

Patient-reported outcomes (PROs) as personalised cancer care: report from a 2023 Australian consensus meeting (PROActive)

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Summary

This viewpoint reports on the outcomes of the 2023 Australian interest holder meeting on the use of patient-reported outcomes (PROs) in cancer care and discusses its findings in the context of the significant national investment into the collection of PRO data in Australia. The interest holders emphasised the importance for PRO data collection to be relevant to the care of individual patients and personalised to their needs and preferences to ensure direct impact on patients' care and outcomes. They also prioritised the coordination and integration of various PRO collection efforts to improve patient outcomes and care quality.

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"Collecting data for data's sake doesn't help me. How can my answers be used, or will be used, to benefit me?"
PROActive workshop participant

Introduction

Patient-reported outcomes (PROs), involving collection of self-reported health status data collected directly from patients, are increasingly recognised as an important part of clinical data collection that has the potential to improve patients' outcomes.^{1,2} There is level-1 evidence that PROs monitoring at the point of care in cancer improves patient satisfaction, overall

well-being, quality of life, treatment compliance, survival, and reduces emergency department presentations.^{1,3-12} Despite this, their use has not yet been routinely adopted into practice. Barriers to the implementation of PROs have been identified across all levels of the health system (i.e., individual, service, system, policy) and relate to resourcing constraints as well as practice behaviours.¹³

The 2023 Australian Cancer Plan (ACP) prioritised embedding collection of PROs into national quality of care monitoring efforts.¹⁴ At the Plan's announcement in November 2023 Cancer Australia in partnership with the Movember Foundation pledged \$22 million towards establishing the Australian Real World Cancer Evidence Network. This joint funding commitment aims to develop a core outcome set and national platform for

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collecting PROs and benchmarking outcomes and experiences.¹⁵ This platform is planned to predominantly be used for reporting and monitoring the quality of cancer care.

Immediately preceding the launch of the ACP, the Clinical Oncology Society of Australia's PROs Working Group held a national workshop of health, policy, and technical professionals, cancer survivors, and carers to identify their priorities for implementation of PROs in cancer care. The aims of this viewpoint paper are to report on the findings of the workshop with particular focus on how priorities identified for implementation fit with the ACP recommendations and present recommendations for future implementation efforts, clinical practice improvements, and resource allocation within the Australian healthcare context.

The PROActive workshop

The PROActive Workshop was held in Melbourne Australia on October 31st, 2023 ahead of the Clinical Oncology Society of Australia's Annual Scientific Meeting. The workshop brought together 58 participants including 44 health, policy, and technical professionals and 14 cancer consumer advocates with lived experience and/or their carers from all States and Territories of Australia. The workshop aims were to identify critical success factors for the implementation of PROs in cancer care to date, and to identify key factors to consider, potential solutions, and future opportunities. All participants provided informed consent to participate in the workshop, for the workshop to be video and audio recorded, and for quotes to be used in any resulting dissemination materials.

To determine the key priorities for the implementation of PROs in cancer care, an affinity mapping technique was employed during the PROActive

Workshop.¹⁶ Participants first reflected individually on challenges, enablers, and ideas for enhancing PRO implementation. These insights were then shared and discussed in a large group using virtual collaboration platforms, Miro and Mentimeter, which enabled participants to visually cluster similar ideas and collectively identify six distinct priority areas.

Participants then self-selected into breakout groups corresponding to one of the six identified areas. Each group explored their selected topic in greater depth, considering the specific actions and requirements for implementation at the person-, provider-, and system-levels. Following these discussions, all participants reconvened as a large group to present and discuss their reflections.

To assess the relative importance of each area, participants took part in a structured dot-voting exercise. Each person received three coloured dots - red (3 points), yellow (2 points), and blue (1 point) - to allocate to the areas they considered most critical. This participatory process provided a transparent mechanism for prioritisation, informed by the collective perspectives of consumers, clinicians, policymakers, and researchers. The six priority areas are presented below in order of their final ranking. The full methodological detail of the workshop is available in the published report.¹⁷

Participants collectively established six key recommendations to enhance the use and impact of PROs within oncology practice (Fig. 1): 1. Integration with other systems, 2. Demonstrating value, 3. Sustainability and adaptability, 4. Minimum standards, 5. Person-tailored approach, 6. Relevance and acceptability. For each recommendation, participants delineated specific actions and implementation considerations across the patient, oncology care provider, healthcare system, and policy levels. A high-level summary of these



Fig. 1: Summary of identified priority areas for Patient-reported outcomes (PROs) advocacy and implementation.

recommendations and their implementation considerations is outlined below.

Priority action areas for PRO advocacy and implementation

The workshop participants emphasised **integration with other systems and uses** for PRO data into broader healthcare initiatives, such as general practice or clinical registry development. At a person level, this would enable seamless access to PRO data for the entire care team, reducing the need for patients to repeatedly share their story, and with patients and/or carers having control over data sharing, whether for clinical or research purposes. At a provider level, integration would facilitate coordinated care across different treatment settings (e.g., radiotherapy in private hospitals, chemotherapy in public settings, family general practitioner involvement), with PROs informing referrals, allocation of resources, and being used to benchmark performance. At a health system level, integration would allow connecting PROs with national health systems like the Australia-wide single electronic health record called MyHealth Record,¹⁸ creating bi-directional data flows accessible to all relevant sites (GPs, hospitals) and establishing permanent, longitudinal records to monitor patient trends over time.

The participants emphasised the importance of demonstrating a **value proposition for users' buy-in and funders' investment**. They felt that there was a need for advocacy efforts to showcase the benefits of PRO programs to secure support and resources at organisational and policy levels. The value proposition at a person level included demonstrating improvements in quality of life, patient empowerment, and reductions in travel and in-person visits through remote monitoring. Provider benefits included enhancing clinical efficiency and prioritising patient needs through triaging, reducing unnecessary appointments, and supporting quality improvement. At a health system level, PRO use could lead to: streamlined resources (including a reduction in emergency department presentations and unnecessary hospital admissions); improved treatment adherence with positive impacts on high-priority populations; and policy change if PROs can be mapped to potential accreditation standards.

Workshop participants also stressed the importance of **sustainability and adaptability** in PROs rollout. Thus, they recommended the development of strategies to ensure the long-term sustainability and adaptability of PRO programs through integration into existing healthcare systems and leveraging advancements in technology. This approach would ensure success at the person-level, as patients would have continuous access to their PRO data, enabling reflection on their health journey with PROs collected once to avoid repetitive surveys, enhancing patient engagement and accuracy. At a provider level, sustainability could be achieved

through clinical championship and routine integration of PRO data in clinical workflows with clinicians receiving structured PRO feedback to assist with patient care, reinforcing the value of PROs in everyday practice. At the health system level, sustainability requires integration with electronic medical records (eMR) and data-sharing capabilities across and between organisations. This can be aided by advocacy for state-level cancer networks to support the use of cancer-specific PROs, ensuring broader adoption across state jurisdictions that fund cancer care in Australia.

To ensure consistency and quality in PRO data collection and implementation across the cancer continuum, the participants felt that the **development of minimum standards** as to both what should be collected from patients (measures and outcomes) as well as an implementation standard was needed. At a person-level, standards should ensure that PRO data collected from patients is clinically actionable, collected through validated tools, and that pathways are implemented to ensure responsiveness to change within reported outcomes and/or breached thresholds. PROMs should also be available in multiple languages to support inclusivity. At a provider level, providers would be supported by a national set of standards, making it easier to integrate PROs into routine care and align with best practices across the healthcare system. These would be further aided by a nationally endorsed set of minimum standards to ensure equitable access to PROs for all people with cancer.

The workshop attendees consistently emphasised the need for **equitable and inclusive PROs** programs that address individual patient needs. At a person-level, this would mean ensuring that the "right person receives the right PROM at the right time," considering factors like goals, cancer stage, treatment, age, and cultural background. Screening questions and free text fields allow comprehensive capture of patient reports. At a provider-level, PRO data collected should be relevant to available treatments, ensuring that PROs inform clinical decisions and care pathways. At the health system-level, personalised modes of collection (e.g., electronic, paper, phone) accommodate changing patient preferences and demographics with ongoing evaluation and feedback loops to assess and improve PROs use.¹⁹

The participants emphasised the importance of ensuring engagement and satisfaction with PRO data collection processes by ensuring **relevance and acceptability** to patients, clinicians, and other interest holders. At a person-level, this requires tailored approaches, including carer-specific support and resources while frequency and timing of data collection are optimised to maintain patient engagement without causing burden. At the provider-level, this calls for the development of localised tailoring of clinical workflows to incorporate PRO data, with online training modules available to

build capacity and knowledge, ensuring that PRO feedback is reviewed and acted upon to keep patients engaged. The health system-level requires buy-in and leadership for clinical teams to engage through the implementation process. This would provide the most suitable environment for PROs to become standard practice.

While all six recommendations align with what is considered best practice in health care delivery and data management, the last two warrant particular attention as they emphasise the need for making PROs “personal” in terms of how burdensome their collection may be and how the results translate into clinical benefits for patients. Participants emphasised the value of patient-reported data in shaping **real-time** interventions that address individual needs and concerns. One workshop participant with lived experience of cancer captured this sentiment, stating:

“I’d like to know that whatever I fill in with my details is going to be used to help me. If you are asking me about how I feel right now, then I would hope you take those answers and use it now to guide my care.”

While the workshop participants recognised that creation of databases and registries is essential for advancing cancer research and quality improvement initiatives, they stressed the need for PRO initiatives to transcend data accumulation and prioritise real-time clinical impact.

The way forward—PROs as *personalised clinical tools*

The reflections of workshop participants highlight some of the challenges and opportunities inherent in the implementation of PROs as part of the ACP. The interest in making PROs directly relevant to their care highlights the desire for integration of PROs collection into the clinical workflows with its inherent need for rapid data availability and reporting to clinicians and patients and the availability of health systems that respond to reports of health outcomes that need attention.²⁰ While this places additional demands on the health system, it is worth noting that the benefits of PROs in cancer care in terms of improvement in survival, or better symptom management, have been documented in these very circumstances, rather than quality registry collections with retrospective reporting.²¹ Indeed, the greatest patient benefits from PROs collections have been observed in this setting where PROs collection is embedded in the overall path of clinical care and leads to a specific clinical response, i.e., real-time feedback to patients to directly inform the patient-clinician encounter.^{1,3-6} However, this level of integration requires investment not just in terms of PRO collection, but also in ensuring clinical staff and

systems are capable of responding to PRO data in a timely manner.^{22,23} Emerging digital health approaches, including artificial intelligence and machine learning, may offer additional opportunities in this space by supporting patient prioritization and tailoring responses based on need, such as delivering self-care tools for low-level concerns and directing high-need cases to healthcare professionals. While the evidence base for these novel methods is still emerging in this context, they represent a potential avenue for enhancing the efficiency and responsiveness of PRO-driven care.²⁴

One example of effective, real-world integration of PROs into both quality monitoring and individual clinical care is the Ontario-based program using the Edmonton Symptom Assessment System (ESAS).²⁵ ESAS is a brief, validated tool that takes approximately 2 min for patients to complete and is now routinely integrated into electronic medical records at the point of care. It captures key symptoms such as pain, fatigue, nausea, and emotional distress, enabling healthcare teams to quickly identify patient needs. By integrating validated tools like ESAS into the clinical workflow, healthcare providers can tailor treatments to individual patient needs, improve symptom management, and make informed clinical decisions. The program has demonstrated significant benefits, including more personalised care, improved communication between patients and providers, better symptom and side effect management, and overall enhanced quality of life for cancer patients.^{8,9,12,26} Additionally, the aggregated PRO data supports research and policy development, driving system-level improvements in cancer care across Ontario. In the Australian and New Zealand context, a recent study examining the use of PROs in oncological care found significant variability in implementation approaches, with uptake primarily concentrated in metropolitan areas.¹¹ This underscores the importance of our recommendations in promoting a more cohesive and equitable approach to PRO integration across diverse healthcare settings.

Since the time these six stakeholder-informed recommendations were developed, the national PanCancer Initiative, co-led by Movember and Cancer Australia, was announced. Given the alignment in timing, we recognised the importance of allowing space for this initiative to define its strategic direction. Now, approximately 16 months on from its announcement, early indications suggest that one of the PanCancer Initiative’s initial areas of focus will be the development of a national core outcome set for PROMs collection. This aligns with one of the stakeholder priorities around defining a minimum dataset. While this is an important foundational step, the remaining recommendations, particularly those relating to implementation supports at the system, provider, and person levels, will require continued attention. We view the work presented in this viewpoint as complementary to emerging

national efforts and hope it can help guide future phases of implementation.

Conclusions

The release of the 2023 Australian Cancer Plan and the plan for significant national investment into the collection of PROs in cancer in Australia has the potential to revolutionise how data informs care delivery at the health system level for the patients of the future. In addition, if PRO collection and response focuses on individual patient care for the patients of today, we may truly realise the potential of PROs in the delivery of personalised cancer care.

Contribution

CM & BK have accessed and verified the data and were responsible for the decision to submit the manuscript. CM wrote the first draft of this viewpoint. All authors reviewed and amended the final manuscript.

Declaration of interests

CM received consultancy fees from Movember for contribution to the PanCancer Initiative Advisory Group. SN received consultancy fees from Movember, Mapi Research Trust and Bertelsmann Foundation. SN received grant funding from the European Organisation for Research and Treatment of Cancer (EORTC).

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