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PATIENT REPORTED MEASURES CANCER SECTOR ENGAGEMENT

MOVEMBER, CANCER AUSTRALIA AND THE DEPARTMENT OF HEALTH, DISABILITY AND AGEING

Prepared for the Australian Real World Cancer Evidence Network (Pan Cancer Initiative) by Aspex Consulting

CONTENTS

LIST OF ABBREVIATIONS

ACCHO	Aboriginal Controlled Community Health Organisation
CALD	Culturally and linguistically diverse
CPD	Continuing professional development
CQR	Clinical Quality Registries
CT	Clinical Trials
EMR	Electronic Medical Record
HRQoL	Health-related Quality of Life
IT	Information Technology
PREM	Patient Reported Experience Measure
PRMs	Patient Reported Measures
PROMs	Patient-reported outcome measures

TERMS

Definitions are as follows:

Patient reported measures
(PRMs) capture information via surveys, which ask patients about their healthcare experiences and the outcomes of their care (Agency for Clinical Innovation n.d.). In this report, the term PRMs refers to PROMs and PREMs.

Patient reported outcome measures
(PROMs) are questionnaires that help patients to report on outcomes relating to their health. These questionnaires focus on various aspects of health, such as symptoms, daily functioning, and quality of life (ACSQHC n.d.[a]).

Patient reported experience measures
(PREMs) are questionnaires that systematically capture a patient's experience of treatment and care they have received. This can include questions about whether the patient felt cared for, whether information was easy to access, and aspects of clinician-patient interactions (ACSQHC n.d.[b]).

SUGGESTED CITATION

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EXECUTIVE SUMMARY

INTRODUCTION

This report, Patient reported measures – Cancer Sector Engagement, presents findings of a project commissioned by Movember, Cancer Australia and the Department of Health, Disability and Ageing. It involved a collaboration of cancer care experts across Australia to:

- Identify critical patient-reported outcome and patient-reported experience domains that are most important and relevant across cancer care.
- Discuss practical considerations for implementing these measures, including equity and inclusivity, to ensure sector-wide relevance.

The information gathered will feed into a core set of nationally agreed Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs), across all cancer types. This work builds upon the sector's existing research and development focus on PROMs and PREMs.

METHOD

The project involved co-design and planning of stakeholder engagement and workshop facilitation in collaboration with Movember and Cancer Australia, with the resultant thematic analysis and key findings summarised by Aspex Consulting in this report.

A total of 12 workshops, averaging ten participants per workshop, were conducted between February and March 2025. Participants from all Australian jurisdictions, with the exception of the Northern Territory, engaged in the workshops. The workshops comprised a broad range of cancer stakeholders – from clinical quality registries, health sector decision makers through to cancer care organisations, academic institutions, Aboriginal and Torres Strait Islander representative bodies and peak organisations.

A pre-reading document outlining the context and purpose of the consultations was distributed before each workshop. In facilitating workshops, Aspex Consulting commenced with a blank canvas, inviting participants to contribute views on those PROMs and PREMs considered relevant across all cancer types. These were captured in real-time on virtual 'post-it' notes using the collaborative online workspace, Miro. From this broad range of domains, participants were further encouraged to identify a short-list considered to be most important.

Workshops were recorded and transcripts. generated with consent, using Microsoft Teams. A rapid literature scan explored alignment of stakeholders' key themes with published evidence.

RESULTS

PROM domains

Workshop participants identified 12 PROM domains (bold text below) as important. A global measure of **quality of life** was prioritised, along with other domains related to quality of life including:

- **Psychological wellbeing –** The impact of cancer on patients' psychological wellbeing included distress, anxiety and depression. **Fear** was rated as an important domain in its own right.
- **Physical health and functioning –** Patients' physical health and functioning may be affected by disease symptoms and/or side-effects. In turn, this often impacts **activities of daily living.**
- **Social functioning –** Patients' social functioning is often adversely affected, impacting roles and relationships with family, friends and the workplace. Social isolation was highlighted as a risk.

The following symptoms are prevalent across most cancer types and ranked as important domains:

- **Pain –** Timely and standardised measures of pain levels are important.
- **Fatigue –** Fatigue's pervasiveness across cancer types was emphasised.
- **Cognitive functioning –** Cognitive impairment affects wellbeing and decision-making capacity.

A range of **other symptoms** included sleep disturbance, nausea neuropathy, vomiting, loss of appetite and nutritional impact to name a few. **Sexual function, sexual wellbeing and reproductive health** was considered important and an area infrequently measured.

Financial toxicity is an important domain, with financial hurdles faced by many patients including changes in employment, out-of-pocket treatment costs and other costs such as transport and parking.

The PROMs listed above were consistent with the findings of the literature scan.

PREM domains

There were eight main PREM domains (in bold text below) identified by workshop participants.

- **Information** should be timely, easy to understand, and relevant to patients' situation and preferences. It should be comprehensive without information overload. Information should be **culturally safe** for First Nations people and responsive to people from culturally and linguistically diverse backgrounds. It should reflect cultural nuances and be inclusive for people identifying as LGBTQIA+.
- **Communication** needs are multi-faceted. This includes allowing sufficient time, demonstrating empathy and respect, addressing patient health literacy, cultural safety and responsiveness and confirming communication needs/preferences are met – that patients feel they've been heard.
- Participants rated the **partnership** between patients and the healthcare treatment team as an important domain. Establishing the extent to which patients seek to be partners in their care is a key dimension.
- **Person-centred care** includes enabling patients' preferences and needs to be met, respecting dignity and canvassing their views about whether, and how, to include family members.
- Disparities in **access** to treatment can affect patient outcomes and experience due to treatment delays, lower rates of treatment uptake, travel burden and differential access to tertiary cancer treatment.
- **Coordination and continuity of care** is important, with many patient facing challenges navigating the healthcare system and interacting with multiple treatment providers and different care settings.
- **Support** was identified as a main domain. Needs include formal support (care navigators or cancer nurse specialists) and informal support (families, friends and peer support).

The PREMs listed above were consistent with the findings of the literature scan.

Barriers and facilitators of PRMs implementation

The barriers identified in workshops were identified along with corresponding facilitators.

- **Patient-related barriers –** These included physical or cognitive impairment and low levels of digital and health literacy. Facilitators included tailored support with multiple modes of completion.
- **System and organisational barriers –** These included a lack of integrated electronic medical records and inadequate IT infrastructure. Integration of PRMs within IT systems, EMRs and into routine workflows enables automation of PRM scheduling and timely access to PRMs.
- **Low clinical and professional engagement –** This can affect willingness or capacity to adopt PRM tools. A key theme was the importance for clinicians of accessing real-time, actionable data.
- **Regulatory and governance challenges –** These include legal, ethical, and cultural considerations, require clear governance guidance including acknowledgement of Indigenous Data Sovereignty.
- **Technological barriers –** Requires investment in integration, design, automation and user support.

The range of barriers listed above were consistent with the findings of the literature scan.

DISCUSSION

An extensive range of issues were raised in this consultation process with the cancer sector.

- **Generic domains –** In considering whether PRMs should be generic or specific to cancer types, the consensus was generic, supplemented by PRMs specific to individual cancer types.
- **Stage of cancer –** Whilst PRMs were considered relevant across all stages, there was a pragmatic agreement to focus initially on patients undergoing active treatment.
- **Age range –** Paediatric, adolescent and young adult populations have specific perspectives. Whilst acknowledging this, given scope considerations, it was accepted that the initial focus is on adults.
- **Equity –** A consistent theme from PRM discussions was the importance of equity. The financial impact of cancer on patients and their families, financial toxicity, was emphasised as was access.
- **Cultural safety and responsiveness –** Through co-design, PRMs need to be relevant to First Nations people and those from culturally and linguistically diverse backgrounds.
- **Inclusivity –** To avoid a hetero-sexual centric bias, more inclusive PRM questions are needed for cancer patients identifying as LGBTQIA+, enabled by co-design.
- **Barriers are not insurmountable –** Despite the identification of multiple barriers, at each workshop, participants were able to identify specific solutions to overcome challenges.
- **Interdependencies between solutions –** The more that PRMs are embedded into workflows, the greater the clinical engagement; as leadership embraces PRMs, the tighter the link to governance.
- **Multiple levels –** PRMs are relevant at a clinician, health service and system level.

CONCLUSION

The findings from this project provide a strong foundation for the development of a nationally consistent approach to implementing patient-reported outcome and experience measures in cancer care. By identifying priority domains and exploring the real-world barriers and enablers to implementation, this work offers practical insights to inform future work. Continued collaboration across clinical, policy, consumer, and research sectors will be key to ensure PRMs are meaningful and embedded in routine practice to improve care and outcomes for all people affected by cancer.

CHAPTER 1

CONTEXT, OBJECTIVES AND ENGAGEMENT

1.1 CONTEXT

This project focused on Australia-wide collaboration of cancer care experts to identify the most important domains of generic (non-disease specific) cancer outcomes and experiences. The information gathered will feed into a core set of nationally agreed Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs), across all cancer types.

1.2 OBJECTIVES

The objectives of the project were to:

1. Gather the perspectives and insights from diverse stakeholder groups regarding the domains or concepts and how they would be able to benefit from collection of generic PROMs and PREMs.
2. Create an open discussion on the key discovery phase topics allowing stakeholders to voice their opinions, concerns, and suggestions. The key topics related to PROM and PREM domains, barriers and facilitators to implementation.
3. Support the identification of key areas for consensus, including, but not limited to, PRM domains, frequency of PRM completion, and methods of delivery, through structured discussions.

1.3 METHODOLOGY

The project methodology involved three phases as outlined in **Table 1-1** on page 9.

Planning phase

The purpose and scope of the stakeholder engagement with the cancer sector was defined in a project work plan with the overall project goal 'to co-facilitate a comprehensive discovery phase to understand perspectives and insights … with a focus on generic patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) for use in cancer care'.

A stakeholder engagement plan defined the breadth of stakeholders relevant to the consultation and was confirmed with Movember and Cancer Australia. The scope of stakeholders included:

- Researchers including representatives from research institutes, academic healthcare settings and various Clinical Quality Registries across different cancer types.
- Health care service executives and decision makers within facilities delivering cancer care.
- Multidisciplinary healthcare team members including but not limited to oncologists, nurses, allied health professionals, and other clinical staff involved in cancer care.
- Representatives from organisations advocating for people with lived experience of cancer and survivors.
- Policy makers, program managers, and data specialists from state and Commonwealth Government health departments.

A pre-reading document sent to all stakeholders in advance of the workshops provided context, outlining the challenges and opportunities for Australia's PRM landscape together with the proposed path to establishing a nationally agreed set of PRMs.

Table 1-1: Project phases

Planning Phase	Engagement Phase	Analysis & Reporting Phase
Engagement Design: Dates and times for twelve, two-hour workshops were set throughout February and March 2025.	**Conducting Workshops**: Facilitated workshops were conducted via Microsoft Teams transcripts.	Thematic analysis of workshop input.
Stakeholder registration: Cancer Australia and Movember sent Expressions of Interest sent to stakeholders. Interested participants registered via Snapforms (online form builder and survey tool) and were provided with pre-reading material.	**Recording workshops**: Through Microsoft Teams transcription.	**Draft Report** of findings. **Rapid literature scan.**
Pre-reading material: Registrants were provided with pre-reading material. This included an overview of the purpose and context of the project including an overview of the Australian Real World Cancer Evidence Network; benefits of PRMs, a description of Australia's Current PRM Landscape: Challenges and Opportunities; Barriers and Facilitators to PRO Integration; and outline of the Journey to a Core Outcome Set; and key definitions of PROMs and PREMs.	**Note taking**: Through Miro virtual whiteboard.	**Final Report** of findings.

Two workshop objectives were outlined:

1. Identify critical patient-reported outcome and patient-reported experience domains most important and relevant across cancer care.
2. Discuss practical considerations for implementing these measures, including equity and inclusivity, to ensure sector-wide relevance.

Engagement phase

Based on the broad categories of in-scope stakeholders, a detailed list of individuals from these stakeholder groups was provided to Aspex by Movember and Cancer Australia. Stakeholders were invited to nominate their interest and availability for two-hour workshops across a nominated range of dates and times. This process provided options and flexibility to enable a diversity of representation.

Size of workshops

The average group size for each workshop was 10 participants, ranging from 4 to 15 in attendance.

Geographic focus

The geographic spread of organisations represented by participants is shown in **Table 1-2**, with the majority of participants (42%) from organisations having a national role, followed by Victorian (22%) and NSW (21%) organisations. Fewer participants were from organisations in South Australia (6%), Queensland (3%), Western Australia (2%), Tasmania (2%) and the ACT (2%). There was no representation from the Northern Territory (although invitations were made).

Participants by sector

Participants represented a broad range of the cancer sector. **Table 1-3** shows that just under one third (31%) of participants were from the research sector, 17% from peak bodies, 13% from health services, 8% from clinical quality registries, 8% from industry organisations, 7% from jurisdictional cancer registries, 5% from integrated cancer services and 3% from Aboriginal Controlled Community Health Organisations (ACCHOs). Appendix 3 lists the organisations with which participants were associated.

Participants by role

Most participants (59%) occupied leadership positions, of these 5% having roles as chair/CEO and 54% roles as managers, directors or coordinators. Most participants occupied leadership roles and were also clinically qualified. A further 15% of participants were professors/associate professors. Aside from these leadership/professorial roles, 15% of participants were research associates/fellows, 4% clinical consultants and 3% medical oncologists (noting that medical oncologists were also represented in leadership and professorial roles). The listing of participants according to their role was based on the primary role identified by participants at workshops.

Workshop facilitation

Aspex facilitated each of the 12 two-hour workshops, which commenced with an overview of the project's purpose and context by representatives from Movember and Cancer Australia. Each workshop was recorded using Microsoft Teams with participant consent.

- **Patient age cohorts**
  At a number of workshops, participants queried whether there would be separate PRMs developed for paediatric and young adult, adult and aged populations. It was noted that the focus of the current project was on adult populations.
- **Workshop structure**
  The workshop discussions commenced with a discussion by participants of their views on the main PROMs and PREMs that were considered important. This discussion was open-ended, with participants encouraged to nominate any domains that they considered relevant to the discussion. In most workshops, participants were also encouraged to prioritise the domains they felt were of overwhelming or very high importance. Through the use of Miro online collaboration software, the facilitators used virtual sticky notes in real time to record the discussion of the main PRMs nominated by participants. This enabled participants to have constant access to the domains being discussed and to review their thoughts on how each was prioritised.

  On average, each workshop generated around 10 to 15 domains for both PROMs and PREMs, with some domains such as 'access' appearing in both categories. Rather than duplicating domains between PROMs and PREMs, the domains that were mentioned as both a PROM and a PREM were assigned to the most appropriate category.

  Once participants had nominated a list of PRMs, the facilitator asked participants to identify a subset of those considered to be of highest priority. This typically generated a subset of 5 to 10 highest priority domains. In the second half of the workshop, participants were asked to consider the main barriers and facilitators relevant to the development and implementation of PRMs. Miro was used to identify barriers and facilitators in real time with virtual sticky notes.

Analysis and reporting phase

Aspex undertook a thematic analysis of the workshop transcripts. This enabled an identification of the range of domains across PROMs and PREMS. The domains were reviewed in terms of frequency of mention across the workshops and also through consideration of those domains prioritised by participants as highly important. This yielded a list of PROMs and PREMs categorised in this report as 'main domains' and a group of 'supplementary domains'.

In addition to the thematic analysis, Aspex undertook a rapid literature scan to contextualise participants' perspectives with recent research evidence. The review was undertaken using Google Scholar and key search terms were based on the domains identified for PROMs and PREMs and the identified key barriers and facilitators.

Table 1-2: Geographic focus of participants' organisations

Geographic focus	Participants (no.)	Participants (%)
National	51	42.1%
Victoria	27	22.3%
New South Wales	25	20.7%
South Australia	7	5.8%
Queensland	4	3.3%
Australian Capital Territory	3	2.5%
Tasmania	2	1.7%
Western Australia	2	1.7%
Total	**121**	**100.0%**

Table 1-3: Participants by sector

Sector/organisation type	Participants (no.)	Participants (%)
Research	37	30.6%
Peak body	21	17.4%
Health service	16	13.2%
Clinical Quality Registry	10	8.3%
Industry	10	8.3%
Cancer registry	9	7.4%
Government	8	6.6%
Integrated Cancer Services	6	5.0%
ACCHO	4	3.3%
Total	**121**	**100%**

Table 1-4: Participants by role

Role/position	Participants (no.)	Participants (%)
Manager/Director/Coordinator	65	53.7%
Associate/fellow	18	14.9%
Professor, A/Professor	18	14.9%
Chair/CEO	6	5.0%
Clinical consultant	5	4.1%
Medical oncologist	4	3.3%
Senior project officer/senior advisor	3	2.5%
Volunteer	2	1.7%
Total	121	100%

CHAPTER 2

PATIENT REPORTED OUTCOME MEASURES

2.1. PRELIMINARY DISCUSSION

2.1.1. Main domains

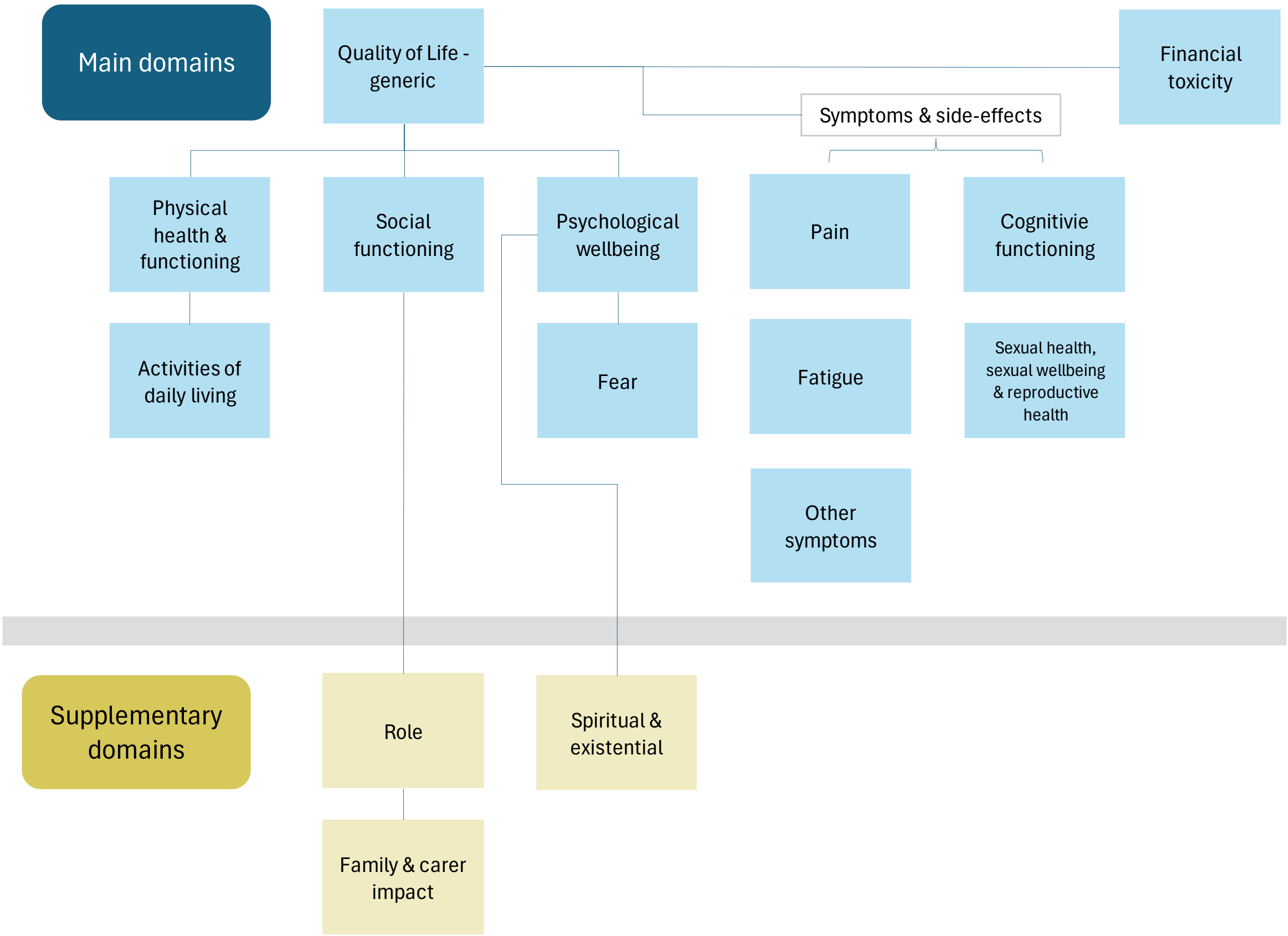
There were 12 domains consistently identified as **important PROMs.** Identified as important in more than half the workshops, these are shown in blue text boxes in **Figure 2-1**.

2.1.2 Supplementary domains

There were three supplementary domains identified:

- Role limitations (identified in 6 workshops)
- Family/carer impact (identified in 5 workshops)
- Spiritual and existential needs (identified in 4 workshops)

Figure 2-1: PROM domains identified as main and supplementary



2.2 DESCRIPTION OF MAIN PROM DOMAINS

1. Quality of life

Quality of life was seen as an important domain. It was described as an all-encompassing global measure of the impact of cancer on patients. Almost all workshop participants identified quality of life as important, although there were concerns that this domain was not sufficiently granular and would not provide clinicians with specific information that could assist them to improve care for patients.

Building on the broad support for a generic quality of life measure, participants emphasised separate sub-domains of quality of life:

- psychological
- physical
- social

The inclusion of a global quality of life (QoL) measure together with other sub-domains (psychological, physical, and social) is consistent with the original conceptualisation of Health-Related Quality of Life (HRQoL) (Wilson et al., 1995). More specifically, HRQoL is typically described as comprising five components: symptom status, functional status, biological and psychological variables, general health perceptions and overall quality of life (Leysen et al., 2025). Measuring HRQoL for cancer patients is considered pivotal to optimal patient-centred healthcare (Fiteni et al., 2011; Piccinin et al., 2025).

2. Psychological wellbeing

The adverse impact of cancer on patients' psychological health and emotional wellbeing was a consistent theme, with several dimensions discussed.

Distress was identified as a common experience for patients at different stages of the cancer journey: following a diagnosis of cancer, during cancer treatment and into survivorship. Distress was often linked to fear, a domain that was considered an important component of psychological wellbeing and an important domain in its own right. Understanding patients' distress was considered important, particularly as there are effective interventions in assisting patients with high levels of distress.

Anxiety and depression were identified as key aspects of psychological health that are more prevalent for patients who have received a cancer diagnosis and are undergoing cancer treatment. Hence, the importance of facilitating access to mental health support for patients experiencing anxiety and depression. As a case in point, the Psycho-oncology Co-operative Research Group (POCOG) has tested implementation of a clinical pathway for anxiety and depression based on distress screening.

Regret was identified as another element of psychological wellbeing. This included regrets over past behaviours, such as in the case of melanoma, exposure to sunshine or, for lung cancer patients, their history as a smoker. Regret was seen to influence a patient's 'psychological healing' going forward.

Consistent with workshop feedback, there is evidence that PROMs have proven particularly useful in identifying psychological distress, anxiety, and depression among cancer patients, enabling timely psychosocial interventions (Luckett, Butow & King, 2009). Furthermore, Nguyen et al. (2020) highlighted that emotional wellbeing is often overlooked in clinical assessments, and PROMs offer a structured method to uncover these needs. Studies show improved mental health among patients who received real-time feedback and support following PROM submissions (Govindaraj et al., 2023).

3. Fear

Linked to psychological wellbeing, fear was identified as important, particularly in relation to patients' fear of recurrence or progression of cancer. Some referred to 'scanxiety' to describe the fears patients have when awaiting scan results. For others, fear was reported to be associated with uncertainty about a patient's prognosis or the impact of the disease on them and their family or, more generally, fear of the unknown. Fear through all phases of treatment and testing was also raised.

Participants often listed fear when discussing the impact on patients' psychological health and emotional wellbeing. Some distinguished between general distress and patient experience of fear.

> *Fear … deserves to be listed separately from distress more broadly.*
>
> ACADEMIC, WORKSHOP 6

Participants felt that there may be value in including fear as separate domain as it is seldom addressed explicitly. Including this domain could enable patients' needs to be better understood and supported.

> *That's where the true value of PROMs is. It's starting conversations that don't routinely happen otherwise.*
>
> ACADEMIC, WORKSHOP 10

The evidence confirms that patients with cancer have elevated levels of anxiety, 10.3% meeting clinical criteria for an anxiety disorder and 19.4% for an adjustment disorder (Mitchell et al., 2011). Anxiety is also experienced below diagnostic criteria levels. This can include fear of cancer recurrence (FCR) or progression, with 22% to 87% of survivors of cancer reporting moderate to high FCR, and 0% to 15% reporting high or clinical levels of FCR (Tauber et al., 2019). A systematic review of the effectiveness of psychological interventions to support patients with fear of cancer recurrence found a small improvement for patients that was largely sustained at follow-up (Tauber et al., 2019).

4. Physical health and functioning

The impact of cancer on patients' physical health and functioning status was considered important. Side-effects as well as disease progression can lead to lower physical health. In turn, changes in physical function may impact patients' mobility and their capacity to undertake activities of daily living.

> *We know that physical activity levels can really impact on a person's response to treatment and even independence.*
>
> CHAIR/CEO, WORKSHOP 10

Participants also commented that at different stages of cancer treatment, declines or improvement in physical health and functioning may occur. This reinforced the importance of considering outcome measures as dynamic, with changes to be expected over the course of a patient's treatment. A further comment was made that patients' comorbidities – either physical or mental health conditions – have a strong influence on patient outcomes.

Physical function is a commonly assessed domain within PROM measures and a key endpoint that is measured in cancer clinical trials (Coles et al., 2024a; Schurr, 2023). A study of patients' perspectives of the most important aspects of physical function identified the following five facets: ability, difficulty, limitation, satisfaction, and completion (Coles et al., 2024b).

5. Activities of daily living

Closely linked to physical health and functioning, the impact of cancer on patients' ability to undertake activities of daily living was frequently discussed. Some considered this to be a proxy measure for the effectiveness of control of symptoms such as pain, muscle strength or shortness of breath.

> *Just people's ability to you know, do work around the house, continue to work, those sorts of things. That's often a good proxy for how burdensome their treatment is and what supports they need.*
>
> ASSOCIATE/FELLOW, WORKSHOP 9

The domain 'activities of daily living' (ADL) is closely related to the domain of physical function. One participant emphasised the need for definitional clarity to distinguish between basic ADLs (bathing, dressing, eating, toileting and transferring between sitting and standing) and instrumental ADLs (tasks to maintain a higher level of independence (managing finances, shopping, meal preparation, etc).

> *Instrumental ADL are the things that if preservation of independence is an outcome measure, we really want, then they're the things that you do for yourself over and above eating, toileting and dressing.*
>
> ACADEMIC, WORKSHOP 12

The point was made that during treatment, many patients' day-to-day functioning can be adversely affected. Despite this, some considered that ADL outcomes for patients are not routinely measured.

A systematic review of the impact of cancer on patients' functioning show that 36.7% of patients reported disability related to basic ADLs and 54.6% of patients reported challenges with instrumental activities of daily living (Neo J et al., 2017). There is some evidence of the efficacy of rehabilitation interventions to support patients' functioning (Sleight A et al., 2022).

6. Social functioning

Social dimensions of quality of life were considered important for patients. Participants highlighted a range of potential social impacts for patients including impacts upon relationships with their partner, family members and friends, and their connection to the workforce and the community.

> *Social support or perhaps even more importantly, social isolation, knowing that predicts quite negative outcomes when somebody's experiencing high levels of social isolation.*
>
> ASSOCIATE/FELLOW, WORKSHOP 6

Other domains raised by participants link closely to social functioning: 'role limitations', 'support', and 'cultural safety and responsiveness'. Each of these domains is discussed separately.

The literature supports the association between social support and improved health related quality of life among adult cancer survivors (Gudina et al., 2021; Hurtado-de-Menoza A et al., 2022; Ruiz-Rodríguez et al., 2022).

7. Pain

The impact of pain was rated as a highly important domain and may be associated with treatment side-effects and/or the impact of cancer. Participants consider that pain is a common symptom across cancer streams. It is important for both patients and the care team to have timely and standardised measures of patients' level of pain.

Despite the widespread experience of pain as a symptom of cancer, patients' pain responses are highly variable. For this reason, reporting on patients' pain needs to be attuned to differences between patients' reporting of their levels of pain. Others commented that there are lots of different types of pain, caused by multiple aspects of cancer and its treatment.

> *If you ask a general question about pain, it can mean very different things to different people. So for example, there's lots of different types of pain. There might be pain caused by multiple aspects of cancer and its treatment.*
>
> ACADEMIC, WORKSHOP 9

There are flow-on consequences for patients experiencing pain on other domains. Participants identified the impact on psychological wellbeing, linking experience of pain with psychological distress and depression, quality of life, physical and social functioning.

> *It's a big issue. It can cause a lot of psychological distress as well as physical. It can be interpreted in lots of different ways and can stop people from engaging in work. So, it seems to be classed with a lot of other poor outcomes.*
>
> ACADEMIC, WORKSHOP 10

Studies confirm that pain is one of the most common symptoms suffered by cancer patients and that there is variation in the extent to which patients' pain levels are effectively managed due to the lack of routine measurement and monitoring (Abahussin A et al., 2019). For this reason, measures of patient reported pain are recommended for inclusion within PROMs (Di Maio et al., 2022; Bhatt K et al., 2024) with evidence from a systematic review that improved patient-clinician feedback about pain levels can improve pain control and lead to a reduction in pain intensity (Adam R et al., 2017).

8. Fatigue

Fatigue was frequently identified as a generic symptom for many cancer patients. Often linked to the side-effects of treatment as well as the impact of cancer, it has a flow-on impact on patients' health-related quality of life and their everyday functioning. Its pervasiveness and experience across cancer types was a reason for including this specific symptom as a main domain.

> *I think it's probably the most universally experienced symptom. In my experience, very debilitating impacts a lot of other aspects of health.*
>
> ASSOCIATE/FELLOW, WORKSHOP 9

Cancer-related fatigue is reported to be one of the most common symptoms of cancer, affecting 65% of patients with cancer (Fabi A et al., 2020) and affecting quality of life (Xu J et al., 2025). Compared to other types of fatigue, cancer-related fatigue is reported to be more severe and persistent, leading to emotional, physical and cognitive tiredness or exhaustion (Weber D and O'Brien K, 2017). Fatigue has a disproportionate impact on patients' capacity to undertake activities of daily living (Lawrence DF, 2004).

9. Cognitive functioning

Participants identified that one important and often distressing symptom of cancer treatment may be a reduction in a patient's cognitive functioning. This can compound other challenges particularly in relation to patients' capacity to comprehend the range and complexity of information associated with cancer treatment. It may influence a patient's decision-making capacity. Subsequently, patients may experience 'decisional regret' over their earlier treatment decisions.

> *Certainly, we know that people find it highly distressing, not being able to think clearly. And we also know that it in very real terms, it impacts treatment and decision-making capacity.*
>
> ASSOCIATE/FELLOW, WORKSHOP 7

Other consequences of a change in cognitive functioning included the potential impact on patients' work capacity. For patients with careers involving a high level of cognitive functioning, this impact can have a disproportionate effect on their preparedness and capacity to return to work. It was noted that standardised measures of cognitive functioning may not be sensitive to the impact of such changes, with patients still scoring in the normal range. For the individual patient, the point was made that it is their own perception and sense of loss of cognitive function which can be most distressing.

Studies have identified that cancer patients frequently undergo cognitive decline, with cognitive changes most commonly affecting attention, memory, and executive functioning (Oliva G, 2024). The causes for cognitive impairment are unclear and may be a combination of the effects of cancer, the associated treatments, co-morbidities and other non-specific factors (Pendergrass JC, 2018).

10. Sexual function, sexual wellbeing and reproductive health

Across most workshops, the potential adverse impact of cancer and cancer treatment on an individual's sexual function, sexual wellbeing and reproductive health was identified as highly important for many patients. Participants commented that this can be more pronounced for some cancer types including prostate cancer, genito-urinary cancer, ovarian cancer, and breast cancer.

> *Just a broader comment, you know around sexual function. I think we know it impacts, you know, to some degree most people with cancer regardless of the site of cancer but it's often undetected.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 7

Participants highlighted that the domain was inherently a sensitive topic and tended not to be routinely included in outcome measures. This was understood to reflect a general reluctance by healthcare professionals to seek to discuss such a personal topic with patients. Despite this, it was felt to have a high impact on patients' emotional wellbeing. The relative lack of reporting was a strong rationale for its inclusion and to encourage greater awareness by clinicians of its importance for patients.

> *We often don't get data around it, and I think there's high unmet need that's just been missed at the moment because it's not typically measured or asked.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 7

Participants drew a distinction between sexual function and sexual wellbeing, highlighting that there may also be changes faced by patients more generally in relation to sexual intimacy and their relationships with partners. These changes may be influenced by symptoms of cancer such as pain and fatigue as well as other changes such as body image or concerns related to post-surgical recovery. The point was made that changes in role can also influence sexual relationships.

> *So, the quality of the relationship… once you've been a carer for someone or you've been cared by someone, it can, you know, it's very hard to be find that person a sexual being at times.*
>
> ASSOCIATE/FELLOW, WORKSHOP 10

Participants also considered that for people identifying as LGBTQIA+, there may be an even lower likelihood for open discussion about sexual function, sexual wellbeing and reproductive health. This was said to reflect a typically heterosexual-centric approach in most healthcare settings.

Reproductive health was identified as important. Participants indicated that this would be likely to include consideration of whether patients' fertility needs were addressed, including fertility preservation before treatment started or access to a fertility specialist to discuss those issues.

Studies confirm the importance attached to sexual health and reproductive health for cancer patients and yet despite their importance, these issues are seldom discussed with patients (Gerstl et al., 2024; Obergugenberger AS, 2024). For some cancer types, such as ovarian cancer, PROM tools include questions about sexuality (Lefkovits YR et al., 2024).

11. Other symptoms and treatment side-effects

A variety of other symptoms and treatment side-effects were identified, including some more relevant to different cancer types:

- Sleep disturbance
- Nausea
- Neuropathy
- Appetite
- Nutritional impact
- Vomiting
- Weight loss
- Muscle wasting
- Body image

Participants noted that specific symptoms are typically associated with different cancer streams. It was felt that having a detailed list of symptoms – such as those listed above – was unlikely to be relevant for the generic measures of PROMs.

One workshop considered that rather than asking about specific symptoms, it may be more appropriate to ask the question 'how well were your symptoms managed?'

In another workshop, the point was made that there is not necessarily a link between the presence of symptoms and needs. Patients may have symptoms that may not adversely affect their health and wellbeing. However, they may well have unmet needs and gaining an awareness of these needs is highly relevant to understanding the impact of cancer and treatment on patients' health and wellbeing.

> *So, if we only focus on symptoms, then we miss people's needs.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 5

Another participant emphasised the importance of identifying unmet needs as a way of triaging appropriate support and interventions tailored to an individual patient's needs.

> *We've moved a lot of our focus towards unmet needs in clinical populations as the most appropriate tool in which to guide clinical, you know triage conversations for patients with different types of cancers.*
>
> ACADEMIC, WORKSHOP 5

In a similar vein, one participant suggested it could be useful to have a blank unspecified domain such as 'other' to allow patients to nominate other things that are important to them.

> *Can you tell us three things that are important to you or something like that. We found in analysis of those data really, really telling insights into what's going on for people.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 4

This was echoed in another workshop with the suggestion for a generic needs-based question.

> *Are you having any side effects, physical or mental that are negatively affecting your life?*
>
> ASSOCIATE/FELLOW, WORKSHOP 12

Some identified longer term or latent effects of treatment, such as reproductive impact. These impacts were identified as having major consequences for patients. However, there is a challenge in identifying these impacts given that the latency period may be outside the PROM measurement period.

Studies have shown an association between monitoring of patient reported symptoms and improvements in HRQoL, survival rates and cost-effective healthcare utilisation (Lizán L et al., 2021). The positive impact of monitoring PROMs on HRQoL and survival rates was confirmed in a systematic review by Baliktisky AK et al. (2024) but they did not find any impact on healthcare resource utilisation (ED visits and hospitalizations). The rationale for inclusion of patient-reported outcome measures of symptoms is that there is often a discrepancy between clinicians' awareness of patients' symptom levels and severity compared to patients (Balitsky AK et al., 2024; Di Maio et al., 2021). Routine symptom monitoring through PROMs can improve patient/provider communication, help to monitor treatment response, and identify unrecognized problems (Montgomery et al., 2020).

The option suggested in one workshop to include an open-ended PROM to include additional patient-identified needs or concerns beyond the standard item list reflects a recent innovation in relation to PROMs. The 'Write in Three Symptoms/Problems' (WISP) measure expands the standard PROM domains/item lists to include up to three additional patient-identified needs or symptoms. WISP is relevant to settings where shorter PROM questionnaires are used including for novel therapies or early phase trials where unexpected adverse events may occur (Rojas-Concha L et al., 2024).

12. Financial impact

The financial challenges experienced by patients and their families – or financial toxicity – was frequently identified as a highly important outcome for patients undergoing cancer treatment. These challenges were multi-faceted and included issues around affordability of treatment due to out-of-pocket costs and travel costs. Financial impact was heightened for patients in regional, rural and remote areas given the additional burden experienced when travelling to city-based health services.

> *With PROMs and PREMs, we often have a focus on clinical and quality of life outcomes. But we don't always capture the barriers to care itself. Such as the financial costs and travel burdens and service availability, particularly in rural areas.*
>
> ASSOCIATE/FELLOW, WORKSHOP 9

Participants commented on the broader financial impact experienced by patients and families due to the potential for reduced or discontinued participation in paid employment. The financial impact can be substantial for families who are challenged by the dual impact of lower household income and the additional costs that may be experienced directly and indirectly from seeking treatment.

> *We can't ignore the financial toxicity of cancer that's … impacted every stage. Not being able to work, not being able to return to work, careers halted and all of that. I think that's really important.*
>
> VOLUNTEER, WORKSHOP 9

This domain is also related to the domain of 'support', such as gaining access to financial support through Centrelink and other supports such as subsidised transport and accommodation options.

Several studies have identified the association between worse financial outcomes for cancer patients and lower health-related quality of life (Ngann TT et al., 2025; Coroneos CJ et al., 2021; Perry LM et al., 2019; Pangestu S and Rencz F, 2023).

2.3 DESCRIPTION OF SUPPLEMENTARY PROM DOMAINS

Role limitations

Role was identified as important, particularly the impact on patients' role in different aspects of their lives – their role within the family, within the workplace and within their community.

This domain is closely linked to the domain 'social functioning'. In discussions about 'role', several related elements were raised. Partly there are challenges that patients and families face when a patient's role changes, reflecting changes in their capacity to do key activities such as paid work, housework or childcare. There is an impact for families when patients withdraw, partially or fully, from these roles, with consequences in terms of financial support or support with practical tasks.

Additionally, for patients coming to terms with their changed role, whether temporary or ongoing, this can often have a major impact on their identity and emotional wellbeing.

> *So if they're no longer able to carry out the typical roles that they've had in the past – having to hand that over to someone else to assist them, if that's needed – can be quite challenging because a lot of people do associate, you know, the things that they do, their ability to work as well with their own identity. So that kind of role identity change seems to be quite a big thing for us.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 2

Studies have confirmed that factors such as finances, employment and responsibility for caring for dependants (e.g. children and elderly relatives) can affect the well-being of cancer survivors, although there is insufficient research into the impact of cancer on patients' everyday roles and responsibilities is limited (Catt S et al., 2017). One systematic review identified a number of cancer-related symptoms consistently associated with inferior work outcomes among cancer survivors. Body image issues and oral dysfunction were associated with lower employment rates, with fatigue and depression linked to lower levels of work performance (Tan C, 2022).

Family and carer impact

Many participants highlighted the flow-on impact of a cancer diagnosis and treatment on patients' families and carers. This included the impact of emotional distress as well as additional impacts associated with changes in a patient's role in the family, in the workforce and other areas. This domain is related to other domains such as 'Social functioning' and 'Support'.

> *One of the key things and this goes not just for Indigenous peoples, but I guess when I've cared for people with cancer in a clinical setting or in a community setting, is very much the carer and family stress. And I think there's not enough emphasis on and it goes a bit to that social connection, that peer connection and all that sort of stuff. But we really need to actually strengthen our models of care.*
>
> CLINICAL CONSULTANT, WORKSHOP 12

Studies of families' and carers' roles in supporting patients with cancer have confirmed the pivotal role they play, which is increasing with the trend towards home-based settings of care. Key challenges for families and carers identified by Harrison et al. (2021) were: dual burden of providing clinical care and managing personal emotional distress; navigating healthcare partnership dynamics; developing a caregiving skillset; and unique supportive needs and barriers to access. Strategies to support the role of family caregivers are emphasised, which include taking into account caregivers' needs so that they can be effective and maintain their own well-being (Berry LL et al., 2016).

Spiritual and existential needs

Many participants commented on the importance of patients' spiritual and existential needs.

> *Often one of the key things to dealing with the anxiety and the depression and you know coming to terms with having cancer, let alone potentially terminal cancer, is having that access to spiritual guidance, whatever form that might take.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 10

Some emphasised the interdependency between spiritual and cultural care needs of patients.

Studies have shown the importance of addressing the spiritual and existential needs of cancer patients, with such needs elevated in the first six months after diagnosis (Stripp TA et al., 2025). Recognising patients' spiritual needs and enabling them to deal with their needs is an important role for the healthcare team (Grant E et al., 2004).

2.4 TIMING OF COMPLETION

In several workshops, participants emphasised that careful consideration be given to the stage of cancer when defining and collecting PROMs. There are likely to be differences in PROMs over the disease trajectory and so it is important to delineate disease stage when PROMs are collected.

> *I would contend that the issues are different during treatment compared to during survivorship.*
>
> ACADEMIC, WORKSHOP 6

CHAPTER 3

PATIENT-REPORTED EXPERIENCE MEASURES

This chapter summarises the main domains and supplementary domains identified by workshop participants in relation to patient-reported experience.

3.1 PRELIMINARY DISCUSSION

3.1.1 Main PREM domains

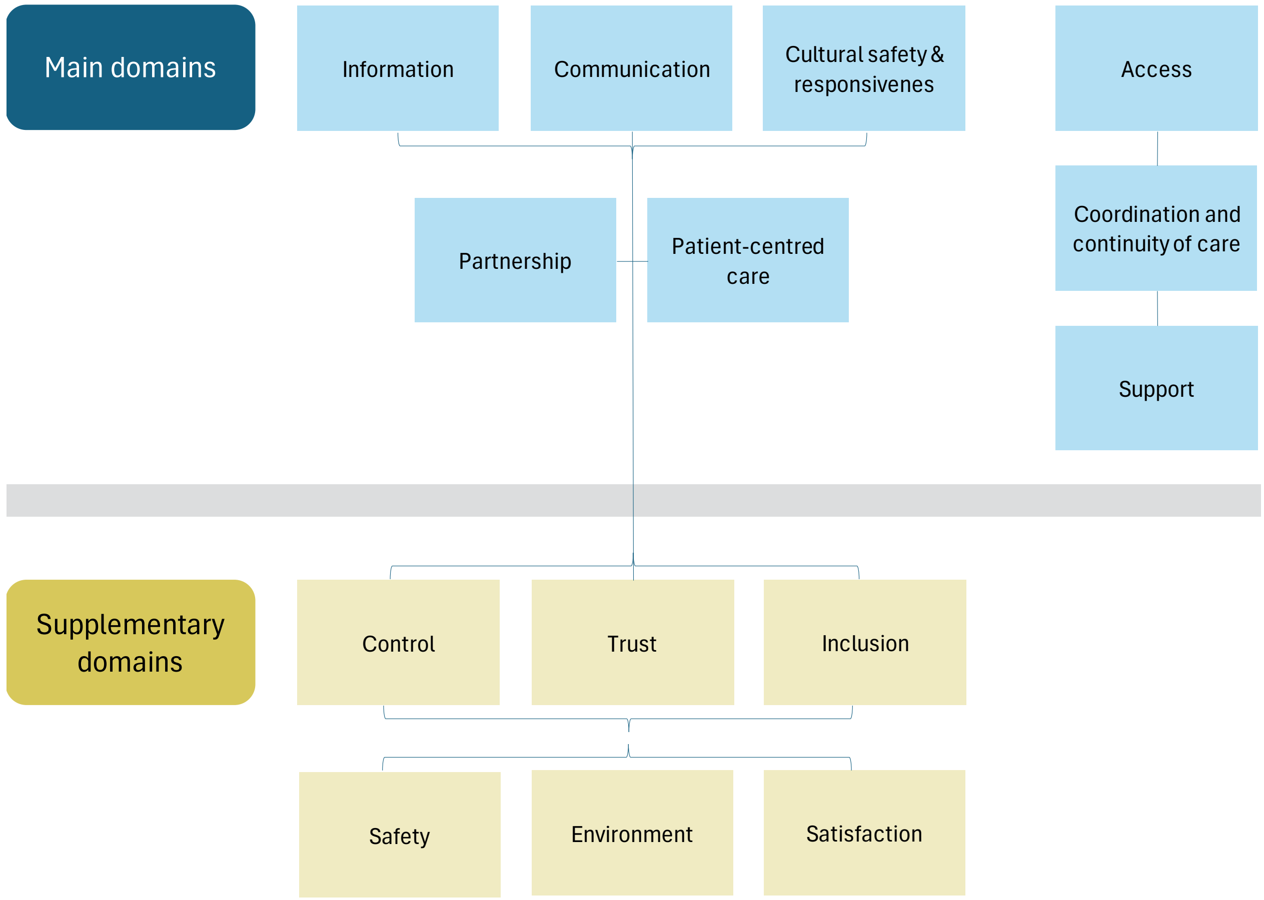
The following eight domains shown in the light blue text boxes in **Figure 3–1** were consistently identified as important **patient reported experience** measures across the workshops. These domains were identified as important in more than half of the workshops.

3.1.2 Supplementary PREM domains

The following six domains were identified as important PREs across six or fewer of the 12 workshops the workshops.

- Control (identified in 4 workshops)
- Satisfaction (identified in 4 workshops)
- Environment (identified in 2 workshops)
- Safety (identified in 2 workshops)
- Trust (identified in 1 workshop)
- Inclusion (identified in 1 workshop)

Figure 3-1: PREM domains identified as main and supplementary



3.2 DESCRIPTION OF MAIN PREM DOMAINS

1. Information

Participants consistently emphasised the importance of adequate and timely information. Information needs to be sufficiently detailed for patients to understand their diagnosis, prognosis and treatment plan. Conversely, patients may feel overwhelmed by information, particularly at initial diagnosis.

> *It's something like an overburdening. Oh God, do I have to read this bloody stuff. Oh, my! What am I missing? You know, what's the essential part I need to know?*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 2

Information adequacy has several parts. It needs to be easy to understand, particularly for people with low levels of health literacy, general literacy and cultural diversity. Enabling patients to understand where and how to access information is key, as is knowing who to contact for additional information.

Other participants gave priority to whether information is inclusive of different groups including people identifying as LGBTQIA+.

For people from cultural and linguistically diverse backgrounds, information needs to be culturally relevant. Beyond translation into community languages, this requires ensuring the meaning attached to words or phrases is congruent with culturally and linguistically diverse populations.

When information needs are not met, this can have a flow-on impact on quality of life.

> *It's not always about the ins and outs of treatment. It's also about, well, what does this mean for me in my general life? And what information do I have access to that I can share with my loved ones?*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 10

Others raised the information needs of carers as important, an element of 'triadic care'.

The mode of sharing information matters. Participants felt there were instances in which information is shared with patients in writing, such as a brochure, when it would be more appropriate through an in-person conversation. A further angle is that patients may be confused by conflicting advice received by different healthcare providers or from other sources such as the internet. One participant noted that this can be particularly problematic if conflicting information comes from the same organisation.

The extent to which cancer patients' information needs are met is associated with measures of patient satisfaction. This includes information about the patient's disease, its treatment and the side effects of treatment (Tran Y et al., 2019). This association with global measures of patient satisfaction is important given the relationship between patient satisfaction levels and HRQoL and self-efficacy. A systematic review of cancer patients' information needs identified the highest priorities were prognosis, disease, and treatment options (Tariman JD et al., 2014). A recent review of patients with advanced stage, incurable cancer found that patients sought information that was tailored to their needs, including how and when information is provided. Patients' preferences included that they have adequate time to receive information and that information is conveyed with openness, and sensitivity to facilitate understanding of prognosis, treatment and care options (Holland-Hart D et al., 2025).

2. Communication

Communication is closely linked to the above domain of information. Patients may experience a lack of warmth, respect or engagement by their clinical treatment team. Communication with patients that lacks empathy, or respect contributes to poor patient experience.

> *Rather than feeling as if they're just another patient, you know, all of that comes down to the communication, the tone, you know, and that's affected by in turn, the culture, the work burden of the staff. And their confidence in being able to do things. So, communication has a huge impact.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 11

The initial communication of a cancer diagnosis is a pivotal patient experience and effective and empathetic communication is key. Communication that lacks empathy may have enduring effects.

> *Often receiving bad news, is something that can cause ongoing trauma for a very long time.*
>
> ACADEMIC, WORKSHOP 1

Communication that is one-sided is problematic for patients' experience. Participants emphasised the importance of patients being heard and feeling listened to. From a patient perspective, this means being able to express what matters to them – including their treatment preferences.

> *An ability to assess how heard someone feels is probably a really good indication of whether or not the language that people are using with people helps them feel confident that their concerns are actually being taken on board.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 10

Timing is important. This included whether patients have sufficient time to understand information and consider options. Allowing time for patients to ask questions is important and empowers patients.

> *The patient can go in and actually say what they want to say. They don't get cut off. So, they're given the time to speak. All those aspects of working with the clinician so that they actually have some control over what they can control.*
>
> CHAIR/CEO, WORKSHOP 2

Participants considered communication involved eliciting patients' views and desires and whether patients were asked about their preferences for decision-making, information and family involvement.

> *As healthcare providers, we don't always… seek feedback about whether or not it is being digested and whether or not it's been effective in informing people about what they're suffering.*
>
> ACADEMIC, WORKSHOP 2

As with the discussion on information, patients need to know who to contact if they need help.

Research into cancer patients' communication needs indicates that there are multiple aspects of communication to be addressed including the content, style, time, and preference needs of cancer patients (Li J et al., 2020). A systematic review of patient experiences of patient-clinician communication during critical moments of breaking bad news identified the diversity of patient preferences. It concluded that multi-disciplinary team members should prioritise communication skills that focus on developing personalised, empathetic communication strategies in clinical practice, catering to diverse patient preferences (Primeau C et al., 2024).

A study by Jolidon et al. (2024) found that patients with lower health literacy reported worse patient experience, with the authors suggesting lower health literacy may limit the information exchange process during healthcare visits, potentially limiting individuals' ability to engage in effective and meaningful patient-doctor communication.

3. Cultural safety and responsiveness

Participants emphasised the centrality of culturally safe and responsive healthcare, impacting both patient outcomes and experience for Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds. When health services are not culturally safe and responsive, patients may have a lower preparedness to seek or continue treatment.

Participants commented that cultural safety and responsiveness matters across all parts of the patient journey and all components of communication. Cultural safety and responsiveness is also influenced by how it is reflected in the physical environment in which health services are delivered.

The approach to obtaining valid measures of cultural safety was identified as a complex issue.

> *We still don't have an agreed tool to determine cultural safety because cultural safety has to come through the lens of the consumer and things like that. And of course, with all of our Indigenous populations across Australia, we're going to have diversity within our own country… we may need to maybe look at some sort of agreed tool that may be a little bit more widespread and encompass all the diversity in our Indigenous communities.*
>
> CLINICAL CONSULTANT, WORKSHOP 12

For patients from culturally and diverse backgrounds, several dimensions of cultural responsiveness were highlighted including, the availability of information that is translated into community languages and access to interpreters. Additionally, communication by the treatment team should be attuned to the cultural norms and preferences of people from diverse CALD backgrounds. This includes an appreciation of how people from different CALD backgrounds may experience disease and their cultural preferences for communicating and seeking support.

Participants emphasised the importance of translating PROMs and PREMs surveys into community languages. Response rates are higher when survey questions are available in people's first languages.

In a further observation, when surveys are translated into a community language it is also important to review the survey questions' alignment with cultural references and cultural appropriateness. This requires a full contextual translation not merely linguistic and requires cultural adaptation and then revalidation. Given the resources involved in this process, participants suggested that using existing PROMs and PREMs measures that have already been validated is likely to be a cost-effective strategy.

Participants commented that culturally responsive care requires understanding how people from different backgrounds experience disease and preferences for communicating and seeking support.

> *Did you experience racism? Did you experience, you know, what were your negative experiences of care? So, patients are wonderful individuals who, you know, probably won't actually overtly tell you what's wrong unless they're given a chance or prompted to say, well, OK, what wasn't great with what your interactions are were with the system or the staff?*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 7

One participant described how cultural norms can in some circumstances contribute to stigmatisation of patients living with cancer. The shared anecdote was of a patient opting not to disclose their cancer diagnosis to family members, forgoing their emotional support out of fear of their negative reaction.

> *A lot of the support networks that they would normally rely on – family and on spiritual support from their church, all those sorts of things – they felt like they couldn't actually engage with that part of their own culture, because of the stigma associated with their diagnosis.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 10

Cancer incidence and mortality rates are higher for Aboriginal and Torres Strait Islander people (AIHW, 2018). The higher disease burden for Aboriginal and Torres Strait Islander people is linked to colonisation (Commonwealth of Australia, 2021) and also to the lack of a strength-based, holistic approach to healthcare (Fogarty W et al., 2018). Enabling the patient experiences of Aboriginal and Torres Strait Islander people to be heard is an important step towards improving their healthcare outcomes (Green M et al., 2021). A review of Aboriginal and Torres Strait Islander people's experience of cancer care identified cultural safety to be a high priority. Cultural safety is related to trust in the system, privacy, and racism (Sanjida S et al., 2021).

There are multiple challenges experienced by people from culturally and linguistically diverse communities in receiving cancer care including language barriers and cultural and religious differences which influence culturally determined understandings of illness (Rost et al., 2020; Rakic et al., 2022). Culturally sensitive care is key to effective communication, promoting understanding of treatment options and more broadly for shared decision-making for CALD patients (Surbone A, 2006). Despite the awareness of the importance of cross-cultural competence as an important contributor to cancer patients' experience of care, there have been insufficient studies of methodological rigour that have demonstrated the effectiveness of interventions to improve cross-cultural competence by cancer care healthcare providers (Rost M et al., 2023).

4. Partnership

Participants considered that patients who feel empowered as partners in their treatment are more likely to have a positive experience of care. Ensuring the patient's voice is heard is important as there are often several different clinicians involved in a patient's care team. Involvement in care planning is important for patients to understand their treatment options.

Participants emphasised that preferences for involvement in treatment decision-making will vary between patients. A PREM question would therefore need to explore whether patients feel that they are involved in treatment decision-making to the extent they choose.

Participants felt that healthcare providers have an important role in encouraging patients' confidence to be partners in their care. It reflects the strength of relationship that is established with the patient.

> *The patient being able to feel comfortable with their clinician and being able to be part of the decision-making process and fully informed so that they have got a good partnership.*
>
> CHAIR/CEO, WORKSHOP 2

There is evidence that shared decision-making is associated with improved levels of patient satisfaction with the experience of care and better patient knowledge about treatment options (Stacey D et al., 2011). Other studies have shown that shared decision-making is associated with improved outcomes in quality of care, physical function, patient satisfaction, and quality of life (Kehl KL et al., 2015). Further, there is evidence that the association between having experienced shared decision-making and positive appraisals of quality and communication held, regardless of a patient's preferred role in the decision-making process (Hawley ST and Jagsi R, 2019). A systematic review of shared decision-making concluded that health care professionals' effectiveness in shared decision-making may be enhanced by training and this in turn may increase the potential that treatment decisions are concordant with patient preferences (Punnett G et al., 2024).

5. Person-centred care

Person-centred care was identified as highly important. Some emphasised whether patients felt cared for, whereas others focussed on whether care was personalised to patient's needs and preferences.

> *Care that is individual and specific, not population based.*
>
> ACADEMIC, WORKSHOP 2

Another participant conveyed this as respecting patients' values and priorities when care planning:

> *People's values, the plans of what they want to achieve over the next few months, and how much their health is impacting on that and also what their aims are for their own medical conditions. So their choices and values and goals around that rather than clinician directed.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 12

Another participant expressed this as 'what matters most to people'.

> *You can ask them in different ways, but in age friendly healthcare…what matters most to the patient is something that's crucial.*
>
> ACADEMIC, WORKSHOP 12

Other aspects of person-centred care included:

- **Dignity:** to what extent do patients feel that their dignity as individuals is respected?
- **Respecting boundaries:** to what extent do patients feel their wishes and views are respected?
- **Responsiveness of care team:** to what extent do patients feel that the care team is responsive to the needs and preferences of patients?
- **Inclusion of a patient's family if this was wanted:** to what extent are patients' views sought about whether, and how, they may wish to include family members in discussions about care planning. This includes respecting views on what is meant by 'family' for different people including First Nations people and people identifying as LGBTQIA+.

The Institute of Medicine defined patient-centred care as "care that is respectful of and responsive to individual patient preferences, needs, and values" (2001). A recent systematic review explored the themes of patient-centred care most commonly reported in studies: themes that were linked to **values** comprised: autonomy, being involved, family, hope, normality, and sincerity; themes linked to **needs** comprised care coordination, information, privacy, support of physical well-being, emotional support (family/friends, peer, provider), and self-support; and themes for **preferences** comprised care coordination, decision-making, information delivery, source of social support, and treatment (Mithcell KR et al., 2020).

The Picker Principles describe person-centred care as an approach that puts people at the heart of health and social services, including care, support, and enablement. It is an approach where users are recognised as individuals, encouraged to play an active role in their care, and where their needs and preferences are understood and respected (Picker Institute Europe, n.d.).

There is some evidence that patient-centred care can enhance quality of care and patients' trust in doctors. This is attributed to improvements in the care planning process, addressing feelings, clear explanation of the problems, spending enough time with the clinicians, addressing uncertainty, and involvement in decisions (Elkefi S and Asan O, 2023).

6. Access

A lack of equitable access to cancer services can be deleterious for patients. This domain was raised both in discussion of PROMs and PREMs. Patients' care may be adversely affected by difficulties experienced in accessing health services readily and on a timely basis. Access challenges are multiple and can include affordability of transport and parking, scheduling of appointments that may clash with work schedules, childcare and other family responsibilities and the difficulties experienced by patients in rural, regional and remote locations who may need to travel away from their local community.

The point was frequently made that for patients in regional, rural and remote areas, there may be a lower level of provision of specialist cancer services available. This in turn results in additional costs such as accommodation and disconnection from their support networks and can adversely affect patients' access to timely treatment and may also limit patients' preparedness to undertake treatment if this requires significant travel away from their local community.

> *There's still significant impacts, including as severe as people not wishing to continue their treatment just on the basis of location access, lack of accommodation, travel, support, all sorts of other things.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 5

Timeliness of treatment was another dimension of access that was discussed.

> *And so, when a patient enters into that treatment plan, you know they don't want to start their chemotherapy and then have to wait however long to do their radiotherapy because there's a backlog or so on and so forth.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 11

This domain is linked to the 'financial toxicity domain'. Patients may face access gaps due to lack of affordable treatment and/or barriers linked to out-of-pocket expenses including parking fees and accommodation amongst other costs.

Other participants discussed 'time toxicity' as a concern. The point was made that patients are having to go to treatment often and having appointments very frequently. Another aspect raised was wait times, whether waiting for treatment or waiting for test results.

Differences across communities such as rural versus metropolitan location and socioeconomic status are associated with variation in access to cancer care and in turn such variation can lead to differences in treatment rates and health care outcomes

(Haier J and Schaefers J, 2022). Additionally, cancer patients with lower socioeconomic status are found to report a worse experience of care (Jolidon V et al., 2024). Timeliness is another aspect of access, with delays in access to cancer treatment associated with worse reported experience (Salessy AE et al., 2022).

7. Coordination and continuity of care

Participants felt that when services are well coordinated this has a positive impact on patient experience. This is regarded as highly relevant for patients undergoing cancer treatment, often with multiple clinicians involved in a multi-disciplinary treatment team.

The related point was the risk of fragmentation of care when patients receive care from different health services in different locations. Without a shared electronic medical record, there are challenges in assuring service coordination across organisational barriers.

Participants felt that frequently patients are overwhelmed by the complexity of navigating the healthcare system. Larger, integrated cancer services may have dedicated care navigator roles to facilitate coordination of care and guide patients' access to support.

Another element discussed under coordination was whether care is delivered in the correct time sequence: 'consecutively things happen as they should.' The element of continuity of care – having access to the same healthcare professional(s) over the course of treatment – was frequently identified as important for patients.

> *Optimal care is that (patients) don't even notice that they're going between different health services because it's all so seamless and they don't need to have a different UR number.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 1

Care coordination features as an important need identified by cancer patients (Mitchell KR et al., 2020). A systematic review of care coordination for cancer patients identified significant positive impacts across both heath care outcomes and patient experience of care (Gorin SS et al., 2017). Care coordination is particularly beneficial for patients with low health literacy (Mora-Pinzon, 2019), with tailored information supporting patients to navigate the health system (Del Vecchio NJ et al., 2021).

8. Support

Feeling supported was considered an important aspect of patients' experience. Participants considered it was important to establish if a patient had unmet support needs. In one workshop this was expressed as 'getting the help that you feel you need'. Another participant phrased it as:

> *It's not just about the treatment, but also all of the wrap-around services.*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 11

The domain of support is multi-faceted and links to the discussion of 'symptoms' and whether patients might have unmet needs. It also relates to the domain of 'role' in which patients may have needs for additional support to meet aspects of their role they have diminished capacity to undertake. Additionally, it relates to other components of follow-up care and treatment that patients may require following active treatment such as reconstructive surgery or management of lymphedema.

Participants identified the importance for patients of both formal and informal support. Formal support included whether patients could access services such as a cancer nurse specialist, a social worker, psycho-oncology, palliative care or a care navigator. Informal support was emphasised including support from family, carers and friends; access to peer support groups; and post-treatment support.

> *Some might not be able to even tell their employer that they have cancer, so that they're actually sort of trying to hide everything so that they can keep their job. The support isn't there.*
>
> CHAIR/CEO, WORKSHOP 2

One participant highlighted genomics as an issue that would be important to address as part of the support provided to patients and families in terms of decision-making.

There is evidence that patients who have access to social support experience improvements in quality of life (Rodriguez IR et al., 2022). Psychosocial support needs of cancer patients affect patients' quality of life, reinforcing the relevance of integrating patient feedback from PREMs to facilitate targeted improvements to better meet patients' emotional and supportive care (Bergerot C et al., 2024).

3.3 DESCRIPTION OF SUPPLEMENTARY PREM DOMAINS

1. Control

Some participants raised patients' preferences to have agency, to have control, as an important domain. This was in relation to many aspects of their cancer treatment, from care planning to other broader control over day-to-day life decisions. Many highlighted that patients may feel a loss of control following diagnosis and becoming a 'patient', particularly when patients are admitted to hospital settings. This domain is linked to many other domains including 'role' and 'person-centred care'.

> *It's the lack of control when you're when you're diagnosed with something and when you're waiting for results to come in or you're not sure what's going on. It's the loss of control. And I really found that because you're not just losing control of your body, but you're in hospital. You have no control over when the meals come. What medications you have when the nurses can change sheets when you're told to have a shower, you lose control of everything. And to me, that's quite a big thing.*
>
> ASSOCIATE/FELLOW, WORKSHOP 1

A participant made the point that some patients seek alternative therapies to regain control. Related to control, others expressed patients' sense of 'self-efficacy' as important.

> *The self-efficacy is one and ensuring that person feels empowered throughout their journey.*
>
> CLINICAL CONSULTANT, WORKSHOP 12

One participant described this as patients being able to manage their own health and healthcare. At another workshop, the point was made that self-efficacy is about empowerment throughout the patient's journey, not just for a single care episode.

> *They're given the necessary information and the time taken to make sure they understand it and to feel like they're in control of their cancer journey and being appropriately engaged throughout.*
>
> CLINICAL CONSULTANT, WORKSHOP 12

There is evidence that self-efficacy in coping with cancer has a significant positive impact on quality of life for cancer patients (Li S et al., 2025; Rha et al., 2022). A study by Yildiz et al. (2023) found that coping style, quality of life, and patient satisfaction with care were associated with self-efficacy for participation in decision-making among patients with advanced cancer.

2. Satisfaction

For some participants, measures of patient satisfaction were relevant in measuring patient experience. Others viewed satisfaction as distinctly different.

One participant considered that measures of satisfaction could be problematic in relation to discussion around psychological care. Discussions involving psychological support for patients may not be appreciated at the time of an acute episode but may be valued by patients in the longer term.

> *I think satisfaction is something that I am very uncomfortable with in, in a lot of senses, particularly if you're looking at satisfaction with, say, psychological care, which can make you very uncomfortable, particularly in the, you know the acute stages and immediately afterwards and it may not be for a period of, you know, 6 to 12 or even several years where you actually start to appreciate that that was helpful.*
>
> ACADEMIC, WORKSHOP 5

The Agency for Health Care Quality and Research makes the following distinction between patient satisfaction and patient reported experience of care. Patient satisfaction assesses patients' expectations and whether those expectations were met. Patient experience considers whether – or how often – various aspects of care (such as clear communication with providers) occurred (AHRQ, n.d.). The Australian Commission on Safety and Quality in Health Care makes a similar distinction:

- **Experience** is process focused – it captures patients' self-reported observations and feelings about their interactions with health service workers, environments and processes.
- **Satisfaction** is opinion focused and is subjective – it captures what patients thought or felt about their experiences, and how satisfied they were with the service (ACSQHC, n.d.[c])

3. Environment

The impact of the healthcare environment was considered by some to influence patient experience. This included factors such as cleanliness; noise levels; and cultural safety. Other elements of the environmental context include availability of food and drinks and a comforting setting.

> *We should think about the physical environment in which the patients are being treated like that's part of the experience. So, whether it's a GP clinic or hospital, is it clean, is it accessible, is it noisy? Is it culturally safe? Is the waiting time 3 hours?*
>
> CHAIR/CEO, WORKSHOP 1

There is some evidence that the environment within which care is provided can influence cancer patients' wellbeing (Clinton-McHarg T et al., 2021). One small scale study found that while physical environment was rated as important by patients, it was considered to be subordinate to psychosocial factors (Browall M, 2013).

4. Safety

In one workshop, safety was identified as a potential domain. This included whether there was both physical safety and emotional safety in the care setting which links to domains such as 'person-centred care' and 'cultural safety and responsiveness'.

> *Did you feel safe? Did you feel cared for?*
>
> MANAGER/DIRECTOR/COORDINATOR, WORKSHOP 1

A scoping review found that there a number of ways in which patients and their families seek to be involved in promoting the safety of their care. This includes their involvement in physical care, well-being, communication, and care coordination to ensure safety and support system resilience (Tillbrook D, 2022).

5. Trust

Another workshop highlighted trust as a separate domain. This included trust in the medical team, whether there was decisional conflict and whether patients are confident that the care provided is helpful. This domain links to 'information' and 'communication', some participants highlighting that trust can be eroded if patients receive different advice from within the care team. It also links to 'coordination and continuity of care', with challenges experienced with care transitions. These can reduce confidence if there is a lack of continuity or consistency in the information received.

> *The danger of having needless confusion and lack of confidence in the system that can grow in patients if they're going to different clinicians or different care providers who are telling them different things.*
>
> ACADEMIC, WORKSHOP 1

There is evidence that trust between patients and healthcare providers can improve quality of life for cancer patients (Baum E et al., 2025). Improved communication skills, continuity of care and openness and honesty are seen as essential to building a trusting relationship (Garubba M et al., 2019).

6. Inclusion

One workshop emphasised inclusion as a domain for consideration. The reference to inclusion was across the following aspects:

- Diverse populations
- Priority populations
- People with diverse sexual and gender identities
- People with disabilities

This domain links to 'person-centred care', 'safety' and 'communication'.

For people identifying as LGBTQIA+ who are living with cancer, there is evidence of worse outcomes in relation to quality of life, higher levels of distress (Ussher JM et al., 2022), and greater dissatisfaction with cancer care (Jabson JM and Kamen CS, 2016). A review of the inclusion of LGBTQIA+ people with cancer on online patient information resources in Australian cancer healthcare settings found that LGBTQIA+ people are 'almost invisible' in Australian cancer information resources (Ussher JM et al., 2023). Of 61 Australian cancer organization websites eight (13%) mentioned LGBTQIA+ people. The key finding was that cancer patient information resources need to be LGBTQIA+ inclusive. Targeted LGBTQIA+ resources are required to address this population's unique needs and improve cultural safety and cancer outcomes.

CHAPTER 4

BARRIERS AND FACILITATORS FOR IMPLEMENTATION

Barriers and facilitators identified during consultations were interwoven – for each barrier identified, participants identified a corresponding enabler. The main barriers and facilitators were as follows:

- Patient-related
- System and organisational
- Clinical and professional
- Regulatory and governance
- Technological

4.1 PATIENT-RELATED BARRIERS AND FACILITATORS

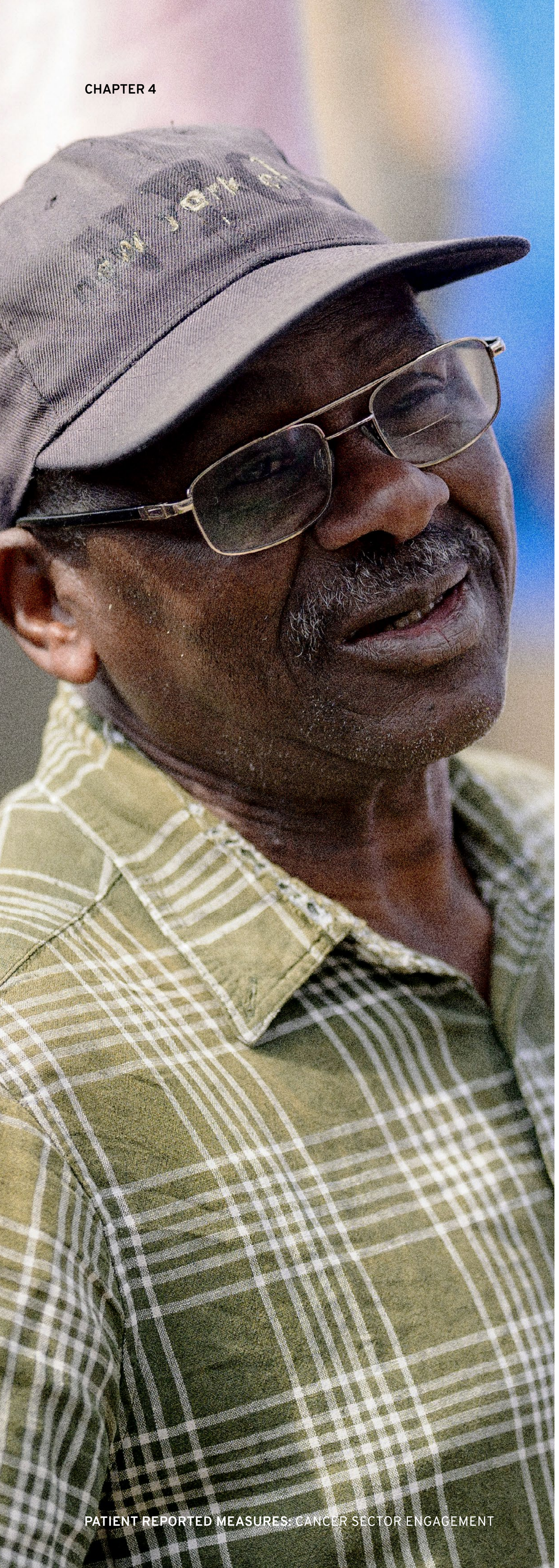
Implementing PRMs requires a nuanced understanding of the diverse challenges patients may face. A range of barriers exist that may hinder effective participation, particularly among patients with complex needs, diverse backgrounds, or varying capacities. However, many of these challenges can be mitigated through thoughtful, inclusive design and support strategies, as summarised in **Table 4-1**.

The issues raised by participants on patient related barriers and enablers accord with research findings. Patients may face barriers completing PROMs due to low health literacy, language and cultural differences, technological difficulties, and emotional burden (PROTEUS – Practice Guide, 2025; Glenwright et al., 2023; Shahid et al., 2022). These issues can reduce relevance or accessibility of PROMs, particularly for older or vulnerable patients. Concerns about data privacy, confidentiality, and lack of feedback also reduce patient motivation to participate (Alhammad et al., 2024).

Facilitators include the use of accessible language, culturally appropriate tools, and multiple modalities (e.g., paper, digital, in-person support) to complete PRMs (Huberts et al., 2024; Anderson et al., 2024; Nguyen et al., 2021). Co-designing PRM processes with diverse communities ensures cultural and contextual relevance (LoGiudice et al., 2006). Clear communication about the purpose of PRMs and timely feedback to patients improves trust, engagement, and relevance.

Table 4-1: Patient-related barriers and facilitators

Barrier	Implication	Facilitator
Physical or cognitive impairments	Impairments often fluctuate over the course of treatment, requiring adaptive levels of support.	Support patients in completing surveys, including involvement of family members, carers, or advocates who can assist those with cognitive limitations or physical restrictions. Tools could be used to make PRMs accessible to people with physical or cognitive impairments or for people who are non verbal.
Digital literacy	Concerns around clicking on unfamiliar links and limited confidence using mobile phones, apps, or email can all impact a patient's ability to engage with electronic PRMs.	Offer alternatives for those without digital access, including paper-based surveys, in-person assistance, first-time guidance and support from proxies or advocates.
Language	CALD patients often require both language and cultural translation of PRMs. However, even when tools are translated, uptake can remain low if cultural context is not considered.	Co-design tools with community input to ensure they are meaningful and appropriate across different cultural groups.
Low health literacy	Limits patients' understanding of the purpose and relevance of PRMs, reducing their willingness to engage.	Questions should be relevant to the patient's situation and patients informed about how their responses will be used.
Long, repetitive, or irrelevant questionnaires	Survey fatigue can limit participation by patients.	Questions should be relevant to the patient's situation and patients informed about how their responses will be used.
Emotional and psychological barriers	Fear of judgement and distress related to sensitive topics can influence participation.	Link patients to appropriate support services, particularly when distress is identified.
Trust and confidentiality	Concerns around privacy and the emotional burden associated with sharing personal health information may limit participation.	Be transparent to help patients understand why the data is being collected and how it will be used.
Cultural safety	If questions are not culturally safe and the staff administering the surveys lack training in cultural responsiveness, participation is likely to suffer.	Co-design with strong community leadership, and train staff to ensure respectful and appropriate interactions throughout the PRM process.



4.2 SYSTEM AND ORGANISATIONAL BARRIERS AND FACILITATORS

Implementing PRMs within health services requires alignment of technical, operational, and cultural elements. Several system-level and organisational barriers exist, but can be mitigated by strategies that support integration, leadership, and continuous learning, as summarised in **Table 4-2.**

Studies have confirmed that PROMs are often poorly integrated into existing systems, causing workflow disruption and duplication. Organisational barriers include insufficient funding, staffing, and IT support, as well as mis-alignment with service priorities. Inconsistent leadership, limited strategic focus, and low cross-sector coordination also hinder scale-up and sustainability (Fontaine et al., 2024).

Embedding PROMs into EMRs and clinical workflows improves efficiency and sustainability (Huberts et al., 2024; Locklear et al., 2024). Facilitators also include national standardisation of PROM tools with local adaptability, use of implementation toolkits and clinician support resources. Visible leadership support, the presence of clinical champions, and strategic prioritisation reinforce the organisational commitment to PROM and PREM implementation (Fontaine et al., 2024; Lyu et al., 2024).

Table 4-2: System and organisational barriers and facilitators

Barrier	Implication	Facilitator
Lack of integrated EMRs and inadequate IT infrastructure	Poor interoperability between systems hinders data sharing, limits access to real-time information and creates inefficiencies.	National standardisation of PRM tools that can be flexibly integrated across various EMRs. Automation of PRM scheduling, particularly when aligned with the patient journey, such as at check-in to outpatient clinics, to streamline data collection. Feedback systems built into EMRs to ensure timely return of results to both clinicians and patients.
Resource constraints	The cost of establishing and maintaining PRM systems, including investment in staff, technology, and ongoing support, can deter services from full-scale implementation.	Embed PRMs into existing workflows and use automation to increase clinician engagement and reduce duplication.
Misalignment of values and disconnection between teams	Lack of a shared vision reduces the perceived relevance of PRMs or their potential to drive improvement. Siloed practices limit awareness of how and where PRMs are already being used.	Provide results to clinicians in a timely manner to support greater clinician engagement and provide feedback to individual patients to help reinforce patient-centred care. Build communities of practice and foster PRM champions to bridge gaps, enable shared learning and cohesive implementation.
Inconsistent leadership engagement	Where executive or clinical leadership does not prioritise PRMs, efforts lack coordination and sustainability.	Strong governance structures, including linking PRMs to Clinical Governance Committees and promoting PRM data use at leadership levels to embed into monitoring and accountability systems.
Lack of evaluations of improvements in care	Without structured evaluations of impact, this limits the case for investment in PRMs.	At the local level, track outcomes, unmet needs, and referral gaps to provide actionable data. Align PRMs with the principles of a learning health system to inform individual care and drive broader quality improvement.

4.3 CLINICAL AND PROFESSIONAL BARRIERS AND FACILITATORS

Clinical and professional engagement is essential for the successful implementation of PRMs. However, clinicians often encounter a range of challenges that reduce their willingness or capacity to adopt these tools. These barriers are significant, but they can be addressed through targeted education, cultural safety training, improved integration into clinical workflows, and appropriate resourcing, as summarised in **Table 4-3.**

Consistent with the themes from workshop participants, research findings suggest that clinicians may perceive PROMs as time-consuming or misaligned with clinical needs, particularly if they lack training in PROM use. Workload pressures and concerns about medico-legal implications can reduce clinician engagement. Without clear benefits to decision-making, clinician support is often limited (Hyland et al., 2023; Anderson et al., 2024).

Facilitators include clinician education and training in how to interpret and use PROMs to inform care decisions (Nguyen et al., 2021; Locklear et al., 2024). Embedding PROM use into professional development pathways, involving clinical champions, clarifying the relevance of PROMs to treatment effectiveness, providing timely, actionable data and linking PROM feedback to decision-making pathways can promote the case for use of PROMs.

Table 4-3: Clinical and professional barriers and facilitators

Barrier	Implication	Facilitator
Technological barriers	Clinicians frequently struggle to access and use PRMs due to inadequate system integration. This can undermine the utility of the tools and contribute to clinician frustration. Additionally, PRM implementation often disrupts established clinical workflows.	Embed PRM platforms into existing clinical systems such as EMRs, using features like single sign-on and automated data entry. Technical training and real-time IT support can also help clinicians use the systems with confidence.
Time and resource constraints	Time-poor clinicians may resist PRM implementation if this requires additional activities to be undertaken that are not reimbursed or recognised in rosters.	Assess and address the resource implications of PRM implementation to support clinical engagement. Explore reimbursement through Medicare, activity-based funding, or private insurance. Link PRMs to strategic plans and accreditation standards to drive prioritisation.
Clinicians feel ill-equipped to administer, interpret, and act on PRM	A lack of training and confidence, coupled with resistance to change, can hinder adoption.	Embed PRM use into the education of health professionals. Build familiarity to encourage uptake. Provide accessible information to patients and clinicians, explaining how data will be used.
Cultural competence	Clinicians may lack cultural competence to support PRM implementation.	Culturally appropriate tools such as pictograms, storybooks, and sign language can support patients with low literacy or from CALD backgrounds.
Data governance and medico-legal risks	Uncertainty of data governance and medico-legal risks is a deterrent to clinician engagement.	Adopt transparent communication around data usage, privacy safeguards, and the role of PRMs in improving care quality.
Lack of access to real-time, actionable data	When PRMs are not effectively integrated into clinical systems, it becomes difficult to respond to concerning symptoms or adverse outcomes in a timely manner. This disconnect reduces clinical buy-in.	In addition to automation, health services should implement dashboards and alerts that flag critical patient responses and route them to the appropriate care team for timely follow-up and intervention.

4.4 REGULATORY AND GOVERNANCE BARRIERS AND FACILITATORS

Implementing PRMs within a regulatory and governance framework presents complex challenges that require careful navigation, including legal, ethical, and cultural angles. Concerns around data management, privacy, and the absence of consistent national standards can undermine trust and engagement. These challenges can be addressed through strong, transparent governance structures and co-designed policies that promote responsible use as summarised in **Table 4-4**.

Research into regulatory and governance issues indicates that the absence of national PRM policies and inconsistent local governance structures creates uncertainty and limits adoption (Fontaine et al., 2024). Concerns about ethical approval, consent, and data sharing reduce confidence in implementation (OECD, 2019). Governance challenges also arise when roles and responsibilities for data ownership, access, and accountability are unclear (PROTEUS -Practice Guide, 2025; Forbes, 2023).

Facilitators include aligning PROMs with national data standards and establishing clear governance and risk management frameworks to ensure legal and ethical compliance (OECD, 2019; Forbes, 2023). Supporting patient-controlled data sharing preferences helps build trust and aligns with privacy best practices (OECD, 2019). Co-designing governance with Aboriginal and Torres Strait Islander communities ensures Indigenous data sovereignty and cultural safety (NIAA, 2024; Lowitja Institute, 2023; Carroll et al., 2021). Clarity of data use—whether for individual care, service improvement, or research—enhances transparency, builds trust, and supports broader system uptake (OECD, 2019).

Table 4-4: Regulatory and governance barriers and facilitators

Barrier	Implication	Facilitator
Data privacy	Uncertainty within the sector about how to comply with data protection laws when collecting, storing, and using PRM data can impede uptake.	Clarify the purpose of PRMs, including their application for clinical care, national benchmarking, research, and quality improvement. Ensure patients understand how their data will be used, stored and managed.
Indigenous Data Sovereignty	Without formal frameworks that recognise the rights of First Nations communities to control their data, PRMs risk reinforcing distrust or perpetuating harm.	Co-design governance frameworks, developed in partnership with Aboriginal and Torres Strait Islander communities and guided by the principles of self-determination and cultural integrity.
Ethical concerns and secondary use of data	Secondary use of data is considered to be contentious. Consumers may have concerns about data storage and privacy of PRM data.	Transparency and consent processes must clearly outline when and how data may be used beyond the immediate care setting. Align PRMs with national data and governance standards and ensure robust privacy safeguards are in place. Patient-controlled sharing preferences, where individuals can choose what data to share and with whom, can further reinforce ethical practices.
A lack of national standards	The lack of national standards may result in inconsistent implementation across healthcare settings.	Adopt a nationally coordinated approach, supported by policy and standardised frameworks, to ensure PRMs are used consistently and equitably.
Applicable governance systems	Services require support to adopt frameworks that reflect both national consistency and local flexibility.	Develop clear governance guidance, including risk management and oversight procedures, to support services confidently and ethically implement PRM processes.

4.5 TECHNOLOGICAL BARRIERS AND FACILITATORS

Technological infrastructure is a critical enabler of PRM, yet it remains a challenging domain. A range of technological barriers, including poor system interoperability, user-unfriendly platforms, limited adaptability, and a lack of technical support can significantly impede adoption and sustainability. Targeted investments in integration, design, automation, and user support can overcome these barriers as summarised in **Table 4-5.**

Studies of PRMs and technology highlight that when PRM platforms are not user-friendly nor well-integrated with clinical systems, this can lead to duplication and inefficiency (Glenwright et al., 2023; The Clinician, 2025). Lack of real-time data visibility, technical support, and standardisation limits PRM use in care decisions (Glenwright et al., 2023; Fontaine et al., 2024). Digital inequity across services and populations presents a further barrier (Fontaine et al., 2024; The Clinician, 2025).

Technological facilitators include embedding PRMs into EMRs, using intuitive and flexible digital tools, and automating scheduling aligned to the patient journey (Locklear et al., 2024). Implementation support tools and dashboards that enable rapid, real-time feedback to clinicians promote integration into decision-making. Training in platform use, technical support resources, and national interoperability standards enhance usability.

Table 4-5: Technological barriers and facilitators

Barrier	Implication	Facilitator
Usability	PRM platforms are often complex, lacking intuitive design for both clinicians and patients.	Adopt user-centred design principles, simple, streamlined interfaces, mobile compatibility, and adaptive design. Tailor PRM tools to patient needs, using features like skip logic, pictograms, screen contrast, and alternate language options.
Adaptability	Limited adaptability of PRM tools restricts benchmarking.	Develop a national core set of measures that can complement disease-based PRMs to support standardisation while accommodating variability. Flexibility must be paired with an iterative approach: measures should evolve based on feedback loops and learning health system principles.
Inadequate technical support infrastructure	Implementation may be compromised if there are insufficient support infrastructures.	Provide support through centralised resources, including technical helpdesks, clinician support resources, implementation toolkits, education packages, guides, and templates.
Automation	Lack of automation into work processes limits uptake.	Embed PRM collection into automated workflows, including through SMS or online check-in tools. Use alerts and threshold-triggered notifications to help clinicians respond in a timely way.

CHAPTER 5

DISCUSSION

The stakeholder workshops with the cancer sector have shown consistent support for development and implementation of patient reported measures for cancer patients. A threshold question is whether PRMs should be specific to cancer types or whether generic PRMs could apply across all cancer types. Workshop participants considered there was value in defining a concise set of generic measures – these measures should supplement, not replace, those specific to individual cancer types.

Stakeholders sought clarity as to which parts of the patient journey generic PRMs should apply. Whilst acknowledging the importance of measuring PRMs across different stages of a disease trajectory, there was a recognition that the focus of the current project on PRM collection post-diagnosis of cancer and over the active treatment stage was a pragmatic and sensible approach to managing scope.

Participants also questioned how scope should be defined to address the very different context of paediatric, adolescent and young adult populations. Whilst not understating the importance of PRMs for younger people, there was again recognition that restricting the scope to adult and older adult populations for this project was a reasonable approach to keep the project manageable.

In every workshop, participants were prepared to nominate a list of PRMs that were considered important to cancer patients and likely to be relevant across most cancer types.

5.1 PROMS

When asked to nominate a list of generic PROMs, the discussions typically started with the broad domains that underpin existing HRQoL measures: global quality of life; psychological wellbeing; physical health and functioning; and social functioning.

Fear was frequently mentioned as an important factor for many patients, including fear of the unknown, fear of prognosis and fear of recurrence. Whilst frequently discussed in the context of psychological health and emotional wellbeing, the emphasis was that this was a significant domain in its own right given its high prevalence and the potential for patients experiencing a high level of distress from fear to be effectively supported by healthcare professionals through routine screening.

The impact of **symptom burden** for patients was consistently raised as an important consideration. In most workshops, the challenge was whether to nominate specific symptoms given that typically symptom lists can be very long and that some symptoms are specific to cancer types. The discussions typically gravitated towards nominating a short-list of symptoms – pain, fatigue and cognitive impairment – that occur for most patients across most cancer types.

A range of other symptoms were also commonly reported including sleep disturbance, nausea, appetite, nutritional impact, neuropathy, vomiting, weight loss, muscle wasting and impact on body image. Whether these other symptoms should be included as a main domain was not resolved. One alternative approach suggested in a few workshops was not to list specific symptoms but rather to ask whether patients had unmet needs. This was felt to be useful to identify aspects of patients' symptom management, or other areas or concerns, where they had unmet needs.

Most participants considered that **sexual health, sexual wellbeing and reproductive health** was an area that was under-reported currently, had a substantial impact on patients' quality of life and was a frequent treatment side-effect or symptom of many cancer types.

One frequently identified domain was **financial toxicity**. This was broadly described as the adverse impact of cancer on patients' financial circumstances, affecting workforce participation, out-of-pocket treatment costs and other impacts related to travel, parking, child-care and other unforeseen costs.

The identification of these PROMs as important for cancer patients aligned with the literature scan.

5.2 PREMS

When the discussion turned to PREMS, participants immediately focused on two related domains: **information and communication**. The conversation around information explored whether patients are able to readily access information when they need it, in a way that they can easily understand and with clarity about how and where to get more information. A common challenge was how to achieve information adequacy without information overload.

Participants explored several dimensions of patient-clinician communication. Effective communication requires clinicians to use language that is easily understood and allows adequate time for patients to ask questions. A recurrent theme was the importance of ensuring that patients feel heard. Have clinicians elicited feedback from patients that they have understood what has been communicated?

Closely related to the domain of communication is whether patients feel they are **partners in their care**. This discussion focused on the empowerment of patients to be actively involved in their care.

The domain of **person-centred care** encapsulates many of the above domains such as communication, shared decision making, cultural safety and responsiveness, and support. Participants emphasised that what matters for patients is that healthcare providers are 'treating the person, not the cancer'.

Cultural safety and responsiveness of cancer care was emphasised in discussions of both PROMs and PREMs. In the case of Aboriginal and Torres

Strait Islander people with cancer, the cultural safety of services can influence the acceptability of seeking and continue with treatment. The extent to which healthcare services provide culturally safe care will also influence patient's experience of care.

Access to cancer treatment was widely recognised as having an important influence on patient experience as well as on outcomes. This spanned considerations such as financial barriers to access, geographic access and timeliness of access. Many referred to the challenges for patients living in rural, regional and remote areas who often experience a lower level of access to specialist services, facing the challenge of leaving their communities to seek treatment.

Coordination and continuity of care was rated as important for patients across different stages of their cancer treatment and disease trajectory. Coordination is key to patients who may be receiving treatment from several health care providers and from separate healthcare services.

For people from culturally and linguistically diverse backgrounds, culturally responsive care requires consideration of interpreter and translation services. An understanding of the cultural norms and beliefs of CALD patients is also key to enabling care that is culturally responsive.

In discussing the domain of **support**, participants highlighted the importance for patients of social support networks. These included informal supports of family and friends as well as more formal supports to facilitate advice and access to information and services such as Centrelink.

The identification of these PREMs as important for cancer patients aligned with the literature scan.

5.3 BARRIERS AND FACILITATORS

Patient-related

A range of barriers were identified that would limit patient participation. Patients with **physical or cognitive impairment** may limit their capacity to complete PRMs. Low levels **of digital and health literacy** may impede participation. These barriers can be addressed through supporting patients to complete surveys through the involvement of family members, carers, or advocates and through in-person assistance of healthcare providers. Providing multiple modes of completion, such as paper-based, phone-assisted, or face-to-face options, along with first-time guidance, can improve uptake.

Cultural safety is a key requirement and requires co-design with Aboriginal and Torres Strait Islander people. For CALD patients with low proficiency in English, PRMs should be available in community languages and culturally validated.

Emotional and psychological barriers, including fear of judgement, survey fatigue, and distress related to sensitive topics may reduce participation. This requires sensitive support for patients by healthcare professionals. Survey design should aim for brevity and ease of survey completion.

More broadly, patients are more likely to participate in PRMs processes if they understand the purpose of collecting PRMs, how the data will be used, and if they trust that data confidentiality will be upheld.

System and organisational

One key system-level challenge is that different health services use different electronic medical record (EMR) systems, and some health services lack EMR systems entirely. The optimal approach is that PRMs are embedded into existing health service IT systems so that the process of capturing PRMs is embedded in the workflow and that access to results is streamlined to ensure timely return of results.

Embedding PRMs into other organisational structures such as quality assurance frameworks and clinical governance committees provides another approach to mainstream their use and promote their relevance as part of a health service's continuous quality improvement focus.

Change management is essential to promote broad uptake and a shared vision. This requires leadership from the highest level of the health service and the support of PRM champions with resourcing, training and implementation rigour.

Clinical and professional

Many of the identified clinical and professional barriers stem from the above systems challenges, particularly in relation to IT. Clinicians are more likely to support the collection of PRM data if data platforms are incorporated within existing IT systems. For time poor clinicians, embedding PRMs into clinical workflows is seen as the most straightforward approach to support uptake.

Clinician training can promote their familiarity and understanding of the approach to PRM collection, address data confidentiality issues and medico-legal concerns and communicate its relevance for real-time clinical care and continuous performance improvement. Training is also relevant for clinicians to enable patients with support needs to participate in the PRM process.

Regulatory and governance

Key regulatory and governance issues were identified. Foremost of these concerns was data privacy, practical requirements at a health service level to uphold regulatory requirements in terms of collection, storage and reporting of PRM data. The importance of addressing indigenous data sovereignty requirements was raised as an area that also needs to be considered, both at the health service level, and more broadly for each jurisdiction and at a national level.

The challenge of secondary use of data was raised. Participants were supportive of the principle of collecting standardised PRM measures to enable benchmarking of health services and jurisdictions. They cautioned that this would require careful navigation of data privacy provisions and de-identification of data for jurisdictional and national reporting purposes.

A broader planning and implementation issue is the appropriateness of governance mechanisms relating to PRM data standards, data ownership, data security, data sharing, data analysis and data reporting at a state/national level.

Technological

A range of technological barriers, including poor system interoperability, user-unfriendly platforms, limited adaptability, and a lack of technical support can significantly impede adoption and sustainability.

Notwithstanding the challenges, many participants felt that there were a range of technological innovations that could act as a catalyst for the wider, more efficient uptake of PRMs and the embedding of PRM collection into automated workflows. The approach to technological innovation requires flexibility and iteration using learning health system principles.

The importance of these barriers and facilitators in relation to PRMs development and implementation aligned with the findings of the literature scan.

CHAPTER 6

CONCLUSION

The development and implementation of a generic set of PROMs and PREMs for all cancer types is a bold aspiration. To explore this goal further, wide-ranging consultations occurred with the cancer sector involving 121 individuals attending 12 online workshops from February to March 2025. Participants included researchers, healthcare professionals (medical, nursing and allied health), representatives from peak bodies, consumer advocacy groups and from Aboriginal and Torres Strait Islander organisations.

MAIN PRM DOMAINS

Workshop participants defined 12 main PROM domains:

- Quality of life – global
- Physical health and functioning
- Activities of daily living
- Social functioning
- Psychological wellbeing
- Fear
- Pain
- Fatigue
- Cognitive functioning
- Sexual function, sexual wellbeing and reproductive health
- Other symptoms and treatment side-effects
- Financial toxicity

There were eight main PREM domains defined:

- Information
- Communication
- Cultural safety and responsiveness
- Partnership
- Person-centred care
- Access
- Coordination and continuity of care
- Support

OVERARCHING THEMES FOR PRM DEVELOPMENT AND IMPLEMENTATION

Overarching themes relevant to the future development and implementation of PRMs emerged.

Generic domains

Participants discussed whether PRM domains should be generic, and cover all cancer types, or specific to individual cancer types. The general consensus was for a generic set of PRM domains that could be supplemented by domains specific to individual cancer types.

Stage of cancer

Several participants emphasised collecting PRMs across the disease trajectory, including into survivorship and palliative care stages. Whilst recognising the relevance of PRMs across the disease trajectory, participants accepted that this project focus was on patients undergoing active treatment.

Age range

Several participants commented that the paediatric, adolescent and young adult population have specific perspectives that may not be as readily accommodated within an all-ages PRM approach. Whilst not downplaying the importance for younger age groups, it was acknowledged that given scope considerations, the current focus was on adults.

Equity

Across all workshops, domains relevant to equity were important for PRMs. Consistently, the financial impact of cancer on patients and their families was prioritised, with financial toxicity a core PROM domain. Access was nominated as a main PREM domain, with many patients affected by geographic and wait-time challenges, particularly in rural, regional and remote areas.

Cultural safety and responsiveness

Cultural safety and responsiveness was emphasised as a key PRM priority. Co-design strategies are pivotal in this process to ensure cultural relevance and appropriateness of questions for Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.

Inclusivity

Participants felt many existing PRM surveys have a hetero-sexual centric focus. More inclusive questionnaire design was recommended for cancer patients identifying as LGBTQIA+.

Barriers are not insurmountable

Multiple barriers to implementation of PRMs were identified. Participants were solution-oriented and for each barrier, strategies to facilitate PRMs were identified.

Solutions are interdependent

Interdependencies exist between solutions. The more that PRMs are embedded in workflows, the greater the clinical engagement; the stronger an organisation-wide commitment to PRMs, the greater the acceptance of PRM roll-out.

Multiple levels

Participants agreed that PRMs are relevant at three levels: patient, health service, and system-level. The most compelling argument put forward is that PRMs must be relevant to clinical care. Providing healthcare professionals with timely PRM information is vital to continuous quality improvement. In turn, this promotes a learning health system. At the health system level, national benchmarking of PRMs is seen as a compelling vision.

IMPLICATIONS OF THE FINDINGS

The findings from this project provide a strong foundation for the development of a nationally consistent approach to implementing patient-reported outcomes and experiences in cancer care. By identifying priority domains and exploring the real-world barriers and enablers to implementation, this work offers practical insights to inform future work. Continued collaboration across clinical, policy, consumer, and research sectors will be essential to ensure PROMs and PREMs are meaningful, equitable, and embedded in routine practice to improve care and outcomes for all people affected by cancer.

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PRM TOOLS

The following PRM tools were identified by workshop participants.

Tool or measure	Description
Distress Thermometer	A tool used to assess and track emotional distress, particularly in individuals affected by cancer.
Edmonton Symptom Assessment Scale (ESAS)	A patient-reported outcome measure (PROM) used to assess the intensity of common symptoms experienced by patients, particularly those with cancer.
Picker Principles of Person-Centred care	A framework for understanding what matters most to most people, and what constitutes high-quality person-centred care.
EORTC Core Quality of Life questionnaire (EORTC QLQ-C30)	Designed to measure cancer patients' physical, psychological and social functions. The questionnaire is composed of multi-item scales and single items.
FACT-G	A 27-item questionnaire designed to measure four domains of HRQOL in cancer patients: Physical, social, emotional, and functional well-being.
NHS National Cancer Patient Experience Survey	Aims to understand the experiences of cancer care across England.
NCI National Cancer Institute – Symptoms of cancer	A list of symptoms that cancer may cause.
OQ®-ASC (Assessment for Signal Clients)	A 40-item self-report measure designed to be used in conjunction with OQ adult outcome questionnaires to assess the type, and severity of problems, that may be impeding treatment progress, specifically, problems with the therapeutic alliance, motivation, social support, and stressful life events.
QLQ-C30	A 30-item core questionnaire of the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life instrument, used to assess the quality of life of cancer patients. It's a widely used tool in cancer research and clinical practice, encompassing both functional and symptom domains, and global health/quality of life.
HOPE	Health Outcomes and Patient Experience (HOPE) is a purpose-built IT platform that enables patients to provide direct and timely feedback to their healthcare teams about outcomes and experiences that matter to them.
Victorian Cancer Patient Experience Survey	A Cancer Patient Experience Survey Toolkit is available to health services. It includes survey tools by treatment type (surgery, radiotherapy, chemotherapy) and a user manual. A database is available to assist with data entry and analysis.
Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)	A measurement system developed by the National Cancer Institute (NCI) to capture symptomatic adverse events reported by patients in cancer clinical trials. PRO-CTCAE complements clinician-reported CTCAE grading, improving the accuracy of adverse event assessment.
SF36	A 36-item questionnaire used to assess an individual's health status and quality of life. It measures health across eight domains: physical functioning, role limitations due to physical health, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health.
5-level EQ-5D version (EQ-5D-5L)	A descriptive system that comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems.
Pain Numerical Rating Scale (NRS)	A widely used tool in cancer care to assess and track pain intensity. It involves patients rating their pain on a scale of 0 to 10, where 0 represents no pain and 10 represents the worst possible pain.
Malnutrition Screening Tool (MST)	For malnutrition screening in cancer care, MST is widely used in Australia and focuses on involuntary weight loss and loss of appetite.
Lawton IADL Scale	A tool used to assess an individual's ability to perform complex tasks necessary for independent living, like using a phone, shopping, or managing finances.
Functional Assessment of Chronic Illness Therapy – Fatigue (FACIT-F) tool	A 40-item measure that assesses self-reported fatigue and its impact upon daily activities and function.
Kessler Psychological Distress Scale (K10)	A 10-item questionnaire intended to yield a global measure of distress based on questions about anxiety and depressive symptoms that a person has experienced in the most recent 4- week period.
MOS Social Support Survey	Measures the availability of support, if needed, in several domains.
MyPOS	MyPOS is a myeloma-specific adaptation of the Palliative care Outcome Scale (POS), developed and validated to address the unique quality of life concerns associated with myeloma.
WHOQOL	WHOQOL is a quality-of-life assessment developed by the WHOQOL Group with fifteen international field centres, simultaneously, in an attempt to develop a quality-of-life assessment that would be applicable cross-culturally.
Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP)	The SCNAT-IP is an evidence based supportive care needs assessment tool which accommodates the language, customs and culture-specific needs of Indigenous people with cancer.
PRO-CTCAE	The NCI Patient Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE®) Measurement System was developed to evaluate symptomatic toxicities by self-report in adults, adolescents and children participating in cancer clinical trials. It was designed to be used as a companion to the Common Terminology Criteria for Adverse Events (CTCAE), the standard lexicon for adverse event reporting in cancer trials.
Patient-Reported Outcomes Measurement Information System (PROMIS)	A system of standardized, patient-reported measures used to assess physical, mental, and social well-being in adults and children. It's designed to be a convenient and appropriate tool for monitoring health status and is used in both research and clinical settings.
Australian Hospital Patient Experience Question Set (AHPEQS)	A 12-question survey answered by patients and is developed by the Commission through extensive consumer involvement.
Cancer Behavior Inventory (CBI-B V1.0-12)	A survey that contains many things that a person might do during and after cancer treatment.

LIST OF ORGANISATIONS

The following table lists the organisations with which workshop participants were associated.

Sector and organisation	Number of participants
ACCHO	**4**
NACCHO	2
VACCHO	2
Cancer registry	**9**
ACT Cancer Registry (ACT Health)	1
Cancer Alliance Qld	1
Cancer Council SA	1
Cancer Council Victoria	2
Cancer Institute NSW	3
Menzies Institute for Medical Research, University of Tasmania; Tasmanian Cancer Registry	1
Clinical Quality Registry	**10**
ACT Health Directorate	1
Lymphoma and related diseases registry	1
Melanoma Clinical Outcomes Registry (MEICOR), University of Sydney	1
Myeloma and Related Diseases Registry	1
National Gynae-Oncology Registry	2
Prostate Cancer Outcomes Registry - Victoria, Monash University	1
Prostate Cancer Outcomes Registry Australia and New Zealand	1
Victorian Lung Cancer Registry	1
Victorian Mesothelioma Outcomes Registry	1
Government	**8**
Australian Institute of Health and Welfare	1
Cancer Australia	1
Cancer Data, Department of Health and Aged Care	**1**
Cancer Portfolio, Tasmanian Department of Health	1
Department of Health	1
Population Health Group, Australian Institute of Health and Welfare	1
Victorian Cancer Agency	1
Health service	**16**
Albury Wodonga Health	1
Albury Wodonga Regional Cancer Centre, La Trobe University, and UNSW	**1**
Austin Health	1
Canberra Region Cancer Centre	1
Cancer Care Servics, Royal Brisbane and Women's Hospital	1
Cancer Statewide Clinical Network Clinical Lead	1
Eastern Palliative Care Association	1
Flinders Medical Centre	1
Hunter New England LHD	1
Icon Group	1
Monash Health	1
Peter MacCallum Cancer Centre	1
Psycho-oncology program, Peter MacCallum Cancer Centre	1
Royal Melbourne Hospital	1
Sir Charles Gardiner Hospital	1
South Western Sydney LHD	1
Industry	**10**
Cemplicity	1
Elekta	2
Icon Group	1
Osara Health	1
Osasuna Pty Ltd	1
The Cinician	1
VALD	1
Varian	1
WeGuide	1

Sector and organisation	Number of participants
Integrated Cancer Services	6
Hume Regional Integrated Cancer Service	2
North Eastern Melbourne Integrated Cancer Service	2
Western & Central Melbourne Integrated Cancer Service	1
Western and Central Melbourne Integrated Cancer Service	1
Peak body	21
Australia and New Zealand Sarcoma Association (ANZSA)	1
Australian Health Care and Hospitals Association	1
Breast Cancer Network Australia	1
Cancer Council Australia	1
Cancer, Palliative Care and Lymphoedema Group, Australian Physiotherapy Association	1
Canteen	1
Leading Lymphoedema Patient Advocate - PC4 Consumer Advisory Group	1
Leukaemia Foundation	3
Lung Foundation Australia	1
McGrath Foundation	2
National Rural Health Alliance	1
NeuroEndocrine Cancer Australia	1
NeuroEndorine Cancer Aust	1
Ovarian Cancer Australia	1
PanCare Foundation	2
PC4	1
Rare Cancers Australia	1

Sector and organisation	Number of participants
Research	**37**
Adelaide University (University of SA)	1
Alfred Health	1
Australasian Leukaemia and Lymphoma Group	1
Australian Institute of Health Innovation, Macquarie University	1
Border Medical Oncology Research Unit	1
Cancer Australia Quality of Life National Technical Service (CQUEST), UTS	1
Cancer Quality of Life Expert Service Team (CQUEST)	1
Cancer Research Program, Monash University	11
Cancer Symptom Trials at the University of Technology Sydney	1
Cancer Symptom Trials UTS	1
Centre for Health Economics Research and Evaluation, UTS	1
Clinical Trial Centre, University of Sydney	1
Curtin University	1
Flinders University	1
Flinders University & PoCoG	1
GI Cancer	1
La Trobe University	11
Melbourne School of Population and Global Health, University of Melbourne	1
Monash University	1
NHMRC Clinical Trials Centre, the University of Sydney	1
North Eastern Melbourne Integrated Cancer Service	1
Ovarian Cancer Research Foundation	1
Palliative Care Clinical Studies Collaborative (PaCCSC) and IMPACCT UTS	1
Peter MacCallum Cancer Centre	1
Psycho-Oncology Cooperative Research Group, The University of Sydney	3
The Daffodil Centre, The University of Sydney	1
TROG Cancer Research	1
University of Queensland	1
University of South Australia	1
University of Southern Queensland	11
University of Sydney	2
University of Sydney	1
University of Sydney - Daffodil Centre	1
UNSW/ Crown Princess Mary Cancer Centre, Westmead Hospital	1
TOTAL	**121**

Movember Team
PO BOX 60
East Melbourne
VICTORIA 8002
Australia

1300 GROW MO
(1300 4769 66)

www.movember.com
info@movember.com

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