of WP2, has successfully received **ISO27001 certification**. This milestone ensures that **data collected on the platform meet top-level security standards**, reinforcing trust in the product. While certification applies to the platform, it is **dependent on Movember-wide processes and systems** to maintain compliance.

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DEFINING CORE OUTCOMES FOR CANCER CARE – JOIN THE DELPHI PROCESS

As part of our commitment to **advancing patient-centred cancer care**, we are inviting key stakeholders to participate in a Delphi consensus process to define a **nationally agreed Core Outcome Set**. This work is essential to ensuring the systematic collection of meaningful patient-reported outcomes and experiences **across all cancer types**, supporting high-quality care and equitable health outcomes.

If you have **expertise or lived experience in cancer care**, we encourage you to take part. The process involves completing **a number of short online surveys**, helping to shape the future of cancer data collection in Australia.

Register your interest [here](#) to contribute to this critical initiative.

ESTABLISHING ADVISORY GROUPS FOR NATIONAL BENCHMARKING AND DATA AUTOMATION

We are establishing Advisory Groups to help guide the activities of **WP3: National Benchmarking** and **WP6: Data Automation**. These Groups will play a vital role in shaping the development of benchmarking frameworks and advancing automation solutions, ensuring that our approach is robust, technically sound, and aligned with national priorities.

WP3: National Benchmarking Advisory Group

A national benchmarking platform will be developed to visualise and compare patient-reported outcomes and experiences across cancer types and regions.

The National Benchmarking Advisory Group will provide guidance on the selection and standardisation of benchmarking indicators, data governance and privacy considerations, strategies for sector-wide engagement and alignment with existing national initiatives.

To achieve this, we seek input from **data experts, health informatics specialists, clinicians, policy representatives, consumer advocates, and Indigenous Data Sovereignty experts**.

WP6: Data Automation Advisory Group

Streamlining and automating data collection are critical efforts in reducing administrative burden and improving real-time insights for clinical quality registries in cancer care. This Advisory Group will guide efforts by advising on current data sources and interoperability challenges within clinical quality registries, opportunities for automation, including AI-based extraction and data linkages, and barriers to scaling automation across multiple registries.

Proposed members will include **CQR leads, data managers, IT and digital health experts, and government and policy representatives**.

If you are interested in contributing to either of these groups, get in touch with us at pancancer@movember.com.



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A PATIENT-CENTRED FEEDBACK TOOL FOR PROSTATE CANCER (WP4)

One thing that has become abundantly clear to us throughout our engagement with both the sector and lived experience is the absolute **need for PRO data to result in action** – ensuring that patient-reported outcomes are not just collected but **actively used to improve care**. Without meaningful application, this data risks becoming a passive exercise rather than a tool for change.

WP4 is focused on addressing a particular set of unmet needs: developing a resource that enables patients to input information about themselves and receive feedback that contextualises their health outcomes in relation to **prostate cancer data**. Our goal is to create a tool that not only provides unique feedback but also helps patients engage more effectively in discussions about their care. By benchmarking PROs against broader data sets, this resource could give individuals a clearer picture of what to expect post-treatment and where they might seek further support.

Beyond comparisons, we also aim to integrate tailored recommendations to ensure that patients can act on their results. Equally important is ensuring that this tool is usable and valuable to clinicians. It has the potential to support informed decision-making by providing structured, evidence-based insights that can guide conversations between patients and their healthcare teams. By embedding best-practice approaches to data interpretation, we hope to create a resource that enhances – not complicates – the way patients and clinicians navigate prostate cancer care together. If successful, this model could also be scaled to other tumour types to broaden the potential impact of this resource.

We are seeking input from key stakeholders across the prostate cancer community to ensure that this resource is both relevant and effective. We want to better understand what gaps currently exist and how we can make this tool as practical and impactful as possible. **If you have expertise in this space, we welcome your insights to help shape the direction of this work.** Email us at pancancer@movember.com

STEERING COMMITTEE MEMBERSHIP:

The Steering Committee plays a crucial role in **overseeing and facilitating the execution of activities** and tasks within the designated work packages. Its primary purpose is to ensure alignment with the strategic objectives and overall mission of the Pan Cancer Initiative. The Committee meets monthly to **guide progress, discuss key developments, and ensure that all work packages remain on track** to achieve their goals.

Membership:

- **Movember** – Sarah Weller, Sibilah Breen, Huw Rees
- **Cancer Australia** – Adam Lambert, Emily Symons
- **Department of Health and Aged Care** – Kellie Browning
- **Monash University** – Nikolajs Zeps, Erica Wood
- **Curtin University** – Fraser Brims
- **Peter MacCallum Cancer Centre** – Julia Lai-Kwon
- **Commission on Excellence and Innovation in Healthcare** – Michael Osborn
- **Cancer Council Victoria** – Sue Evans
- **Cancer Alliance Queensland** – Danica Cossio
- **Australian Institute of Health and Welfare** – Amy Young
- **University of Queensland** – Gail Garvey

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.