



Australian Government



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AUSTRALIAN REAL WORLD CANCER EVIDENCE NETWORK (PAN CANCER INITIATIVE)

JUNE 2025 NEWSLETTER

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TRANSFORMING CANCER DATA COLLECTION ACROSS AUSTRALIA

In last month's newsletter we shared the progress Work Package 2 (WP2) is making in the development of a secure national platform for the electronic collection of patient-reported outcome and experience measures (PROMs and PREMs) from cancer patients across Australia. This month we're excited to share how the national ePRMs platform will transform cancer data collection across Australia.

The Challenge

Feedback at our recent workshops with Clinical Quality Registries (CQRs) revealed shared challenges facing cancer registries across Australia. Technical hurdles dominate the landscape – from resource constraints for IT support and data management to substantial setup and maintenance costs. Patient engagement with and completion of PRMs remains equally challenging, with registries reporting limitations in accessible email addresses, compounded by digital communication distrust, and the need for culturally appropriate services for diverse populations.

The Opportunity

The workshops also highlighted the tremendous potential realised when these barriers are overcome. These include operational advantages of automated systems integrating into workflows and the patient benefits of mobile-compatible, user-friendly platforms. This is precisely the

collaborative challenge the national ePRMs platform is designed to address: building upon strong foundations to systematically tackle technical and engagement barriers that limit broader adoption of PRMs in the cancer sector.

The Collaborative Solution

Movember has developed and refined a secure, **national digital platform** that is scalable across cancers and has successfully collected PROs via the Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR-ANZ) since September 2023. Participants receive personalised email invitations to complete their EPIC-26 questionnaire with a unique secure link which provides immediate access whilst offering the flexibility to save progress and return later. Once completed, responses flow directly into the registry database, whilst automated reminder protocols optimise completion rates.



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The national ePRM platform approach centres on three fundamental principles:

Fully Supported CQR Integration

- A dedicated team will provide comprehensive implementation support, including training and ongoing technical assistance, addressing local resource constraints.
- Organisations maintain complete independence with a dedicated platform instance, ensuring absolute data sovereignty.
- CQRs have full control of protocol parameters (e.g. questionnaire selection, PRM timing, participant communications and branding)
- The platform's design supports extensive question formats, including multiple choice, Likert scales, free text responses and conditional branching logic.
- The flexible architecture supports integration with existing registry databases (e.g. Redcap)

Future-Ready Technical Architecture:

- Built with FHIR compliance and ISO-27001 certification, ensuring alignment with evolving digital health standards and maximising interoperability with other health data systems.

Inclusive Accessibility:

- Applying Web Content Accessibility Guidelines (WCAG), enables diverse participation. Features include screen reader compatibility, keyboard-only navigation and cognitive load reduction strategies.
- The platform can support multilingual questionnaire delivery and culturally appropriate communication protocols.

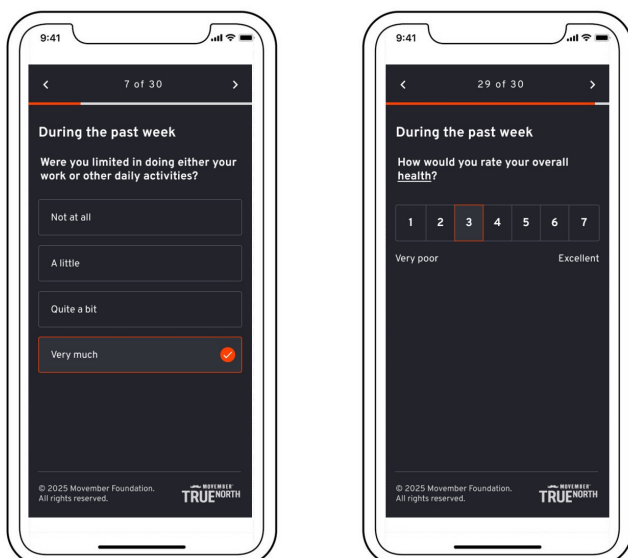
Join the Conversation

In July we will be inviting the Pan Cancer CQRs to participate in dedicated engagement sessions. These collaborative discussions will explore how the national ePRMs platform can support specific registry objectives and provide clarity on the timelines for the implementation of this platform.

Work Package Two provides an opportunity to collectively strengthen Australia's real world cancer data enabling improved patient care and outcomes

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.



Prototype of EORTC-QLQ-C30, in mobile view