



Government of **Western Australia**  
Department of **Health**

# WA Continuous Improvement in Care (CIC) Transition Project:

Current State Report – The use of Patient Reported  
Experience and/or Outcome Measures

February 2023

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# 1. Executive Summary

This report presents the findings of a current state analysis of validated Patient Reported Measures (PRMs) undertaken from August 2022 to January 2023 across the WA health sector. The current state report was commissioned by Health Networks Branch at the Department of Health (WA) and performed by the Continuous Improvement in Care (CIC) – Cancer Project. It evaluates the status of Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs), with a view to identifying and understanding their actual and potential use, associated processes, issues and any opportunities for improvement. The outcomes of the current state analysis provide a recent snapshot (as at February 2023) of both PROMs and PREMs to inform:

- the WA Health Executive Committee’s (HEC) Safety and Quality Committee about the current PRMs approach in WA
- development of a detailed Transition Plan for the future transition of the CIC Cancer Project – including a custom-built information system that supports the collection, use and reporting of PROMs – into WA Health. This plan will outline the business requirements necessary to support the use of the CIC Cancer framework as a ‘proof of concept’ project.

The current state report was facilitated through the formation of the WA CIC Transition Project and comprised a desktop review, literature review, and targeted stakeholder engagement across the WA health sector. Input from other Australian jurisdictions was also sought, both individually and through the Australian Commission of Safety and Quality in Health Care’s (ACSQHC) PROMs Roundtable opportunities in late 2022.

## Findings

Stakeholders engaged across the WA health sector exhibited a significant enthusiasm for PRMs given local and international evidence regarding the important role PRMs can play in promoting the provision of patient-centred care at both the individual and system level. The analysis found that there is considerable PRM-related activity across the WA Health system which aligns with the state (i.e. the WA Sustainable Health Review (SHR)), and national priorities; however, this activity is not necessarily cohesive or immediately visible.

## PREMs

The WA Health system has a long history of evaluating patient satisfaction and experience to inform improvements in care delivery and other services. Within the private sector this is often facilitated through the ‘Voice of the Patient’ survey. For WA Health, considerable work has been achieved more recently with PREMs through the successful development and introduction of the MySay Healthcare Survey led by South Metropolitan Health Service Safety, Quality and Consumer Engagement (SMHS SQ&CE) that measures patient experience for all overnight and same-day patients. The initiative is coordinated through an established governance model and agreed collaborative approach between WA Health Service Providers (HSPs) and the WA Department of Health. The Your Experience of Service (YES) survey – developed through the National Mental Health Consumer Experiences of Care Project – was commenced state-wide in 2018 by the WA Mental Health Commission (MHC) for use with paediatric, adolescent, and adult consumers across all public-funded community and inpatient mental health services.

## PROMs

A number of PROMs activities occur across the WA Health system. This includes work being progressed at a system level via SHR Recommendation 4 and the Outcome Measures Project (OMP) through engagement with the Independent Oversight Committee. At the HSP level the majority of PROMs related initiatives have originated from translational research or clinical quality projects aimed at driving improvements in patient-centred care. Unlike PREMs, these activities are not integrated nor is there any overall coordination or oversight. Currently, therefore, there is no capability for the WA Health system to ensure that effective governance has been established and that any data outcomes or learnings from PROMs captured at a local level are being used to inform and effect change across the system. The fragmented nature of this approach means that there is no agreed framework, guiding

principles or business rules to ensure improvements are being informed by evidence-based best practice and data collected is accurate and able to be benchmarked now and in the future.

Whilst this current state is not ideal, it provides an opportunity for the Department of Health (WA) to take the lead in establishing a consistent and coordinated approach to PRMs with WA Health HSPs. As seen in other jurisdictions and countries, this can effectively drive changes to improve patient care and outcomes whilst reducing service delivery costs.

## Results Matrix

Activity	Current state
<b>System level</b> (detailed information to be found in Section 8.2.1 of this report)	
SHR4 Steering Group expansion of the use of <i>Care Opinion</i>	Program evaluation underway to focus on outcomes measures and agreed PREMs/PROMs.
<i>Outcome Measures Project</i>	ISPD PSP Division, in collaboration with the WACOSS and the IOC, are developing new indicators to illustrate inequities in healthcare.
National PROMs pilot project of the <i>Australian Orthopaedic Association National Joint Replacement Registry</i>	WA Department of Health funds provided to the national rollout of PROMs for hip, knee, and shoulder replacements across public/private hospitals via the AOANJRR.
<b>PRMs</b> (detailed information to be found in Section 8.2.2 of this report)	
<i>Clinical Quality Registries</i>	Organisations or services from the private and public sectors of the WA Health system currently participate in 19 registries
<i>WA Health Cancer Data and PRM Survey</i>	The majority of respondents indicated that either their program or organisation were not currently collecting PRMs (43%), or they were unsure if PRMs were being collected (41%). Almost 2/3 of respondents rated the level of priority they would assign indicators/metrics if there was an opportunity to access them as 'Essential' or 'High'.
<b>PREMs</b> (detailed information to be found in Section 8.2.3 of this report)	
<i>Patient Evaluation of Health Services (PEHS) survey</i>	No longer in use, this survey was intended to monitor and benchmark patient satisfaction levels with 7 different aspects of health care provided.
<i>MySay Healthcare Survey (MySay)</i>	Online survey offered to all overnight and same-day patients to measure patient experience to inform improvement initiatives aimed at improving the patient experience at a ward, department, service, hospital, and organisation level.  Joint initiative is in place to incorporate the <i>MySay</i> dataset and PREMs indicators into the Safety and Quality Indicator Set.
<i>Net Promoter Score (NPS)</i>	Well established within patient experience surveys undertaken across all private sites and services, mainly through 'Voice of the Patient' survey programs administered by Press Ganey.
<i>Your Experience of Service (YES) survey</i>	Conducted annually across all public funded community and inpatient mental health services for paediatric, adolescent, and adult consumers. Results are collated by the Mental Health Commission and communicated back to consumers/carers and health services to identify areas for improvement. At a state level, the survey results are reported into <i>SQuIS</i> and reviewed quarterly by the Quality Surveillance Group.
<b>PROMs</b> (detailed information to be found in Section 8.2.4 of this report)	
Use of validated tools to drive improvements in patient-centred care: <i>DT, SCNAT-IP, EORTC QLQ-C30, EQ-5D, PCOC SAS, QOL-CS,</i>	A number of discrete PROMs initiatives are being undertaken by specific clinical specialties, departments, and services across both public and private sectors of the WA Health System. Initiatives are at various stages of piloting or implementation and are, in the majority, disconnected from each other.

## 2. Commissioning of Report

This Current State Report – The use of Patient Reported Experience and/or Outcome Measures was commissioned by the Health Networks Branch at the Department of Health (WA) through an in-reach arrangement with the University of Western Australia (UWA) and undertaken by the UWA Continuous Improvement in Care (CIC) – Cancer Project under Grant Funding Agreement Document ‘Continuous Improvement in Care – Cancer (CIC- Cancer) Transition planning and Current state - WA Health Patient Reported Experience and Outcomes Measures (PREMs/PROMs) DoH20229727’.

## 3. Background

Whilst overall disease related outcomes in WA are amongst the best in the world, and have substantially increased over the past 30 years, significant clinical variation in patient outcomes continues to occur.(1) For example, whilst the clinical pathway for people diagnosed with cancer varies dependent on disease and treatment related factors, there are inequities for Western Australians in access to quality care and disparities in practice. These differences are particularly evident for Aboriginal people and those living in rural and remote locations.(2)

Evidence indicates that to achieve the best outcomes for patients whilst reducing the costs associated with the delivery of high-quality care, healthcare provision must develop and implement a more transparent, value-based model.(3) At the heart of this model is patient-centred care – the foundation of high reliability healthcare systems, also one of the six dimensions of healthcare quality.(4) Although substantial improvements in the efficacy of healthcare delivery have been achieved through a shift to patient-centred care, the metrics used to evaluate these improvements or monitor outcomes are often clinical and performance based. While these are important measures, the patients’ voice may not have been incorporated to the degree with which it can effectively inform a healthcare organisation on the patients’ perception of their care. In effect, a critical misalignment may exist between a healthcare organisation’s objectives and the metrics used to accurately evaluate its service delivery; thereby contributing to fragmented services and a lack of timely, efficient, and appropriate patient care.(4)

A number of Australian jurisdictions and other countries (e.g. Canada, Netherlands, New Zealand, Sweden, United Kingdom, United States) have successfully led or started to lead transformative change across their healthcare systems through implementation of value-based frameworks applicable to their local context. These frameworks strive to deliver and measure value in terms of health outcomes (quality of life (QoL)), patients’ experience of care, efficient and effective care concerning costs, and staff experience in line with evidence-based best practice e.g. the Institute for Healthcare Improvement’s Quadruple Aim.(5) This translates to a focus not only on traditional clinical indicators, but also broader multi-dimensional metrics, whereby health outcomes are defined as the outcomes that matter most to patients, e.g., a patient’s QoL and their ability to work throughout the course of their treatment. To quantify what matters most to patients requires use of consistent, rigorous measures and evaluation methodologies to demonstrate the impact of care on patient outcomes. Validated survey tools – referred to as Patient Reported Measures (PRMs) – are used to collect this information. The survey metrics collected provide information to health teams that informs patient interactions, promotes communication, allows shared decision-making, and improves the quality of care. Whilst this information provides the greatest benefit at point of care, it can also be used in aggregated form – at both service and system levels – to drive continuous improvement, encourage sharing of innovative and effective practices, and inform value-based health care models.(6)

### Continuous Improvement in Care - Cancer (CIC Cancer) Project

The CIC Cancer Project is a phased implementation, longitudinal, prospective research project that commenced in 2017 with the aim of developing PRMs which could be incorporated into standard clinical practice – at the point of care – to inform patient care along the cancer pathway and thereby improve patient outcomes. CIC Cancer was identified as a project suitable to demonstrate the translation of research into clinical practice, given the close alignment with the WA Cancer Plan 2020-25 (2) priorities and significant contribution to the delivery of the

Sustainable Health Review (7) Recommendation 4 (SHR Rec 4) '*Commit to new approaches to support citizen and community partnerships in design, delivery and evaluation of sustainable health and social care services and reported outcomes.*' Through a small grant funded in-reach arrangement with Health Networks, a Project Manager from the CIC Cancer Project worked within Health Networks to undertake a current state report of validated PREMs and PROMs in use in WA. Information regarding the governance of the WA CIC Transition Project and the CIC Cancer Project is provided in Appendix 2.

## 4. Purpose

As part of the WA CIC Transition Project this Current State Report provides a snapshot of PROMs and PREMs activities occurring across the WA Health system to inform the:

- WA Health Executive Committee's (HEC) Safety and Quality Committee about PREMs and PROMs in WA; and
- development of a detailed Transition Plan to inform future transition of the CIC Cancer framework and its custom-built information system – which supports the collection, use and reporting of PROMs – into WA Health through the implementation of a 'proof of concept' project.

## 5. Definitions

### 5.1. Patient Reported Measures (PRMs)

Patient Reported Measures (PRMs) are a distinct type of metrics which capture a patient's perspective of their care and are integral to building a patient-centred system of structuring, monitoring, delivering, and financing health care.(8) Internationally PRMs have been collected for many years, typically for the purposes of research, clinical quality registries, and quality improvement. This work has evolved to demonstrate that components of patients' perceptions can be reliably measured and used to predict different outcomes.(9) For example, research indicates that if clinicians do not provide a positive, patient-centred approach to their interactions, patients are less satisfied, less enabled, and may have a greater symptom burden and higher rates of referral.

Effective and sustainable utilisation of PRMs requires the systematic collection and use of discrete measures which are a direct account of patients' experiences of care, perceptions of their quality of life (QoL), physical function, symptoms, mental and emotional wellbeing, effects of treatment, and ability to do the things that are important to them.(5)

There are two types of PRMs – PREMs and PROMs. For a conceptual view see Appendix 3.

### 5.2. Patient Reported Experience Measures (PREMs)

PREMs capture and assess the patient's experience and perception of their healthcare and services.(10) These measures ask patients to describe, rather than simply evaluate, their encounters with health services. Anonymous completion of these questionnaires provides an overview of a patient's experience of care to inform local service improvement and enable response to identified issues.

PREMs are designed to determine whether patients have experienced certain care processes or interactions with healthcare systems and the degree to which their needs were met, rather than their satisfaction with the care received (as this may be subject to bias).(11) For example, PREMs may be employed to collect information on the patient experience of attending a hospital's Emergency Department (ED). This information could in turn be used to inform urgent care service delivery and development, and drive improvements through benchmarking with other EDs.

[Measuring the Patient Perspective – Patient Satisfaction and Patient Experience](#)

The terms 'patient satisfaction' and 'patient experience' are at times used interchangeably, however, they have different meanings, measurement, and implications for the quality of care. In brief, patient satisfaction is about how the patient felt regarding their care encounter based on their expectations, whilst patient experience reflects a patient's perception of what happened and how.(11)

- **Patient satisfaction** is a subjective quantitative measure related to a patient's expectations during their care encounter. This means that different patients may have different levels of satisfaction for the same quality of healthcare due to different kinds of expectations.
- **Patient experience** is an objective, qualitative measure that refers to the patient's perception and experience of an encounter with the healthcare system, including their care, access to services and all interactions. Patient experience encompasses aspects of health care delivery that patient's value highly when they try to access or receive care, for example timely referrals and appointments, easy access to information, and good communication with health care staff and services.(12)

Over time there has been a significant shift towards assessing patient care experiences to inform implementation of activities which lead to high-quality patient centred care and system changes. This shift has occurred with the increasing body of evidence which demonstrates that patient experience surveys are reliable, valid, correlate across individuals and settings with other quality indicators, and are predictive of better outcomes.(13)

### 5.3. Patient Reported Outcome Measures (PROMs)

PROMs capture patients' perspectives on how illness or care has impacted their overall health and wellbeing.(9) They are directly reported by the patient without interpretation by a clinician or anyone else and pertain to the patient's health, QoL, or functional status which can be associated with health care or treatment. Standardised and validated tools that measure patient outcomes, can be generic or include quality of life or symptoms related to a specific disease or condition.(14) Information from PROMs can be used for care planning and decision-making, to provide timely person-centred care and ensure referrals are appropriate and based on identified patient needs.

PROMs have been found to enable clinicians to engage more effectively with their patients by facilitating discussions about what matters most to the patient in real-time. The identification of patient-reported health issues is important when screening for specific symptoms or health problems and monitoring patients' outcomes over time to inform treatment decisions and planning (especially for issues that may go unnoticed without specific prompting).(15) Examples of such issues include: does the patient have any ongoing pain? Is that pain preventing them from any activities that are important to them? Are there compromises they would prefer to make between pain and certain side-effects?

PROMs are captured at a point in time and usually measured on at least two or more occasions of the patient's care pathway. There are three different types of PROMs, as listed with examples in Table 1.

**Table 1. Three Types of PROMs with examples of tools**

PROMs Type	Example Tools
<b>Generic</b> Measure aspects of health that are common to most patients, so can be used across healthcare settings and conditions.	Short Form-36 (SF-36) is suitable for use across most patient populations.(16)
<b>Condition-specific</b> Have questions that relate directly to specific health conditions and their associated treatments.	European Organisation for Research and Treatment of Cancer – Quality of Life of Cancer Patients (EORTC QLQ-C30) is for use across all cancer types.(17)



<p><b>Population-specific</b></p> <p>Apply to specific service sectors or segments of the population.</p>	<p>Aboriginal Health - Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP).(18)</p>
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## 6. Metric Considerations

### Validity, Reliability and Sensitivity

Given PRMs use self-rated scales and indices specifically developed to identify a patient’s perceived views of their care and outcomes, it is important that survey tools and associated guidelines used to administer them have been critically appraised for validity, reliability, sensitivity, and any bias in the design.(19) NSW Health and the Agency for Clinical Innovation (ACI) concluded in their 2021 publication ‘*Analytic principles for PROMs*’ (20) that well validated, standardised approaches to comparing outcomes between healthcare providers is limited and there is a lack of a shared understanding with regard to interpreting results over time or the progression of a patient’s condition or disease. This lack of a shared understanding presents a substantial risk for the misinterpretation of data, wasted opportunities to learn from patients’ perspectives, preventable harm, shortcomings in action, and faults in policy. Consequently, it is important that the collection and use of PRMs is administered systematically with data validation and analytical processes conducted in line with evidence-based best practice guidelines and business rules. These processes ensure that any inferences ascertained from patient data will be valid, reliable, and robust – providing confidence in the interpretation of patient reporting of their health, symptoms, quality of life and the things that matter to them as a patient.(21)

## 7. Benefits of Patient Reported Measures

Utilising both clinical and PRMs to systematically evaluate outcomes ensures that all staff, from those at the point of care through to service and system level, are focused on maximising 'what matters' from the perspective of the patient receiving care. These measures can not only inform care planning between patients and clinicians but can be used to improve care delivery, evaluate the impact of care, guide resource allocation, and inform policy decisions.(22)

Research into clinical indicators and patient reported outcomes has established that clinical indicators frequently do not correlate with how a patient has perceived their care, treatment outcome/s, or quality of life. Consequently, it is recommended that the patient's perception of their own health and wellbeing is routinely asked at the point of care.(23)

Findings from other research studies have demonstrated that there are significant and wide-ranging benefits which can be realised by using PRMs.

- a) Patients engaged in their healthcare often experience better outcomes and choose less costly interventions. Research demonstrates that engaged patients often feel more empowered to improve their own health and wellbeing by actively participating in their care and treatment. For example, a patient with lower back pain may choose to see a physiotherapist rather than attend the emergency department of a hospital.(24)
- b) Measuring and using patient reported outcomes allows for more effective communication and shared decision-making between patients and clinicians. Research shows that when patients and their carers are engaged in making decisions about their care and treatment, they are more likely to be compliant with their treatment plan/s because these align with their needs, preferences, and values.(25) Furthermore, numerous studies demonstrated that if patient decision aids, such as procedure specific information sheets, are used to support patients in this process there is added benefit of reduced use of invasive treatment options without impacting health outcomes and the costs of care are reduced.

- c) Measuring patient reported outcomes is invaluable as the information comes directly from the patient without interpretation by anyone else and as such observer bias is reduced. These measures can form an important part of a clinician's toolkit of assessment approaches and are critical to informing current clinical practice and the development of innovative patient centred approaches to care.(20)
- d) Systematically collected patient reported outcome data may reflect underlying health status more accurately than clinical reporting and also predict meaningful clinical outcomes including survival. Patient symptoms can go undetected during standard clinic appointments, and clinicians may underestimate the impact of symptoms from spending only a short time with the patient. Collection of PROMs allows healthcare providers and services to better understand the patient's experience of their condition and how the care received has impacted the patient.(26)
- e) PROMs have been shown to improve patient-centred care by helping clinicians to systematically, and more effectively, quantify disease specific and general measures of function and health; providing valuable data to assist with clinical care over time. For example, for a patient with severe symptoms of fatigue and nausea from cancer treatment, clinicians can use the PROMs to evaluate how much those symptoms impact the patient's ability to function and undertake normal daily activities. This informs discussions, improves interactions, and enables a shared decision-making process to be established so that the patient's care plan can be adjusted to improve the patient's quality of life.(27)
- f) PROMs also provide opportunities for clinicians to reflect on how outcomes have been achieved, particularly when benchmarked with trends or comparative data, and to initiate or accelerate change and improvement.(28)

A contextual view of the key uses of PROMs are outlined in Appendix 4

## 8. Current State Analysis - Methodology

The CIC Cancer Project Manager conducted a current state analysis of validated PREMs and PROMs in use across WA between August 2022 and January 2023. A number of processes were employed to ensure that the current state analysis was conducted effectively, efficiently and with due diligence. These included:

- Desktop review
- Literature review
- Stakeholder engagement and consultation

### 8.1. Desktop Review

A desktop review was performed during the WA CIC Transition Project initiation phase and throughout the first two quarters of the agreed project timeline. This facilitated the capture and evaluation of information to apprise both stakeholder engagement across the WA public and private health sectors and the current state analysis of PRMs. The desktop review involved examination of organisational websites for existing internal (where possible) and publicly available information with any references to PRMs, PREMs and PROMs for both public and private healthcare service providers within WA.

A desktop review is reliant on website searches. The information captured, therefore, is dependent on when the site was last updated. Where possible, cross-checking or verification of this information was incorporated into stakeholder consultation to improve reliability.

For those organisations indicating they are collecting PRMs, the desktop review identified that the majority published the definition/s of the PRMs, the potential purpose and benefits of the use of the measures, together with high level results. A closer examination of many of the organisations that reported an interest in PRMs collection, showed awareness rather than active engagement in any form of systematic PREMs and/or PROMs data collection.

## 8.2. Literature Review

A review of national and international literature on PRMs, PREMs and PROMs was also completed during project initiation and continued throughout the current state analysis process. This review process continued iteratively throughout stakeholder engagement and consultation phases. Identified references often led to other literature and information sources. In particular, the literature review paid reference to contemporaneous research results (national and international), evidence-based best practice, methodologies, validated tools, datasets, governance, domains, and metric considerations. Additionally, benefits and barriers, frameworks for implementation, challenges, support, resources and training for consumers and staff on PRMs were included in the review to inform the analysis and future directions (Appendix 5).

## 8.3. Stakeholder Engagement

### CIC Cancer Project - Engagement Context

The work undertaken by the CIC Cancer Project has primarily focused on the development of innovative and financially sustainable solutions which may assist the health system to deliver person-centred, value-based care and equity in health outcomes. This strongly aligns with the higher-level strategies of State and National Health Reform agendas. Transitioning these solutions to WA Health through the WA CIC Transition Project can aid achievement of recommendations and strategies within, but not limited to, the 2020–25 Addendum to National Health Reform Agreement (29), the Sustainable Health Review (SHR) Enduring Strategies and Recommendations and the WA Cancer Plan 2020-2025.

### Collaborative Consultation

A stakeholder engagement plan was developed. It was identified that the WA CIC Transition Project and WA Cancer Data Strategy Project would concurrently commence current state analysis projects which included PRMs reviews. The leads for these projects, therefore, chose to establish a partnership approach to jointly undertake stakeholder consultation where possible. Where relevant synergies were identified, these project groups also partnered with the Cancer Multidisciplinary Activity Program (CanMAP) Project. This joint approach, reduced duplication of effort, encouraged collaboration, and minimised stakeholder disruption.

### WA Health Cancer Data and PRM Survey

Recognising the constraints to undertake extensive stakeholder consultation within the agreed timeframe, for both the WA Cancer Data Strategy Project and the WA CIC Transition Project, a conjoint stakeholder survey was also undertaken. The stakeholder survey was developed in collaboration with the WA Cancer Data Strategy Project Working Group, the CIC Cancer Project Team, and Health Networks Branch management team. The WA Department of Health Consultation Hub on Citizen Space was used to develop and host the survey development. A state-wide communication strategy was developed in conjunction with the survey to promote awareness and encourage completion.

## 8.4. Limitations

Limitations were experienced during the ascertainment and compilation of information from stakeholders and other sources for the current state analysis. Despite efforts to address the encountered gaps, information provided in this current state analysis is not inclusive of all activities occurring with PRMs across WA. Key limitations included:

- The Health Networks Branch are supporting the delivery of recommendations from the SHR and the WA Cancer Plan, both of which involve the implementation of PRMs. Given the potential for synergies it was opportune to undertake the current state analysis alongside the WA Cancer Data Strategy. Some stakeholders, however, found this confusing until clarification was provided and this may have impacted the engagement of other staff and participation in the WA Health Cancer Data and PRM Survey. Delays were experienced during the development of the WA Health Cancer Data and PRM Survey to allow for additional

stakeholder consultation and to obtain appropriate governance approval. This led to the survey being distributed a month later than planned, in early December 2022 with the impending holiday period. To mitigate the impact of this delay, the survey remained open for seven weeks and additional promotional activities were undertaken, including targeted reminders in the final week (late January 2023).

- Capacity and competing priority constraints on staff working in the state and national healthcare system, resulted in varying levels of success in ascertaining information from referred contacts or sources despite concerted communication efforts. For example, six of the Australian Clinical Quality Registries were contacted for further information, but only one responded.

## 9. Findings

### 8.1 Summary of Findings

#### System level

- In 2022, the SHR4 Steering Group initiated planning activities aimed at expanding the use of Care Opinion, through engagement with the WA Health HSPs and consumers. Program evaluation is currently underway with SHR Rec Leads to focus on outcomes measures and agreed PREMs/PROMs.
- The Information System and Performance Directorate (ISPD), Purchasing and System Performance (PSP) Division are working with the Western Australian Council of Social Service (WACOSS) and the Independent Oversight Committee (IOC) to develop new indicators that illustrate inequities in healthcare i.e. equitable access to hospital procedures.
- The Patient Safety and Clinical Quality Directorate, Clinical Excellence Division has been the WA representative for the national PROMs pilot project of the Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR). WA Department of Health funds have been provided to the national rollout of PROMs for hip, knee, and shoulder replacements across public/private hospitals via the AOANJRR.

#### Patient Reported Measures

- The current state analysis identified that many hospital sites and services across the WA public and private health sectors participate in state and national Clinical Quality Registries (CQR). A number of the CQR datasets have incorporated PRMs into the suite of outcome measures collected and reported. A review of the ACSQHC's Australian Register of Clinical Registries and the registry websites identified nineteen (19) registries with which organisations or services from the private and public sectors of the WA Health system currently participate.
- The majority of WA Health Cancer Data and PRM Survey respondents indicated that either their program or organisation were not currently collecting PRMs (43%), or they were unsure if PRMs were currently being collected (41%). The remainder of the survey respondents (16%) revealed that PRMs were currently being collected by their program/organisation. Within the Cancer data section of the survey, respondents were asked to rate the level of priority they would assign to a list of indicators/metrics if there was an opportunity to access them. All PRMs were rated as 'Essential' or 'High' metric priorities for cancer data by WA Health system survey respondents.

#### Patient Reported Experience Measures

- Historically, over many years an annual Patient Evaluation of Health Services (PEHS) survey was conducted state-wide by the WA Department of Health Epidemiology branch in collaboration with the Survey Research

Centre at Edith Cowan University. This survey was intended to monitor and benchmark patient satisfaction levels with seven different 'aspects of health care' provided across the WA Health system.

- The current state-wide MySay Healthcare Survey is a voluntary online survey offered to all overnight and same-day patients to measure patient experience (it has an adult version and a parent version for paediatric patients). MySay Healthcare Survey data is used by HSPs to inform initiatives aimed at improving the patient experience at a ward, department, service, hospital, and organisation level. The survey data also enables monitoring over time and benchmarking of patient experience between services. At a state level, there is a joint initiative between the Patient Safety and Clinical Quality Directorate, Clinical Excellence Division and Information and Performance Governance to incorporate the MySay dataset and PREMs indicators into the Safety and Quality Indicator Set (SQiS).
- The use of the Net Promoter Score (NPS) has been well established within patient experience surveys undertaken across all private sites and services within the WA health system for some time, mainly through the 'Voice of the Patient' survey programs administered by Press Ganey.
- The Your Experience of Service (YES) survey was commenced state-wide in 2018 by the WA Mental Health Commission (MHC) and is conducted annually across all public funded community and inpatient mental health services for paediatric, adolescent, and adult consumers. It was designed in collaboration with mental health consumers and developed from the recovery principles of the National Standards for Mental Health Services through the National Mental Health Consumer Experiences of Care Project. Results of the YES survey are collated by the MHC and communicated back to consumers, carers, and health services, who use this feedback to identify areas for improvement. At a state level, the survey results are reported into SQiS and reviewed quarterly by the Quality Surveillance Group (QSG).

## Patient Reported Outcome Measures

- To drive improvements in patient-centred care a number of discrete PROMs initiatives are being undertaken by specific clinical specialties, departments, and services across both public and private sectors of the WA Health System. Each of these initiatives is using a validated tool and are briefly outlined below:
  - ▶ **Distress Thermometer** - currently in use across a number of cancer services in the WA Health System, including those provided by WACHS and NMHS Cancer Network WA.
  - ▶ **Supportive Care Needs Assessment Tool for Aboriginal People (SCNAT-AP)** - has been trialled and implemented for cancer patients by WACHS Nursing & Midwifery - Cancer Services.
  - ▶ **International Consortium for Health Outcomes Measurement (ICHOM) sets of Patient-Centred Outcome Measures for Oncology** - the main measures used by the CIC Cancer Project for breast, colorectal and lung cancer at Royal Perth Hospital; breast and lung cancer at Fiona Stanley Hospital (FSH); breast cancer at SJoG Subiaco and colorectal cancer at SJoG Midland. NMHS has also been piloting Quality of Life Survivor (QOL-CS) and ICHOM measure sets, and these pilots are currently being expanded. Activities are also underway for the lung cancer service at SCGH to commence activities under CIC Cancer.
  - ▶ **EQ-5D ®** - included in the PROMs of the CIC Cancer Project for the cancer services listed above.
  - ▶ **EORTC QLQ-HN43** - identified by FSH Head & Neck Cancer as an ideal tool for collecting PROMs from their patient cohort. The team were initiating the set-up of this within their local processes and online MDT documentation to commence collection of PROMs in late 2022.
- All public and private services that provide palliative care services in WA have implemented the Palliative Care Outcomes Collaboration Symptom Assessment Scale (PCOC SAS). PCOC is a national palliative care project funded by the Australian Government Department of Health

- The responses to the WA Health Cancer Data and PRM Survey question about whether a program or organisation was currently collecting and using PROMs were limited. Respondents were at times confused with the type of PRMs they were collecting such that outcome measures were mistakenly identified as experience measures. The lower response rate and limited information received from the survey correlated with feedback from other staff engaged in the face-to-face consultation. An example of this is where three respondents individually indicated that PROMs were being collected - the Hospital Anxiety and Depression Scale by NMHS, an unknown tool by SMHS Medical Urology, and the EORTC QLQ-30 by SMHS Lymphoedema and Oncology, however, no further information was provided.
- The Organisation for Economic Co-operation and Development (OECD) launched the Patient-Reported Indicators Surveys (PaRIS) initiative in 2017 which is focused on patients with chronic conditions and aims to fill this information gap in primary health care, through PREMs and PROMs. Stakeholder consultation and survey results indicate that to date NMHS, Health Networks and CIC Cancer have engaged with the PaRIS initiative and contributed data in line with governance and research requirements.

## 8.2 Findings in Detail

### 8.2.1 Current Strategic Activities and Awareness in WA (system level)

#### Sustainable Health Review – Recommendation 4 (SHR4)

Health Networks, Clinical Excellence Division oversees the delivery of SHR4 activities and milestones, specifically the deliverable '*Transparent public reporting of patient and carer reported experience and outcomes (PREMs and PROMs) by July 2023 with ongoing development of measures in line with emerging best practice.*'

To support the current state analysis, the Health Networks Clinical Leads Forum at the October 2022 meeting was used as an opportunity to highlight current activities relating to PRMs, raise awareness of the upcoming state-wide survey, discuss present clinical use of PRMs and prompt further discussion on PREMs and PROMs. Further clinical engagement planning was anticipated following this meeting; however, it was agreed that this would be best informed by the Current State Analysis report. Early planning has also occurred to determine consumer awareness of PREMs and PROMs and the key factors for public dissemination.

#### Care Opinion

Care Opinion (formerly known as Patient Opinion) is an independent moderated online platform which enables healthcare consumers to provide anonymous feedback – both positive and negative – through public sharing of their experiences of using healthcare services.<sup>(30)</sup> Consumer experiences shared publicly are termed 'consumer or patient stories'. Once submitted the feedback is communicated to the participating healthcare organisation. WA HSP's have well established processes to ensure all consumer stories about their services are provided with a timely response from appropriate senior or Executive staff. The response from the healthcare organisation is then posted with the consumer story and any subsequent discussion.

In WA, these consumer stories are used to identify areas for improvement, at a local, service, and system level as appropriate. Whilst Care Opinion is not a patient experience measure per se, it provides accessible qualitative feedback to both the WA Healthcare system and consumers through the sharing of a patient lived experience and the healthcare organisations' response. Health Networks manages the Care Opinion Dashboards, providing a high-level summary of activity in Care Opinion for each HSP on a quarterly basis.

In 2022, the SHR4 Steering Group initiated planning activities aimed at expanding the use of Care Opinion. A potential outcome of this planning may be engagement with the HSP administrators for Care Opinion, patient experience teams, and consumers to identify any issues or barriers specific to Care Opinion and how these may be addressed. Ways in which awareness, and use, of Care Opinion could be further developed, including system level

monitoring of safety and quality themes and implementation within the broader social services sector are also being considered.

### Outcome Measures Project

Australians with illnesses that can be effectively treated by hospital-based medical and surgical procedures should have equitable access to these procedures. Studies have shown that whilst Aboriginal and Torres Strait Islander people are more likely to be hospitalised than other Australians, they are less likely to receive a medical or surgical procedure while in hospital.(31)

The Information System and Performance Directorate (ISPD), Purchasing and System Performance (PSP) Division are working with the Western Australian Council of Social Service (WACOSS) and the Independent Oversight Committee (IOC) to develop new indicators that illustrate inequities in healthcare i.e. access to hospital procedures. These indicators will be based on measures in the Australian Institute of Health and Welfare (AIHW) definition of the indicator '3.06 Access to hospital procedures'. Program evaluation is also currently underway with SHR Rec Leads to focus on outcomes measures and agreed PREMs/PROMs.

### Safety and Quality Indicator Set (SQiS)

The Patient Safety and Clinical Quality Directorate, Clinical Excellence Division has been the WA representative for the national PROMs pilot project of the Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR).(32) The overall aim of collecting PROMs data via the registry is to aid improvement of the quality and cost-effectiveness of healthcare delivery at a national level. Yet before this could be achieved it was essential to establish that PROMs could be collected accurately, efficiently, and affordably for uploading to a national collection.

The pilot project assessed AOANJRR's capacity to directly consent patients and collect pre- and post-operative PROMs which could be integrated within the AOANJRR. Participants were those patients receiving elective hip, knee, and shoulder arthroplasty. WA Department of Health funds have been provided to rollout the pilot project across public/private hospitals.

### Strategic Awareness & Visibility

During WA CIC Transition Project initiation, good stakeholder awareness was identified in relation to the concept of PRMs at a system level, especially with regard to the WA Department of Health work being undertaken to progress the requirements of SHR Rec 4. Whilst awareness was evident, it was found to be at a broad conceptual level with limited knowledge and understanding of the definitions, types, tools, uses, and benefits of PRMs, PREMs and PROMs. This limited knowledge and understanding was recognised as a significant barrier to effectively engaging key stakeholders, especially WA Health senior staff and Executive, so that organisational support for investment in PRMs as a system-wide strategic priority could be achieved. This led to the development of a PREMs and PROMs Conceptual framework (Appendix 13) and presentations at key forums to build consumer, clinician and senior staff support for PRMs.

Additionally, a Discussion Paper '*Patient Reported Experience and Outcome Measures (PREMs and PROMs): Driving improvements in outcomes that matter most to patients and healthcare efficiencies through a patient-centred, value-based approach*' was provided as part of a submission to the HEC Safety and Quality Committee. This submission considered the evidence-based best practice definitions of PRMs and discussed coordinated approaches and progress of other jurisdictions in achieving optimal outcomes for patients whilst reducing the costs associated with the delivery of high-quality care. It was agreed the HEC Safety and Quality Committee would consider findings from the current state report on completion.



## 8.2.2 PRMs

### Clinical Quality Registries (CQRs)

CQRs are bodies that systematically monitor the quality (appropriateness and effectiveness) of health care, within specific clinical domains, by routinely collecting, analysing, and reporting health-related information. The information is used to identify benchmarks, significant outcome variance, and inform improvements in healthcare quality. A number of CQR datasets, have incorporated PRMs into the suite of outcome measures collected and reported.

It is important to note, that this is not a mandatory requirement and as such the data may not be reliable. In addition, the specifications of reporting processes and procedures are not always clear. Data is often collected retrospectively and therefore cannot be used in real-time to inform patient-clinician interactions and patient management at point-of-care. For example, collaboratives such as the Australasian Rehabilitation Outcomes Centre, provide patient outcome reports to participating clinical services on a six-monthly basis.

Through the desktop review of websites and stakeholder consultation, it was identified that across the WA public and private health sectors many hospital sites and services participate in state and national Clinical Quality Registries (CQR).

A review of the ACSQHC's Australian Register of Clinical Registries, and the registry websites, was also undertaken to identify any registries with which organisations or services from the WA Health system currently participate. Multiple organisations from both public and private sectors of the WA health system, were reported to participate in nineteen clinical registries. (Additional detail - Appendix 5)

1. Australasian Rehabilitation Outcomes Centre (AROC).
2. The Australian Benralizumab Registry (the ABenRA).
3. Australasian Severe Asthma Registry (ASAR).
4. The Australasian Myositis Registry.
5. Burns Registry of Australia and New Zealand.
6. Bariatric Surgery Registry.
7. Continuous Improvement in Care - Cancer Project (CIC Cancer).
8. Perth Hip and Knee Research Registry.
9. ANZICS Adult Patient Database.
10. The Australian Breast Device Registry (ABDR).
11. Australia and New Zealand Dialysis and Transplant Registry (ANZDATA).
12. National Cardiac Registry (NCR).
13. Myeloma and related Diseases Registry (MRDR).
14. Trauma Registry at Royal Perth Hospital.
15. Australian & New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS).
16. Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR).
17. Binational Colorectal Cancer Audit (BCCA).
18. Transcatheter Aortic Valve Implantation (TAVI) Registry.
19. Clinical Alliance and Research in ECT and Related Treatments (CARE) Network.

## [WA Health Cancer Data and PRM Survey Results](#)

The 'Cancer Data and Patient Reported Measures (PRMs)' state-wide survey was open from 05/12/2022 to 20/01/2023 via the Citizen Space platform. One hundred and one (n=101) surveys were completed from across the public and private sectors. The WA Department of Health, SMHS and NMHS had the largest proportion of survey participants at 23%, 21% and 19% respectively.

The majority of survey responses indicated that either their program/organisation was not currently collecting PRMs (43%), or they were unsure if their program/organisation was collecting PRMs (41%). The remainder of the survey responses (16%) affirmed that their program/organisation was currently collecting PRMs (either PREMs or PROMS, or both). With the exception of two questions related to future plans with PROMs, once respondents had completed the initial PRMs questions the response rate dropped by 93% to seven and the majority of respondents didn't answer the subsequent survey questions. Overall information from the survey is outlined below and the responses to more specific questions has been incorporated into the relevant sections for PREMs and PROMs which follow.

Some survey responses also reflected a lack of understanding with regard to PRMs, similar to that encountered in other aspects of the review, and/or confusion between the measure terms and their methodology. For example, when answering questions some respondents confused the type of PRMs they were collecting in their specialty, whereby outcome measures were mistakenly identified as experience measures.

In regard to the survey question about whether the respondent's program/organisation has plans to collect PRMs in the future, there were 84 responses – 61% were 'Not sure', 12% answered 'No' and 9% answered 'Yes'. The subsequent question asked respondents to indicate that if they weren't currently collecting PRMs whether there was interest in collecting PRMs in the future with 74 responses – 39% were 'Not sure', 26% answered 'Yes' and 7% answered 'No'.

Within the Cancer data section of the survey, respondents were asked to rate the level of priority they would assign to a list of indicators/metrics if there was an opportunity to access them. Within that list three options for PRMs were included, PREMs, PROMs – Generic, and PROMs – Condition-specific. As Table 2 indicates, all were rated as 'Essential' or 'High' metric priorities for cancer data.

Table 2. WA Health Cancer Data and PRM Survey - Cancer Data Questions related to Metric Priorities

PRM by Metric Priority	PREMs	PROMs - Generic (QoL)	PROMs - Condition specific
Not a priority	3%	4%	4%
Low priority	4%	2%	2%
Medium priority	9%	10%	9%
<b>High priority</b>	<b>22%</b>	<b>30%</b>	<b>28%</b>
<b>Essential</b>	<b>41%</b>	<b>31%</b>	<b>32%</b>
Unable to comment	6%	10%	12%
Not Answered	15%	13%	13%

### 8.2.3 PREMs

There are a number of local, state, and national policy and legislative drivers that advocate or direct healthcare services to ensure consumers, carers and the community are actively engaged in the planning, delivery, and evaluation of health care across WA. Based on these requirements, each health service or organisation regularly develops its own strategic plan to set the priorities and guide activities of the organisation for a set period. Consumer, carer, and community engagement is one of those priorities.

The best approach to gathering feedback lies in providing patients, consumers, and carers with a range of avenues which they can easily access to share their experience/s. In WA patient feedback is encouraged through the complaints, compliments, and contacts process; the Care Opinion website; patient experience surveys; and local or department specific activities. The following information is a synopsis of key PREMs activities currently occurring within the WA Health System.

### [Patient Evaluation of Health Services \(PEHS\) Survey](#)

Until recently WA Health had an annual Patient Evaluation of Health Services (PEHS) survey conducted state-wide by the WA Department of Health Epidemiology branch in collaboration with the Survey Research Centre at Edith Cowan University for many years. This survey was intended to monitor and benchmark patient satisfaction levels in seven different aspects of health care provided.

1. Access – getting into hospital.
2. Consistency – continuity of care
3. Informed – information and communication.
4. Involvement – involvement in decisions about care and treatment
5. Needs – meeting the patient’s personal needs.
6. Residential – residential aspects of the hospital
7. Time and care – the time and attention paid to patient care.

Acknowledging that the PEHS survey measured patient satisfaction, this survey was developed in consultation with consumers and conducted through telephone interviews by the Survey Research Centre at Edith Cowan University using the computer assisted telephone interview (CATI) system. Reports provided feedback to hospitals and indicated areas of high performance and those that required review or action to improve care.

### [MySay Healthcare Survey](#)

The MySay Healthcare Survey is a voluntary online survey offered to all overnight and same-day patients to measure patient experience. It was developed through a collaborative of WA HSPs, led by SMHS Safety, Quality and Consumer Engagement who established both a WA Health Steering and Working Group as part of a robust governance model. The MySay survey is comprised of the Australian Hospitals Patient Experience Question Set (AHPEQS) and Net Promoter Score (NPS), with HSPs allowed to include one or two additional questions. As the survey contains both the AHPEQS and NPS it meets the minimum set of PREMs recommended nationally for patient experience surveys by the ACSQHC. The survey, methodology and business rules created were endorsed and piloting was undertaken successfully across WA HSPs, with the official launch in July 2020. The survey is conducted with patients (excludes Mental Health patients – see section ‘Your Experience of Service (YES) survey below) across all health services in WA and there is an adult version and a parent version for paediatric patients. Survey data is used by HSPs to inform improvement initiatives aimed at improving the patient experience at a ward, department, service, hospital, and organisation level. The survey data also enables both monitoring over time and benchmarking of patient experience between services.

In 2022, SMHS released a MySay Healthcare Survey Dashboard to support its sites and services in monitoring patient experience data to identify areas for improvement and recognise excellent care. At a state level, there is a joint initiative between the Patient Safety and Clinical Quality Directorate, Clinical Excellence Division and Information and Performance Governance to incorporate the MySay dataset and PREMs indicators into the Safety and Quality Indicator Set (SQiS). This will allow interstate benchmarking with other jurisdictions collecting data against these same specifications. Additionally, there are plans to add a select number of agreed indicators into the WA Health Service Performance Reporting (HSPR).

### Australian Hospital Patient Experience Question Set (AHPEQS)

The AHPEQS was developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC) to measure patient experience of treatment and care whilst admitted to hospital. The dataset is specific to the Australian context and enables healthcare services to listen to patients and use their experiences to help improve patient care. It was developed through nine phases of qualitative and quantitative research involving consumers, carers, health professionals, academics, managers, and policymakers. The survey consists of 12 questions based on what patients stated was important, and on what clinicians, managers and policymakers identified as practical. Specifically, the questions ask patient to consider short statements about their recent admission or encounter with a healthcare service. For example, *'My views and concerns were listened to'* and *'It was clear to me that staff had communicated with each other about my treatment and care'*.(33)

### Net Promoter Score (NPS)

The Net Promoter Score (NPS) is a measure that provides an organisation with insight into how its consumers experience the service it delivers and the ability to monitor this over time and following the implementation of improvement initiatives. Consumer perception is measured through one question using a scale of 0-10: *"How likely are you to recommend this hospital to a friend or colleague?"*. The NPS scores categorise poor and positive feedback – those who respond with a score of 9-10 are called 'promoters'; those who score 7-8 are called 'passives' and those who score 0-6 are called 'detractors'. The NPS is calculated by subtracting the percentage of detractors from the percentage of promoters.(34)

The use of the NPS is well established within patient experience surveys undertaken across all private sites and services within WA, many through their 'Voice of the Patient' survey programs administered by Press Ganey. NPS is not restricted by service type so it can be used across all healthcare settings. As such it is a key patient experience measure used to benchmark with peer organisations and engage consumers to improve the delivery of patient care and other services.

### Your Experience of Service (YES) Survey

The Your Experience of Service (YES) survey was commenced state-wide in 2018 by the WA Mental Health Commission (MHC) and is conducted annually across all public funded community and inpatient mental health services for paediatric, adolescent, and adult consumers. It was designed in collaboration with mental health consumers and developed from the recovery principles of the National Standards for Mental Health Services through the National Mental Health Consumer Experiences of Care Project – funded by the Commonwealth Department of Health and led by the Victorian Department of Health. Consumers and carers were consulted nationally, and a trial of the survey was conducted across Australia in 2012-13.

The purpose of the YES survey is to gather information from consumers about their experiences of care using a nationally consistent measure that supports quality improvement, service evaluation and benchmarking. Across six broad domains, the survey uses two Likert rating scales to capture 21 Experience items, three Outcome items and one overall experience item. The domains are:

- Making a difference
- Providing information and support
- Valuing individuality
- Supporting active participation
- Showing respect
- Ensuring safety and fairness

Eligible patients receive an SMS containing a survey-link 48 hours post-discharge inviting them to participate in the survey. Patients have six weeks to complete the survey and all responses are confidential - no response can be connected to a specific patient. Results are collated by the MHC and communicated back to consumers and carers,

and health services to identify areas for improvement. At a state level, the survey results are reported into SQuIS and reviewed quarterly by the Quality Surveillance Group (QSG).(35)

### [Cancer Patient Experience Survey \(CaPES\)](#)

In 2021, the Cancer Network WA, commissioned the Cancer and Palliative Care Research and Evaluation Unit at the University of WA to conduct the Cancer Patient Experience Survey (CaPES). This project was initiated as part of an engagement strategy recognising patient experience as one pillar of health sustainability, with the aim of identifying areas in cancer care that are important to patients by ascertaining gaps in healthcare service delivery and variations in patient experience.

The CaPES project used an adapted version of the co-designed patient experience questionnaire developed by All.Can International. Data collected reflected a variety of patient experiences along the continuum of cancer care and the impact each part of the cancer journey had on the patient's quality of life. Potential participants were identified from the WA Cancer Registry, aged  $\geq 18$  years and only those diagnosed with a primary cancer between 1st January and 31st December 2019 were included. Surveys were distributed the week beginning 15 November 2021, to people reported on the WACR as diagnosed within that calendar year ( $n=10,348$ ). As of the 28th of June 2022, 31.3% of the surveys had been returned ( $n=3238$ ) and the findings are now available.(36) It is anticipated that this survey will be repeated on a regular basis.

### [All.Can International Patient Survey](#)

All.Can is an international multi-stakeholder not-for-profit organisation undertaking initiatives to inform and generate political and public engagement on the need to improve the efficiency of cancer care by focusing on what really matters to patients and the society. All.Can define inefficiency as "anywhere resources are not focused on what matters to patients" and recognise that inefficiencies need to be addressed across the entire cancer care continuum, and at the levels of system, services, processes, and technology. All.Can seeks to ensure resources are directed towards achieving better health outcomes while contributing to health systems' overall sustainability.(37)

The organisation brings together patient organisations, healthcare professionals, academics, and industry to generate evidence through research and collaboration which highlights best practices and contributes to policy development regarding efficiencies which can improve cancer care. The All.Can international patient survey aims to obtain cancer patients' perspectives on where they encountered inefficiency in their care throughout the entire care continuum and the broader impact of cancer on their lives. It was noted that the most recent patient survey was conducted in Australia in partnership with All.Can Australia and the University of Western Australia in 2018.(37)

### [WA Health Cancer Data and PRM Survey Results](#)

With regard to PREMs, the WA Health Cancer Data and PRM Survey respondents' answers indicated that both the MySay Healthcare Survey and the YES Survey had been implemented within their organisations and are used to inform clinical care, service delivery, and quality improvement initiatives. An additional "Patient Satisfaction Questionnaire" was noted as having been fully implemented by a respondent from the WA Kirkbride Melanoma Advisory Service to measure specific care delivered by the service and WACHS has designed their own unvalidated survey tool.

## 8.2.4 PROMs

To drive improvements in patient-centred care a number of PROMs initiatives are being undertaken by specific clinical specialties, departments, and service providers across both public and private sectors of the WA health system. In contrast to other Australian jurisdictions, these initiatives are discrete projects using different measures, frameworks, guiding principles and processes as defined by a specific research program or quality improvement initiative and agreed to by the specialty or organisation involved. Whilst there is some commonality between the tools being used for PROMs collection, these initiatives are at various stages of piloting or implementation. The majority of

the initiatives are disconnected from each other, such that measurement, use of data and outcomes to generate improvements are not agreed or visible across services. This lack of a coordinated approach was apparent during stakeholder consultation, where despite teams or services being collaborative, they were not always aware of work occurring in the same area or of others undertaking similar projects at an organisation, service, or system level despite sometimes using the same or similar PROMs tools. During consultation most clinicians and teams were found to be extremely keen to undertake PROMs collection for their patients. They acknowledged, however, that they hadn't started as they were cognisant of the work involved (and resources required) to properly coordinate, trial proof-of-concept and implement measures, and reporting within the constraints of their current capacity. The remainder of this section details the key PROMs activities and initiatives currently occurring within WA, identified through review processes and stakeholder engagement – noting that this information is not exhaustive due to project limitations (see section 7.4).

### Distress Thermometer (DT)

Whilst distress is experienced by many patients and may be manageable, as a symptom it is often overlooked and therefore underreported, despite its negative impact on patient care and quality of life. This is especially so for cancer patients where distress frequently begins at initial diagnosis and continues throughout the continuum of care into survivorship or palliative care.(38) The Distress Thermometer (DT) was developed by the United States National Comprehensive Cancer Network to improve the identification, management and treatment of psychological distress in oncology patients and is the recommended screening tool by Cancer Australia. The DT is a self-reported instrument that uses a 0-10 rating scale, which prompts the patient to identify sources of distress using a 'problem list'. The DT has demonstrated reasonable validity, reliability and specificity for general distress, depression, and anxiety, and as a screening tool is comparable with longer measures of psychological symptoms.(39)

Stakeholder consultation and survey results revealed that the DT is currently in use across a number of cancer services in WA, including those provided by WACHS and NMHS Cancer Network WA. For example, in 2020 WACHS Nursing & Midwifery (NM) - Cancer Services led the implementation of the DT into the admission process and documentation in the patient's medical record across WACHS sites and services that provide care for cancer patients. Given the perceived success of the DT to inform individual patient care and referrals for cancer patients in WACHS, the NM-Cancer Services are planning to include the DT in their audit schedule for 2023 with a view to using results to inform local and service-wide improvements.

### Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP)

Validated PROMs are useful clinical tools which provide a structured, systematic, and replicable method that assist clinicians to comprehensively assess and monitor patient symptoms, needs and their severity. When routinely used evidence shows that they improve patient care and outcomes by enabling a person-centred approach to addressing patient symptoms and needs. This has been particularly evident in supportive care where the symptom burden of patients living with cancer is high and complex, and routine patient-reported symptom monitoring has improved health-related QoL, whilst reducing emergency department attendances and admissions to hospital.(40)

The Supportive Care Needs Survey - Short Form 34 (SCNS-SF34) is a validated tool used internationally to measure the perceived support needs of adult cancer patients across five domains (psychological, health system and information, physical and daily living, patient care and support, and sexuality needs). Given the disparities that exist in outcomes for Indigenous people diagnosed with cancer compared to the non-Indigenous population, the SCNS-SF34 was adapted in NSW by Professor Gail Garvey to create a culturally specific tool for Indigenous people in Australia. The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) is now a validated, culturally specific assessment tool that captures the unique unmet supportive care needs of Indigenous people diagnosed with cancer.(41)

WACHS NM - Cancer Services also led a trial in the use of SCNAT-IP across the HSP's relevant services. In consultation with local Indigenous consumers the SCNAT-IP has been adapted for use across WACHS sites and

services. Noting that feedback from local Indigenous consumers has led to the amended title of 'Supportive Care Needs Assessment Tool for Aboriginal People' (SCNAT-AP). WACHS have subsequently undertaken full implementation of the SCNAT-AP across their cancer services and are planning to increase the use of PROMs in the clinical setting to embed them as standard practice (business as usual). This will provide better ongoing capture patient outcomes and drive improvement in service provision.

#### [European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire \(EORTC QLQ-C30\)](#)

The EORTC QLQ-C30 was developed by the EuroQoL Group (an international network of multidisciplinary researchers). Originally published in 1993, the EORTC QLQ-C30 is among the most widely used PROMs in cancer research and clinical practice. The EORTC QLQ-C30 is a validated tool designed to assess QoL for cancer patients, including physical, psychological, and social functions, and is composed of multi-item scales and single items. The EORTC QLQ-C30 is the core questionnaire and additional questionnaires have been developed for specific cancer types – for example, the EORTC QLQ-BR23 contains 23 questions specific to breast cancer care and QoL. All EORTC-QLQs ask patients to rate their symptoms or issues during the past week or past four weeks.(17)

The ICHOM datasets use the EORTC QLQ-C30 as their core PROMs cancer questionnaire combined with the appropriate cancer specific questionnaires.(42) As outlined in Appendix 2, the ICHOM datasets are the main measures used by the CIC Cancer project. The cancer services engaged in this demonstration project are based at a number of metropolitan hospitals within WA. The WA Health Cancer Data and PRM Survey responses also indicated that the NMHS has been piloting ICHOM datasets, and that pilot is currently being expanded.

#### [EuroQol – Five Dimension \(EQ-5D\)](#)

EQ-5D is a standardised tool which measures health-related quality of life over time by assessing health status in terms of the five (5) domains of health: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The domains are not specific to any one patient cohort or health condition and therefore widely applicable. The EQ-5D provides a simple descriptive profile and single index value for health status that can be used in the clinical and economic evaluation of health care.(43)

As previously discussed, the CIC Cancer Project currently use the ICHOM datasets for PROMs, with the addition of the EQ-5D, in breast, colorectal and lung cancer at Royal Perth Hospital, breast and lung cancer at Fiona Stanley Hospital, breast cancer at SJoG Subiaco, and colorectal cancer at SJoG Midland. Recent discussions have occurred with Executive and clinicians at NMHS regarding PROMs and expanding CIC Cancer to include lung cancer patients from Sir Charles Gairdner Hospital.

During stakeholder consultation it was identified that Head & Neck Cancer at Fiona Stanley Hospital were keen to start collecting PROMs. Following liaison with the CIC Cancer Project team, they began setting-up their local processes and online multi-disciplinary team documentation to commence using the EORTC QLQ-HN43 for the collection of PROMs in late 2022.

#### [Palliative Care Outcomes Collaborative \(PCOC\) Symptom Assessment Scale \(SAS\)](#)

PCOC is a national palliative care project funded by the Australian Government Department of Health which provides six-monthly patient outcome reports to participating clinical services to facilitate benchmarking at a state and national level. PCOC enables clinicians to receive a comparative analysis of their outcomes on a regular basis and benchmarking workshops are held every six months to increase understanding of how clinicians can use outcome data to drive quality improvement.(44)

PCOC SAS is a patient-reported scale used to measure subjective aspects related to health. It evaluates perceived distress and is designed to be used by patients from any disease or treatment group and age but can also be used by proxies. The scale assesses eight dimensions: pain, insomnia (difficulty sleeping), nausea, bowel problems, appetite problems, breathing problems, fatigue, and a 'other' item, which may be added to the measure.(45)

PCOC SAS has been incorporated into routine care in all Australian PCOC-registered services, where the measure is used daily within inpatient settings. Its use is supported by a national education program, online educational materials, and calibration sessions, supported by a clinical manual and information.(44)

All public and private service providers that provide palliative care in WA that participate in PCOC, have implemented the PCOC SAS. Earlier this year the Palliative Aged Care Outcomes Program (PACOP) was established via the same model and streaming fund and has begun to be implemented in aged care facilities in WA.(44)

### Quality of Life Survivor (QOL-CS)

The QOL-CS is based on previous versions of the QOL tool, developed to measure the specific concerns of long-term cancer survivors using four QoL domains: physical, psychological, social, and spiritual wellbeing. Findings demonstrate that the QOL-CS and its subscales are valid and reliable.(46)

As outlined in the WA Health Cancer Data and PRM Survey results, a respondent from NMHS indicated that the HSP has been piloting the QOL-CS and is currently in the process of expanding that pilot.

### WA Health Cancer Data and PRM Survey Results

Response to the WA Health Cancer Data and PRM Survey in relation to whether their organisation was currently collecting and using PROMs was limited, but information received correlated with feedback from colleagues engaged in the face-to-face consultation. A response on behalf of a group at NMHS indicated that a pilot of ICHOM datasets, the DT and QOL-CS had been occurring within the HSP and was currently being expanded with the intention of informing 'individual patient care and shared decision-making', 'clinical care, service delivery and quality improvement initiatives', 'clinical registries' and 'policy and resource management'. A respondent from the Cancer Network WA - WA Psycho-oncology Service indicated that the Hospital Anxiety and Depression Scale is being used within the NMHS, however they were 'unsure' of the level of implementation of this PROMs except that it is 'not routinely collected for every patient' but is being used for 'individual patient care and shared decision-making', 'clinical care, service delivery and quality improvement initiatives' and 'specific and overall outcomes for the patient'.

From SMHS, a respondent from Urology identified that PROMs were being collected, however, no further information was provided, and further investigation was limited by the lack of information provided. Another respondent from SMHS specified that the EORTC QLQ-30 (Cancer - core generic) was being used within the allied health area of lymphoedema and oncology. Whilst the respondent was unsure as to the extent of the use, they did indicate that the PROMs were being used to inform 'clinical care, service delivery and quality improvement initiatives', 'individual patient care and shared decision-making', 'research' and 'specific and overall outcomes for the patient'.

One respondent from a WA Health HSP summarised the shared view conveyed by many participant responses to the survey question 'Does your program/organisation have any plans to change PROMs collection in the future?', as per below:

*"PROMs should be a key agenda for all OP services, not just Cancer patients. [We] really need strategic and executive support to drive the full implementation of PROMs and good clinical data collection platforms to easily collect, with visibility of these for clinicians at the individual patient interface."*



## 8.3 External Snapshot

### International

Canada, Netherlands, New Zealand, Sweden, United Kingdom, and United States are just some of the countries who have implemented PRMs as a part of health system reform aimed at improving quality, effectiveness, and efficiencies in care delivery through value-based health care reform.

In 2017, the Organisation for Economic Co-operation and Development (OECD) launched the Patient-Reported Indicators Surveys (PaRIS) initiative with the aim of making health systems more people-centred. At the core of this is the ability to systematically collect data on what matters most to patients. The PaRIS initiative is focused on patients with chronic conditions and aims to fill this information gap in primary health care, through PREMs and PROMs.<sup>(47)</sup> Stakeholder consultation and survey results indicate that to date NMHS, Health Networks, and CIC Cancer have engaged with the PaRIS initiative and contributed data in line with governance and research requirements.

International trends reveal that PRM programs continue to be implemented or expanded internationally, and research to develop PRMs or evaluate their impact on patient care and outcomes has increased exponentially in the last three years, including COVID-19 specific PRMs in 2019. A prospective consecutive cohort was recruited from the post-COVID-19 Respiratory Clinic (PCRC) located in two hospitals in Vancouver, Canada. The PCRC was established to facilitate follow-up of all patients discharged after hospitalisation for COVID-19 and found that over 75% of patients admitted to hospital with COVID-19 had abnormal PROMs three-months after initial symptoms, with a third of patients reporting at least moderate impairment in major dimensions of quality of life. The findings highlight the impact that COVID-19 has on patients even after reported recovery from the acute phase of the disease and emphasises the need for a comprehensive multidisciplinary approach to deliver the most appropriate care to these patients.<sup>(48)</sup>

A study published in the International Journal of Radiation Oncology which collected data from 382 patients, across 15 countries led to the EORTC Quality of Life Group announcing the validation of the first comprehensive and reliable PROMs questionnaire for anal cancer in November 2022. Anal cancer is rare, but its incidence is climbing and, although it is highly treatable, a patient's quality of life can be seriously impacted. The health-related quality of life questionnaire for anal cancer (QLQ-ANL27) supplements the EORTC cancer generic tool (QLQ-C30) and aims to measure concerns specific to people with anal cancer treated with chemoradiotherapy. The PROMs questionnaire was found to be easy to complete and acceptable across geographical regions and is now available in 16 language versions.<sup>(49)</sup>

### Australia

Information obtained from organisational websites, discussions with colleagues in other jurisdictions, and attendance at the ACSHC PROMs roundtable with state and territory representatives, indicates that NSW is the leading Australian jurisdiction engaged in PRMs data collection. This has been achieved through the work of the NSW Health Leading Better Value Care Initiative with the Agency for Clinical Innovation (ACI). The design of the NSW PRMs program is iterative and uses a co-design approach between NSW ACI, clinicians, and consumers in proof-of-concept sites that have implemented PRMs across acute and primary healthcare settings. Health Outcomes and Patient Experience (HOPE) is the state-wide patient experience system. Initiatives are occurring in integrated care and cancer care with the ACI using the PROM Information System (PROMIS) developed through the National Institutes of Health US Department of Health and Human Services.

There are an increasing number of public and private sector healthcare organisations implementing the ICHOM standard sets in Australia; for example, Ramsay Health Care and the HCF Research Foundation. The NSW ACI has

also established a strategic partnership with ICHOM. Other states have been progressing work with PRMs, including Queensland and Victoria who have conducted extensive PRMs consultation and are currently progressing implementation of a state-wide PRMs program. The Commission on Excellence and Innovation in Health (CEIH) in South Australia formed a large central team in July 2022 to undertake the planning and implementation of PRMs using a state-wide standardised approach. They established a Patient Reported Measures Research Collaborative and have held two PRMs Research Symposiums – the most recent held in November 2022 with the theme ‘Using patient-reported measures to improve health care for culturally and linguistically diverse and other under-represented populations’. In January 2023, the CEIH PRM Program announced the successful vendor of a software solution for the SA PRMs Program. This will be rolled out in 2023 with pilots in selected SA services. Further stages will be designed in collaboration with SA Health Local Health Networks.

Jurisdictions are keen to learn from each other, and NSW are keen to support this. As such a PRM Community of Practice has been established, led by NSW Health ACI with representations from other states. Further to the work undertaken by the ACSQHC on PRMs nationally, the ACSQHC have outlined their next steps which include a PROMs 2022-24 Work Plan that commits to ongoing work to support the implementation of PROMs, comprising the following:

- development of recommendations on generic and selected condition-specific PROMs;
- a facilitated network of implementers; and
- continued involvement and participation in the OECD PaRIS initiative.

## 10. Recommendation/s

The key emerging theme from the current state report was that while there is currently a fragmented approach to PRMs, there is an opportunity for WA to drive changes required to improve patient experiences and outcomes and support the delivery of high quality, sustainable care. Well-coordinated work is already underway for PREMs and there is a strong appetite – demonstrated by both clinicians and organisations during consultation – for the implementation of PROMs. Considerable gains could be achieved through the development and application of a cohesive and coordinated approach to PRMs. This approach would be best facilitated by the WA Department of Health working collaboratively with HSPs to establish, coordinate and integrate a state-wide program for PRMs, in line with evidence-based best practice. The following next steps are recommended towards a state-wide approach to PRMs

- a) Development of a WA CIC Project Transition Plan with a PROMs proof-of-concept project, to inform future transition into WA Health of a PRM Program and the business requirements necessary to sustainably support an ongoing program. This proof-of-concept project would work with HSPs to evaluate the CIC PROMs framework and its custom-built information system for the ongoing collection, use, and reporting of PROMs from point of care through to the service and system levels.
- b) Development of a common set of PRMs guiding principles and processes (toolkit) informed by current practice with PREMs, the outcomes of the proposed proof-of-concept project for PROMs, and consultation with HSPs. This would create a consistent and systematic approach to PRMs across the WA Health System such that measures could be used to accurately and reliably inform care delivery. The coordinated measurement, reporting and use of PRMs would also drive improvements and inform change in patient-centred care.

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## Appendix 1

### Abbreviations – Patient Reported Measures

AHPEQS	Australian Hospitals Patient Experience Question Set
CaPES	Cancer Patient Experience Survey (adapted from All.Can survey)
DT	Distress thermometer
EORTC QLQ	European Organisation for Research and Treatment of Cancer – Quality of Life of Cancer Patients
EORTC QLQ-C30	Generic Cancer - 30 questions
EORTC QLQ-ANL27	Anal – 27 questions
EORTC QLQ-BR23	Breast – 23 questions
EORTC QLQ-CR29	Colorectal – 29 questions
EORTC QLQ-HN43	Head and Neck – 43 questions
EORTC QLQ-LC13	Lung – 13 questions
EQ-5D	EuroQol – Five Dimension
MOST	Measure of Ovarian Symptoms and Treatment concerns
NPS	Net Provider Score
PCOC SAS	Palliative Care Outcomes Collaboration Symptom Assessment Score
QOL-CS	Quality of Life - Cancer Survivor
SCNAT-IP	Supportive Care Needs Assessment Tool for Indigenous adapted from People Supportive Care Needs Survey - Short Form 34
SF-36	36 item - Short Form - survey
YES survey	Your Experience of Service survey

## Abbreviations - Other

ACI	Agency for Clinical Innovation (NSW Health)
ACSQHC	Australian Commission of Safety and Quality in Health Care
AIHW	Australian Institute of Health and Welfare
AOANJRR	Australian Orthopaedic Association National Joint Replacement Registry
CEIH	Commission on Excellence and Innovation in Health
CIC	Continuous Improvement in Care
CQR	Clinical Quality Registries
ED	Emergency Department
HEC	Health Executive Committee
HSP	Health Service Provider
ISPD	Information System and Performance Directorate
MHC	Mental Health Commission
NMHS	North Metropolitan Health Service
NPS	Net Provider Score
OECD	Organisation for Economic Co-operation and Development
OMP	Outcome Measures Project
PaRIS	Patient-Reported Indicators Surveys
PEHS	Patient Evaluation of Health Services
PRMs	Patient Reported Measures
PREMs	Patient Reported Experience Measures
PROMs	Patient Reported Outcome Measures
PSP	Purchasing and System Performance
QoL	Quality of Life
QSG	Quality Surveillance Group
Rec	Recommendation
SHR	Sustainable Health Review
SMHS	South Metropolitan Health Service
SMHS SQ&CE	SMHS Safety, Quality and Consumer Engagement
SQuIS	Safety and Quality Indicator Set
WACHS	WA Country Health Service
WACOSS	Western Australian Council of Social Service

## Appendix 2

### WA CIC Transition Project - Governance

Governance has been conducted as per section 3.4 of the Grant Funding Agreement Document 'Continuous Improvement in Care – Cancer (CIC- Cancer) Transition planning and Current state - WA Health Patient Reported Experience and Outcomes Measures (PREMs/PROMs) DoH20229727'. To oversee the operation of the Agreement, a small Management Committee was formed by CIC Cancer with Health Networks Branch and Patient Safety and Clinical Quality (PSCQ) of the Clinical Leadership and Excellence Division with nominated representatives. The Management Committee met approximately monthly to:

- review the period since the previous meeting, activity occurring during that period and action any follow-up issues required;
- pre-plan the next round of activities, and organise logistics and services ahead of these needs; and
- develop the forward schedule for the coming operational requirements.

### CIC Cancer Project

CIC Cancer is a phased implementation, longitudinal, prospective research project that commenced in 2017 with the aim of developing PRMs which could be incorporated into standard clinical practice – at the point of care – to inform patient care throughout the patient's cancer journey and thereby improve patient outcomes. Through a collaboration between the University of WA, University of Notre Dame, Murdoch University, Curtin University, St John of God (SJoG) Healthcare and WA Health, the CIC Cancer project has developed and implemented data collection and reporting of internationally validated PROMs, PREMs and costing data in four specific cancer-types.

With clinical champion consultation, the project has employed the ICHOM validated methodology and datasets for three common cancers (breast, colorectal and lung cancer), and developed related tools for ovarian cancer patients – a less common and poorer outcome disease. ICHOM brings together patient representatives, lead clinicians and registry leaders from across the world to develop and recommend sets of PROMs that are comprehensive, evidence-based and cost-conscious for monitoring by healthcare providers. Each set focuses on patient-centred results and provides an internationally agreed methodology for measuring outcomes suitable for comparative analysis and benchmarking. These measures include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. For example, the cancer datasets include physical, emotional, cognitive and social functioning, ability to work and overall well-being measured using the EORTC QLQ-C30 with the addition of more specific questions relevant to the cancer type.(17)

Work undertaken by CIC Cancer has also included the exploration of how data collected in this way may inform healthcare decision-making through economic evaluation and the development of bundles of care in partnership with cross-sectoral services. To facilitate this the EQ-5D ® value set was added to each of the PROMs across all cancer-types within the CIC Cancer Project. Extensive research has shown that the EQ-5D is not only short and cognitively undemanding, but also valid, reliable, responsive, and can be used across a wide range of conditions and populations to describe and value health for clinical and economic appraisal.(43) The EQ-5D contains a set of rated responses to 5 dimensions of health (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) and a visual analogue scale to quantitatively measure overall health on that day. These results can then be converted to a single summary index which at an individual level assists in monitoring a patient's health status over time; at an organisational level it can inform decision-making; and at a system level inform population health over time.



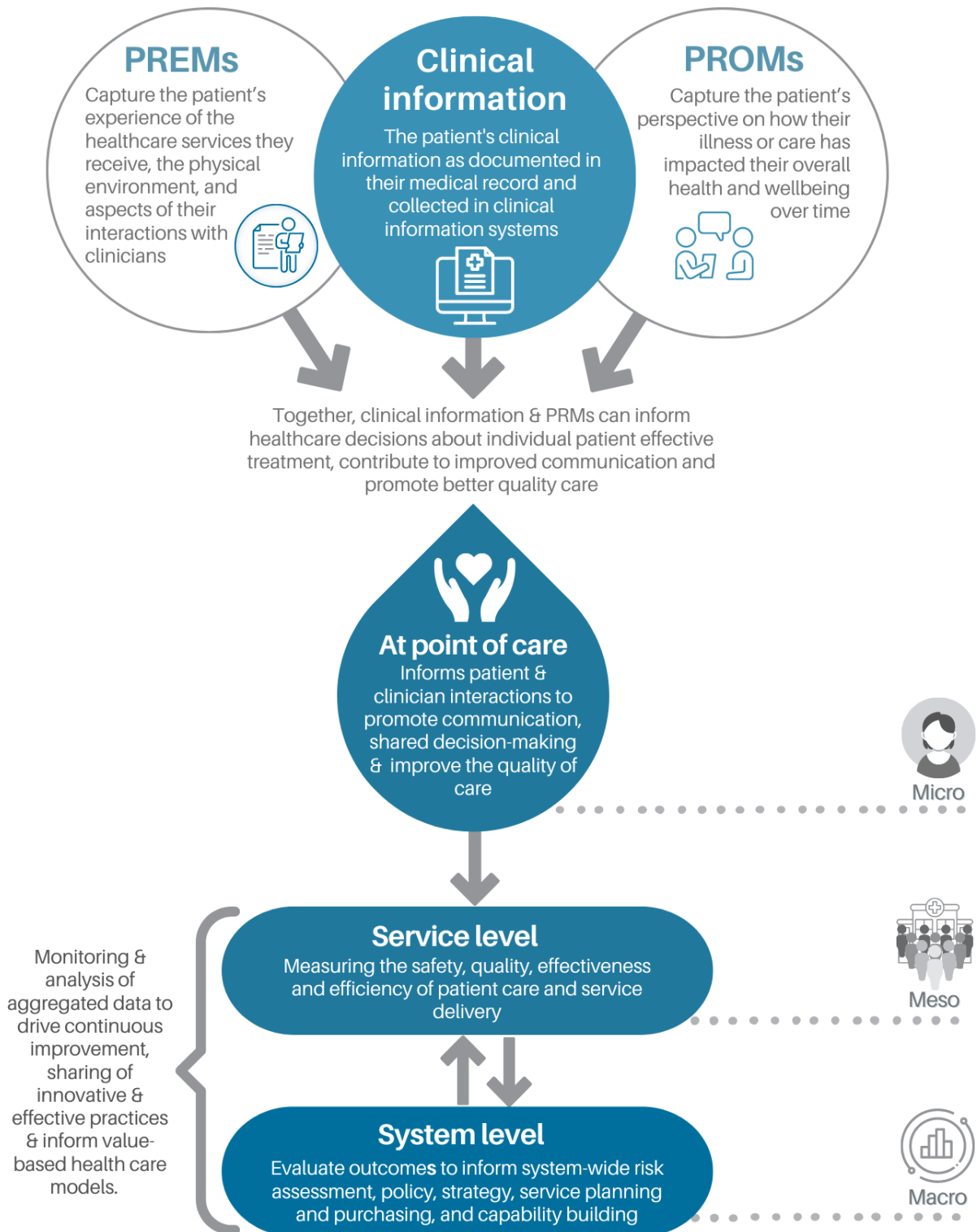
The CIC Cancer Project developed a custom-built informatics system for the collection of clinical data for specific cancer-types and patient reported metrics across public hospitals (three sites – Royal Perth, Fiona Stanley and King Edward Memorial Hospitals) and SJoG hospitals (two sites – Subiaco and Midland). The CIC Information System (CICIS) is opensource, therefore it is scalable, highly configurable and integrates easily with other applications. A number of clinical information systems have been planned for integration with CICIS so that clinical, pathology and treatment data can be pulled directly into CICIS (without the need for manual data entry by staff) and reviewed alongside PROMs at point of care. A key objective of the CIC Cancer Project was to handover this system to both WA Health and SJoG for implementation and for PROMs to become a part of standard clinical practice, especially as the system has the potential to be easily expanded to provide data collection and reporting across a wider range of cancers and other conditions. As such CICIS has been installed within the WA Health cloud-based infrastructure and integrated with the WA Health Patient Administration System (WebPAS), to facilitate automatic synchronisation of demographic patient data. Following extensive testing and collaboration with Health Support Services (HSS), CICIS had a successful 'Technical Go-Live' on the 24th of March 2022. The system is currently used by Senior Project Officers/Research Nurses working collaboratively with the relevant clinical teams as per the cancer types and sites outlined above. The version of CICIS which has been installed and is being used within the SJoG ICT infrastructure for both Subiaco and Midland is currently awaiting integration with WebPAS. This was due to occur in 2022 but has been postponed due to competing IT priorities within SJoG Healthcare now scheduled for April 2023.

As an extension of the CIC Cancer project and its overarching goals, a data visualisation 'proof of concept' initiative has also been undertaken with the PROMs data collected to date, with clinical champion and consumer consultation. This data visualisation was originally developed for each of the cancer types using Power BI; however due to delays encountered with HSS, the data visualisations have been re-created within the CICIS using Python infrastructure. This interactive dashboard-style reporting functionality aims to provide information for shared decision-making at the point of care, where research suggests it has the biggest impact such that when PROMs are discussed during patient-clinician interactions quality of care is enhanced. Additionally, they support the implementation and integration of PROMs into care through user-friendly, simple visual depictions and interactive interfaces that enable results to be easily interpreted and compared.

# Appendix 3

## Conceptual Framework - Patient Reported Measures

### Patient Reported Experience and Outcome Measures: Driving improvement in patient centred care



# Appendix 4

## Patient Reported Outcome Measures – Micro | Meso | Macro

<h1>PATIENT REPORTED OUTCOME MEASURES</h1> <p>Key ways to use PROMs data at the micro, meso, and macro levels within the healthcare system</p>		
MICRO	MESO	MACRO
<p>Patient and Clinician Informs point of care communication and shared decision-making</p> <p>Patient completes the PROMs prior to or during a clinical encounter. The PROMs can be used to:</p> <ul style="list-style-type: none"> <li>Identify health issues as reported by patients, especially those that may go unnoticed without specific prompting (e.g. pain, anxiety).</li> <li>Screen for specific symptoms or health problems.</li> <li>Monitor patients' outcomes over time to inform treatment decisions.</li> <li>Triage patients according to their self-reported health problems to inform care delivery.</li> <li>Empower patients to share how they feel about their health with their care providers and foster shared decision-making.</li> </ul>	<p>Healthcare Organisation Informs the measurement and evaluation of service delivery</p> <p>Data collected through PROMs from multiple patients across a number of different healthcare services, at specific times throughout their patient care journey, is aggregated and analysed to:</p> <ul style="list-style-type: none"> <li>Assess and monitor patients' health outcomes at a service level.</li> <li>Evaluate the outcomes of an organisation in comparison with best practice and benchmarks.</li> <li>Examine the effectiveness of a health intervention or program.</li> <li>Establish benchmarks and best practice for specialties and providers (individuals).</li> <li>Measure outcomes as compared to cost and healthcare utilisation at the organisation level.</li> </ul>	<p>Healthcare System Informs system-wide risk, resource and policy planning</p> <p>Data collected via PROMs from multiple patients, over specific time periods from different healthcare sites and services is aggregated and analysed to:</p> <ul style="list-style-type: none"> <li>Compare provider effectiveness and efficiency of outcomes across the healthcare system.</li> <li>Compare patients' response to treatments or interventions across healthcare delivery services.</li> <li>Identify key health issues at the system level.</li> <li>Establish benchmarks and best practices for providers and organisations.</li> <li>Measure outcomes as compared to cost and healthcare utilisation at the system level.</li> </ul>
<small>Adapted from the Al Sayah et al. J Patient Rep Outcomes 2021, 5(Suppl 2):98</small>		<small>WA CIC Transition Project 2022</small>

# Appendix 5

## Literature Review with Concept Matrix - References Extract

No.	References	Outline	Author/ Organisation	Type	Publication	Year	Concepts											Link	
							Cancer	Health Economics	Health Outcomes	Metrics	Patient centred care	Patient satisfaction	PRMs	PREMs	PROMs	Quality improvement	Strategic Planning & Policy		VBHC
1	Western Australian Department of Health (2020). Western Australian Burden of Disease Study (WABoDS) 2015 – Summary Report: 2020. Perth: Department of Health WA.	The study provides an assessment of the impact of 216 diseases and 29 risk factors on the WA population and allows for disease comparisons due to loss of life and disability in a consistent manner. Findings from this study are useful for policy formulation, research, practice and health service planning. The Western Australian Department of Health, Epidemiology Branch partnership with the Australian Institute of Health and Welfare conduct the WABoDS.	Department of Health Western Australia. Australia.	Report	Western Australian Department of Health, Perth WA.	2020	✓	✓	✓	✓									<a href="https://ww2.health.wa.gov.au/Reports-and-publications/Western-Australian-Burden-of-Disease-Study-2015">https://ww2.health.wa.gov.au/Reports-and-publications/Western-Australian-Burden-of-Disease-Study-2015</a>
2	Western Australian Department of Health. WA Cancer Plan 2020–2025. Perth: Health Networks, Western Australian Department of Health; 2020.	The WA Cancer Plan 2020–2025 builds on the WA Cancer Plan 2012–2017 with the aim of continuing to work towards ensuring cancer services are well-coordinated, high quality and accessible to all consumers., whilst providing a long-term approach to cancer research.	Health Networks, Western Australian Department of Health. Australia.	Strategic Plan	Western Australian Department of Health, Perth WA.	2020	✓		✓		✓		✓	✓	✓	✓	✓	✓	<a href="https://ww2.health.wa.gov.au/Articles/U_Z/WA-Cancer-Plan">https://ww2.health.wa.gov.au/Articles/U_Z/WA-Cancer-Plan</a>
3	Institute of Medicine. 2001. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: The National Academies Press. <a href="https://doi.org/10.17226/10027">https://doi.org/10.17226/10027</a>	A follow-up report to the Institute of Medicine's 'To Err Is Human: Building a Safer Health System' which concentrated on patient safety. Crossing the Quality Chasm is a more comprehensive report focused on quality-related issues more broadly and the limitations of the existing U.S. health care system - overuse, underuse and misuse of health care resources and treatments. The report advocates for a fundamental redesign of the U.S. health care system and provides strategic direction for the fundamental reform of health care needed to ensure that all Americans receive care that is safe, effective, patient centred, timely, efficient, and equitable.	Committee on Quality of Health Care in America, Institute of Medicine. United States.	Report	National Academies Press, Washington DC.	2001		✓	✓	✓	✓	✓		✓		✓	✓	<a href="https://nap.nationalacademies.org/download/10027">https://nap.nationalacademies.org/download/10027</a>	



9	Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K, Payne S. Observational study of effect of patient centeredness and positive approach on outcomes of general practice consultations. BMJ. 2001 Oct 20;323(7318):908-11. doi:10.1136/bmj.323.7318.908. PMID: 11668137; PMCID: PMC58543.	The objective of the study was to measure patients' perceptions of patient centeredness and the relation of these perceptions to outcomes. Through factor analysis the study identified five components which effected patients the most, each of which related to clinician and patient interaction/s: a) communication and partnership, b) personal rapport/relationship (a doctor who knows the patient), c) health promotion, d) positive approach and e) an interest in the effect of treatment on the patient's life. Satisfaction was related to communication and partnership, plus a positive approach. Enablement was greater with interest in the effect on the patient's life, health promotion, and a positive approach. A positive approach was also associated with reduced symptom burden at one month. Referrals were fewer if patients felt they had a personal relationship with their doctor.	Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K, Payne S.	Research Article	British Medical Journal - Primary Care	2001														<a href="https://www.bmj.com/content/323/7318/908">https://www.bmj.com/content/323/7318/908</a>
10	Berkowitz B. The Patient Experience and Patient Satisfaction: Measurement of a Complex Dynamic. Online Journal of Issues in Nursing. 2016;21(1):12. doi:10.3912/OJIN.Vol21No01Man01	This article discusses the challenges faced with measurement of the patient experience, including a lack of consistent terminology and multiple contributing factors, through the review of a brief selection of literature to help readers appreciate the complexity of measurement. Clinical practice examples are used to help readers consider governance factors, organisational environments, and research - each of which can offer clarity around important factors that impact a patient's experience and subsequent satisfaction with the provision of care.	Berkowitz, B. New York, United States.	Research Article	Journal of Issues in Nursing	2016														<a href="https://ojin.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol-21-2016/No1-Jan-2016/The-Patient-Experience-and-Patient-Satisfaction.html">https://ojin.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol-21-2016/No1-Jan-2016/The-Patient-Experience-and-Patient-Satisfaction.html</a>
11	Developing a Patient-Reported Experience Measure for use in children's palliative care settings.	This article was a prospective scoping review aimed at identifying PROMs which have been proposed in paediatric palliative care (PPC) and clarifying the specific measures used in order to enhance their care. The findings of this review were intended to inform researchers and healthcare personnel caring for children and adolescents in PPC. In addition, through the highlighting of knowledge gaps regarding the use of PROMs in PPC, the review suggested future needs within this field of research for consideration given the impact on improving the quality of care in PPC.	York Health Economics Consortium, York, United Kingdom.	Scoping Review Research Article	Website: University of York - Social Policy Research Unit, Social Policy and Social Work	2021														<a href="https://pure.york.ac.uk/portal/en/projects/developing-a-patient-reported-experience-measure-for-use-in-child">https://pure.york.ac.uk/portal/en/projects/developing-a-patient-reported-experience-measure-for-use-in-child</a>
12	Mercury Healthcare Website. How Is the Patient Experience Different from Patient Satisfaction? 2021.	This blog for healthcare professionals and other staff of the organisation outlined how patient satisfaction and patient experience are often used interchangeably, but the two terms have entirely different meanings and implications for care quality and measurement.	Mercury Healthcare, Denver, Colorado, United States.	Online Article	Website: Mercury Healthcare Blog	2021														<a href="https://www.mercuryhealthcare.com/blog/patient-experience-vs-patient-satisfaction#:~:text=Measuring%20both%20patient%20experience%20and%20patient%20satisfaction%20has,satisfaction%20is%20about%20the%20patient%E2%80%99s%20expectations%20for%20care">https://www.mercuryhealthcare.com/blog/patient-experience-vs-patient-satisfaction#:~:text=Measuring%20both%20patient%20experience%20and%20patient%20satisfaction%20has,satisfaction%20is%20about%20the%20patient%E2%80%99s%20expectations%20for%20care</a>

13	Cleary PD. Evolving Concepts of Patient-Centred Care and the Assessment of Patient Care Experiences: Optimism and Opposition. J Health Polit Policy Law. 2016 Aug;41(4):675-96. doi: 10.1215/03616878-3620881. Epub 2016 Apr 28. PMID: 27127265	This article discusses the shift of researchers and health care providers from just measuring patient satisfaction as a part of medical care to considering it as a key indicator of care quality. Particularly the evolution of patient surveys from being service orientated in their questions to asking patients to evaluate (or rate) objective characteristics of their care. Additionally, the article discusses the unfounded concerns about patient experience measures and the argument that patients cannot evaluate the quality of their care. The article concludes that meeting the informational, emotional, and physical needs of patients is a critical aspect of care quality, and validated patient experience measures can effectively contribute to the evaluation of patient care.	Cleary, Paul.D. Yale University, New Haven, Connecticut, United States.	Journal Article	Journal of Health Politics, Policy & Law	2016													<a href="https://web-p-ebscohost-com.eplibresources.health.wa.gov.au/ehost/pdfviewer/pdfviewer?vid=0&amp;sid=be1611de-5137-4aec-8e8a-96f3d8b41133%40redis">https://web-p-ebscohost-com.eplibresources.health.wa.gov.au/ehost/pdfviewer/pdfviewer?vid=0&amp;sid=be1611de-5137-4aec-8e8a-96f3d8b41133%40redis</a>
14	NSW Health and Agency for Clinical Innovation. Patient Reported Measures Framework. NSW Health, 2019.	This document outlines how the NSW health system will be organised to support the provision of value-based health care, centred on what matters most to patients with PRMs. The framework provides a structure through which NSW Health aims to transform the health system by improving outcomes, experience and quality of care. It clearly establishes NSW Health's vision, purpose, definitions, guiding principles, approach and horizons for PRMs over 5+ years.	NSW Health and Agency for Clinical Innovation. NSW Health, Australia.	Webpage	NSW Health, Value-Based Health Care (VBHC) State-wide Program - Patient Reported Measures: Framework to a Page.	2019	-												<a href="https://www.health.nsw.gov.au/Value/Documents/prm-framework.pdf#:~:text=Outcomes%20(PROMs)%20E2%80%93directly%20reported%20by%20the%20patient%20without,what%20happened%20during%20their%20encounters%20with%20health%20services.">https://www.health.nsw.gov.au/Value/Documents/prm-framework.pdf#:~:text=Outcomes%20(PROMs)%20E2%80%93directly%20reported%20by%20the%20patient%20without,what%20happened%20during%20their%20encounters%20with%20health%20services.</a>
15	Al Sayah F, Jin X, Johnson JA. Selection of patient-reported outcome measures (PROMs) for use in health systems. J Patient Rep Outcomes. 2021 Oct 12;5(Suppl 2):99. doi: 10.1186/s41687-021-00374-2. PMID: 34637010; PMCID: PMC8511255.	The article outlines and discusses the important considerations for the implementation of PROMs in health systems, including standardisation and consistency of measurement across the system to ensure an integrated approach for PROM(s) selection for use by end-users in health systems.	Fatima Al Sayah, Xuejing Jin and Jeffrey A. Johnson Alberta, Canada and Beijing, China.	Research Article - Supplement	Journal of Patient-Reported Outcomes	2021													<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8511255/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8511255/</a>
16	Short Form 36 (SF-36) PDF with References. Brandeis University	The Short Form (36) Health Survey is a 36-item, patient-reported survey of patient health. The SF-36 is a measure of health status and an abbreviated variant of it, the SF-6D, is commonly used in health economics as a variable in the quality-adjusted life year calculation to determine the cost-effectiveness of a health treatment.	Development: Stewart, A. L., & Ware, J. E., Jr. (Eds.). (1992). Measuring functioning and well-being: The medical outcomes study approach. Duke University Press. North Carolina, United States.	Survey Tool	Webpage: Brandeis University														<a href="https://www.brandeis.edu/roybal/docs/SF-36_website_PDF.pdf">https://www.brandeis.edu/roybal/docs/SF-36_website_PDF.pdf</a>

17	European Organisation for Research and Treatment of Cancer (EORTC) - Quality of Life Questionnaire - Cancer 30 (EORTC QLQ-C30).	The EORTC QLQ-30 is a questionnaire designed to assess (some of) the different aspects that define the QoL of (a specific group of) cancer patients.	EORTC Quality of Life Group. Europe and United Kingdom.	Survey Tool	Website: European Organisation for Research and Treatment of Cancer (EORTC) - Quality of Life	2022	✓	-	-	-	-	-	✓	-	✓	-	-	<a href="https://qol.eortc.org/">https://qol.eortc.org/</a>
18	Garvey G, Thewes B, Davis E, Giris A, Valery PC, Giam K, Hocking A, Jackson J, He VY, Yip D. Routine screening of Indigenous cancer patients' unmet support needs: a qualitative study of patient and clinician attitudes. Int J Equity Health. 2016 Jun 10;15:90. doi: 10.1186/s12939-016-0380-2. PMID: 27286811; PMCID: PMC4902957.	The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) is a validated 26-item questionnaire developed to assess their unmet supportive care needs. This study was a qualitative evaluation of patient and clinician attitudes towards the feasibility and acceptability of SCNAT-IP in routine care. The study confirmed that SCNAT-IP is applicable to both the research and clinical cancer care settings. Indigenous patients found the SCNAT-IP beneficial and easy to understand, they also reported feeling valued and heard. Clinical staff reported multiple benefits from using the SCNAT-IP, including opportunities for early intervention. In addition, clinical staff also appreciated the comprehensive and systematic nature of the tool.	Garvey G, Thewes B, Davis E, Giris A, Valery PC, Giam K, Hocking A, Jackson J, He VY, Yip D. Menzies School of Health Research, Brisbane, QLD, Australia.	Research Article	International Journal for Equity in Health	2016	✓		✓				✓					<a href="https://link.springer.com/article/10.1007/s00520-015-2770-1">https://link.springer.com/article/10.1007/s00520-015-2770-1</a>
19	Dobrozsi S, Panepinto J. Patient-reported outcomes in clinical practice. Hematology Am Soc Hematol Educ Program. 2015;2015:501-6. doi: 10.1182/asheducation-2015.1.501. PMID: 26637765.	This article outlines how PROs systematically quantify the patient perspective to not only assess impairment in the clinical setting but to also provide valuable data which assist with clinical care. It also discusses the evidence that shows the integration of PROs into clinical care can be challenging to initiate, but it is essential to making care truly patient-centred. The article provides suggestions for the implementation and integration of PROs, including the following key elements for success - (1) buy-in of administrative leaders, clinicians, and patients; (2) customisation of PROMs to meet the goals and needs of each clinical specialty/setting, and (3) electronic capture of PRO data. Additionally, it also provides examples of opportunities to use PROs to tailor individual patient care to improve patient outcomes, patient-clinician communication, and the quality of care for haematology/oncology patients.	Sarah Dobrozsi and Julie Panepinto. Paediatric Hematology/Oncology, Wisconsin, United States.	Research Article	The American Society of Hematology: Education Program.	2015	✓	✓	✓	✓	✓	✓	✓	✓	✓			<a href="https://watermark.silverchair.com/bep00115000501.pdf">https://watermark.silverchair.com/bep00115000501.pdf</a>



20	Mukherjee, Suzanne Kathleen Mary; Beresford, Bryony Anne; Richardson, Natalie et al. / The health care experiences of children and young people with a life-limiting condition and their parents: Scoping review protocol. 2021. 53 p.	This paper documents the scoping review protocol enlisted to develop a conceptual framework and the key domains which formed the basis of a PREMs developed for paediatric palliative care. This PREMs is aimed at assessing young people's and parents' experiences of using palliative care services, and how the relationships they have with health/care staff in those services make them feel.	Social Policy and Social Work, Social Policy Research Unit, University of York, York, United Kingdom.	Research Article	Unspecified. White Rose Research Online Repository.	2021														<a href="https://eprints.whiterose.ac.uk/175542/1/Scoping_review_protocol_The_health_care_experiences_of_child_and_young_people_with_a_life_limiting_condition_and_their_parents.docx.pdf">https://eprints.whiterose.ac.uk/175542/1/Scoping_review_protocol_The_health_care_experiences_of_child_and_young_people_with_a_life_limiting_condition_and_their_parents.docx.pdf</a>
21	NSW Health and Agency for Clinical Innovation. About patient-reported measures. 2020.	This webpage defines PRMs, why they are used and the evidence to support their use, along with a brief explanation about the state-wide PRM Program in NSW. The webpage has embedded content consisting of videos and transcripts aimed at assisting the understanding of these concepts and discusses communicating about PRMs in a culturally appropriate way. In particular, the webpage acknowledges the establishment of a PRMs Aboriginal Health Working Group, essential for the development of measures relevant to Aboriginal and Torre Strait Islander people.	NSW Health & Agency for Clinical Innovation. NSW, Australia.	Webpage	Agency for Clinical Innovation & NSW Health State-wide programs - PRMs	2020														<a href="https://aci.health.nsw.gov.au/statewide-programs/prms/about#:~:text=There%20is%20good%20evidence%20to%20demonstrate%20that%20patients.to%20support%20clinician%20decision-making%20and%20shared%20care%20planning.">https://aci.health.nsw.gov.au/statewide-programs/prms/about#:~:text=There%20is%20good%20evidence%20to%20demonstrate%20that%20patients.to%20support%20clinician%20decision-making%20and%20shared%20care%20planning.</a>
22	Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population; Board on Health Care Services; Institute of Medicine; Levit L, Balogh E, Nass S, et al., editors. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. Washington (DC): National Academies Press (US); 2013 Dec 27.	Section 3 of this report discusses 'Patient-Centred Communication and Shared Decision Making' in the context of cancer, but this is universally applicable across all conditions. The discussion, whilst acknowledging the challenges to both patients and clinicians, focuses on the importance of communication and how it can be improved across the healthcare system. Using evidence-based research the report makes a number of recommendations, including but not limited to the following: - Making more comprehensive information available, - Improving shared decision-making using decision aids, - Prioritising clinician training in communication, - Communicating information and preparing cancer care plans, and - Advancing new payment models (bundled payment).	Committee on Quality of Cancer Care in America, Institute of Medicine. United States.	Report	National Academies Press, Washington DC.	2013														<a href="https://www.ncbi.nlm.nih.gov/books/NBK202146/?report=printable">https://www.ncbi.nlm.nih.gov/books/NBK202146/?report=printable</a>
23	Rivera SC, Kyte DG, Aiyegbusi OL, Slade AL, McMullan C, Calvert MJ. The impact of patient-reported outcome (PRO) data from clinical trials: a systematic review and critical analysis. Health Qual Life Outcomes. 2019 Oct 16;17(1):156. doi: 10.1186/s12955-019-1220-z. PMID: 31619266; PMCID: PMC6796482.	Whilst PROs have been used in research for some time there is substantial evidence to indicate that PROs related information is often delayed or omitted from reporting and publication. Omissions of this type constitute research waste and mean that important PRO evidence may not be available to benefit patients and society. This research article discusses the outcomes of a systematic review into measuring the range of potential impacts from PRO clinical trial data, potential PRO impact metrics, barriers/facilitators to maximising PRO impact, and the examination of real-world evidence of PRO trial data impact based on Research Excellence Framework (REF) impact case studies.	Rivera SC, Kyte DG, Aiyegbusi OL, Slade AL, McMullan C, Calvert MJ. University of Birmingham. Birmingham, United Kingdom.	Research Article	Health Quality of Life Outcomes	2019														<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6796482/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6796482/</a>

24	Welsh Value in Health Centre. What are PROMs? NHS, Wales.	This webpage provides an evidence-based definition of both PRMs and PROMs, together with a patient story video. This video shows what patient reported outcomes meant to a patient during his experience as both an inpatient and outpatient, after a traumatic sports injury, and two operations over two-years. The webpage also summarises the effect PROMs can have on indirect care and how it is a part of a data-drive, value-based healthcare approach.	Welsh Value in Health Centre (NHS Wales). Wales, United Kingdom.	Webpage	Welsh Value in Health Centre. (NHS Wales)	2020	-	-	✓	✓	-	-	✓	-	✓	-	✓	<a href="https://vbhc.nhs.wales/professionals/what-are-proms/#:-:text=Patient-Reported%20Outcome%20Measures%20%28PROMs%29%20are%20that%20have,to%20understand%20changes%20in%20people%E2%80%99s%20quality%20of%20life.">https://vbhc.nhs.wales/professionals/what-are-proms/#:-:text=Patient-Reported%20Outcome%20Measures%20%28PROMs%29%20are%20that%20have,to%20understand%20changes%20in%20people%E2%80%99s%20quality%20of%20life.</a>
25	NSW Agency for Clinical Innovation. Analytic principles for patient-reported outcome measures. Sydney: ACI; 2021.	This report discusses and defines the guiding principles which need to underpin and inform the effective analyses of PROMs, based on current evidence-based knowledge and methodology to ensure the validity and reliability of data. The guiding principles were articulated by ACI in preparation for the introduction of the Health Outcomes and Patient Experience (HOPE) system into NSW Health. However, these guiding principles are relevant to similar PRM sources which are expected to deliver valid and reliable patient-reported data to inform both clinicians and decision-makers. Noting that the methodology and analyses for PREMs are well established, as such they are not considered in this report.	NSW Agency for Clinical Innovation. NSW, Australia.	Report	NSW Agency for Clinical Innovation Technical Report.	2021		✓	✓	✓	✓		✓		✓	✓	✓	<a href="https://aci.health.nsw.gov.au/_data/assets/pdf_file/0007/633454/Analytic-Principles-for-Patient-Reported-Outcome-Measures.pdf">https://aci.health.nsw.gov.au/_data/assets/pdf_file/0007/633454/Analytic-Principles-for-Patient-Reported-Outcome-Measures.pdf</a>
26	Australian Commission on Safety and Quality in Health Care (ACSQHC), Framework for Australian clinical quality registries. Sydney. ACSQHC, March 2014.	This document outlines the ACSQHC's work with jurisdictions, the National Health Information and Performance Principal Committee, the National E-Health Transition Authority and CQR experts to develop strategic principles and a framework for CQRs. This framework is intended to progress national arrangements for CQRs as a mechanism by which jurisdictions can authorise and secure record-level data, within high-priority clinical domains, to measure, monitor and report on the appropriateness and effectiveness of health care.	Australian Commission on Safety and Quality in Health Care, Sydney. NSW, Australia.	Strategic Framework	Australian Commission on Safety and Quality in Health Care.	2014		✓	✓	✓					✓	✓		<a href="https://www.safetyandquality.gov.au/sites/default/files/migrated/Framework-for-Australian-Clinical-Quality-Registries.pdf">https://www.safetyandquality.gov.au/sites/default/files/migrated/Framework-for-Australian-Clinical-Quality-Registries.pdf</a>
27	McGee RG. How to Include Patient-Reported Outcome Measures in Clinical Trials. Curr Osteoporosis Rep. 2020 Oct;18(5):480-485. doi: 10.1007/s11914-020-00611-5. PMID: 32757118.	This article discusses the range of tools which can be used to facilitate the collection of PROMs, the benefits of PROMs - how information directly from the patient can enable better care and how PROMs can be incorporated effectively into clinical trials.	Richard G. McGee. Newcastle, NSW, Australia.	Research Article	Current Osteoporosis Reports	2020			✓		✓				✓			<a href="https://link.springer.com/article/10.1007/s11914-020-00611-5">https://link.springer.com/article/10.1007/s11914-020-00611-5</a>
28	Nelson EC, Eftimovska E, Lind C, Hager A, Wasson JH, Lindblad S. Patient reported outcome measures in practice. BMJ. 2015 Feb 10;350:g7818. doi: 10.1136/bmj.g7818. PMID: 25670183.	This article articulates that numerous, standardised PROMs were developed in response to the lack of understanding of the effect of disease and treatment on patients' daily lives. Yet the full benefits of these measures have not been realised because they have not been used effectively to improve quality of care from the patient's perspective. Two examples of PROMs in the primary and acute care settings were used to illustrate how implementing PROMs into everyday clinical practice has the potential to narrow the gap between the clinician's and the patient's perspective and help tailor treatment plans to meet the patient's preferences and needs.	Nelson EC, Eftimovska E, Lind C, Hager A, Wasson JH and Lindblad S. New Hampshire, United States and Stockholm, Sweden.	Research Article	British Medical Journal - Clinical Research Edition	2015			✓	✓	✓		✓		✓	✓		<a href="https://www.bmj.com/content/bmj/350/bmj.g7818.full.pdf">https://www.bmj.com/content/bmj/350/bmj.g7818.full.pdf</a>

29	Kathryn Yorkston, Carolyn Baylor. Patient-Reported Outcomes Measures: An Introduction for Clinicians. 2019. Perspectives of the ASHA Special Interest Groups. 8-15. V 4. N 1. R doi:10.1044/2018_PERS-ST-2018-0001. U <a href="https://pubs.asha.org/doi/abs/10.1044/2018_PERS-ST-2018-0001">https://pubs.asha.org/doi/abs/10.1044/2018_PERS-ST-2018-0001</a>	This article introduces the concepts and definitions of PROMs, as well as the history of PROMs in the area of communication disorders. It notes that patients with communication disorders are best placed to convey their lived experiences - i.e. physical symptoms, environmental influences, personal views and preferences. The article also notes the broader global history around PROMs development and improvements over time in the quality of PROMs tools and their application, such that high quality tools have made it possible to more effectively capture and incorporate patients' perspectives into clinical outcomes research.	Kathryn Yorkston, Carolyn Baylor. Maryland, United States.	Journal Article	Perspectives of the ASHA Special Interest Group. American Speech-Language-Hearing Association's Special Interest Groups (SIGs).	2019	-	-												<a href="https://pubs.asha.org/doi/abs/10.1044/2018_PERS-ST-2018-0001">https://pubs.asha.org/doi/abs/10.1044/2018_PERS-ST-2018-0001</a>
30	Australian Health Ministers. The National Health Reform Agreement (NHRA) Long Term Reforms Roadmap. 2021.	This webpage provides information on the 2020–25 NHRA, including what the agreement is about, the goals of the agreement and the long-term system-wide health reforms planned under section C of the NHRA. The webpage also includes status updates on the NHRA, following endorsement of the NHRA Long Term Reforms Roadmap by all Australian Health Ministers at the Health Ministers' Meeting on 17 September 2021.	Australian Health Ministers. ACT, Australia.	Webpage	Website: 2020–25 Australian Government, Department of Health and Aging. National Health Reform Agreement (NHRA).	2021	-													<a href="https://www.health.gov.au/our-work/2020-25-national-health-reform-agreement-nhra">https://www.health.gov.au/our-work/2020-25-national-health-reform-agreement-nhra</a>
31	Care Opinion Australia Website. About Care Opinion, March 2021.	This Care Opinion webpage hosts all the "About Care Opinion" information for consumers and any other users, which is broadly structured under "What is Care Opinion?" and "Why use Care Opinion?".	Care Opinion Australia. QLD, Australia.	Webpage	Website: Care Opinion Australia.	2021	-	-												<a href="https://www.careopinion.org.au/info/about">https://www.careopinion.org.au/info/about</a>
32	Goodrich J, Cornwell J. (2008). Seeing the person in the patient: the Point of Care review paper. London: The King's Fund.	The Point of Care programme ran at The King's Fund from 2007-13, with the aim of improving patients' and families' experience of care. This review paper was informed by existing research and qualitative studies with patients and families, hospital staff and board members, and discussed a number of issues patients experience with their care and the factors that shape that experience. Patient experience themes were described, analysed and discussed with the inclusion of patient stories and feedback. Each theme that emerged was assessed using a systems approach to evaluate the current circumstances and determine potential interventions or initiatives that may create sustainable changes in patient care at the micro, meso and macro levels.	Goodrich J. and Cornwell J. London, United Kingdom.	Review paper	The King's Fund Website.	2008														<a href="https://www.kingsfund.org.uk/publications/seeing-person-patient">https://www.kingsfund.org.uk/publications/seeing-person-patient</a>
33	International Consortium for Health Outcomes Measurement (ICHOM). Patient Centred Outcome Measure Sets.	The ICHOM Connect website is an online platform where ICHOM's Patient Centred Outcome Measure Sets can be downloaded, along with the implementation resources and other information. The website also supports a professional network for value-based healthcare so that members can network, share ideas and discuss the implementation of ICHOM's Sets of Patient-Centred Outcome Measures.	ICHOM Connect and Accreditation. (International Collaborative)	Online platform	Website: ICHOM Connect	2022	-													<a href="https://connect.ichom.org/what-are-patient-centered-outcomes-measures/">https://connect.ichom.org/what-are-patient-centered-outcomes-measures/</a>
34	EuroQol Research Foundation - EQ-5D instruments – EQ-5D (euroqol.org)	The EuroQol EQ-5D website opens with a video explaining the EQ-5D's development and its application as a highly effective PROMs tool "in about two & a half minutes". The remainder of the EQ-5D landing page provides a comprehensive array of information and resources on the different versions of the EQ-5D developed to date along with digital demonstrations.	EuroQol Research Foundation (International Collaborative)	Website	Website: European Quality of Life (EuroQol) Research Foundation	2022														<a href="https://euroqol.org/eq-5d-instruments/">https://euroqol.org/eq-5d-instruments/</a>

35	Australian Institute of Health and Welfare 2015. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015. Cat. no. IHW 147. Canberra: AIHW.	This report is the most recent report from the AIHW and the eighth in a series that covers topics important for the improvement of the health and welfare of Australia's Aboriginal and Torres Strait Islander people. This report provides a comprehensive statistical picture of the health and welfare of Australia's Indigenous population, including trends and differences by factors including indigenous and non-indigenous, age, sex and, in particular remoteness.	Australian Institute of Health and Welfare. ACT, Australia.	Report	Australian Institute of Health and Welfare	2015	✓	✓	✓	✓											<a href="https://www.aihw.gov.au/reports/indigenous-welfare/indigenous-health-welfare-2015/contents/table-of-contents">https://www.aihw.gov.au/reports/indigenous-welfare/indigenous-health-welfare-2015/contents/table-of-contents</a>
36	Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR). PROMs Pilot Final Report 20 <sup>th</sup> February 2020. South Australia, Australia.	The report details all aspects of the successful pilot project undertaken by AOANJRR across Australian jurisdictions, to test the feasibility and stakeholder engagement for collecting PROMs and incorporating this with procedure data already collected by the AOANJRR. Ultimately, the collection of PROMs data is intended to aid improvements to the quality and cost-effectiveness of healthcare delivery at a national level.	AOANJRR, South Australia, Australia.	Report	The AOANJRR Website.	2020			✓	✓	✓	✓					✓	✓	✓		<a href="https://aoanjrr.sahmri.com/proms-pilot-report">https://aoanjrr.sahmri.com/proms-pilot-report</a>
37	Australian Institute of Health and Welfare 2015. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015. Cat. no. IHW 147. Canberra: AIHW.	This report is the most recent report from the AIHW and the eighth in a series that covers topics important for the improvement of the health and welfare of Australia's Aboriginal and Torres Strait Islander people. This report provides a comprehensive statistical picture of the health and welfare of Australia's Indigenous population, including trends and differences by factors including indigenous and non-indigenous, age, sex and, in particular remoteness.	Australian Institute of Health and Welfare. ACT, Australia.	Report	Australian Institute of Health and Welfare	2015	✓	✓	✓	✓											<a href="https://www.aihw.gov.au/reports/indigenous-welfare/indigenous-health-welfare-2015/contents/table-of-contents">https://www.aihw.gov.au/reports/indigenous-welfare/indigenous-health-welfare-2015/contents/table-of-contents</a>
38	Australian Commission on Safety and Quality in Health Care (ACSQHC). Australian Hospital Patient Experience Question Set (AHPEQS) 2017.	The AHPEQS is a survey tool developed by the ACSQHC with 12 questions that ask a patient to assess the quality of their experiences during a recent hospital stay or visit to a healthcare service.	Australian Commission on Safety and Quality in Health Care. NSW, Australia	Survey Tool	Website: Australian Commission on Safety and Quality in Health Care	2017	-	-	-								-		-	-	<a href="https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/patient-experience/about-ahpeqs">https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/patient-experience/about-ahpeqs</a>
39	Qualtrics XM. Net Promoter Score. 2023	The Net Promoter Score (NPS) is a metric used in customer experience programs which has been translated into the healthcare setting. This webpage provides information on all aspects of the NPS, from definition, calculation, measurement, the difference between transactional vs relational NPS programs and how to create a NPS survey.	Qualtrics XM. Experience Management and Software Solutions	Webpage	Website: Qualtrics XM	2023	-	-	-												<a href="https://www.qualtrics.com/au/experience-management/customer/net-promoter-score/?rid=ip&amp;prevsite=en&amp;newsite=au&amp;geo=AU&amp;geomatch=au">https://www.qualtrics.com/au/experience-management/customer/net-promoter-score/?rid=ip&amp;prevsite=en&amp;newsite=au&amp;geo=AU&amp;geomatch=au</a>
40	Australian Mental Health Outcomes and Classification Network. Your Experience of Service (YES) Survey. 2015.	The YES Survey is a questionnaire developed with mental health consumers, based on the Recovery Principles of the Australian National Standards for Mental Health Services.	Australian Mental Health Outcomes and Classification Network (AMHOCN) NSW, Australia.	Survey Tool	Website: Australian Mental Health Outcomes and Classification Network	2015				✓	✓								✓	✓	<a href="https://www.amhocn.org/your-experience-service-surveys">https://www.amhocn.org/your-experience-service-surveys</a>

41	All. Can International. Patient insights on cancer care: opportunities for improving efficiency. Findings from the international All.Can patient survey. 2018. International.	This report summarises the methodology and findings from the All.Can patient survey conducted by Quality Health, with close input from the All.Can International research and evidence working group. From January – November 2018, almost 4,000 respondents from more than 10 countries participated in the survey aimed at gaining a better understanding of where patients consider their cancer care is not focused on what matters to them i.e. inefficient.	All. Can International. Brussels, Belgium	Report	Website: All. Can International	2019	✓	✓	✓	✓	✓	-	-	-	✓	✓	<a href="http://www.all-can.org/what-we-do/policy-research/patient-survey/">www.all-can.org/what-we-do/policy-research/patient-survey/</a>
42	Ownby KK. Use of the Distress Thermometer in Clinical Practice. J Adv Pract Oncol. 2019 Mar;10(2):175-179. Epub 2019 Mar 1. PMID: 31538028; PMCID: PMC6750919.	This research article defines distress and outlines how it is experienced by many cancer patients from initial diagnosis, throughout treatment to survivorship or palliation. All cancer patients are at risk of distress and the impact it has on the patient's quality of life (QoL) is far-reaching. Based on this evidence, the National Comprehensive Cancer Network introduced the distress thermometer (and problem list) to assist with the identification of distress and development of appropriate interventions to improve patient QoL.	Ownby KK. Houston, Texas, United States.	Research Article	Journal of Advanced Practitioner in Oncology	2019	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6750919/pdf/advp-10-175.pdf">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6750919/pdf/advp-10-175.pdf</a>
43	Australian Institute of Health and Welfare. Meteor Metadata Online Registry. Person—distress status in past week. METEOR identifier 483587. Definition: The level of distress experienced by the person over the past week. 2015	This nationally agreed data definition recommends that the visual distress thermometer is used for assessing the person's level of distress, generally within a clinical setting. It was reproduced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management (V.3.2012).	AIHW Meteor Metadata Online Registry	Data Definition	Website: Australian Institute of Health and Welfare (AIHW) 2015–2023	2015	✓	-	✓	✓	✓	-	-	-	✓	-	<a href="https://meteor.aihw.gov.au/content/483594">https://meteor.aihw.gov.au/content/483594</a>
44	Garvey, G., Beesley, V.L., Janda, M. et al. The development of a supportive care needs assessment tool for Indigenous people with cancer. BMC Cancer 12, 300 (2012). <a href="https://doi.org/10.1186/1471-2407-12-300">https://doi.org/10.1186/1471-2407-12-300</a>	This research paper discusses how existing needs assessment tools have not considered the cultural issues for the Indigenous Australian population, such as language, customs and specific needs. The paper also provides an overview of the work undertaken to adapt an existing supportive care needs assessment tool, Supportive Care Needs Survey - Short Form 34 (SCNS-SF34), for use with Indigenous Australians with cancer.	Gail Garvey, Vanessa L Beesley, Monika Janda, Catherine Jacka, Adèle C Green, Peter O'Rourke and Patricia C Valery. QLD, Australia.	Research Article	BioMed Central (BMC) Cancer.	2012	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	<a href="https://bmccancer.biomedcentral.com/articles/10.1186/1471-2407-12-300#citeas">https://bmccancer.biomedcentral.com/articles/10.1186/1471-2407-12-300#citeas</a>

45	<p>Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, Rogak L, Bennett AV, Dueck AC, Atkinson TM, Chou JF, Dulko D, Sit L, Barz A, Novotny P, Fruscione M, Sloan JA, Schrag D. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. <i>J Clin Oncol</i>. 2016 Feb 20;34(6):557-65. doi: 10.1200/JCO.2015.63.0830. Epub 2015 Dec 7. Erratum in: <i>J Clin Oncol</i>. 2016 Jun 20;34(18):2198. Erratum in: <i>J Clin Oncol</i>. 2019 Feb 20;37(6):528. PMID: 26644527; PMCID: PMC4872028.</p>	<p>This article summarised the findings from a randomised-control trial into the systematic collection of symptom information using the EQ-5D. The participants were patients receiving routine outpatient chemotherapy for advanced solid tumours at a large speciality cancer centre. Clinical benefits were found to be associated with symptom self-reporting during cancer care, especially in the first 6-months.</p>	<p>Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, Rogak L, Bennett AV, Dueck AC, Atkinson TM, Chou JF, Dulko D, Sit L, Barz A, Novotny P, Fruscione M, Sloan JA, Schrag D. New York, United States.</p>	<p>Research Article</p>	<p>Journal of Clinical Oncology.</p>	<p>2016</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p><a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4872028/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4872028/</a></p>
46	<p>Daveson BA, Allingham SF, Clapham S, Johnson CE, Currow DC, Yates P, et al. (2021) The PCOC Symptom Assessment Scale (SAS): A valid measure for daily use at point of care and in palliative care programs. <i>PLoS ONE</i> 16(3): e0247250. <a href="https://doi.org/10.1371/journal.pone.0247250">https://doi.org/10.1371/journal.pone.0247250</a></p>	<p>This article details a retrospective, multi-site, cohort study involving secondary analysis of routinely collected measures to test the psychometric properties of the Palliative Care Outcomes Collaboration Symptom Assessment Scale (PCOC SAS). 80% of specialist palliative care providers across Australia participated in this study. Findings of the study demonstrated that the PCOC SAS is a valid and reliable PROM, suitable for use in routine clinical care with patients requiring palliative and/or end-of-life care. Additionally, the study also determined that because of the characteristics of PCOC SAS it has the ability to be used as part of routine clinical care across care settings, for patients of varying ages and for other conditions.</p>	<p>Barbara A. Daveson, Samuel Frederic Allingham, Sabina Clapham, Claire E. Johnson, David C. Currow, Patsy Yates and Kathy Eagar. Australia.</p>	<p>Research Article</p>	<p>PLOS One</p>	<p>2021</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p><a href="https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0247250">https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0247250</a></p>
47	<p>B. R. Ferrell, K. Hassey Dow, and M. Grant. "Measurement of the Quality of Life in Cancer Survivors." <i>Quality of Life Research</i> 4, no. 6 (1995): 523-31. <a href="http://www.jstor.org/stable/4034362">http://www.jstor.org/stable/4034362</a>.</p>	<p>This article discusses the Quality of Life (QoL) instrument developed to measure the specific concerns of long term cancer survivors and outlines a survey study used to assess the psychometric properties of the tool. The survey study was conducted with members of the National Coalition for Cancer Survivorship and consisted of a demographic tool, the QOL-Cancer Survivor (QOL-CS) and the Functional Assessment of Cancer Therapy - General (FACT-G) tool. Of specific focus were the domains of QoL most important to cancer survivors and possible interventions to support and promote adaptation. The findings of the study indicate that the QOL-CS and its subscales adequately measure QOL in cancer survivors.</p>	<p>B. R. Ferrell, K. Hassey Dow, and M. Grant. California, United States.</p>	<p>Research Article</p>	<p>Quality of Life Research.</p>	<p>1995</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p>✓</p>	<p><a href="https://pubmed.ncbi.nlm.nih.gov/8556012/">https://pubmed.ncbi.nlm.nih.gov/8556012/</a></p>

48	<p>Organisation for Economic Co-operation and Development (OECD) Website. Patient-Reported Indicator Surveys (PaRIS), 2019.</p>	<p>This webpage is the primary information page for the PaRIS on the OECD Health website and is aimed at both consumers and health professionals. The webpage introduces PaRIS, outlines the aim of the initiative, describes who and why the outcomes of PaRIS will help, and provides links to key documents. Additionally, the webpage contains pertinent information on the data protection and privacy aspects of PaRIS, the PaRIS Technical Advisory Community and Patient Advisory Panel.</p>	<p>Organisation for Economic Co-operation and Development (OECD)</p>	<p>Project Outline &amp; Update</p>	<p>Website: OECD - Health - PaRIS.</p>	<p>2022</p>	-	-			-	-								-	<p><a href="https://www.oecd.org/health/paris/">https://www.oecd.org/health/paris/</a></p>
49	<p>Wong AW, Shah AS, Johnston JC, Carlsten C, Ryerson CJ. Patient-reported outcome measures after COVID-19: a prospective cohort study. Eur Respir J. 2020 Nov 26;56(5):2003276. doi: 10.1183/13993003.03276-2020. PMID: 33008936; PMCID: PMC7530908.</p>	<p>This research article (published as a letter to the editor) discusses the initial focus of COVID-19 research and the transition to focusing on longer term sequelae. This prospective consecutive cohort study collected PROMs from patients recruited from a Post-COVID-19 Respiratory Clinic (PCRC). PROMs were collected at the initial clinic visit and then approximately 3 months after initial symptom onset, via the 5-level EuroQol 5-Dimensions (EQ-5D-5L), Frailty Index, University of California San Diego Shortness of Breath Questionnaire, Patient Health Questionnaire-9 and Pittsburgh Sleep Quality Index. This study explored the results of PROMs in the context of COVID-19 and comparatively with pre-existing comorbidities. Overall results revealed patients admitted to hospital with COVID-19 continued to struggle after their initial recovery from the acute disease phase and this was due to a wide-range of issues that extend beyond respiratory sequelae.</p>	<p>Wong AW, Shah AS, Johnston JC, Carlsten C and Ryerson CJ. Vancouver, Canada.</p>	<p>Research Article Letter (Letter to the Editor)</p>	<p>European Respiratory Journal.</p>	<p>2020</p>															<p><a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7530908/pdf/ERJ-03276-2020.pdf">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7530908/pdf/ERJ-03276-2020.pdf</a></p>

50	<p>Sodergren SC, Johnson CD, Gilbert A, Darlington AS, Cocks K, Guren MG, Rivin Del Campo E, Brannan C, Christensen P, Chu W, Chung H, Dennis K, Desideri I, Gilbert DC, Glynn-Jones R, Jefford M, Johansson M, Johnsson A, Juul T, Kardamakis D, Lai-Kwon J, McFarlane V, Miguel IMC, Nugent K, Peters F, Riechelmann RP, Turhal NS, Wong S, Vassiliou V; European Organisation for Research and Treatment of Cancer Quality of Life Group. International Validation of the EORTC QLQ-ANL27, a Field Study to Test the Anal Cancer-Specific Health-Related Quality of Life Questionnaire. <i>Int J Radiat Oncol Biol Phys.</i> 2022 Nov 17:S0360-3016(22)03507-6. doi: 10.1016/j.ijrobp.2022.11.002. Epub ahead of print. PMID: 36402360.</p>	<p>This webpage is where news, press releases and information are e-published by the EORTC's Quality of Life Group. In November 2022 the EORTC e-published a study (ahead of print) which field tested across fifteen countries the EORTC QLQ-ANL27 - the first EORTC anal cancer-specific QoL questionnaire. The EORTC QLQ-ANL27 aims to measure concerns specific to people with anal cancer treated with chemoradiotherapy. The findings of this study confirmed the reliability and validity of this anal cancer-specific questionnaire and its acceptability across different geographical regions</p>	<p>Sodergren SC, et al. Europe and United Kingdom.</p>	<p>Research Article</p>	<p>Website: Epublised by EORTC Quality of Life Group. Ahead of print.</p>	<p>2022</p>		✓		✓	✓	✓		✓		✓			<p><a href="https://www.eortc.org/bl-og/2022/11/18/first-eortc-anal-cancer-specific-questionnaire-validated/">https://www.eortc.org/bl-og/2022/11/18/first-eortc-anal-cancer-specific-questionnaire-validated/</a></p>
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## Appendix 6

### Current State Analysis – Australian Clinical Registries Review 2022

No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
1.	<p><u>Australasian Rehabilitation Outcomes Centre (AROC)</u></p> <p>Australian Registry ID: ACSQHC-ARCR-006</p>	To provide a national benchmarking system that can be used to improve rehabilitation outcomes in both the public and private sectors (by FIM score, LOS (length of stay) & risk adjusted).	Australia New Zealand (est. 2002)	<p>Australasian Faculty of Rehabilitation Medicine (AFRM)</p> <p>The University of Wollongong, Illawarra, and Shoalhaven Local Health District Health and Medical (#HREC 2019/ETH13154)</p>	<p>Feedback to contributing clinicians.</p> <p>Shared with clinicians.</p> <p>Shared with hospital executive.</p> <p>Shared with consumers.</p> <p>Shared with medical colleges.</p> <p>Reported to state/territory health departments.</p> <p>Reported in annual report.</p> <p>Reported in other public reports.</p> <p>Quality improvement/benchmarking workshops: The purpose of these workshops is to examine the benchmarking data, share information and learn from services who are achieving the best outcomes. Service reports: each individual rehabilitation service receives a suite of reports that presents their data and compares this to aggregated national data.</p>	<p><u>Western Australia:</u></p> <p>Albany Hospital</p> <p>Armadale Kelmscott Memorial Hospital</p> <p>Bunbury Hospital (South West Health Campus)</p> <p>Busselton Health Campus</p> <p>Fiona Stanley Hospital</p> <p>Fremantle Hospital and Health Service</p> <p>Northam Hospital Rehabilitation Service</p> <p>Osborne Park Hospital</p> <p>Peel Health Campus</p> <p>Perth Children's Hospital</p> <p>Rockingham General Hospital</p> <p>Royal Perth Bentley Hospital Group (Bentley)</p> <p>Sir Charles Gairdner Hospital</p> <p>Attadale Rehabilitation Hospital</p> <p>Glengarry Hospital</p> <p>Hollywood Private Hospital</p> <p>Joondalup Health Campus (Ramsay Health)</p> <p>Mount Hospital</p> <p>St John of God Mount Lawley Hospital</p> <p>St John of God Midland Hospital</p>	The AM-CCRQ is an optional rehabilitation specific patient experience survey that is available for members.	Planning is underway to introduce a new range of PROMs in future versions of the data collection. A PoC (Proof of Concept) Pilot is currently underway.
2.	<p><u>The Australian Benralizumab Registry (the ABenRA)</u></p> <p>Australian Registry ID: ACSQHC-ARCR-015</p>	<p>The aim of the registry is to assess the change in patient reported asthma related symptoms after enrolment in the benralizumab registry following initiation of benralizumab in a real-world setting in the full study population and pre-specified subgroups.</p> <p>Collects and reports on data from people with severe refractory eosinophilic asthma who receive benralizumab:</p> <p>As part of the PBS subsidised benralizumab</p>	Australia (est.2019)	Ethics approval received from Hunter New England HREC:2019/ETH 08669	<p>Reported in Annual Report.</p> <p>Reported in other public reports.</p> <p>Shared with clinicians.</p> <p>Shared with medical colleges.</p>	<p><u>Western Australia:</u></p> <p>Fiona Stanley Hospital</p>	Nil	Yes

## Current State Analysis – Australian Clinical Registries Review 2022

No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
		<p>treatment cycle, and the Pharmaceutical Benefits Scheme (PBS) Section 100 Special Authority Program, or for severe refractory eosinophilic asthma outside of the PBS restrictions.</p> <p>The ABenRA provides a mechanism for sharing information which will help researchers and clinicians to better understand the use, efficacy, and safety associated with the treatment of severe asthma with benralizumab.</p>						
3.	<p><u>Australasian Severe Asthma Registry (ASAR)</u></p> <p>Australian Registry ID: ACSQHC-ARCR-017</p>	<p>The Australasian Severe Asthma Network (ASAN) is a multicentre clinical research network that:</p> <ul style="list-style-type: none"> <li>-Collects and reports on data from people with severe asthma.</li> <li>-Facilitates clinical research in this population.</li> <li>-Seeks to improve clinical practice for this condition.</li> </ul> <p>The ASAN provides a mechanism for sharing information which helps researchers and clinicians to better understand severe asthma and develop optimised clinical management strategies.</p> <p>The ASAN collects data relating to patients who are diagnosed with Severe Refractory Asthma (SA) and who are recruited from participating sites across Australia, Singapore, and New Zealand.</p>	<p>Australia Singapore New Zealand (est.2019)</p>	<p>Hunter New England HREC Reference No: 12/11/21/4.04; NSW REGIS Reference No: 2019/ETH03836</p>	<p>Reported in Annual Report. Reported in other public reports. Shared with clinicians. Shared with consumers. Shared with medical colleges.</p>	<p><u>Western Australia:</u> Fiona Stanley Hospital</p>	<p>Nil</p>	<p>Asthma Control Questionnaire (ACQ) Asthma Quality of Life Questionnaire (AQLQ)</p>
4.	<p><u>The Australasian Myositis Registry</u></p> <p>Australian Registry ID: ACSQHC-ARCR-080</p>	<p>The Myositis Registry is a multi-centre, international, longitudinal, observational program for patients with myositis that has been designed to track the natural history and progression of the disease and patient outcomes.</p> <p>The benefits of the Myositis Registry are twofold: for clinicians and researchers, the Myositis Registry will provide an important tool for novel insights into disease mechanisms, diagnostic tools and identify potential treatments and</p>	<p>Australia (est.2019)</p>	<p>2019-007 Murdoch University Human Research Ethics Committee</p>	<p>Feedback to contributing clinicians – summary reports. Shared with other clinicians – anonymised data sets available on request. Shared with hospital executive. Shared with consumers – consumers can log into a 'patient portal' and information also fed back via consumer advocacy groups.</p>	<p><u>Western Australia:</u> Institute of Immunology and Infectious Diseases (IID). Murdoch University and The Perron Institute for Translational and Neurological Sciences (both WA) – Lead Site.</p>	<p>Nil</p>	<p>Manual Muscle Testing (MMT); IBM Functional Rating Scale (IBM-FRS); Short Form 36 (SF-36); Health Assessment Questionnaire</p>

## Current State Analysis – Australian Clinical Registries Review 2022

No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
		<p>targets for therapies; and for patients the Myositis Registry will offer an opportunity to take an active role in their clinical care via a 'Patient Portal,' which allows the patient to access their data and monitor their condition.</p> <p>The Myositis Registry also provides a research feasibility and recruitment facility, as the database population can be analysed to identify potential research candidates and determine study feasibility within disease sub-groups, including for studies with extensive phenotype inclusion criteria. Potential research participants can be notified of research opportunities without their confidentiality being compromised, allowing the patient to make informed choices regarding research participation.</p>			<p>Shared with medical colleges.</p> <p>Reported to state/territory health departments – as requested.</p> <p>Reported in Annual Report – within annual reports from the sponsoring institutions.</p> <p>Reported in other public reports.</p>			<p>(HAQ);</p> <p>Patient Global Activity (PaGA);</p> <p>Physician Global Activity (PhGA);</p> <p>Myositis Disease Activity Assessment Tool (MDAAT).</p>
5.	<p><u>Burns Registry of Australia and New Zealand</u></p> <p>Australian Registry ID: ACSQHC-ARCR-092</p>	<p>The Burns Registry of ANZ is a clinical quality registry capturing epidemiological, quality of care, and outcome data for adult and paediatric burn patients across Australian and New Zealand burn units.</p> <p>The purpose of the registry is to monitor burn injury incidence and causation, identify objective and verifiable evidence-based information on treatment, outcomes, and quality of care to encourage higher standards of both burn injury prevention and patient care.</p>	<p>Australia New Zealand (est. 2009)</p>	<p>CF08/2431 - 2008001248, Monash University HREC</p>	<p>Reported in Annual Report.</p> <p>Shared with clinicians.</p> <p>Feedback to contributing clinicians.</p>	<p><u>Western Australia:</u> Fiona Stanley Hospital Perth Children's Hospital</p>	<p>Nil</p>	<p>Nil</p>
6.	<p><u>Bariatric Surgery Registry</u></p> <p>Australian Registry ID: ACSQHC-ARCR-106</p>	<p>To measure outcomes for patients undergoing bariatric surgery and therefore the safety and quality of bariatric procedures across public and private hospitals in Australia &amp; New Zealand.</p>	<p>Australia New Zealand (est. 2009)</p>	<p>School of Public Health and Preventive Medicine. HREC/18/Alfred/7 5 (NMA 40238)</p>	<p>Feedback to contributing clinicians.</p> <p>Reported in Annual Report.</p> <p>Reported to State/Territory health departments.</p> <p>Shared with hospital executive.</p>	<p><u>Western Australia:</u> Bethesda Hospital Glengarry Private Hospital Hollywood Private Hospital Joondalup Health Campus (Ramsay Health) Mount Hospital Peel Health Campus St John of God Murdoch Hospital St John of God Mt Lawley Hospital St John Of God Subiaco Hospital Waikiki Private Hospital</p>	<p>Nil</p>	<p>PROMs for the Bariatric Surgery Registry are currently under development and planned for collection in 2022-23</p>

## Current State Analysis – Australian Clinical Registries Review 2022

No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
7.	<p><u>Continuous Improvement in Care - Cancer Project (CIC Cancer)</u></p> <p>Australian Registry ID: ACSQHC-ARCR-150</p>	<p>CIC Cancer Project is a multi-institutional program of research that seeks to bring value-based healthcare (VBHC) to public and private healthcare settings in Western Australia (WA). The project aims to create value through improving outcomes whilst containing costs (www.ciccancer.com). This is achieved through measuring and acting on variations in outcomes that are important for people diagnosed with breast, colorectal, lung, prostate and ovarian cancer.</p> <p>The results of combined clinical and patient-reported outcome measures will feed back into clinical management processes to improve care; help determine needs for clinical intervention and allow units to assess and improve their practices.</p>	Western Australia	South Metropolitan Health Services HREC RGS 1117 and SJoG Health Care #1422	<p>Feedback to contributing clinicians - planned.</p> <p>Reported to State/Territory health departments - planned.</p> <p>Shared with consumers - planned.</p> <p>Shared with hospital executive - planned.</p> <p>Shared with other clinicians - planned.</p>	<p><u>Western Australia:</u></p> <p>Fiona Stanley Hospital King Edward Memorial Hospital Royal Perth Hospital St John of God Hospital, Subiaco St John of God Midland Public &amp; Private Hospital</p>	PoC Pilot All.Can	PoC Pilot Consortium for Health Outcomes Measurement International (ICHOM) data sets and developed dataset for ovarian cancer.
8.	<p><u>Perth Hip and Knee Research Registry</u></p> <p>Australian Registry ID: ACSQHC-ARCR-290</p>	<p>To prospectively capture data to allow comparisons in techniques of undertaking hip and knee arthroplasty (joint replacement) surgery. This will look at methods of performing the surgery including the use of advanced technology and robotics, as well as methods of individualising position of implants during surgery.</p> <p>All patients undergoing hip or knee replacement surgery at Perth Hip and Knee Clinic will be eligible for inclusion.</p> <p>Patient demographics, intra-operative measurements and data, post-operative patient reported outcome measures, clinical assessment and patient satisfaction will be measured as will radiographic analysis undertaken as routine of care.</p>	Western Australia (est.2017)	SJoG Health Care HREC ref1388	<p>Feedback to contributing clinicians.</p> <p>Shared with other clinicians.</p> <p>Publication in peer reviewed journals.</p>	<p><u>Western Australia:</u></p> <p>St John of God Hospital, Murdoch St John of God Hospital, Subiaco St John of God Midland Public &amp; Private Hospital</p>	Nil	<p>Forgotten Joint Score - 12 (FJS-12); Oxford Knee Score (OKS); Knee injury &amp; Osteoarthritis Outcome Score, Joint Replacement (KOOS Jr); EuroQol Group (EQ-5d); Visual Analog scale (VAS); Pain scores Oxford Hip Score (OHS); Hip disability &amp; Osteoarthritis Outcome</p>

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No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
								Score, Joint Replacement (HOOS-JR)
9.	<u>ANZICS Adult Patient Database</u> Australian Registry ID: ACSQHC-ARCR-294	To collect outcomes for all patients admitted into an ICU. Australian & New Zealand Intensive Care Society (ANZICS) ANZICS maintains a series of clinical registries that are designed to track outcomes from patients who are admitted into an intensive care unit. A bi-national peer review and quality assurance program to provide audit and benchmarking services for Intensive Care Units (ICUs) across Australian and New Zealand	Australia New Zealand (est. 1992)	ANZICS Centre for Outcome and Resource Evaluation (ANZICS CORE) Quality improvement initiative A Declared Quality Assurance Activity under the Commonwealth Health Insurance Act 1973	Reported in Annual Report. Shared with clinicians. Shared with consumers. Shared with hospital executive. Online clinical reports available to all submitting units. Formalised quarterly reports to all jurisdictional funders, with access to online data and reports. Results of annual survey of Critical Care Resources results provided to submitting units and jurisdictions. Activity reports detailing adult and paediatric Intensive Care practices, resources and outcomes produced annually. 15-20 publications in peer-reviewed journals per year.	<u>Western Australia ICUs/PICUs:</u> Armadale Health Service Bunbury Regional Hospital Fiona Stanley Hospital Joondalup Health Campus (Ramsay Health) Mount Hospital Perth Children's Hospital PICU Rockingham General Hospital Royal Perth Hospital ICU Sir Charles Gairdner Hospital St John of God Health Care (Subiaco) St John of God Hospital (Murdoch) St John of God Midland Public & Private	In development	In development
10.	<u>The Australian Breast Device Registry (ABDR)</u> Australian Registry ID: ACSQHC-ARCR-322	The ABDR's continuing mission is to improve patient outcomes by identifying and reporting on possible trends and complications associated with breast device surgery; tracking the long-term safety and performance of implantable breast devices; monitoring performance of breast devices and benchmarking the quality of surgery involving breast implants, breast tissue expanders and acellular dermal matrices; and identifying best surgical practice and optimal patient health outcome. The ABDR collects information about breast devices using a simple data collection form (DCF) completed by surgeons at the time of surgery across the eligible sites Australia-wide. ABDR collects data related to all surgical procedures involving breast implants, breast	Australia (est.2015)	Multiple HRECs, lead site is Alfred Hospital HREC 5/15 and Monash University	Feedback to contributing clinicians. Shared with clinicians. Shared with consumers. Shared with hospital executive. Reported in Annual Report. Reported in other public reports.	<u>Western Australia:</u> Bethesda Hospital Bunbury Day Surgery Cambridge Day Surgery Colin Street Day Surgery Concept Fertility Centre and Day Hospital Glengarry Private Hospital Hollywood Private Hospital Joondalup Health Campus Mount Hospital Peel Health Campus St John of God Bunbury Hospital SJOG Midland Public & Private Hospital (previously Swan District Hospital) St John of God Mt Lawley Hospital St John of God Murdoch Hospital St John of God Subiaco Hospital	Nil	BREAST-Q Implant Surveillance module (BREAST-Q IS)

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No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
		<p>tissue expanders and acellular dermal matrices (or similar) undertaken nationally. This includes insertions, revisions of in situ devices, and explants without replacement. Information from the DCFs generates a powerful set of accurate and validated data that can be analysed and reported to individual surgeons, hospitals, the department of health and other key stakeholders.</p> <p>The ABDR produces information on device failure rates, complications and revision rates of procedures involving breast devices nationally. Additional to data collected at the time of surgery and revision surgery, the ABDR asks patients brief questions about their health at 1, 2, 5 and 10years post-surgery (PROMs substudy).</p>				<p>St John of God Wembley Day Surgery Southbank Day Surgery Subiaco Private Hospital Waikiki Private Hospital West Leederville Private Hospital</p>		
11.	<p><u><a href="#">Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)</a></u> Australian Registry ID: ACSQHC-ARCR-341</p>	<p>ANZDATA is a clinical quality registry that collects and produces a wide range of statistics relating to the outcomes of treatment of those with end stage kidney disease (ESKD). ANZDATA has been in operation since 1977 (but contains data from precursor registries dating back to 1963). All renal units in Australia and New Zealand contribute data to ANZDATA. The Registry's fundamental purpose is to report on the incidence, prevalence and outcomes of dialysis and transplant treatment for patients with ESKD, by providing information that is complete, accurate, clear, relevant, readily available and timely.</p> <p>Data from the Registry is regularly used to inform clinical practice, monitor quality of clinical care, plan health services, and conduct research projects.</p>	Australia (est.1977)	South Australian Health and Medical Research Institute	<p>Feedback to contributing clinicians. Reported in Annual Report. Reported in other public reports. Reported to state/territory health departments. Shared with consumers. Shared with hospital executive. Shared with other clinicians.</p>	<p><u>Western Australia:</u> Fiona Stanley Hospital Perth Children's Hospital Royal Perth Hospital Sir Charles Gairdner Hospital</p>	Nil	PoC Pilot program and registry Clinical Trials underway currently using EQ5D
12.	<u><a href="#">National Cardiac</a></u>	NCR is a clinical quality registry that collects information on patients receiving treatment for cardiac conditions via state/territory-based	Australia (est.2019)	Alfred Health Ethics Committee 63109 (Local	<p>Reported in Annual Report. Participating state/territory cardiac registries can access inbuilt</p>	Western Australia	Nil	Nil

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No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
	<p><u>Registry (NCR)</u> Australian Registry ID: ACSQHC-ARCR-346</p>	<p>cardiac registries. The purpose of the NCR is to document outcome variance and opportunities for excellence in the quality of cardiac health care across Australia. In 2021 data collection commenced across number of state/territories and as it matures the following objectives will be realised.</p> <p>Objectives:</p> <ul style="list-style-type: none"> <li>-Use a collaborative, federated model for effective engagement, participation and support from stakeholders.</li> <li>-Provide a platform to receive State and Territory data and measure performance as determined by agreed quality indicators.</li> <li>-Transparently report on clinical, procedural and patient outcomes to clinicians, hospitals, government and community.</li> <li>-Provide national benchmarking of key quality performance measures for cardiac conditions/procedures/devices and secondary prevention.</li> <li>-The NCR will be rolled out in modules, each covering different areas of cardiac healthcare. The first module covers Percutaneous coronary intervention (PCI).</li> </ul>		Reference: Project 59/21)	<p>benchmarked reports. Participating state/territory cardiac registries can share reports with hospitals executives, state/territory health departments, other clinicians. Shared with consumers via annual report.</p>			
13.	<p><u>Myeloma and related Diseases Registry (MRDR)</u> Australian Registry ID: ACSQHC-ARCR-438</p>	<p>MRDR is a prospective clinical quality registry aims to improve myeloma outcomes by providing an evidence-base for the best strategies to diagnose, treat and support people with myeloma and related diseases. It is a registry of newly diagnosed patients with multiple myeloma, MGUS, plasma cell leukaemia or plasmacytoma. It collects information on demographics, diagnosis, treatment, response to therapy and outcomes including survival, progression free survival and quality of life.</p> <p>The aims of the Myeloma &amp; Related Diseases</p>	Australia New Zealand (est. 2012)	HREC/16/Alfred/1 26	<p>Feedback to contributing clinicians in six monthly site data reports. Reported in Annual Report. Shared with clinicians. Shared with hospital executive. Publish quarterly registry updates in MyeNews, published by Myeloma Australia, a national myeloma patient advocacy foundation.</p>	<p><u>Western Australia:</u> Sir Charles Gairdner Hospital Hollywood Private Hospital</p>	Nil	Collect EQ-5D-5L

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No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
		<p>Registry are to:</p> <ul style="list-style-type: none"> <li>-Monitor access to care.</li> <li>-Benchmark outcomes nationally and internationally.</li> <li>-Explore variation in practice, process and outcome measures.</li> </ul> <p>Monitor trends in incidence and survival.</p> <ul style="list-style-type: none"> <li>-Explore the factors that influence outcomes including survival and quality of life.</li> </ul> <p>Act as a resource for clinical trials.</p> <ul style="list-style-type: none"> <li>-The MRDR has an industry-funded "sister registry", the Asia-Pacific MRDR (APAC MRDR), with the same aims and purpose. The APAC-MRDR collects data that mirrors the ANZ registry from Korea, Singapore, and Malaysia with other countries to follow.</li> </ul>						
14.	<p><u>Trauma Registry at Royal Perth Hospital (RPH)</u></p> <p>Australian Registry ID: ACSQHC-ARCR-355</p>	<p>Quality improvement initiative</p> <p>The criteria for inclusion into the registry are:</p> <ul style="list-style-type: none"> <li>-All trauma patients who present to RPH for treatment within 7 days of their date of trauma and who were hospitalised for greater than 24 hours at RPH.</li> <li>-All trauma-related deaths at RPH regardless of hospital length of stay.</li> <li>-Patients who have suffered the effects of poisoning and drug overdose are excluded from the registry.</li> <li>-The Registry population is divided into major and minor trauma admissions according to the Injury Severity Score (ISS).</li> </ul>	<p>Western Australia (est. Aug.1994)</p>	<p>Royal Perth Hospital</p>		<p><u>Western Australia:</u></p> <p>Fiona Stanley Hospital Joondalup Health Campus Perth Children's Hospital Royal Perth Hospital Sir Charles Gairdner Hospital St John of God Midland Hospital</p>	<p>Nil</p>	<p>Nil</p>
15.	<p><u>Australian &amp; New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS)</u></p>	<p>To provide a standardised system for data collection &amp; tracking of patient outcomes to monitor &amp; improve the results of cardiac surgery. This has led to the identification of key performance indicators &amp; generation of local standards, enabling benchmarking of individual and unit performance across Australia &amp; New Zealand.</p>	<p>Australia (est. 2001 VIC, national 2007)</p>	<p>Victorian Department of Health NSW Clinical Excellence Commission (CEC) Queensland</p>	<p>Feedback to contributing clinicians. Hospitals and surgeons have access to their own data via the online web portal. Shared with clinicians. Reported in Annual Report. Reported in other public reports. Shared with hospital executive. Shared with medical colleges.</p>	<p>Ramsay Health??</p> <p><u>Western Australia:</u></p> <p>Fiona Stanley Hospital Sir Charles Gairdner Hospital Mount Hospital St John of God Hospital (Subiaco)</p>	<p>Nil</p>	<p>Nil</p>



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No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
	Australian Registry ID: ACSQHC-ARCR-406			Health Participating units.	Reported to State/Territory health departments.			
16.	<u>Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)</u> Australian Registry ID: ACSQHC-ARCR-504	To improve and maintain the quality of care for individuals receiving joint replacement surgery (hip, knee, shoulder, elbow, wrist, ankle & spinal disc replacement).	Australia (est. 1999, national 2002)	Australian Orthopaedic Association (AO)	Reported in an annual report. Reported in other public reports. Shared with clinicians. Shared with consumers. Shared with hospital executive. Feedback to contributing clinicians. Reported to State/Territory health departments.	<u>Western Australia:</u> Albany Regional Hospital Armadale Health Service Bethesda Hospital Bunbury Regional Hospital Busselton Health Campus Fiona Stanley Hospital Fremantle Hospital Geraldton Hospital Joondalup Health Campus (Ramsay Health) Kalgoorlie Health Campus Osborne Park Hospital Peel Health Campus Rockingham General Hospital Royal Perth Hospital Sir Charles Gairdner Hospital Hollywood Private Hospital Mount Hospital St John of God Bunbury Hospital St John of God Geraldton Hospital St John of God Midland Hospital St John of God Mt Lawley Hospital St John of God Murdoch Hospital St John of God Subiaco Hospital Waikiki Private Hospital	Nil	PoC Pilot Standard PROMs collected by the AOANJRR pre-operative and 6 months post-operative: EQ5D5L HOOS/KOOS (mid-level) Oxford Hip, Knee, Shoulder Additional PROMs for Registry Nested Clinical Trials: Forgotten Joint Score HOOS Junior
17.	<u>Binational Colorectal Cancer Audit (BCCA)</u> Australian Registry ID: ACSQHC-ARCR-461	BCCA is a Clinical Quality Registry was started as a clinical audit and is a surgeon-led surgical audit applicable to all surgeons who perform colorectal cancer surgery. BCCA data is used for clinical audit of the surgical practices of Australian and New Zealand (ANZ) surgeons for the purpose of quality assurance. The audit also works towards creating a large dataset of ANZ data that can be	Australia New Zealand (est. 2007)	Monash Health HREC/17/MH/242  BCCA is governed by a collaboration of invested parties (CSSANZ, RACS,	Feedback to contributing clinicians. Reported in Annual Report. A clinician can review their performance against all contributing surgeons at their site and at all contributors to the database at any time. Clinical Quality Reports on risk-adjusted	<u>Western Australia:</u> Fiona Stanley Hospital Hollywood Private Hospital Joondalup Health Campus St John of God Hospital Murdoch St John of God Hospital Subiaco	Nil	Nil

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No.	Clinical Registry	Aim	Scope	Oversight	Reporting process	Participating providers/sites	PREMs	PROMs
		used for research and quality improvement purposes, with the aim of advancing knowledge and understanding of treatment for colorectal cancer. By creating this dataset BCCA will be able to identify areas pertinent to patient safety, identify benchmarks and identify sites that may be performing outside the common bounds of the larger group. BCCA collects information on patient and tumour characteristics, colorectal cancer management, complications of treatment, and clinical quality indicators relating to quality of surgical and hospital care.		NZAGS, GSA, and consumers)	key quality indicators are provided to contributing units/surgeons at a site.			
18.	<u>Transcatheter Aortic Valve Implantation (TAVI) Registry</u> Australian Registry ID: Nil	TAVI is a clinical quality registry that monitors the clinical outcomes of patients undergoing aortic valve replacement via a transcatheter approach.	Australia (est.2018)	Australasian Cardiac Outcomes Registry (ACOR) Ltd		<u>Western Australia:</u> Ramsay Health	Unknown	Unknown
19.	<u>Clinical Alliance and Research in ECT and Related Treatments (CARE) Network</u> Australian Registry ID: Nil	To identify & address translational gaps and unwarranted clinical variation in practice by collecting key clinical data that is designed to assess patient outcomes and ensure that facilities are compliant with state-based regulation.	Australia (est.2015)	University of NSW		<u>Western Australia:</u> Ramsay Health	Unknown	Unknown

Review and follow-up with CQR Contacts conducted October-November 2022

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