PROACTIVE WORKSHOP

Summary report

Published: July 2024

EXECUTIVE SUMMARY

The national PROActive Workshop was convened in response to the growing recognition of the critical role that Patient-Reported Outcomes (PROs) play in cancer care. Despite extensive evidence supporting the benefits of PROs, their implementation across Australia remains inconsistent. The workshop aimed to discuss this gap by identifying current priority areas for advocacy and action. Action areas are presented in ranked order from most to least (yet, still) important to address immediately as determined by workshop participants.

ADVOCACY PRIORITY AREAS:

01

Integration into other systems/uses

There is significant potential for integrating clinical PRO collections into other healthcare initiatives, such as general practice or clinical registry development. Leveraging PRO data in broader healthcare systems can enhance the utility and impact of these programs.

02

Demonstrating value proposition

Demonstrating the value proposition of PRO programs is necessary to garner buy-in and investment from stakeholders. Showcasing the tangible benefits and outcomes of PRO implementation can secure support and resources for these initiatives. These demonstrations are often wanted at local levels (e.g. within a health district or health service).

03

Sustainability & Adaptability

Ensuring the long-term sustainability and adaptability of PRO programs is essential. This involves integrating PRO initiatives into existing cancer care systems and workflows and developing strategies to maintain program relevance over time.

04

Development of minimum standards

Establishing minimum standards for PRO clinical data collection and implementation across different cancer types is vital. This standardisation will facilitate consistent and comparable data collection, enabling more effective use of PROs in clinical practice. The importance of also having a standard for PRO implementation was particularly highlighted.

05

Person-tailored & action oriented

PRO programs should be person-tailored, equitable, and inclusive, minimising duplicate collection burden on patients. Considerations for equity and inclusivity must be integrated into program design to ensure all patients can benefit from PROs. PRO collections should also be 'action-oriented', or accompanied by an action pathway if needed, to ensure any immediate benefits to person-tailored care.

06

Relevance & acceptability

Developed PRO collection programs must be relevant and acceptable to both patients and clinicians. Enhancing engagement and satisfaction with PRO data collection processes is crucial to their success and utility in clinical settings.

WHY THE WORKSHOP?

The national PROActive Workshop was convened in response to the growing recognition of the critical role that Patient-Reported Outcomes (PROs) play in cancer care. Despite extensive evidence supporting the benefits of PROs, their implementation across Australia remains inconsistent. The workshop aimed to discuss this gap by identifying current priority areas for advocacy and action.

AIMS:

The primary objectives of the PROActive Workshop were to:

Identify priority action areas to work towards a national approach for PRO advocacy and implementation

Inform the development of national priorities and an advocacy plan for the routine collection and implementation of PROs in cancer clinical care.

PARTICIPANTS:

Workshop participants represented a range of key stakeholders including*:

| 17 Clinical Implementors | 15 Government/Policy roles | 9 Academic Researchers | 14 Lived-experience consumers | 12 Cancer advocacy organisations |

*partipants may hold duel roles

METHODS:

Identification of Priority Action Areas
An open floor discussion was held where participants were invited to list and discuss topics they believed were critical for PRO advocacy. These topics were dynamically written on the presentation screen and refined through group discussion. Six key priority areas were identified through this group discussion.

Priority Ranking Process
Participants then self-selected into smaller groups based on their interest in one of the six identified priority areas for deeper discussion around how to action and what would be required to achieve the priority area. Each group discussed their chosen priority area in detail, including changes or considerations needed at the patient, healthcare provider, and cancer service levels. Following these discussions, the groups presented summaries of their discussions to all workshop participants and allowed for any further comments or insights. We were additionally interested in identifying the top three priority areas of the six that, if enacted upon, could provide high impact change. We therefore asked all workshop participants to engage in a further voting exercise where they nominated their top three priority action areas, thus identifying the most critical areas for future advocacy and strategic efforts in PRO implementation.

HOW TO INTERPRET:

Participants of the workshop discussed implementation factors and advocacy areas required across three levels: Person (patients)-, providers-, and system-level. The results of these discussions are presented by each priority area identified across these three domains. Priority areas are presented in order of final ranked importance.

Person- level

Provider-level

System-level

PRIORITY ACTION AREA 1:
Integration into other systems/uses

This priority action area explores opportunities and challenges in integrating PRO data into broader healthcare initiatives, such as general practice or clinical registry development. The ultimate goal would be to strive for seamless integration between different systems to ensure PRO data is accessible across various healthcare systems to provide comprehensive, continuous care.

PERSON LEVEL
Patient-centred access was deemed to be important by considering:
- The whole care team can access the collected PRO information, which would allow for seamless transitions across systems so the patient only needs to share their story once.
- Making PRO data accessible to patients, allowing them to track their health and care journey.
- Adapting PROs to relevant points in the patient journey, ensuring the data collected is always pertinent.
- Providing patients with the choice and control over data sharing, whether it be with clinicians or for research purposes.

PROVIDER LEVEL
Focusing on system integration at the provider level was thought to contribute towards enhanced coordination and performance by:
- Collecting data to assist with appropriate referrals, ensuring timely and relevant care interventions.
- Achieving horizontal integration between providers, such as coordinating care when a patient is receiving treatments at different hospitals (e.g., radiotherapy at a private hospital and chemotherapy at a public hospital).
- Using clinical PRO collection to build registries to benchmark performance, allowing providers to compare their outcomes with other hospitals, local health districts (LHDs), or states/territories.

SYSTEM LEVEL
The main focus was on the ideal of achieving national and system-level Integration, considering these key points:
- Integrating PRO data with system-level data, potentially linking with national systems like MyHealth Record and electronic medical records (eMR).
- Ensuring an integrated response, where reactions or referrals are integrated into the system in a bi-directional manner, accessible to other sites like GPs and private hospitals.
- Implementing robust systems to ensure data security while maintaining accessibility for authorised external sites.
- Establishing permanent and longitudinal records, recognising that trends over time are critical for comprehensive patient care.

> *The goal here would be that people would only need to tell their story once – so there is a central repository of information that there is seamless access for all of the members of your care team.*
> *- Clinical implementor*

THE BOTTOM LINE:
In summary, integrating PRO data into other healthcare systems is vital for enhancing the coordination, efficiency, and quality of patient care. This integration ensures that patients only need to provide their information once, that care is consistent across different providers, and that data is secure yet accessible for comprehensive, longitudinal health monitoring.

PRIORITY ACTION AREA 2:
Demonstrating value proposition

This priority action area focuses on advocating for the benefits of PRO programs to stakeholders to secure support and resources at organisational and policy levels. Emphasising the use of PROs as clinical tools to enhance care is crucial for gaining the necessary buy-in and investment. Demonstrating the value proposition of PROs that highlights the tangible benefits of PRO programs to patients, providers, and the healthcare system was deemed necessary to secure support and resources to develop PRO collection programs. It was preferable if data were available on the evidence-base of PROs from an Australian-perspective and from local levels.

> " We needed to convince high-level decision makers and we could only do that by presenting the evidence that systematic collection of PROs improve outcomes for the institution and improves overall survival for the person, but also improves performance of the hospital, and may provide potential savings and benefits for the decisionmaker.
> -Clinical Implementor "

PERSON LEVEL
Patient Benefits that should be demonstrated:
- Enhancement of quality of life and quality of care.
- Empowerment of patients through self-management and reducing the need for in-person attendance.
- Decreasing travel requirements for patients by utilising PROs for remote monitoring and care adjustments.

PROVIDER LEVEL
Efficiency and Quality Improvement should be demonstrated by:
- Using PROs for triaging and avoiding unnecessary future interactions, which increases efficiency.
- Improving the quality of care for patients and contributing to quality improvement in research.
- Collecting data once but using it multiple times to optimise the time of both patients and clinicians.

SYSTEM LEVEL
Cost Reduction and Improved Outcomes should be demonstrated by:
- Reducing unnecessary follow-up appointments and emergency department presentations.
- Enhancing overall life quality, treatment adherence, and outcomes.
- Positively impacting high-priority and diverse populations, including CALD, remote, LGBTQIA+, and Indigenous communities.
- Increasing consumer engagement, which in turn benefits patient experience and informs system improvements.
- Developing a toolkit mapped to accreditation standards, advocating for federal and state support and incorporating these standards into CEO key performance indicators (KPIs).

THE BOTTOM LINE:
Demonstrating the value proposition of PRO programs is essential for gaining the necessary buy-in and investment. By showcasing the benefits at multiple levels, this priority action area aims to secure support and resources, ensuring the successful implementation and sustainability of PRO initiatives.

PRIORITY ACTION AREA 3:
Sustainability & adaptability

The priority area of sustainability and adaptability focuses on ensuring the long-term viability and flexibility of PRO initiatives. This involves developing strategies that integrate systemic changes and workflows to make PROs transferrable across different cancers and treatments, minimising repetition, and ensuring they are user-friendly for diverse communities. Leveraging existing systems and advancements in AI is crucial for optimal uptake and relevance.

PERSON LEVEL

- Access and Reflection: Ensuring that patients can access their PRO data to reflect on their healthcare experiences, excluding privacy concerns.
- Reduction of Repetition: Collecting data once to prevent patients from repeatedly completing surveys, which enhances the accuracy and willingness to participate.
- Follow-Up and Validation: Patients need to know that their PROs are reviewed and understood by healthcare providers, and how completing PROs benefits them.

PROVIDER LEVEL

- Routine Data Presentation: Incorporating PRO data presentation into routine practice in clinics.
- Holistic Data Capture: Including non-cancer items (e.g., sexual function) to gain a holistic understanding of the patient's health.
- Educational Promotion: Engaging professional organizations like COSA, CNSA, and universities to champion PROs to their members.
- Meaningful Insights: Providing qualitative responses that offer significant insights for clinicians.

SYSTEM LEVEL

- Data Sharing: Developing the capability to hold and access PROs and other data, and share information across organisations, hospitals, clinicians, and systems.
- Integration with EMR Systems: Utilising existing systems and integrating PROs into electronic medical record (eMR) systems.
- Responsive Systems: Systems must respond to changes and issues reported in PROs to maintain patient engagement and demonstrate the utility of PRO data.
- State-Level Advocacy: Cancer networks at the state level advocating for cancer-specific PROs.

> *To make PROs more sustainable and engaging for the patient, the healthcare provider and system need to respond to the patient and make sure the patient sees it is being utilised and is actually being engaged with. There is a reason to be using the system, otherwise why would you do it? It's just another form to fill out.*
> -Lived experience consumer

THE BOTTOM LINE:
The sustainability and adaptability of PRO programs are critical for their long-term success and relevance. Addressing these aspects at the person, provider, and system levels will ensure that PRO initiatives are effective, efficient, and truly patient-centered. By focusing on these areas, we can enhance the impact of PROs on patient care and support the continuous improvement of cancer treatment and survivorship.

PRIORITY ACTION AREA 4:
Development of minimum standards

> "First we considered who the minimum standards needed to be relevant to and we thought it needed to be relevant to patients, carers, and providers with a focus on understanding what is clinically relevant and actionable and making sure we prioritise those items.
> -Clinical implementor/academic researcher

The priority action area of minimum standards focuses on establishing standardised guidelines to ensure consistency and quality in PRO data collection and implementation across the cancer continuum. This area emphasises the need for a cohesive and validated approach to collecting PROs that can be utilised effectively in clinical settings. Given the discussion around development of minimum standards is more of a methodological approach, this priority action area will be outlined by practical advice discussed during the workshop rather than the Person, Provider, System-level outline as detailed by the other priority areas.

WHAT?
- Generic and Specific Items: Incorporating a mix of general items (covering physical, psychosocial, and emotional aspects) and specific items (related to diagnosis, treatment modalities, etc.).
- Clinically Actionable PROs: Ensuring PROs are validated, responsive to change, and ideally available in multiple languages to cater to diverse patient populations.

HOW?
- Environmental Scan: Conducting a comprehensive review of national and global practices across the cancer continuum to identify commonalities and set a national item set for compliance and uptake.
- Modified Delphi Process: Utilizing a structured communication technique to reach a consensus on the minimum standards.
- Seeking Endorsement: Presenting the standards to key action and interest groups for endorsement and support (e.g., funding bodies, peak bodies like COSA, and key stakeholders - including patients and carers).
- Standard of Care: Treating PRO data collection as a standard part of clinical care, similar to blood tests and radiology assessments.

CONTEXT AND KEY STAKEHOLDERS
- Applicability Across the Cancer Continuum: Ensuring that minimum standards for PROs are relevant from the time of diagnosis through to survivorship.
- Patients, carers, healthcare providers, and other stakeholders involved in cancer care need to be included in these conversations and the development process.

THE BOTTOM LINE:
The minimum standards priority action area seeks to establish a unified and effective framework for PRO data collection, ensuring that the data collected is relevant, actionable, and integrated into routine clinical care.

PRIORITY ACTION AREA 5:
Person-tailored & action oriented

This priority action area emphasises the importance of developing PRO programs that are tailored, equitable, and inclusive, addressing challenges at the patient, provider, and system levels. It focuses on ensuring that PRO data collection is personalised, relevant, and minimally burdensome to patients.

PERSON LEVEL
- Personalisation: Ensuring the right person receives the right PROM at the right time.
- Ethical Data Collection: Collecting only necessary data and ensuring its ethical use.
- Holistic Approach: Considering the whole person, including goals, priorities, cancer stage, treatment choice, point of care, age, socio-economic determinants, cultural background, health literacy, spiritual values, and physical and emotional abilities.
- Screening Questions: Reviewing screening questions first to identify the specific PROMs needed for the patient.
- Free Text Fields: Including free text fields to capture qualitative data and ensure comprehensive patient input.

PROVIDER LEVEL
- Resource Availability: Recognising that service availability varies across hospitals and centres, ensuring that collected data is relevant to available treatments and can be actioned based on the resources available in the local area.

SYSTEM LEVEL
- Personalised Modes of Collection: Adapting the mode of collection to the patient's demographic (e.g., app, paper, phone, email) and allowing it to change over time to accommodate preferences.
- Continuous Feedback: Implementing review and feedback mechanisms to assess and improve the execution of PROMs.
- Burden Reduction: Addressing the length, frequency, and relevance of PROs to minimise burden and enhance personalisation.

THE BOTTOM LINE:
The person-tailored priority action area aims to create PRO programs that are adaptable and responsive to individual patient needs, enhancing the relevance and effectiveness of PRO data collection in clinical care.

> *We need to make sure we are giving our PROs to the right person, so that it is tailored to the right person, right time, and specific to their circumstance, rather than a generalised or standardised type of questionnaire. Basically, right person, right time, right environment and resources to take action.*
> *-Govenment/policy participant*

PRIORITY ACTION AREA 6:
Relevance & acceptability

The priority action area of relevance and acceptability focuses on enhancing engagement and satisfaction with PRO data collection processes at both the individual and clinician levels. This area emphasises the need for tailored approaches that resonate with patients, carers, healthcare providers, and broader system stakeholders.

> We have to make sure anything we build or implement is fit for purpose – no point developing a fantastic questionnaire and it doesn't fit the particular cancer stream or highlight what is important to patients and clinicians.
> -Lived experience consumer

PERSON LEVEL
- Carer Engagement and Support: Specific resources and support for carers to ensure they are involved and informed.
- Frequency and Appropriateness of Data Collection: Ensuring the timing and method of PRO collection keeps patients engaged without being burdensome.
- Education and Awareness: Providing patients with the necessary information to understand the importance and use of PROs in their care.

PROVIDER LEVEL
- Online Training Modules: Offering accessible online training for providers to learn about PRO processes and implementation.
- Localised Clinical Workflows: Integrating PROs into clinical decision-making processes that involve both patients and providers, ensuring transparency and understanding.
- Feedback and Action: Ensuring that PROs are reviewed and acted upon so that patients see the value in their participation and do not feel their efforts are wasted.

SYSTEM LEVEL
- Shared Care Model: Implementing a shared care approach where different stakeholders can contribute to and benefit from PRO data.
- Diverse Methods of Collection: Utilising various collection methods, including face-to-face, electronic (phone or computer), and paper, to ensure inclusivity.
- Fit for Purpose: Adapting PRO tools to fit the specific needs of different demographics, such as rural vs. metropolitan areas, and specific cancer streams.
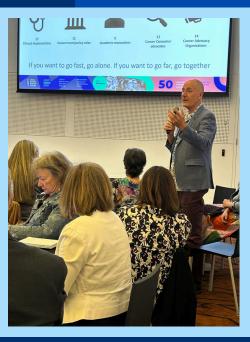
THE BOTTOM LINE:
Overall, the relevance and acceptability priority action area seeks to make PRO collection a meaningful and beneficial process for patients, carers, and all stakeholders involved, ensuring that the data collected is actionable and valued.

CONCLUSION

The PROActive Workshop generated actionable insights and consensus around priority advocacy areas for advancing PRO implementation in cancer care. Moving forward, identified priorities will inform strategic efforts to enhance patient-centeredness and optimise treatment outcomes in oncology. The outcomes of the workshop underscore the imperative of sustained advocacy and collaborative initiatives to realise the full potential of PROs in cancer clinical care. The task at hand now is to develop a roadmap of how best to operationalise these advocacy areas to ensure routine PRO collection programs can be implemented across Australia .

ACKNOWLEDGEMENTS

FUNDING & SUPPORT

UNSW Health Systems Research

Clinical Oncology Society of Australia