



**Clinical
Oncology
Society of
Australia**

Implementing monitoring of patient-reported outcomes into cancer care in Australia

**A COSA Think Tank
Thursday 23 August 2018**

Report

Contents

Executive summary	3
Where are we now?	3
Considerations for implementing PRO monitoring	4
Recommended next steps	5
Introduction	7
Where are we now? Current evidence base and use of PROs	8
Why collect and monitor PROs?	8
PRO monitoring programs.....	9
Implementing monitoring of PROs in Australia: what do we need to consider?	10
Goals of PRO monitoring	11
Scope and relevance of PROs	12
Building the evidence base.....	12
IT considerations and systems integration.....	12
Encouraging uptake: addressing potential barriers.....	13
Flexibility, scalability and sustainability	13
Embedding PRO monitoring at different levels of cancer care	13
Embedding PRO monitoring at the clinical / patient level	14
Embedding PRO monitoring at the service level	15
Embedding PRO monitoring at the system/policy level	16
Research considerations for the implementation of PRO monitoring	17
Enablers for implementation of PRO monitoring	18
Connections and collaborations	19
Recommendations	20
Key recommendations	20
Next steps.....	20
Acknowledgement	20
Appendix I: Think Tank Agenda	21
Appendix II: Think Tank Participant List	22
Appendix III: Summary of current PRO activity provided by Think Tank participants (provided with approval)	23

Executive summary

While available evidence indicates a benefit to monitoring and responding to patient-reported outcomes (PROs), many questions remain for implementation. Embedding PRO assessment as part of routine cancer care in Australia will require a collaborative process of testing, sharing and learning to find a pragmatic approach that is relevant, acceptable and beneficial for all stakeholders.

In August 2018, the Clinical Oncology Society of Australia (COSA) Survivorship Group convened a Think Tank to start the process of developing a roadmap to support implementation of patient-reported outcome (PRO) monitoring into clinical cancer care in Australia. The Think Tank provided the opportunity to review available evidence, identify considerations for implementation at patient, service and policy levels, and highlight opportunities for collaboration and action.

Where are we now?

PROs are a central tenet of patient-centred care, as they recognise and value the idea that the patient is the best informant of their sensations, emotions and social functioning. They are likely to be of greatest benefit when used to identify issues that are not routinely assessed as part of routine clinical care.

A considerable amount of evidence has been generated on the use, effectiveness and impact of PRO monitoring in clinical practice. This includes evidence from randomised clinical trials in cancer and other areas of health. Available evidence about the feasibility and benefits of PRO monitoring varies in quality and this can sometimes be used as a barrier to implementation. Think Tank participants reflected on the level of evidence required to justify routine PRO assessment within cancer services, noting that in addition to the growing evidence base, there is a moral imperative to measure and respond to the issues that matter most to people with cancer as part of their routine clinical care. It was agreed that a PRO implementation roadmap could help to support the transition from research to standard of care by learning from experience to date, acknowledging areas of uncertainty and continuing to build a real-world evidence base.

Current evidence has been generated from a broad range of paper- and web-based systems designed for use in different health conditions and settings. A 2014 review identified 33 PRO monitoring systems in current or previous use internationally (none in Australia at that time).¹ Not all systems are integrated in the electronic health record (EHR).

The 'ideal' system for PRO monitoring will be context specific, but feedback from existing systems suggests that common features may include:

- automated prompts and reminders to encourage patients to complete assessments
- link to evidence-based care recommendations based on score thresholds and algorithms to drive action in response to need
- integration into the EHR for real-time clinical use and feedback to patients
- a flexible, adaptable system to appropriately manage cultural, linguistic and literacy needs.

¹ Jensen RE, Snyder CF, Abernethy AP, et al. Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care. *Journal of Oncology Practice*. 2014;10(4):e215-e222.

Considerations for implementing PRO monitoring

While available evidence indicates a benefit for PRO monitoring, questions remain for its implementation. Think Tank participants noted that consideration needs to be given to:

- the **goal(s) and scope for PRO monitoring**
- the **most effective and efficient methods for collecting and reporting PROs**
- systems and resources needed to **ensure scalability and sustainability**
- how to **encourage uptake**.

Think Tank participants highlighted the opportunity to look beyond wellness indicators and **define clinical and system level goals** for PRO monitoring:

- **clinical goals:**
 - identify patient concerns or issues that healthcare professionals (HCPs) do not routinely assess, with option to offer treatment where appropriate
 - identify unmet patient needs and link patients with health services that may not be routinely or easily accessed
 - identify carer and family issues (as proxy for the patient or to identify their own unmet needs)
- **system-level goals:**
 - provide services with a quality indicator to demonstrate a commitment to patient-centred care
 - demonstrate a cost-benefit for health service utilisation as well as appropriateness of care.

When considering **scope**, Think Tank participants agreed that any model for PRO monitoring should take account of the needs and unique challenges faced by Australia's most vulnerable patient populations as a minimum requirement. This includes:

- determining a minimum set of PROs that are appropriate for all populations
- ensuring that PROMs used to collect agreed PROs are appropriate or adaptable for all populations
- providing PROMs in a variety of formats suitable (including both paper-based and computer-based formats, in-language formats for culturally and linguistically diverse populations, telephone-based formats for people with low levels of general, health and computer literacy and spoken options for people with visual impairment or low literacy).

A number of barriers to the **uptake of PRO assessment** were highlighted throughout the Think Tank. These ranged from HCP level barriers such as lack of awareness and perceptions of risk, to system-level issues such as lack of resource and variability in IT systems. It was agreed that uptake of PRO monitoring is likely to be enhanced by including HCPs, consumers, health services and policy makers in implementation planning to ensure that PROs are appropriate to clinical care and that PROMs are usable and useful at the point of care and can be supported in the long-term.

From an HCP and policy maker perspective, it was agreed that a clear value proposition, supported by a robust communication plan would be a key step in encouraging uptake. Key messages would include:

- monitoring and response to PROs is a valuable way to improve patient care and outcomes, based on a more nuanced assessment that considers unmet need in addition to response to clinical care
- monitoring of PROs provides a way of ensuring patients access appropriate clinical care and can identify issues that are not being picked up using existing pathways / measures
- if shared between services, PROs may also provide a means to support coordinated care across the pathway of primary, secondary and tertiary care and may be used in shared care models
- PROs can also act as an important quality indicator and can be used to identify population-level needs.

From a systems perspective, key considerations will include:

- how PROMs should interact and integrate with My Health Record
- how to address real and perceived concerns about data security and confidentiality
- how to integrate PROMs across multiple settings, including primary, tertiary, allied health and community systems, to ensure continuity of care
- how to ensure PROMs can be used in settings that do not have access to EHR.

Other factors identified by Think Tank participants as being important to the successful uptake and sustainability of PRO monitoring in clinical cancer care included:

- **education** of HCPs: why PRO assessment is important, and how to incorporate it as part of everyday practice
- a pragmatic approach to designing **systems and tools** to optimise PRO collection: while a single tool is unlikely to be appropriate, given variation in IT systems across and within health services, tools should include at least a core set of the same PROs to support consistency across services
- **clinical champions and consumer advocates** to advocate for the value of PRO assessment and encourage endorsement and funding to support PRO assessment and its ongoing evaluation
- **connections and collaborations** between Australian and international organisations to learn from each other and avoid duplication
- **a planned approach to ongoing evaluation** to demonstrate the value and impact of PRO monitoring
- **an assessment of cost-effectiveness** that can be used to advocate for funding to ensure the sustainability of PRO monitoring.

Recommended next steps

Implementation of PRO monitoring in clinical cancer care in Australia is a matter of system redesign. As such, it requires careful planning that positions PRO monitoring as a way of supplementing and improving patient data activities, without unduly adding additional work on top of what is already being collected.

Discussions during the Think Tank identified some key areas that could be progressed at the patient / HCP, service and system levels based on evidence to date, as well as activities that could benefit from collaboration. Participants also identified a number of suggested areas for future research. These ideas are likely to form the basis for the PRO implementation roadmap. Recommended next steps in the development of the roadmap are listed below.

- Build on the Think Tank momentum to form an action-oriented PRO working group, led by the COSA Survivorship Group, that can:
 - facilitate an engaged PRO community
 - continue to share learnings
 - inform a coordinated approach to PRO implementation research
 - champion a consistent approach to communication and advocacy around the benefits of PRO assessment in clinical cancer care.
- Develop the PRO implementation roadmap, to include:
 - a clear value proposition for routine PRO assessment in cancer care
 - a plan to harness learnings and data from state-based approaches to standardised collection of PROs in cancer care and chronic disease to support the value proposition
 - case studies and consumer stories

- a business case that recognises the value agenda and can be used effectively to advocate for funding and resources to support implementation of PRO monitoring
- a communication plan with clear messaging for consumer, HCP and policy audiences
- a plan for engagement with relevant organisations, including but not limited to consumer groups, through which to learn, share and jointly promote learnings and opportunities.

Introduction

This report provides a summary of a Think Tank convened by the Clinical Oncology Society of Australia (COSA) Survivorship Group in August 2018. The aim of the Think Tank was to facilitate sharing and idea generation to inform a roadmap for implementation of patient reported outcome (PRO) monitoring as part of routine clinical cancer care in Australia.

The Think Tank was attended by 32 participants, representing clinical, research, consumer and policy perspectives from across Australia (see agenda and participant list in Appendix I and II).

During the Think Tank, participants were encouraged to:

- reflect on evidence for use of PROs at the individual patient level for needs assessment, risk stratification and effective monitoring and management of treatment side effects, cancer symptoms and functional concerns for people with cancer
- reflect on evidence for use of PROs for service-level monitoring of delivery of cancer care
- discuss approaches and ideas to integrate monitoring and response to PROs across the cancer care community (including primary care, community care and specialist cancer services)
- identify key steps and recommendations at patient, service and system levels for implementation of PRO monitoring as part of routine clinical cancer care
- identify gaps in evidence that require further research and identify how these can be best addressed in the Australian context
- think about what could be achieved through collaboration and sharing.

Definitions used in this report

A **patient-reported outcome (PRO)** is an indicator of a patient's health status, as reported by a patient without amendment or interpretation of response by a health professional or other person.² PROs provide information about a patient's condition and response to treatment (such as treatment side effects and pain), functioning and overall wellbeing (such as physical functioning, social and emotional wellbeing, sexuality) and psychological symptoms (such as happiness).

A **patient-reported outcome measure (PROM)** is a measurement tool or instrument used to assess a PRO. PROMs are standardised, valid and appropriate for use in a range of cultures. PROMs are available in a range of formats. They have clearly defined methods for administration and response, and well-documented methods for scoring, analysing and interpreting results within the target population. (Note that PROMs are different to patient-reported experience measures (PREMs), which provide a means for patients to provide direct feedback on their care to drive improvement in services).

The definition of **health-related quality of life (HRQOL)** used most commonly in relation to PROMs in cancer research is '*...a multidimensional construct encompassing perceptions of both positive and negative aspects of dimensions, such as physical, emotional, social, and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease or its treatment.*'³

² U.S. Department of Health and Human Services Food and Drug Administration. 2009. <https://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf>

³ Osoba, D. Lessons learned from measuring HRQOL in oncology. JCO 1994; 12(3): 608-616

Where are we now? Current evidence base and use of PROs

Although available evidence about the feasibility and benefits of PRO monitoring varies in quality, there is a growing sense of a moral imperative to measure and respond to the issues that matter most to people with cancer as part of their routine clinical care. Think Tank participants reflected on the level of evidence required to justify implementation beyond a research setting – i.e. when will the system be ready to implement routine PRO assessment within cancer services? It was agreed that the PRO implementation roadmap should support the transition from research to standard of care by learning from experience to date, acknowledging areas of uncertainty and continuing to build a real-world evidence base.

The summary below is based on presentations at the Think Tank by Professor Madeline King, Cancer Australia Chair in Cancer QoL and Director, QoL Office, Faculties of Science and Medicine, University of Sydney and Professor Afaf Girgis, Director, Psycho-Oncology Research Group, Centre for Oncology Education and Research Translation, Ingham Institute for Applied Medical Research, UNSW Sydney. Presentations are available via the Survivorship Group page at www.cosa.org.au.

Why collect and monitor PROs?

PROs are a central tenet of patient-centred care, as they recognise and value the idea that the patient is the best informant of their sensations, emotions and social functioning. They are likely to be of greatest benefit when used to identify issues that are not routinely assessed as part of routine clinical care. PROMs can complement clinical measures, such as blood pressure monitoring.

The premise for systematic PRO assessment in the clinical setting is that it may help:

- monitor response to therapy
- focus goals of care
- facilitate communication and shared decision making
- improve symptom control
- increase patient satisfaction
- allow for earlier integration of palliative care and other support services
- enhance continuity of care
- improve quality of care
- improve survival.

Current evidence has shown that PRO assessment improves communication between a patient and their healthcare professionals (HCPs) and can increase HCP awareness of the impact of a health condition on a patient's life. The impact of PRO monitoring for patient management, satisfaction with care and health outcomes, such as HRQoL and survival has been demonstrated in some contexts in both cancer^{4,5} and non-cancer settings. However, the extent to which these benefits are generalisable to all cancer groups cannot be determined as yet.

When reviewing the evidence supporting PRO assessment, it is important to recognise that some of the potential benefits rely on broader system issues beyond the process of PRO collection and response. For

⁴ Basch E, Deal A, Dueck AC et al. Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. JAMA. 2017;318(2):197-198.

⁵ <https://www.asco.org/about-asco/press-center/news-releases/web-based-system-self-reporting-symptoms-helps-patients-live>

example, an impact on continuity of care would require PRO information to be shared across the care continuum, while an impact on quality of care requires data to be reviewed and acted on at a system level.

PRO monitoring programs

A 2014 review identified 33 PRO monitoring systems, in current or previous use internationally (none in Australia at that time).⁶ Not all systems are integrated in the electronic health record (EHR).

Think Tank participants also shared their current experience and plans for PRO assessment in cancer care. A full listing of the information provided by participants is included in Appendix III.

Examples of PRO monitoring systems not integrated in the EHR include:

- [Cancer Care Ontario Cancer Symptom Screening Program](#) (using the Edmonton Symptom Assessment System – ESAS)
- [KLIK project \(The Netherlands\)](#) – a web-based system for systematic monitoring of quality of life for children with chronic disease and their parents
- [Symptom Care at Home \(University of Utah and Huntsman Cancer Institute\)](#) to monitor the needs of patients living at home (those in active treatment and patients and their carers at end of life)
- [ADAPT – Anxiety and Depression Pathway Program \(University of Sydney\)](#) to identify anxiety and depression in adult cancer patients
- [STAR \(Symptom Tracking and Reporting\)](#) and [PRO-TECT \(Patient Reported Outcomes to Enhance Cancer Treatment\)](#) (Memorial Sloan-Kettering and University of California) for patients with advanced / metastatic cancer; it was noted during the Think Tank that [evidence from the STAR trial showing improved survival for patients with metastatic disease undergoing symptom monitoring during chemotherapy](#) generated considerable interest at the American Society of Clinical Oncology annual meeting in 2017.

Examples of PRO monitoring systems that are integrated into the EHR include:

- [Patient ViewPoint \(Johns Hopkins Cancer Centre\)](#) (feasibility testing in breast and prostate cancer)
- [eRAPID \(University of Leeds\)](#) for symptom reporting in patients receiving chemotherapy
- [PROMPT-Care \(Patient-Reported Outcome Measures for Personalised Treatment and Care\)](#) (University of NSW, Ingham Institute, South West Sydney Local Health District, Illawarra Shoalhaven Local Health District) monitoring symptoms, distress and unmet need for all cancer patients.

Challenges that have been described for existing systems include:

- patient factors – including access to computers, health and computer literacy, language and cultural differences
- departmental barriers – including IT and human resources needed at the front and back end of a system
- technology barriers – including system integration across health settings and patient electronic medical record (EHR) functionality and accessibility.

Considerations when designing and implementing a system for PRO assessment include:

- what measures to collect – and why
- relevance of measures for different patient groups

⁶ Jensen RE, Snyder CF, Abernethy AP, et al. Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care. *Journal of Oncology Practice*. 2014;10(4):e215-e222.

- who will review PROs
- how to interpret and act on PROs (including education / tools to support review and response, and recommendations and resources to act on identified areas of need)
- how to incentivise collection and response to PROs
- what will be done with the data collected
- cost and cost-effectiveness
- scalability and sustainability of PRO monitoring systems – how to embed systems beyond trial periods and keep systems up to date.

Reflecting on an ‘ideal’ system for PRO monitoring it was suggested that this may include:

- automated prompts and reminders to encourage patients to complete assessments
- link to evidence-based care recommendations based on score thresholds and algorithms to drive action in response to need
- integration into the EHR for real-time clinical use and feedback to patients
- a flexible and adaptable system to appropriately manage the cultural, linguistic and literacy needs of a patient.

Implementing monitoring of PROs in Australia: what do we need to consider?

While available evidence indicates a benefit for PRO monitoring, questions remain for its implementation as part of routine clinical cancer care.

This section of the report summarises the considerations raised by Think Tank participants for the successful implementation of PRO monitoring as part of routine clinical cancer care in Australia.

Think Tank participants noted that consideration needs to be given to:

- **the goal(s) and scope for PRO monitoring:**
 - what are we measuring, and why?
 - what is the minimum we should be assessing and what should we aspire to collect in a gold standard model?
 - how do we ensure we are asking the right questions for different patient groups? (based on factors such as age and cultural background)
 - should we start by considering the unique needs and considerations for our most vulnerable patient populations?
 - how do we reflect the fact that people with cancer also have other health conditions that may influence unmet needs?
- **the most effective and efficient methods for collecting PROs:**
 - do we have sufficient evidence to determine the optimal approach to PRO assessment and use?
 - how do format and language used in patient-reported outcome measures (PROMs) need to be adapted for different patient demographics and levels of general, health and digital literacy?
 - when is the right time and setting to assess PROs and who is best placed to respond to the information collected?
 - how do we develop a strategy for integration of PROMs into the EHR and who needs to be involved?

- **how to encourage uptake:**
 - what determines a HCP's and a service's preparedness to implement PRO monitoring?
 - what are the likely barriers to PRO monitoring (real and perceived) and how can these be addressed?
 - how can we incorporate PRO assessment as part of structured clinical pathways to ensure patients receive appropriate and timely feedback and care based on the needs they identify?
 - what 'currency' can be used to support uptake?
- **systems and resources needed to ensure scalability and sustainability:**
 - what are the capabilities of different healthcare settings across Australia to implement PRO assessment as part of routine cancer care?
 - what systems are needed to support automation and updates?
 - what human resources are needed to support education and use?
 - what is the cost-effectiveness of routine assessment and response to PROs in cancer care?
 - how should we be evaluating impact in order to continue to build the evidence base?

The Think Tank did not explicitly discuss the use of PROs at a population level. However, the need to consider how to link PROs with other relevant data sets, including biobank data, was noted.

Goals of PRO monitoring

There is a need to clarify the goal(s) of PRO monitoring in Australian cancer care in order to drive and encourage implementation. The following value proposition was proposed during the Think Tank and was widely accepted by the group:

By collecting and using PROs, we are connecting patients to the services they need in a timely and efficient way that is cost-effective.

In medical oncology, measures of patient survival (overall survival and progression-free survival) are used as the 'currency' to drive practice change. Discussion during the Think Tank suggested that PROs may create another 'currency' to drive change issues that are important for patients and their families.

Currently, initiatives in NSW and Victoria use PRO monitoring to measure patient wellness and quality of life. However, participants suggested that there is an opportunity to look beyond these indicators and use PRO monitoring to:

- identify patient concerns or issues that HCPs do not routinely assess, and/or to assess routine issues (e.g. fatigue) more systematically and quicker
- identify unmet patient needs and link patients with health services that may not be routinely or easily accessed
- provide services with a quality indicator that can be used to demonstrate a commitment to patient-centred care
- identify carer and family issues (as proxy for the patient or to identify their own unmet needs)
- demonstrate a cost-benefit for health service utilisation as well as appropriateness of care.

When setting goals for PRO monitoring, it was suggested that:

- survival should not be the primary endpoint for PRO monitoring
- the purpose of PRO monitoring should focus on improvement for patients as opposed to just the collection of PROs themselves

- the ‘Quadruple Aim’ (enhancing patient experience, improving population health, reducing costs and improving the work life of HCPs)^{7,8} may be an appropriate way to define the goal(s) of PRO monitoring.

Scope and relevance of PROs

Clarity around the goal(s) of PRO monitoring will help to define which PROs should be collected. It may be valuable to consider the needs of the most vulnerable patients as a starting point.

Australia is a diverse country. Many population groups, including culturally and linguistically diverse populations and Aboriginal and Torres Strait Islander communities, face unique challenges in accessing health services and care aligned with their needs. Think Tank participants agreed that any model for PRO monitoring should take account of the needs and unique challenges faced by Australia’s most vulnerable patient populations as a minimum requirement. This includes:

- determining a minimum set of PROs that are appropriate for all populations
- ensuring that PROMs used to collect agreed PROs are appropriate or adaptable for all populations
- providing PROMs in a variety of formats suitable (including both paper-based and computer-based formats, in-language formats for culturally and linguistically diverse populations, telephone-based formats for people with low levels of general, health and computer literacy and spoken options for people with visual impairment).

Building the evidence base

While it is recognised that there may be a perceived ‘moral imperative’ to implement PRO monitoring as standard of care, it is recognised that the evidence base is not yet fully established and reported benefits on outcomes such as survival have not yet been replicated. Think Tank participants proposed that the PRO implementation roadmap should include an efficacy and implementation research strategy.

Australia is in a strong position to undertake implementation research about effective methods for PRO monitoring and about the benefits of collecting and responding to PROs. Randomised controlled trials are unlikely to be practical and implementation research is more likely to yield meaningful information, with improvements and adjustments made in response to research outcomes over time.

IT considerations and systems integration

Implementation of PRO monitoring will require consideration of how best to overcome the real and perceived challenges posed by collection of electronic health data as well as integration with the different information systems used within and across different health settings.

Think Tank participants suggested that an ideal PRO monitoring system should be integrated with the EHR, and include automated prompts, reminders and variable assessment schedules based on PRO data input.

It was suggested that a strategy for integrating PROMs with existing data collection / EHR systems should be developed in parallel with/as part of a PRO monitoring implementation strategy. Likely challenges to be considered include:

- how PROMs should interact and integrate with My Health Record
- how to address real and perceived concerns about data security and confidentiality

⁷ Bodenheimer T and Sinsky C. From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider. *Ann Fam Med* 2014; 12: 573–576.

⁸ Sikka R, Morath JM and Leape L. The Quadruple Aim: care, health, cost and meaning in work. *BMJ Qual Saf* 2015; 24: 608–610.

- how to integrate PROMs across multiple settings, including primary, tertiary, allied health and community systems, to ensure continuity of care
- how to ensure PROMs can be used in settings that do not have access to EHR.

Encouraging uptake: addressing potential barriers

Uptake of PRO monitoring is likely to be enhanced by including HCPs and health services in implementation planning to ensure that PROs are appropriate to clinical care and that PROMs are usable and useful at the point of care.

Think Tank participants identified potential barriers to routine PRO assessment at individual patient / HCP, service and system levels. Barriers include lack of understanding of the value of routine PRO assessment, HCP confidence in PRO monitoring and using an assessment tool at point of care, perceptions of the impact of PRO assessment on consultation time and perceptions of the medicolegal risk associated with collection, sharing and reporting of PROs.

It was agreed that having a clear value proposition, supported by a robust communication plan would be a key starting point in encouraging uptake. Key messages to be communicated include:

- monitoring and response to PROs is a valuable way to improve patient care and patient outcomes, based on a more nuanced assessment that considers unmet need in addition to response to clinical care
- monitoring of PROs provides a way of ensuring patients access appropriate clinical care and can identify issues that are not being picked up using existing pathways / measures
- if shared between services, PROs may also provide a means to support coordinated care across the pathway of primary, secondary and tertiary care and may be used in shared care models
- PROs can also act as an important quality indicator and can be used to identify population-level needs.

Flexibility, scalability and sustainability

A model for PRO monitoring in clinical cancer care should be scalable and sustainable. Sustainability of PRO monitoring will rely on its incorporation into structured clinical pathways, ensuring that patients receive timely and appropriate feedback and care in response to identified issues

PRO monitoring models in current use in Australia are typically localised, and consideration of factors influencing scalability will be important as part of implementation. This will include measuring the cost-effectiveness of PRO monitoring as well as consideration of the system capabilities of different health settings, including primary, tertiary and allied care, and public and private settings. As PROMs are developed and implemented, it will also be important to strive for consistency in approach to avoid duplication and ensure that PRO data can be compared at a national level.

The model should also consider a variety of formats for the collection of PROs that can be implemented across various settings and are accessible to all patients. This may include paper-based tools, computer and app-based tools and telephone services.

Embedding PRO monitoring at different levels of cancer care

Participants explored specific considerations for implementation of PRO monitoring at each level of the cancer system (clinical / patient level, service level, system / policy level) as well as identifying how ongoing research can be facilitated.

The following pages summarise the outcomes of small group discussions during the Think Tank.

Embedding PRO monitoring at the clinical / patient level

What do we know for certain?	What are we ready to do now?
<p>We know that PRO monitoring at the patient level can:</p> <ul style="list-style-type: none"> • improve communication about, and identification of, a patient’s symptoms. • improve the patient–HCP relationship • help a patient feel empowered • standardise patient outcomes measurement • facilitate holistic/patient-centred care when a patient’s values and priorities are considered in treatment planning • allow healthcare professionals to focus on patient-identified issues • provide an optimal way to capture patient-identified issues where attempts to collect data outside of the patient record are likely to fail; this may facilitate understanding and interpretation of patient information across healthcare professions 	<ul style="list-style-type: none"> • Based on work by various state-based authorities in Australia, and overseas, we are in a position to identify a core recommended minimum set of PROs (e.g. symptoms, aspects of functioning) • We are ready to engage with consumer advisory groups to: <ul style="list-style-type: none"> ○ discuss the appropriateness and usefulness of a minimum set of PROs ○ identify what consumers consider to be appropriate in terms of ‘completion burden’ (e.g. how long consumers are willing to spend reporting PROs in different formats) ○ explore opportunities for advocacy ○ provide education about PRO monitoring, to better enable consumers to have informed input in decisions • We are ready to engage with professional societies to get buy-in and discuss opportunities for partnership.
What could benefit from collaboration?	What needs further research?
<p>Collaboration and partnership will enable us to:</p> <ul style="list-style-type: none"> • work towards making PRO monitoring a standard of care • decide on the instruments (PROMs) to assess the core recommended minimum set of PROs • develop education and training resources for HCPs • link to hospital accreditation • encourage buy-in from HCPs (e.g. through collaboration with Australian Medical Council and AHPRA) • develop a position statement in consultation with key stakeholders (e.g. health professionals, patient advocacy groups) and in partnership with other groups (e.g. Cancer Council) to lobby for funding and endorsement • develop an IT strategy for integration of a PRO monitoring system across multiple clinical settings 	<p>Further research is needed to determine:</p> <ul style="list-style-type: none"> • ‘add-on’ PROs required for specific cancer types • how best to implement PRO monitoring in various clinical settings • how best to evaluate the benefits of PRO monitoring and its implementation • the health economic implications of PRO monitoring in the clinical setting (e.g. modelling cost-effectiveness) • how to integrate PRO data from the patient-level into service-level and policy-level decision making

Embedding PRO monitoring at the service level

What do we know for certain?	What are we ready to do now?
<ul style="list-style-type: none"> • Clinical quality registries can improve overall care, but it can be challenging to capture the relevant data; PROs are likely to be easier to collect and the data will be useful to inform improvements in care • There appears to be growing consensus on the benefits of PRO monitoring • PRO monitoring addresses the need for a patient-directed quality indicator • PROs provide longitudinal data that can be monitored over time • PRO monitoring can formalise and focus the collection of data that is already occurring in an uncoordinated manner 	<ul style="list-style-type: none"> • There is an enthusiasm and willingness to come together (moving out of 'silos') to combine efforts and determine a minimum PRO dataset
What could benefit from collaboration?	What needs further research?
<p>Collaboration and partnership will enable us to:</p> <ul style="list-style-type: none"> • maximise available research funding • collaborate to determine the enablers and infrastructure needed to support an approach that works across IT systems • develop comparable datasets to enable benchmarking across services • present a united voice to policy makers about the need to consider cancer-specific PROs • determine what needs to be measured and how frequently • identify optimal and pragmatic models for implementation • determine how best to provide feedback to HCPs and health services in a constructive manner • consistently evaluate the outcomes and impact of PRO monitoring. 	<p>Further research is needed to:</p> <ul style="list-style-type: none"> • explore the collection and use of PROs in community care settings • determine what PROs are most relevant across the cancer continuum and how they may vary from diagnosis through to survivorship or end-of-life care • determine what makes a health service prepared to implement PROs (e.g. what is needed within a service for success?) • identify valid measures of quality, and how best to collect these measures in a timely manner • measure the benefits of implementation and feedback • better understand how quality and processes are improved • determine how best to ensure sustainability.

Embedding PRO monitoring at the system/policy level

What do we know for certain?	What are we ready to do now?
<ul style="list-style-type: none"> • Patients value HCPs supporting them to support themselves • Services are available to address the unmet needs of patients; however, HCPs do not always connect patients with these services • By collecting and using, PROs we are connecting patients to the services they need in a timely and efficient way that is cost-effective 	<p>As a starting point we are ready to:</p> <ul style="list-style-type: none"> • determine whether services can collect and report on PROs • define PROMs • develop a toolkit so people can select the appropriate PROM for their setting; the toolkit will help to promote a level of standardisation with a minimum dataset • use the Optimal Care Pathways as a framework for implementation through existing cancer networks
What could benefit from collaboration?	What needs further research?
<p>Collaboration and partnership will enable us to:</p> <ul style="list-style-type: none"> • gather data that already exist • use available data to support our value statement • articulate a case for funding and endorsement to support PRO monitoring as a standard of care. 	<p>Further research is needed to:</p> <ul style="list-style-type: none"> • develop a flexible PRO monitoring system (including tools) that can adapt to the cultural needs of patients • work out how best to build a vulnerability screen into PRO monitoring in order to ensure we are delivering appropriate care for the most vulnerable patient populations <p>As we undertake further research, it will be important to ensure that efficacy and implementation data are made available to ensure continual service improvement</p>

Research considerations for the implementation of PRO monitoring

What do we know for certain?	What are we ready to do now?
<ul style="list-style-type: none"> • Implementation research is a common denominator across all cancer types and survivorship. • There is some suggestion that data-derived research is not considered 'real research'. This suggestion needs further investigation. • There is no clear funding pathway for implementation research in cancer. The Medical Research Futures Fund (MMRF) and translational research centres may be potential funders 	<ul style="list-style-type: none"> • We are ready to implement screening for distress in cancer using validated and easy-to-use tools
What could benefit from collaboration?	What needs further research?
<p>Collaboration and partnership will enable us to:</p> <ul style="list-style-type: none"> • form an implementation research group focused on PRO monitoring • develop a forum to support a strategic approach to sharing of information, research and resources within the space 	<p>Further research is needed to:</p> <ul style="list-style-type: none"> • determine how to implement screening for distress in cancer nationally • determine how to undertake implementation across: <ul style="list-style-type: none"> ○ multiple patient populations with unique language, literacy and cultural considerations ○ multiple IT systems and delivery settings

Enablers for implementation of PRO monitoring

Enablers for implementation of PRO monitoring include:

- education of healthcare professionals to ensure the benefit and value of PRO monitoring is well understood
- pragmatic systems and tools to optimise PRO collection
- clinical champions and consumer advocates to help lobby for the endorsement and funding of a PRO monitoring model
- funding to ensure the sustainability of PRO monitoring
- connections and collaborations with Australian and international organisations working in this space to learn from each other and avoid duplication.

Throughout the Think Tank, a number of factors were identified as essential to the successful implementation of PRO monitoring in clinical cancer care.

Enabler	Detail
Education	<ul style="list-style-type: none"> • There is a need to educate HCPs on the benefit and value of collecting and using PROs, positioning PRO monitoring as an important aspect of patient care • Education should also extend to how to integrate a measurement tool such as a PROM into clinical practice • Education should be incorporated from the undergraduate level to continuing professional development
Systems and tools	<ul style="list-style-type: none"> • An easy-to-use, practical and automated system for PRO monitoring will be key to success • While it is acknowledged that one national PRO monitoring system may not be practical, there is a need to ensure clarity and consistency in the data collected across the multiple available systems • A national IT strategy should be developed in parallel with a PRO monitoring implementation strategy
Champions and advocates	<ul style="list-style-type: none"> • Clinical champions and consumer advocates have been invaluable in advocating for implementation of national initiatives, such as the development of Regional Cancer Centres • Clinical champions and consumer advocates are likely to play a vital role in helping communicate the importance of, and need for, PRO monitoring in clinical cancer care • A robust advocacy strategy will help deliver targeted and focused messaging about the benefits of PRO monitoring
Funding	<ul style="list-style-type: none"> • Funding will be vital to ensure the sustainability of a PRO monitoring system • Potential sources of funding identified by Think Tank participants include: <ul style="list-style-type: none"> ○ Government/ MRFF data and infrastructure funding ○ Partnership grant opportunities • Consumers will be valuable advocates to lobby the government for funding to 'bring the patient voice back into cancer care'

Connections and collaborations

Successful implementation of PRO monitoring will require collaboration with other groups working in this area, to enable the sharing of research and resources and avoid duplication. Think Tank participants identified a number of potential collaborators and partners, both in Australia and internationally.

Australian organisations	International organisations
<ul style="list-style-type: none">• National and State Cancer Councils• Cancer Institute NSW• Agency for Clinical Innovation (ACI)• Australian Commission on Safety and Quality in Health Care (ACSQHC)• Other healthcare quality and safety agencies• National Health and Medical Research Council (NHMRC)• Australian Digital Health Agency• Cancer registries	<ul style="list-style-type: none">• International Society for Quality in Healthcare (ISQua)• European Organisation for Research and Treatment of Cancer (EORTC)• International Society for Quality of Life Research (ISOQOL)• International Consortium for Health Outcomes Measures (ICHOM)• Institute for Clinical Evaluative Sciences (ICES)

Of note, among these potential collaborators:

- Cancer Council Australia is currently undertaking a project defining cancer data in Australia; a data summit is planned for 2019 and may provide a useful forum to discuss PROs
- ACSQHC have an advisory group on PROMs (not just focused on cancer care); engagement to avoid duplication and learn from each other will be important
- ACI is currently undertaking work in PRO monitoring within NSW (not in cancer care); cancer-specific PRO monitoring work will be undertaken by Cancer Institute NSW
- ISOQOL has a PRO research group that is currently conducting feasibility and implementation trials
- the annual NHMRC Symposium on Research Translation may be an appropriate forum to host an annual meeting to discuss and inform a national approach to PRO monitoring implementation research.

It was suggested that it may also be helpful to collaborate with ethics committees to provide them with greater understanding on how PRO data may be used in research and standard practice.

Recommendations

Implementation of PRO monitoring in clinical cancer care in Australia is a matter of system redesign. As such, it requires careful planning that positions PRO monitoring 'in place of' current patient data activities, as opposed to 'on top of' what is already being collected.

Think Tank participants outlined several recommendations about how to plan a coordinated approach to PRO monitoring in cancer care.

Key recommendations

- Build on the Think Tank momentum to form an action-oriented PRO working group, led by the COSA Survivorship Group, that can:
 - facilitate an engaged PRO community
 - continue to share learnings
 - inform a coordinated approach to PRO implementation research
 - champion a consistent approach to communication and advocacy around the benefits of PRO assessment in clinical cancer care.
- Develop the PRO implementation roadmap, to include:
 - a clear value proposition for routine PRO assessment in cancer care
 - a plan to harness learnings and data from state-based approaches to standardised collection of PROs in cancer care and chronic disease to support the value proposition
 - case studies and consumer stories
 - a business case with a clear 'ask' that recognises the value agenda and can be used effectively to advocate for funding and resources to support implementation of PRO monitoring
 - a communication plan
 - a plan for engagement with relevant organisations, including but not limited to consumer groups, through which to learn, share and jointly promote learnings and opportunities.

Next steps

COSA will present the Think Tank report at the next meeting of COSA Council (November 2018). The action-oriented PRO working group, led by the COSA Survivorship Group, will form a plan to action the key recommendations of the report. Those recommendations, where appropriate and within remit, will be built into the Survivorship Group's plan for 2019/20 to assist COSA's budget planning and resourcing process. In the meantime, COSA members and Think Tank participants are encouraged to continue to share ideas and learnings through the COSA Survivorship Group.

Acknowledgement

Funding for the COSA PRO Implementation Think Tank was provided through an unrestricted grant from MSD Australia.

Appendix I: Think Tank Agenda

Time	Session	Speaker / facilitator
8.45am	Arrival tea and coffee	
9.00–9.15am	Welcome and introductions	Bogda Koczwara Alison Evans
9.15–9.45am	What are PROs and what is the evidence that they work in practice?	Madeleine King
9.45–10.30am	PRO programs in practice: examples and lessons learned	Afaf Girgis
10.30– 10.45am	Morning tea	
10.45– 11.30am	PRO implementation – Key questions & issues for PRO-in-practice newbies	Bogda Koczwara
11.30am– 12.15pm	Discussion: What are our key implementation questions for PROs at patient, clinician, service and system levels?	Alison Evans
12.15– 12.50pm	Lunch	
12.50–1.00pm	Introduction to the group work	Alison Evans
1.00–2.00pm	Group work: Implementing PROs in cancer care <ul style="list-style-type: none"> • Group 1: Supporting clinicians in the collection and use of PROs as part of routine cancer care • Group 2: Supporting an integrated service-level approach to the collection and use of PROs as part of routine cancer care • Group 3: System and policy level requirements to achieve consistent, streamlined and cost-effective collection and use of PROs as part of routine cancer care • Group 4: Ensuring equity: applying PROs to different population groups – what do we need to consider? 	Small group discussion
2.00–2.40pm	Feedback and discussion	Alison Evans
2.40–2.55pm	Prioritising next steps – our action plan	Alison Evans
2.55–3.00pm	Closing remarks	Bogda Koczwara
3:00pm	Close	

Appendix II: Think Tank Participant List

Name	Affiliation
Meera Agar	University of Technology Sydney
Georgina Akers	Department of Health & Human Services Victoria
Antoinette Anazodo	The Sydney Youth Cancer Service
Sanchia Aranda	Cancer Council Australia
Shirley Baxter	Cancer Voices NSW
Ray Chan	QUT / Princess Alexandra Hospital Queensland
Richard Cohn	Sydney Children's Hospital / ANZCHOG
Meredith Cummins	Cancer Nurses Society of Australia - CNSA
Geoff Delaney	South Western Sydney Local Health District NSW
Haryana Dhillon	University of Sydney
Ivana Durcinoska	Ingham Institute for Applied Medical Research
Gail Garvey	Menzies School of Health Research Queensland
Craig Gedye	Calvary Mater Newcastle / NSW Statewide Biobank
Afaf Girgis	Ingham Institute for Applied Medical Research, UNSW
Hayley Griffin	COSA
Michael Jefford	Australian Cancer Survivorship Centre
Emma Kemp	Flinders Centre for Innovation in Cancer South Australia
Madeleine King	University of Sydney
Bogda Koczwarra	Flinders Centre for Innovation in Cancer South Australia
Eng-Siew Koh	South Western Sydney Local Health District NSW
Fiona McDonald	Canteen
Gillian Mackay	COSA
Marie Malica	COSA
Lesley Millar	University of WA Medical School
Caroline Nehill	Cancer Australia
Joel Rhee	PC4
Shelley Rushton	Cancer Institute NSW
Claudia Rutherford	University of Sydney
Sabe Sabesan	Townsville Hospital Queensland
Joanne Shaw	PoCoG
Janette Vardy	Concord Cancer Centre NSW
Kate Whittaker	Cancer Council Australia
Alison Evans	Facilitator, Alison Evans Consulting
Jen Henwood	Scribe, Henwood HealthComms

Appendix III: Summary of current PRO activity provided by Think Tank participants (provided with approval)

Activity	Who	What
Service-level PRO collection Research State-level plans	Meera Agar	PROMPT CARE (with NSW wide implementation being considered I think) STOP PAIN cancer trial - we can provide more detail if needed The challenge of those who don't speak English or can't read
Research State-level plans	Antoinette Anazodo, Sydney Childrens Hospital and Prince of Wales Hospital	Looking at implementing PRO prior to reproductive survivorship clinic Looking at implementing PROMPT Care study
Research	Ray Chan Princess Alexandra Hospital and Queensland University of Technology	MASCC is leading an international survey study to understand what people are doing with PROs collected in routine care (informing direct clinical care, research and benchmarking). I am also mentoring a post-doc to develop a symptom-monitoring app for paediatric patients, which will collect PROs as routine care, and prompt self-management and clinicians' responses. This study is funded and ongoing. In my organisation, there is an ongoing research project that screens patient distress and symptoms (and weight etc) for head and neck cancer patients in the waiting room. This is already in routine care. Based on PROs, referral alerts are generated to nursing and allied health staff. This online platform is currently being rolled out to all tumour stream.
Service-level PRO collection Research State-level plans	Meredith Cummins, CNSA and Unicorn Foundation	Neuroendocrine Tumours Clinical setting and online forums Paper & Electronic (app) Demographics include public / private, regional / rural Measuring financial toxicity and its impact, care delivery, partnerships, trust
Service-level PRO collection Research State-level plans	Geoff Delaney, South Western Sydney Local Health District and Ingham institute	We are performing PROMPT Care across four hospitals, all cancers across continuum of care We are exploring feasibility We are interested in developing a CALD solution Cancer Institute NSW are planning to rollout PROMPT Care across NSW
Research State-level plans	Gail Garvey, Menzies School of Health Research	We are funded by Cancer Australia to support the implementation of a culturally appropriate tool to assess unmet supportive care needs tool of Indigenous cancer patients. We are training staff in cancer care centres across Australia on how to use this tool and implement it into the usual care of cancer patients. We are developing a multi-attribute utility instrument to measure quality of life (and QALYs) for Indigenous Australians. The instrument will measure and value quality of life dimensions important to Indigenous people in a culturally appropriate and sensitive way.

Activity	Who	What
Service-level PRO collection State-level plans	Craig Gedye, Calvary Mater Newcastle	Trial with Haryana Dillon Implementation in standard care using VisionTree
Service-level PRO collection Research State-level plans	Michael Jefford, Peter MacCallum Cancer Centre	Clinical practice: <ul style="list-style-type: none"> • Electronic completion of health assessment questionnaire (all cancer types) • Paper-based distress screening (all cancer types) Research: <ul style="list-style-type: none"> • Paper-based screening for sleep problems (various cancers) • Paper based screening for fear of cancer recurrence / progression (melanoma) • Electronic assessment of survivor needs (breast cancer) Service/state-level activity: <ul style="list-style-type: none"> • Implementation of Epic EMR at Parkville (Peter Mac, RMH, RWH) • State-based focus towards routine screening for distress
Service-level PRO collection Research State-level plans	David Joske, SolarisCancerCare, Sir Charles Gairdner Hospital (SCGH), WA cancer Network Survivorship Collaborative	Plan is to collect PROs for users of Solaris. SCGH uses Press Ganey and Patient Opinion feedback. WA cancer Network is planning a large study to do this for the common cancers to refine models of care (PI Prof C Saunders). PROs are increasingly included in cancer drug and clinical trials.
Service-level PRO collection State-level plans	Dorothy Keefe, SA Cancer Service	As part of implementing an electronic prescribing system and EHR, we are building toxicity PROs into the systems (but it is slow work!) They are vital and need to be included in every service.
Research State-level plans	Madeleine King, QOL Office, University of Sydney	My research - at this stage I'm conducting a review of reviews of use of PROs in clinical care (with Claudia Rutherford), with the aim of synthesising the evidence and determining if there are certain characteristics of the setting, population and PRO data collection design (what PROMs, when, what is done with the PROM data by whom) are systematically linked with use of PROMs being more/less effective. Strategies in NSW – NSW Health has conducted pilots in numerous sites & settings, recently contracted an IT company to facilitate implementation across NSW Health.
Research	Bogda Koczwara	We are examining routine PRO collection in the setting of cancer survivorship but have not started this research as yet

Activity	Who	What
Service-level PRO collection Research	Eng-Siew Koh	Involved in roll-out and recruitment to PROMPT-Care project across range of tumour sites and phase of care
Research	Ian Olver University of South Australia	We are looking at PROs of the symptom clusters that are reported as nausea
State-level plans	Shelley Rushton Cancer Institute NSW	Implementing state-wide functionality to collect PROs (NSW)
Research State-level plans	Claudia Rutherford, University of Sydney	My fellowship project is looking at implementing PROs into bowel cancer survivorship. Relevant PROs will be collected electronically at planned time-points, and depending on responses provided, clinical pathways will be in place (high scores on PROs will be triaged to nominated clinicians, moderate scores will promote dissemination of online interventions or reading materials, and low scores will inform patients they are doing well and will be asked to completed surveys in the future).
Research	Christobel Saunders, University of Western Australia	The Continuous Improvement in Care - Cancer (CIC Cancer) Project is implementing a strategy involving consumers, clinicians, health services, and researchers to measure outcomes important to patients. Using the International Consortium for Health Outcome Measures (ICHOM) standard datasets, information will be collected, via a customised web-based informatics platform, that reflects both the disease process and patient reported outcomes. We believe this is the first time that this strategy has been implemented simultaneously across multiple hospitals in both the public and private healthcare sectors. Additional information from across the cancer care pathway (diagnosis, treatment, survivorship, end of life) will also be accessed. This will include results of procedures, processes, structures and systems. Evaluation of this information will identify key deficits in care pathways; seek to explain variations in health outcomes; generate and trial new interventions; and inform health service providers – directly improving the lives of people diagnosed with cancer.
Service-level PRO collection Research State-level plans	Joanne Shaw, PoCoG	Implementation research Electronic screening for anxiety and depression using ESAS/DT and HADs as part of the ADAPT program Using a portal managed by nursing staff Looking to incorporate integrated clinical pathways into the ADAPT portal which will utilise a wider range of PROs
Service-level PRO collection Research State-level plans	Janette Vardy University of Sydney, Concord Cancer Centre	Extensive PROs collected by paper for every patient attending Sydney Survivorship Centre. Post primary adjuvant treatment. Most common tumour types: colorectal cancer, breast cancer, upper GI cancer, lymphoma. All entered into RedCap database. This is now standard of care at Concord in Survivorship and less so in medical oncology in general. Participating in trial screening for distress.

Activity	Who	What
Service-level PRO collection State-level plans	Kathryn Whitfield, DHHS Victoria	Some tumour specific PROs collected within pilots/projects we fund. Population PREMs. Paper based.