

November 2016

# **Patient-reported Outcome Measures**

## **An environmental scan of the Australian healthcare sector**

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## Preface

This environmental scan report describes the current status of the collection and use of patient-reported outcome measures (PROMs) in Australian health care. To our knowledge, this is the first time that the fragmented and often isolated PROMs initiatives taking place all over the country have been documented together.

PROMs are questionnaires which patients complete. They ask for the patient's assessment of how health services and interventions have, over time, affected their quality of life, daily functioning, symptom severity, and other dimensions of health which only patients can know. PROMs promise to fill a vital gap in our knowledge about outcomes and about whether healthcare interventions actually make a difference to people's lives.

This preface is the Australian Commission on Safety and Quality in Health Care's (the Commission's) introduction to the report that follows. The report was written by Cristina Thompson and colleagues at the Australian Health Services Research Institute (AHSRI), University of Wollongong. In this preface, we briefly put the report into context and highlight some of its main messages and potential uses.

### Why was this document commissioned?

In Australia, PROMs are an emerging method of assessing the quality of health care. They are not yet embedded in routine measurement at regional, jurisdictional or national level. Internationally, such routine and consistent measurement is being developed or is already embedded in the health systems of several Organisation for Economic Co-operation and Development (OECD) countries.

The Commission is scoping an appropriate role at national level to support the consistent and routine use of PROMs to drive quality improvement in a way that brings patients' voices and outcomes to the fore. Before scoping this role, it was necessary to find out what is already being done with PROMs in Australia. This report was commissioned to map the current situation.

In mid-2016, the Commission sought expressions of interest for undertaking this environmental scan and its companion document, a literature review. The Australian Health Services Research Institute (AHSRI) at University of Wollongong made a strong submission based on extensive prior experience in PROMs-related research and in the application of PROMs within health services.

### What were the main findings and recommendations?

The most important finding of this report is that although many organisations in the healthcare sector are interested in PROMs, their actual development, collection and use is currently patchy and inconsistent.

However, there are many initiatives highlighted in the report which show innovative and robust existing and planned uses for this patient-reported information. Some of the foundations for routine use of PROMs are therefore already in place. There are also exciting plans in some jurisdictions for larger-scale use of PROMs to measure integration of care across multiple services and to track the healthcare journeys of people with chronic conditions.

The report makes several recommendations for the Commission's potential role in helping to build on this existing work to help embed PROMs in Australian health care. These will be

taken into consideration (but not necessarily taken up) as the Commission develops its future work on PROMs.

## How can this document help you?

The Commission intends that governments, researchers, managers, health professionals and consumer groups will find this document a useful resource when exploring how PROMs might help their organisation achieve a more person-centred approach to quality and safety improvement. The table at the back of the report provides web links to more information and contacts for the initiatives mentioned.

The information contained within this environmental scan is based on a search of information publicly available on organisational websites that was conducted from June to August 2016. There will unavoidably be initiatives that we have failed to find; the Commission is interested to hear from any organisation where PROMs work is being conducted that is not reflected in this scan.

## What will the Commission do next?

The Commission is releasing a separate literature review alongside this environmental scan. We recommend reading the two reports together, as the literature review puts PROMs into a wider, international context and synthesises research evidence on best practice in their development, collection and use.

The Commission will now use the findings of the two documents as a basis for developing a series of options for a national framework and resources. These will support governments and health services around Australia to use PROMs in ways that are backed by evidence and which build on and learn from existing initiatives.

This work complements other current work at the Commission. Scoping the role of PROMs in assessing low-value care for certain conditions was one of the recommendations of the first *Australian Atlas on Healthcare Variation*, and the version two of the National Safety and Quality Health Service (NSQHS) Standards promotes a strong focus on person-centred care.

# Patient-reported outcome measures: an environmental scan of the Australian healthcare sector

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Australian Commission on Safety and Quality in Health Care

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November 2016

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**Annotation:**

The information contained within this environmental scan is not intended to be exhaustive. It is based on a search of information publicly available on organisational websites that was conducted from June to August 2016.

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## Contents

List of abbreviations and acronyms .....	ii
Key messages .....	iv
1 Introduction.....	1
1.1 Background and context.....	1
1.2 Scope of the project .....	2
1.3 Structure of this report.....	3
2 Definitional issues .....	4
2.1 Measuring patient experiences .....	4
3 Methods .....	6
3.1 Search strategy .....	6
3.2 Search terms and parameters .....	6
3.3 General exclusions and limitations.....	8
4 Findings .....	9
4.1 Overview of findings.....	9
4.2 Organisations engaged in the development/collection of PROMs – national and state level .....	10
4.3 Organisations integrating PROMs into other data collections.....	15
4.4 Organisations actively promoting the use of PROMs but not collecting data .....	24
5 Discussion.....	27
5.1 Current status of PROMs in the Australian health sector .....	27
5.2 PROMs data collection and aggregation .....	27
5.3 Gaps in the collection and use of PROMs in Australia .....	28
6 References.....	29

## List of figures and tables

Figure 1 Role of the ACI – implementing patient-reported measures .....	18
Table 1 Number of entries in environmental scan by organisation type.....	8

## List of appendices

Appendix 1 Examples of search results .....	34
Appendix 2 Patterns of collection of PROMs in Australia .....	36
Appendix 3 List of clinical registries .....	76

## List of abbreviations and acronyms

ACI	Agency for Clinical Innovation
AHSRI	Australian Health Services Research Institute
ALSWH	Australian Longitudinal Study on Women’s Health
ANZCTR	Australian New Zealand Clinical Trials Registry
AQoL	Assessment of Quality of Life
AROC	Australasian Rehabilitation Outcomes Centre
ABS	Australian Bureau of Statistics
ACSQHC	Australian Commission on Safety and Quality in Health Care
ACGR	Australian Corneal Graft Registry
AHOC	Australian Health Outcomes Collaboration
AHHA	Australian Healthcare and Hospitals Association
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
AMHOCN	Australian Mental Health Outcomes and Classification Network
ARAD	Australian Rheumatology Association Database
BHI	Bureau of Health Information
CONROD	Centre of National Research on Disability and Rehabilitation Medicine
CHSD	Centre for Health Service Development
CI NSW	Cancer Institute New South Wales
CEC	Clinical Excellence Commission
COSA	Clinical Oncology Society of Australia
CATI	Computer Assisted Telephone Interviewing
CADOSA	Coronary Angiogram Database of South Australia
DOMS	Dementia Outcomes Measurement Suite
ePPOC	Electronic Persistent Pain Outcomes Collaboration
EUREQUO	European Registry of Quality Outcomes for Cataract and Refractive Surgery
HRQoL	Health-related quality of life
HCF	Hospitals Contribution Fund of Australia Limited
HSRAANZ	Health Services Research Association of Australia and New Zealand
ICHOM	International Consortium for Health Outcomes Measurement
ISOQOL	International Society for Quality of Life
IPCOR	Irish Prostate Cancer Outcomes Research
MHRF	Medibank Health Research Fund



NCDR	National Cardiovascular Data Registry
NOCC	National Outcomes and Casemix Collection
NSQHS	National Safety and Quality Health Service (Standards)
NHPA	National Health Performance Authority
NHS	National Health Service
PCOC	Palliative Care Outcomes Collaboration
PREMs	Patient-reported experience measures
PROs	Patient-reported outcomes
PROMs	Patient-reported outcome measures
PROMIS	Patient-Reported Outcomes Measurement Information System
PRO-SIG	Patient-Reported Outcomes Special Interest Group
PROSPER	Patient-Reported Outcomes Safety Event Reporting
PHMA	Private Mental Health Alliance
PCOR-ANZ	Prostate Cancer Outcomes Registry - Australia and New Zealand
PCR	Prostate Cancer Registry
PEQ	Psychological Evaluation Questionnaire
PoCoG	Psycho-Oncology Co-operative Research Group
QOL	Quality of Life
RCT	Randomised Controlled Trial
SACCESS	South Australian Consumer Experience Surveillance System
TORU	Trauma and Orthopaedic Research Unit
TRIP	Turning Research into Practice
UNSW	University of New South Wales
VSTORM	Victorian State Trauma Outcomes Registry Monitoring (VSTORM) Group
VSTR	Victorian State Trauma Registry
VCCC	Victorian Comprehensive Cancer Centre

## Key messages

- This environmental scan captures the current status of patient-reported outcome measures (PROMs) in the Australian public and private health sector. The analysis also identifies any obvious gaps in the collection and use of PROMs in Australia.
- Information was obtained through a purposive search of organisational websites.
- A classification system or typology was developed to cluster information by organisations engaged in the development and/or implementation of PROMs. Over 100 organisational websites were reviewed.
- An environmental scan reliant on website searching has limitations. In the majority of instances information was restricted and if available, it included little detail and specificity. Therefore, the scan cannot be seen as exhaustive; it is intended to provide a picture of the patterns of the collection and use of PROMs using publicly available information.
- The key findings from the environmental scan indicate that:
  - The patterns of collection of PROMs in the Australian context are highly variable.
  - There is increasing interest and promotion of PROMs across a broad range of organisations but less evidence of actual data collection (mandated or otherwise) at a national or state level.
  - A small number of PROMs are being integrated into existing survey initiatives at both state and health district level; these are usually items embedded in patient experience surveys e.g. Cancer Institute NSW, Bureau of Health Information (NSW), Department of Health and Human Services Victoria.
  - The organisations most frequently engaged in the development and implementation of PROMs are academic institutions / research centres in collaboration with clinicians (e.g. Psycho-Oncology Co-operative Research Group, University of Sydney; Australian Health Services Research Institute, University of Wollongong) and university based clinical registries e.g. Monash Clinical Registries, Monash University.
  - There are several well-established consortia that provide leadership in this field with a focus on benchmarking. For example government funded entities such as the Australian Mental Health Outcomes and Classification Network (AMHOCN), the Palliative Care Outcomes Collaboration (PCOC), the electronic Persistent Pain Outcomes Collaboration (ePPOC) and the Australasian Rehabilitation Outcomes Centre (AROC) at the Australian Health Services Research Institute (AHSRI).
  - Collaboratives such as PCOC, ePPOC and AROC provide patient outcome reports to participating clinical services on a six-monthly basis that facilitate comparison with state/territory and national benchmarks. The timeliness of reporting is a particular advantage of this approach as clinicians receive a comparative analysis of their outcomes on a regular basis. In addition benchmarking workshops are held every six months to increase understanding of how clinicians can use outcome data to drive quality improvement.
  - The data collected by clinical registries is used in varying degrees for peer review, quality assurance and research. For example, there are registries that allow participating clinicians to audit their own patient outcomes, anonymously comparing results with other clinicians. Others provide benchmarking of outcomes and quality of care against

comparable units and international standards. Researchers can also apply for access to specific sets of data from the relevant data custodian.

- Based on the information available using organisational websites – NSW Health emerges as a leading public sector agency engaged in PROMs data collection through the work of the Agency for Clinical Innovation (ACI) and Cancer Institute NSW. Several Local Health Districts in NSW are implementing demonstration projects including small scale collection of PROMs. Initiatives are occurring in integrated care and cancer care and the ACI is using the Patient-Reported Outcomes Measurement 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 institutions implementing the International Consortium for Health Outcomes Measurement (ICHOM) standard sets in Australia, for example, Ramsay Health Care and the HCF Research Foundation. The NSW Agency for Clinical Innovation has established a strategic partnership with ICHOM.
- Review of the websites of a selection of peak national bodies representing health professionals found limited references to PROMs.
- Several health-related advocacy organisations have strong interest in PROMs but are not engaged in national data collection, for example Bowel Cancer Australia has supported the development of a reference guide for the *ICHOM Colorectal Cancer Standard Set*, which includes PROMs. The Movember Foundation has funded a project to establish guidelines and key attributes for electronic patient-reported outcome measurement (ePROM) tools.
- The Consumer Health Forum of Australia has advocated for the inclusion of the consumer perspective in the delivery of health care and presented on PREMs and PROMs at the 2016 *International Forum on Quality and Safety in Healthcare*.
- There is a high degree of interest across the health sector generally about the application of PROMs to safety and quality improvement, however no consistent national approach with each jurisdiction determining its own practice.
- The limited information available from Australian organisational websites about the use of PROMs prevents in depth exploration of how patient-reported outcome information is used at an aggregated level to improve safety and quality in health care.
- There is interest by many organisations but actual benchmarking applications of PROMs data are relatively few.
- There are examples of promising approaches e.g. inclusion of PROMs data by clinical registries and interest at the state level in moving toward international benchmarking by the use of standard sets for diverse conditions and diseases (e.g. ICHOM standard sets).
- Due to their broader potential application, generic measures may be more commonly used, but the use of specific measures for major diseases (e.g. cancer) and conditions (e.g. mental health conditions) is relatively widespread.
- There is considerable expertise in national aggregation and benchmarking of data observed in consortia/collaboratives such as the Palliative Care Outcomes Collaboration.
- These promising approaches could be encouraged by organisations such as the Commission.

## 1 Introduction

This environmental scan has been undertaken by the Centre for Health Service Development (CHSD), Australian Health Services Research Institute, University of Wollongong to inform the work of the Australian Commission on Safety and Quality in Health Care (ACSQHC), subsequently referred to as the Commission. It is an 'early stage' piece of work that may contribute to the development of a framework to support national collation of patient-reported outcomes (PROs). It is not the intention of the Commission to develop indicators or tools for national data collection.

### 1.1 Background and context

The Commission is an Australian Government agency that leads and coordinates national improvements in safety and quality in health care. Over the past five years, it has taken a national leadership role in developing measures of patient experience through a program of work in this field.

In 2010, Australian Health Ministers endorsed the *Australian Safety and Quality Framework for Health Care*.<sup>1</sup> The framework identifies consumer-centred care as the first of three dimensions required for a safe and high-quality health system in Australia. Including this dimension in the framework recognises the importance of placing patients and consumers at the centre of the healthcare system.

The Commission explains that patient-centred care is a broad concept, covering different strategies and approaches. Patient-centred approaches, through actively working with consumers to ensure their needs are being met, can result in improved safety, quality and cost-effectiveness, as well as improved patient and staff satisfaction. There is clear evidence that:

*'...patient centred care has significant benefits associated with clinical quality and outcomes, the experience of care, the business and operations of delivering health services, and the work environment'.<sup>2</sup>*

The current version of the *National Safety and Quality Health Service (NSQHS) Standards*, released in 2012, were developed by the Commission to improve the quality of health service provision in Australia and provide a nationally consistent statement of the level of care consumers can expect from health service organisations.<sup>3</sup> They provide a uniform set of standards for safety and quality applicable across a wide variety of healthcare services.

Version 2 of the *NSQHS Standards* is under development by the Commission and in tandem with resources for implementation, scheduled for release in late 2017. Accreditation based upon Version 2 is planned for 2019.<sup>4</sup> There is an increasing emphasis throughout Version 2 on the achievement of a greater level of patient-centeredness in health service organisations, through involving patients in decisions about their own care. One way to ensure that health care is delivered in partnership with patients is to ask about their own perspective of the impact of treatments and care through routine use of patient-reported outcome measures (PROMs). This should also assist in the evaluation of the outcomes of treatments and services.

In 2015, the Commission released the first *Australian Atlas of Healthcare Variation*, developed in collaboration with the Australian, state and territory governments, specialist medical

colleges, clinicians and consumer representatives. The atlas is the first in a series, and explores the significant variation in health care provision across Australia. It identifies opportunities for improving health care delivery as well as the efficiency and effectiveness of the healthcare system. It focuses on six specific clinical areas, comprising:

- Antimicrobial dispensing
- Diagnostic interventions
- Surgical interventions
- Opioid dispensing
- Interventions for chronic diseases
- Interventions for mental health
- Psychotropic medicines.

The *Australian Atlas of Healthcare Variation* recommends the routine, nationally consistent use of PROMs to address unwarranted variation for four particular conditions and procedures (radical prostatectomy, lumbar spine surgery, knee pain and cataract surgery).<sup>5</sup>

The Commission has had limited previous involvement with PROMs or their measurement and is seeking to scope an appropriate role in relation to patient-reported outcomes (PROs), in the context of its mandate to support the health system to deliver patient-centred care as part of high quality and safe services. Consistent with its other activities, the Commission's role may be the provision of guidance and resources to the Australian healthcare sector on the use of PROMs and/or publication of a framework for national-level collection or collation of PROM results.

## 1.2 Scope of the project

The objective of this project is to produce an environmental scan and literature review on the subject of PROs and their measurement with a particular focus on the potential purpose and benefits of national-level collation or collection. The literature review is the subject of a separate companion report: *Patient-reported outcome measures: Literature review*.<sup>6</sup>

Environmental scans are a recognised and valuable tool in health policy decision making and program planning.<sup>7</sup> Albright (2004) defines environmental scanning as 'a method for identifying, collecting and translating information about external influences into useful plans and decisions'.<sup>8</sup>

This report delivers the environmental scan and:

- Captures the current status of PROMs in the Australian public and private health sector;
- Maps what is going on in Australia in PROMs at the national, jurisdictional and organisational level; and
- Explores how PRO information is used at an aggregated level to improve quality and safety in health care in Australia.

The environmental scan highlights existing and emerging trends in the collation and use of PROMs in Australia to improve safety and quality and identifies:

- Who is doing what;
- What data is being collected and how;
- How the data is being used; and
- Who is leading in this field in Australia (referring to the collection, collation and use of PROs to improve quality and safety).

The analysis also identifies any obvious gaps in the collection and use of PROMs in Australia.

### 1.3 Structure of this report

This report comprises five sections:

- **Introduction:** provides an overview of the scope of the project and brief background to provide context for this work.
- **Definitional issues:** includes an explanation of key concepts used throughout the report.
- **Methods:** describes the search strategy undertaken and process for analysis and synthesis of findings.
- **Findings:** presents the key findings in tabular format with explanatory narrative.
- **Discussion:** identifies any obvious gaps in the collection and use of PROMs in Australia, particularly gaps in what is being collected and how the data is being used.

## 2 Definitional issues

### 2.1 Measuring patient experiences

There is a long history in health care of collecting patient satisfaction data.<sup>9</sup> A measure of overall satisfaction with care has practical utility,<sup>10,11</sup> is highly relevant to patients<sup>12</sup> and is included in most intervention studies as a key outcome-related variable.<sup>13</sup> However, satisfaction measures are subjective and likely to be influenced by factors outside the control of service providers, such as patients' expectations and personal characteristics.<sup>14</sup> The limitation of considering patient satisfaction alone has led to the development of greater interest in alternative metrics to capture patient-reported feedback.

#### 2.1.1 Patient-reported experience measures (PREMs)

To provide specific information to guide and evaluate quality improvements, experience measures are needed in addition to satisfaction measures.<sup>15</sup> Experience measures ask patients to describe, rather than simply evaluate, what happened during their encounters with health services. Collecting both types of measures also offers the opportunity to identify particular aspects of patients' experiences, which have the strongest influence on their satisfaction.<sup>9</sup> PREMs focus primarily on process issues, such as waiting times or satisfaction, and may or may not be related to the outcomes of treatment.<sup>16</sup>

Some examples of PREMs include:

- time spent waiting
- access to and ability to navigate services
- involvement in decision making
- knowledge of care plan and pathways
- quality of communication
- support to manage long-term condition
- whether the patient would recommend the service to family and friends.<sup>17</sup>

PREMs and PROMs should be viewed as distinct types of metrics to capture patients' perspectives on the quality and safety of the treatment and care they receive.

#### 2.1.2 Patient-reported outcomes and patient-reported outcome measures

Patient-reported outcomes (PROs) can be defined as follows:

*'A PRO is directly reported by the patient without interpretation of the patient's response by a clinician or anyone else and pertains to the patient's health, quality of life, or functional status associated with health care or treatment'.<sup>18</sup>*

PROMs are the tools or instruments used to measure PROs.<sup>19</sup>

PROMs generally focus on outcomes of care and may include for example, patients reporting on their symptoms, functional status and health-related quality-of-life (HRQoL) during and after their treatment. The reliance on PROs is driven by the view that patients are the best

judge of their own welfare.<sup>20</sup> They can be generic and measure ‘general’ health status (generic PROMs) or disease-specific (for example, for asthma or diabetes) or condition-specific (the PROMs do not focus on a particular disease but on a broader health condition or state, for example mental health).

*‘PROMs have been used widely in clinical trials and other research settings. Extensive work on the development of PROM-type survey tools has been undertaken in recent years, such that there now exist a large number of PROM instruments, many of which have been well validated’.*<sup>21</sup>

PROMs include varied assessments and measures:

- health status assessments
- HRQoL
- symptom reporting measures
- satisfaction with care
- treatment satisfaction measures
- economic impact measures
- instruments for assessing specific dimensions of patient experience such as depression and anxiety.<sup>22,23</sup>

PROMs are considered:

*‘...core elements of a patient-centred, quality-oriented healthcare system’.*<sup>24</sup>

Throughout this report the term PROMs will be used as the Commission’s focus is the current status of PROMs in the Australian health sector.



### 3 Methods

The main purpose of this report is to map what is going on in Australia with PROMs at the national, jurisdictional and when possible, organisational level.

#### 3.1 Search strategy

Information was obtained through a purposive search of organisational websites. Information about all types of PROMs was sought, particularly the potential purpose and benefits of national-level collection or collation of PROMs.

This included relevant Australian, state and territory government sites (predominantly health departments), leading private health service entities (for example Ramsay Health Care, Australian Private Hospitals Association), other research entities (for example university-based research centres) and any related national healthcare organisations with a monitoring and/or quality improvement mandate.

As the search progressed, additional organisations were added to the list if they were identified as systematically collecting PROMs or contributing to the development and implementation of PROMs in domains considered within the scope of the project brief.

#### 3.2 Search terms and parameters

In the first round of searching the search parameters were broad. A series of search terms (in various combinations) were entered into the Google search engine to identify Australian organisations with an interest or active engagement in the collection of PROMs. Search terms were:

- 'patient-reported outcome measures' and 'Australian organisations'
- 'patient-reported health outcome measures' and 'Australian organisations'
- 'patient-reported outcomes' and 'health care'
- 'patient-reported outcome data' and Australia
- 'patient-reported health outcome data' and Australia
- 'aggregate patient-reported outcome data' and Australia
- 'patient-reported surveys' and Australia.

Both hyphenated and non-hyphenated versions of the search term 'patient-reported' were tested. Each combination of search terms generated results that varied from as low as six results ('patient-reported outcome measures' and 'Australian organisations') to over 200,000 results ('patient-reported outcomes' and 'health care'). The first 20 - 30 results for each search term were scanned to identify potential organisations for inclusion in the environmental scan. As might be expected the more specific the search terms the more limited the results (refer to Appendix 1).

This resulted in the development of a typology that was used by the research team to generate a wider list of national and state/territory based organisations that were perceived to have an interest in PROMs. The preliminary search outputs were provided to the Commission for review

and comment, which resulted in a final list of organisations for inclusion in the environmental scan (refer to Appendix 2).

A cross check of the search outputs was completed by conducting additional searches using the terms 'patient-reported outcome', 'patient-reported health outcome', 'patient-reported outcome measure' and 'patient outcome data' using Google but by restricting the search to Australia and:

- filetype:pdf
- site:gov.au
- site:org.au

The first two search parameters did not identify any 'new' organisations, the third search parameter generated several organisations that either collect or support development of PROMs (most commonly disease-specific or condition-specific PROMs), for example, the Palliative Care Outcomes Collaboration, Australian Rheumatology Association, Victorian Orthopaedic Trauma Registry, the Epworth Knowledge Bank and Asthma Australia.

The research team systematically searched the website of each organisation listed for references to PROMs, PROs, patient experience surveys and benchmarking, using the search terms listed below:

- 'patient-reported'
- 'patient-reported outcome measure'
- 'patient-reported health outcome measure'
- 'survey'
- 'benchmarking'.

As a final check the Google search engine was used with the relevant organisational name in combination with the search term 'patient-reported outcomes'.

If additional relevant organisations were identified through the searches of the Australian grey literature, which were completed as part of the accompanying literature review, they were incorporated into this environmental scan. As a member of the research team had recently attended the *International Consortium for Health Outcomes Measurement (ICHOM) 2016 Conference* held in London, it was possible to procure a list of the Australian delegates. This generated a small number of additional organisations with a specific interest in PROMs that were included.

The research team considered searching using specific PROM instruments as search terms e.g. SF-12, however given the time constraints for this deliverable and plethora of generic and condition-specific instruments; this was not seen to be feasible. If this information was identified through searches of organisational websites it is included in Appendix 2.

A typology of organisations and the number of each type of organisation included in the scan are provided in Table 1.

**Table 1**      **Number of entries in environmental scan by organisation type**

Category	Typology	Number of entries
1	Academic institution / research centre	33
2	Government department/entity	26
3	Public healthcare provider	10
4	Private healthcare provider	3
5	Private health insurance organisation	2
6	Peak national body representing health professionals / healthcare organisations	10
7	Health-related advocacy organisation	8
8	Consortium/collaborative	10
<b>Total</b>		<b>102</b>

### 3.3 General exclusions and limitations

Given the short timeframe for the searching, collation and synthesis of information there were inevitably a number of organisations excluded. For example, it was not possible to include individual hospitals that were collecting PROMs in a particular discipline, specialty or clinical setting.

Several exclusions were made as these entities were deemed to be out of scope:

- Primary healthcare organisations working in this field (for example, WA Primary Health Alliance, Primary Health Care Research and Information Service).
- Commercial entities that provided information technology support for aggregated data collection or consultancy services (for example, Complexity Science Medical Systems).
- Organisations using PROMs in clinical trials or to substantiate medical product labelling claims.

An environmental scan reliant on website searching has limitations. In the majority of instances information was restricted and if available, it included little detail and specificity. Frequently there was no indication as to when the information on the website had last been updated. Therefore, the scan cannot be seen as exhaustive; it is intended to provide a picture of the patterns of the collection and use of PROMs using publicly available information. A reasonably large number of the organisations that were identified by web-based searching on closer examination appeared to have an interest in PROMs, as opposed to being actively engaged in any form of systematic data collection.

## 4 Findings

The environmental scan has explored the current use of PROMs in the Australian healthcare sector. The initial intention was to focus on the potential purpose and benefits of national-level collation or collection of this data to support quality and safety improvements in healthcare services. However after a comprehensive review of wide-ranging organisational websites it is clear that there is limited detailed information about organisations' engagement in the collection of PROMs available from their respective websites. This probably reflects limited activity in this area but may also be a consequence of organisations not including detailed information about their use of PROMs on their websites.

### 4.1 Overview of findings

The key findings from the environmental scan indicate that:

- The patterns of collection of PROMs in the Australian context are highly variable.
- There is increasing interest and promotion of PROMs across a broad range of organisations but less evidence of actual data collection (mandated or otherwise) at a national or state level.
- A small number of PROMs are being integrated into existing survey initiatives at both state and health district level; these are usually items embedded in patient experience surveys (e.g. Cancer Institute NSW, Bureau of Health Information (NSW), Department of Health and Human Services Victoria).
- The organisations most frequently engaged in the development and implementation of PROMs are academic institutions / research centres in collaboration with clinicians (e.g. Psycho-Oncology Co-operative Research Group, University of Sydney; Australian Health Services Research Institute, University of Wollongong) and university-based clinical registries (e.g. Monash Clinical Registries, Monash University).
- There are several well-established consortia that provide leadership in this field with a focus on benchmarking. For example government funded entities such as the Australian Mental Health Outcomes and Classification Network (AMHOCN), the Palliative Care Outcomes Collaboration (PCOC), the electronic Persistent Pain Outcomes Collaboration (ePPOC) and the Australasian Rehabilitation Outcomes Centre (AROC) at the Australian Health Services Research Institute (AHSRI).
- Collaboratives such as PCOC, ePPOC and AROC, provide patient outcome reports to participating clinical services on a six-monthly basis that facilitate comparison with state/territory and national benchmarks. The timeliness of reporting is a particular advantage of this approach as clinicians receive a comparative analysis of their outcomes on a regular basis. In addition benchmarking workshops are held every six months to increase understanding of how clinicians can use outcome data to drive quality improvement.
- The data collected by clinical registries is used in varying degrees for peer review, quality assurance and research. For example, there are registries that allow participating clinicians to audit their own patient outcomes, anonymously comparing results with other clinicians. Others provide benchmarking of outcomes and quality of care against comparable units and international standards. Researchers can also apply for access to specific sets of data from the relevant data custodian.

- Based on the information available using organisational websites, NSW Health emerges as a leading public sector agency engaged in PROMs data collection through the work of the Agency for Clinical Innovation (ACI) and Cancer Institute NSW. Several Local Health Districts in NSW are implementing demonstration projects including small scale collection of PROMs. Initiatives are occurring in integrated care and cancer care and the ACI is using the Patient-Reported Outcomes Measurement 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 institutions implementing the International Consortium for Health Outcomes Measurement (ICHOM) standard sets in Australia, for example, Ramsay Health Care and the HCF Research Foundation. The NSW Agency for Clinical Innovation has established a strategic partnership with ICHOM.
- Review of the websites of a selection of peak national bodies representing health professionals found limited references to PROMs.
- Several health-related advocacy organisations have strong interest in PROMs but are not engaged in national data collection, for example Bowel Cancer Australia has supported the development of a reference guide for the *ICHOM Colorectal Cancer Standard Set*, which includes PROMs. The Movember Foundation has funded a project to establish guidelines and key attributes for electronic patient-reported outcome measurement (ePROM) tools.
- The Consumer Health Forum of Australia has advocated for the inclusion of the consumer perspective in the delivery of health care and presented on PREMs and PROMs at the 2016 *International Forum on Quality and Safety in Healthcare*.

In summary, there are three distinct types of Australian organisations/entities included in this environmental scan (the classification of organisations is included in Table 1):

1. Health-related organisations engaged in the development and/or collection of PROMs at the national or state level (most activity is occurring through university-based research centres; clinical registries with a focus on disease- or condition-specific PROMs and consortia/collaboratives that focus on a specific specialty/discipline);
2. Health-related organisations that have integrated a small number of PROMs/measures of health status into other data collection processes (most of this activity is occurring through government departments and related entities with a focus on generic PROMs in population health studies); and
3. Health-related organisations that are actively promoting the use of PROMs (for example through funding research) but are not actually collecting data.

## 4.2 Organisations engaged in the development/collection of PROMs – national and state level

### 4.2.1 Academic institutions / research centres

At a national level the most active organisations include academic institutions / research centres and consortia/collaboratives. There is a range of research centres across Australia supporting research and data collection that encompasses PROMs. While these organisations are based in various states and territories, their focus is frequently national. For example the **University of Queensland (in collaboration with the University of Newcastle)** has been

conducting the *Australian Longitudinal Study on Women's Health* since 1996. This is a longitudinal survey of over 58,000 women in three age cohorts. Using PROMs and other items the study assesses women's physical and mental health, as well as psychosocial aspects of health (such as socio-demographic and lifestyle factors) and their use of health services. The study has provided data about the health of women across the lifespan, and informed various government policies.

The **Sax Institute** based in NSW coordinates the *45 and Up Study*, a large ongoing study that aims to answer health and quality of life questions and help manage and prevent illness through improved knowledge of conditions such as cancer, heart disease, depression, obesity and diabetes. Numerous data items are collected including PROMs relating to health status and function (e.g. from the SF-36).

Several entities at the **University of New South Wales (UNSW)** are engaged in PROMs related research projects. For example, the Simpson Centre for Health Services Research has produced scoping reviews for the Agency for Clinical Innovation (NSW Health) about the use of PROMs in integrated care. The **Centre for Big Data Research in Health** includes the Health Services and Outcomes Unit, which undertakes research to identify variations and disparities in the use, outcomes and costs of health services, investigates the factors that drive these, and evaluates the outcomes of health policies and programs. In 2013, the team was awarded Cancer Institute NSW funding to develop and implement an integrated e-health platform to support and enable cancer survivors to achieve and maintain improved health and wellbeing and better cancer outcomes.

The **University of Sydney** hosts the Cancer Australia Quality of Life Chair, Quality of Life Office, the **Psycho-Oncology Co-operative Research Group (PoCoG)** and the Patient-Reported Outcomes Special Interest Group (PRO-SIG). The Psycho-Oncology Co-operative Research Group has published in the field of PROMs and oncology. The PRO-SIG provides a forum for discussion of HRQoL and the use of PROMs relating to cancer care.

Researchers from the **University of Newcastle** are engaged in a project to develop a PROM that can be used in clinical and research settings to assess the impact of severe asthma on patients' lives. It will also provide a valid and reliable tool that can be used by clinicians and researchers to assess response to novel treatment interventions in severe asthma.

Another example of an academic institution / research centre engaged in the use of PROMs is the **Centre of National Research on Disability and Rehabilitation Medicine (CONROD)**, which has recently changed its name to the **Recover Injury Research Centre**. This organisation is a joint initiative of the University of Queensland, Griffith University and the Motor Accident Insurance Commission and was established in 1997. It was home to the Queensland Trauma Registry until 2012 (when it merged with the Australian Trauma Registry) and it undertakes research on disability and rehabilitation, which often includes the use of PROMs (e.g. pain, function and health status).

The **International Centre for Allied Health Evidence (University of South Australia)** has produced outcome calculators for: basic outcomes, musculoskeletal, neurological disorders, incontinence and chronic disease measurement. The outcome measures represent several aspects of functioning and/or disability, which are measured at the level of body

functions/structure, the individual and society, as defined by the International Classification of Functioning.

The **Flinders Centre for Ophthalmology, Eye and Vision Research (Flinders University)** is engaged in patient-centred measurement in ophthalmology and has integrated the use of PROMs in the European Registry of Quality Outcomes for Cataract and Refractive Surgery (EUREQUO) database. The Flinders team is conducting research to develop more effective ways of evaluating medical treatments from the patient's perspective. The project is using new technology to develop an Internet-based measurement system that is adaptable and far more accurate than current questionnaire programs. The aim is to make it valid for use across English-speaking countries.

The Australian Corneal Graft Registry (ACGR), which opened in May 1985, is coordinated at Flinders. Over the years, it has collected information on more than 30,000 corneal grafts. At registration various clinical information items are recorded. Follow-up then occurs at approximately yearly intervals and includes information on the survival of the graft, the visual outcomes, and any relevant post-operative events and treatments.

Within Victoria several university-based research centres have published work about the use of PROMs, for example, the **Australian Centre on Quality of Life (Deakin University)** has conducted various projects using Quality of Life instruments. Researchers from the **Melbourne Institute (University of Melbourne)** have published about options for supporting value-based health care; this concept is increasingly associated with the use of health outcome indicators and PROMs.

#### 4.2.2 Clinical registries

There is a breadth of clinical registries operational within Australia that focus predominantly on specific diseases, procedures or specialties (refer to Appendix 3). There are several academic institutions supporting clinical registries. The **School of Public Health and Preventive Medicine (Monash University)** has extensive experience in the establishment and maintenance of clinical registries – they may be state-based or national. These registries are population-based and collect an identical minimum data set from patients treated in multiple hospitals or clinics throughout the country. Consistency is ensured through the use of identical definitions and data collection procedures. The **Commission** has developed key guidance documents about the governance, operation and technical requirements of clinical quality registries, and continues to develop work in this area.<sup>25,26</sup>

Evans<sup>27</sup> explains that clinical registries encompass large databases that are managed and analysed to:

- Identify variation in treatment and outcomes (including PROMs)
- Monitor appropriateness of treatment
- Identify deficiencies in access to treatment
- Provide an early warning system if care deteriorates
- Facilitate research to improve quality of care.

Some registries currently collecting PROMs are listed below:

- **Victoria State Trauma Registry** uses the SF-12, EQ-5D, Glasgow Outcome Scale – Extended, among others.
- **Victorian Cardiac Outcomes Registry** uses the EQ-5D.
- **Victorian Lung Cancer Registry** uses the SF-12 (and notes that there is no short form disease-specific tool).
- The **Save Sight Institute** is based at the University of Sydney and houses clinical registries for macular degeneration, diabetic retinopathy and keratoconus (using the ICHOM data set including PROMs).
- **Prostate Cancer Outcome Registry-Australia and New Zealand** uses the SF-12 and EPIC-26 PROMs (these include general health / quality of life and disease-specific items).

The primary aim of the **Prostate Cancer Outcomes Registry - Australia and New Zealand** (PCOR-ANZ) is to improve the quality of care provided to men with prostate cancer. It is an international initiative funded by the Movember Foundation and part of the School of Public Health and Preventive Medicine at Monash University. Several jurisdictions contribute data to the registry and they are responsible for the ethical management and governance of their own local registry database and the periodic transfer of data to the PCOR-ANZ. Information from the registry is used to monitor diagnosis, treatment, complications, and long term quality of life outcomes.

**The South Australian Prostate Cancer Registry** also participates in the ICHOM development of the standard set of measures for prostate cancer. The registry is using recommended PROMs, is undertaking comparative studies with the Victorian Prostate Cancer Clinical Registry and collaborates with both Australian and international groups about the use of PROMs in these datasets.<sup>28</sup>

The data within clinical registries is primarily used for research purposes (researchers apply for access to specific sets of data from the relevant data custodian). The **Save Sight Registries** allow participating clinicians to audit their own patient outcomes, anonymously comparing results with other clinicians. The **Australian and New Zealand Intensive Care Society Centre for Outcome and Resource Evaluation (CORE)** maintain four data registries. Benchmarking of outcomes and quality of care against comparable units and international standards occurs. If the performance of a unit falls outside expected norms notification may be made to the relevant jurisdictional health authority.

#### 4.2.3 Consortia/collaboratives

The **Australian Health Services Research Institute (University of Wollongong)** is the home of several national consortia/collaboratives that are engaged in research and data collection relating to PROMs including the:

- Australian Health Outcomes Collaboration (AHOC)
- Australasian Rehabilitation Outcomes Centre (AROC)
- Palliative Care Outcomes Collaboration (PCOC)
- electronic Persistent Pain Outcomes Collaboration (ePPOC).



The Australian Health Outcomes Clearing House was established in 1994 at the Australian Institute of Health and Welfare (AIHW), and served as a site for the dissemination of information about health outcomes research, practice and policy in Australia and overseas. In 1997 the Clearing House became the **Australian Health Outcomes Collaboration** (AHOC) based at the Australian Health Services Research Institute. AHOC provides advice and training on the selection of measures for health outcomes (including PROMs) and contributes to research projects about the implementation of the health outcomes approach and the measurement tools that might be used (both generic, disease- and condition-specific measures). It has developed a number of PROMs for both the assessment and evaluation of incontinence treatments and measurement sets for aged care. AHOC has connections with international groups such as ICHOM and the Mapi Research Trust and the International Society for Quality of Life Research (ISOQOL) and has convened Australian health outcome conferences and seminars. AHOC was responsible for the development of the *Dementia Outcomes Measurement Suite* and is involved in the ICHOM dementia working group to develop a standard set of measures for dementia including PROMs.

The **Australasian Rehabilitation Outcomes Centre** (AROC) is a joint initiative of the Australian rehabilitation sector (providers, funders, regulators and consumers). With the support of its industry partners, AROC has been established by the Australasian Faculty of Rehabilitation Medicine of the Royal Australasian College of Physicians. Since 2002 it has been concerned with the outcomes benchmarking of rehabilitation services in Australia and New Zealand and there are 372 participating services. Currently AROC does not collect patient-reported outcomes, however it uses a selection of clinician reported tools including the Functional Independence Measure. It has recently received funding to develop a patient experience survey for sub-acute rehabilitation services, which may include PROMs items.

The **Palliative Care Outcomes Collaboration** (PCOC) is a national program that was established in mid-2005 and is funded under the *National Palliative Care Program* supported by the Australian Government Department of Health. PCOC supports continuous improvement in palliative care through routine clinical outcome measurement, periodic surveys and benchmarking. PCOC has divided Australia into four zones for the purpose of engaging with palliative care services, with each zone represented by a chief investigator from one of the four collaborating universities: University of Wollongong, Flinders University, Queensland University of Technology and the University of Western Australia.<sup>29</sup>

The goal of the PCOC is to use standardised, validated clinical assessment tools to benchmark and measure outcomes in palliative care and assist palliative care service providers to improve practice and meet the *National Palliative Care Standards* developed by Palliative Care Australia. Research to improve the evidence base for the clinical assessment tools is ongoing. The PCOC dataset includes the clinical assessment tools: Palliative Care Phase, Palliative Care Problem Severity Score, Symptom Assessment Scale, Australia-modified Karnofsky Performance Status Scale and Resource Utilisation Groups – Activities of Daily Living. The Symptom Assessment Scale is a patient-reported assessment of distress relating to individual physical symptoms. The symptoms included in the scale are the seven most common experienced by palliative patients: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. The instrument is ideally a patient-rated tool but is structured to allow either the patient, family member or clinician to assess the symptoms.

The **electronic Persistent Pain Outcomes Collaboration** (ePPOC) is a new program, which aims to help improve services and outcomes for patients suffering with chronic pain through benchmarking of care and treatment. ePPOC is an initiative of the Faculty of Pain Medicine, and has been further developed by the Faculty, the Australian Pain Society and the wider pain sector. ePPOC involves the collection of a standard set of data items and assessment tools by specialist pain services throughout Australia and New Zealand to measure outcomes for their patients as a result of treatment. This information will be used to develop a national benchmarking system for the pain sector. The information will also enable development of a coordinated approach to research into the management of pain in Australasia.

The first phase of ePPOC began in 2013, with eight adult pain services in NSW trialling the measures, process and software for collection of the information. ePPOC is now being progressively rolled out to adult and paediatric specialist pain services throughout Australia and New Zealand. All adult and paediatric pain service questionnaires are patient-reported.

Collaboratives such as PCOC, ePPOC and AROC provide patient outcome reports to participating clinical services on a six-monthly basis that facilitate comparison with state/territory and national benchmarks. In addition benchmarking workshops are held every six months to increase understanding of how clinicians can use outcome data to drive quality improvement.

The **Australian Mental Health Outcomes and Classification Network** (AMHOCN) is another example of a national collaborative that contributes to outcome measurement. AMHOCN was established by the Australian Government to work collaboratively with the states and territories and others in the mental health sector to implement routine outcome measurement in public mental health services. AMHOCN consists of three components: a data bureau responsible for receiving and processing information; an analysis and reporting component providing analysis and reports of submitted data; and a training and service development component supporting training in the measures and their use for clinical practice, service management and development purposes.

AMHOCN supports the implementation of the *National Outcome and Casemix Collection (NOCC)*. The scope is all inpatient, ambulatory and 24-hour community residential mental health services, nationally. The NOCC provides a coherent picture of mental health outcomes in each state and territory, which can be used to measure clinical effectiveness across different service sectors and age cohorts.

The **South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC)** was established in 1998, further information is included in Section 4.3.1.2.

## **4.3 Organisations integrating PROMs into other data collections**

### **4.3.1 Government departments / entities / public healthcare providers**

#### **4.3.1.1 Australian Government**

A number of Australian Government entities are well placed to contribute to the development and/or collection of PROMs. Many of these institutions have expertise in data collection at a national level and have conducted surveys and/or analysed and reported on patient-level data

collection. The **Australian Government Department of Health** is associated with several organisations that are investigating the potential to integrate PROMs into existing data collections (refer to the previous entry explaining the work of the Australian Mental Health Outcomes and Classification Network and the Palliative Care Outcomes Collaboration).

The **Australian Commission on Safety and Quality in Health Care** (ACSQHC) as an organisation concerned with quality and safety in health care in Australia, has produced numerous reports related to health outcomes assessment (e.g. *Australian Atlas of Healthcare Variation*, guidelines relating to the implementation of clinical registries, analyses of PREMs and patient satisfaction surveys). It has also funded the current environmental scan and literature review relating to PROMs.

**Cancer Australia** is in the process of developing a framework of *National Cancer Control Indicators* to facilitate national-level reporting of key cancer control indicators. The Quality of Life (QOL) Office is funded by Cancer Australia as part of the Support for Clinical Trials Program. The QOL Office is directed by the Cancer Australia Chair in Cancer Quality of Life (QOL Chair), and this position is based at the University of Sydney.

The **Australian Bureau of Statistics** (ABS) has included a number of health status instruments such as the SF-36V1 health status survey and the Kessler 10 psychological distress scale in national surveys (1997 and thereafter), providing Australian normative data for these commonly used generic and condition-specific PROMs. Dunbar<sup>30</sup> notes that patient experience surveys are conducted at the national-level by the ABS.

The **Australian Institute of Health and Welfare** (AIHW) publishes a biennial report (the most current edition is *Australia's Health 2014*) that is mainly concerned with health indicators rather than PROMs, but includes some wellbeing indicators and some global indices of health status / health-related quality of life (i.e. PROMs items) derived from ABS health survey data. It also holds data collections such as the *National Death Index* and the *National Hospital Morbidity Database* that can be used in data linkage studies focusing on patient health outcomes (which may include PROMs data).

AIHW has also produced an assessment of the Australian Rheumatology Association (ARA) database, a national Australian database that collects information from individuals with inflammatory arthritis. It is of interest because of its potential to support data linkage and thereby analysis of patient movements across health settings and patient outcomes (given its methodology includes consent arrangements to undertake linkage to other specified datasets). Information is collected from patients every 6 to 12 months using questionnaires and ongoing permission is sought to collect information from state and national registries and all other relevant health records for the life of the registry.<sup>31</sup> Comprehensive data on self-assessed quality of life is collected using several standard quality of life instruments including: the 36-Item Short Form Health Survey (SF-36), the Assessment of Quality of Life (AQoL), the EQ-5D and arthritis specific disability assessed by the 'physical function' scale of the Health Assessment Questionnaire. Comprehensive data on disability burden using self-assessed disability tools is also collected. As at December 2013 out of 342 registered rheumatologists in Australia there were 268 contributing to the ARA database.<sup>31</sup>

The **Australian Government Department of Veterans' Affairs** and the **Department of Defence** are working closely together on their outcome-related research priorities to meet the needs of serving and ex-serving personnel and their families. The Applied Research Programme funds evidence-based research in four domains: longitudinal studies, data analysis and modelling, family studies and interventions. For example families' research focuses on factors impacting on the physical and emotional wellbeing of partners and children of veterans. The **Centre for Traumatic Stress Studies (University of Adelaide)**, is undertaking the *Transition and Wellbeing Research Programme* to examine the impact of military service on the mental, physical and social health of serving and ex-serving personnel and their families, and builds on previous Department of Defence research such as the *Military Health Outcomes Programme*.<sup>32</sup>

The Department of Veterans' Affairs funds treatment for veterans with post-traumatic stress disorder at centres accredited by the **Australian Centre for Post-traumatic Mental Health** and PROMs and clinical rating measures are collected by these programs. There are 11 participating centres, which contribute outcome-related and PROMs information (e.g. WHOQOL-BREF; Hospital Anxiety and Depression Scale) to a central collection point that enables some comparisons about the effectiveness of these programs to be made.<sup>33</sup>

#### **4.3.1.2 State and territory health departments**

The engagement of state and territory health departments in the use of PROMs is highly variable. NSW Health and its associated entities (the Agency for Clinical Innovation, Clinical Excellence Commission, Bureau of Health Information and Cancer Institute NSW) are actively integrating PROMs into existing data collections.

##### **New South Wales**

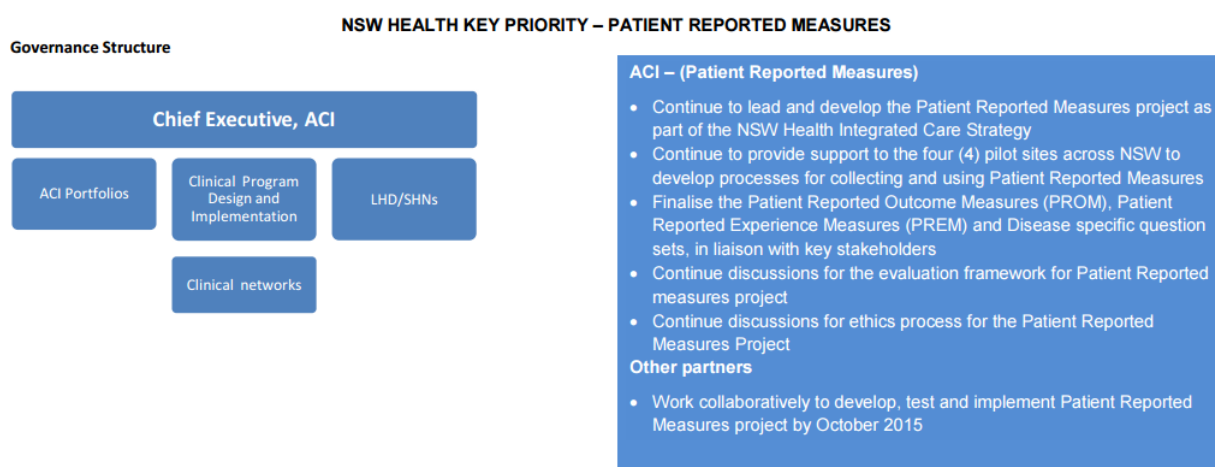
PROMs are a key strategic priority for **NSW Health** and this work is being led by the **Agency for Clinical Innovation (ACI)** but includes Local Health Districts, the Ministry of Health itself, Bureau of Health Information, Cancer Institute NSW and the Department's eHealth entity (refer to Figure 1).

The *NSW State Health Plan: Towards 2021* includes a commitment to invest \$120 million over four years to implement new, innovative locally led models of integrated care across the state. The ACI is responsible for managing the patient-reported measure component of the *NSW Health Integrated Care Strategy*. In late 2014, the ACI commissioned a rapid scoping review, *Integrated Care: Patient-reported outcome measures and patient-reported experience measures - a rapid scoping review*.<sup>34</sup> The Strategy includes establishing integrated care 'demonstrator sites' to develop and test system-wide approaches to integrated care in partnership with the Pillars and the Ministry. A key evaluation component of the strategy is to increase the capacity for patients to provide immediate feedback about their care by embedding real-time patient feedback and PROMs into local systems.<sup>35</sup> The ACI is investigating the use of the PROMIS Global Health (10) SF for overall evaluation in tandem with condition-specific measures and PREMs.<sup>36</sup>

The ACI is also working with up to ten proof of concept sites and their partners to co-design, develop, test, refine and implement PROMs in accordance with local models of integrated care (started July 2015), for example: Western Sydney, Nepean Blue Mountains, Northern Sydney, Mid North Coast, Southern NSW, Sydney, St Vincent's Hospital.<sup>37</sup>

The **Clinical Excellence Commission (CEC)** is responsible for leading safety and quality improvement in the NSW public health system. It was established in 2004 to promote and support improved clinical care, safety and quality across NSW.<sup>38</sup> As far back as 2010, the CEC noted growing interest internationally in the use of PROMs to trigger incentive payments on the basis of tangible improvements in patient health and wellbeing following care.<sup>39</sup> The CEC enters into a ‘Service Compact’ or annual agreement between the Secretary NSW Health and CEC that outlines the organisation’s service requirements. It identifies as one of the key system priorities for 2015/16 ‘Patient-reported measures’ – including both PROMs and PREMs.<sup>40</sup>

**Figure 1 Role of the ACI – implementing patient-reported measures**



**Key Objectives:**

- o Enable patients to provide direct, timely feedback about their health related quality of life and outcome measures

KEY FOCUS AREAS / KEY DELIVERABLES	PARTNER ORGANISATIONS							
	LEAD ORGANISATION	LHD/ SHNs	MoH: SRFB	CEC	BHI	Cancer Institute	ACI	eHealth
Patient Reported Measures	ACI	✓				✓	✓	✓
Patient Reported Outcome Measures	ACI	✓	✓		✓	✓	✓	✓
Patient Reported Experience Measures	ACI	✓		✓	✓	✓	✓	✓
Real time patient outcomes (Patient Experience Trackers)	ACI	✓						
Implementing Patient Reported Measures to enable real time feedback about PROMs to health care providers	ACI	✓	✓			✓	✓	✓

The **Bureau of Health Information (BHI)** provides information and analysis about the performance of the NSW health system; it prepares and publishes regular reports that encompass safety and quality, effectiveness, efficiency and the responsiveness of the system to the health needs of the people of NSW. Much of the work of BHI is concerned with health outcome related performance indicators that may be used in benchmarking the performance of hospitals in NSW and for international comparisons (Commonwealth Fund Survey). The BHI administers the *NSW Patient Survey Program* (the Survey Program), which is a suite of surveys that collects information on the experiences of patients receiving care in public hospitals and other public healthcare facilities across NSW.

Each year, the surveys are reviewed and if necessary adjusted to ensure that the questions are performing well on a technical level, and the content continues to align with patients’ and stakeholders’ needs in the NSW healthcare context. In 2010 and 2011, the NSW Health patient survey was tailored for use by people using mental health services.<sup>41</sup> The BHI administered ‘Community Mental Health Survey’ includes four PROMs items.<sup>42</sup> The BHI’s *Patient Perspectives Series* draws on patient survey data (mainly PREMs) to examine different themes or elements

of performance in the NSW public healthcare system. PROM items have been added to the *2014 Adult Admitted Patient Survey*.<sup>43</sup>

The **Cancer Institute NSW** (CI NSW) has a long-standing interest in using PROs in the cancer setting that dates back to 2008. Since that time the CI NSW has also operated a *Patient-Reported Experience Program Advisory Committee* and completed several projects in this field. For example during the period from June to August 2009, the Psycho-Oncology Co-operative Research Group (PoCoG) was commissioned by the CI NSW to design and undertake a critical review of PROMs relevant to cancer care.<sup>44</sup>

The CI NSW engaged the Centre for Health Service Development (University of Wollongong) in 2015 to undertake a Delphi study to develop 20 prioritised indicators of cancer patient experience that could be used to promote and guide quality improvement activities in NSW cancer services. Throughout 2015/2016 it has supported several initiatives among NSW Local Health Districts to implement PROs. For example the Illawarra Shoalhaven Local Health District is trialling the implementation of an integrated eHealth platform, using PROs to enable cancer survivors to achieve and maintain improved health and wellbeing and better cancer outcomes. The data collection process is integrated with hospitals' electronic medical record.

The 2016 *Patient Experience Symposium* included a joint workshop with the ACI NSW about using PROs and experience to improve care. The *NSW Cancer Plan* released in 2016, focuses on patient-centred quality care across the cancer pathway, from prevention to treatment and survivorship. One of several strategies deemed to be of particular importance includes: 'Patient-reported experience measures and patient-reported outcome measures (PROMs) contribution to system improvement'.

### **Queensland**

A suite of statewide patient surveys has been conducted over recent years by the Queensland Government Statistician's Office on behalf of **Queensland Health**. The focus of these has been on PREMs, in the areas of general surgery specialist outpatient clinics, maternity and orthopaedic specialist outpatient clinics, emergency department and small hospitals. Results of the surveys are used in monitoring and evaluating the quality of health services provided and to assist in quality improvement activity planning at the facility and statewide levels.

The Director of Health Outcomes Australia presented at a recent meeting chaired by the *Queensland Clinical Senate* on 17-18 March 2016, titled 'Value based healthcare—shifting from volume to value', including information on PROMs and ICHOM. Representatives of Queensland Health have reviewed the work of the CI NSW relating to the implementation of PREMs and PROMs in cancer care and participated in the recent *Cancer Patient Experience Indicators Project* through the Delphi study.

### **South Australia**

**SA Health** is supporting the *Transforming Health* initiative, which emphasises the importance of PROs, patient clinical outcomes and system outcomes for quality of care. The *SA Health Clinical Data Strategy* aims to implement an integrated, consolidated clinical data reporting system. The SA Health Clinical Data Steering Committee is accountable for Streams 2 and 3 of the Strategy, which are 'Developing a standard set of management and clinical measures' to support routine performance assessment of services and 'Developing a specific set of clinical

indicators for clinical specialties' to facilitate analysis of the clinical aspects of service delivery and patient outcomes.<sup>45</sup>

The **Coronary Angiogram Database of South Australia (CADOSA)** is a statewide quality improvement clinical registry program supported by SA Health. The CADOSA project was established in 2011, and has been collecting consistent hospital-based data since 2012. A similar program in the United States called the National Cardiovascular Data Registry has aided as a model framework for the development of the CADOSA registry. Data is collected directly from patients by telephone interview at one month and twelve months post angiogram. The questionnaire gathers information about their quality of life and overall physical and mental functioning. In addition, CADOSA collects the data recommended by ICHOM, which includes both health outcome related indicators and PROMs data. It undertakes data comparisons with a similar Victorian registry.

The **South Australian Prostate Cancer Clinical Outcome Collaborative (SA-PCCOC)** is a disease-specific registry that is a collaborative venture of the University of Adelaide, Flinders University, The Queen Elizabeth Hospital, the Royal Adelaide and the Repatriation General Hospital. Outcomes measured include biochemical recurrence, prostate-specific death and death from any cause, pathology, treatment outcomes and complications and patient-reported symptoms.

In 2012, SA Health completed its first ever specialised population health survey of Aboriginal people, titled the *South Australian Aboriginal Health Survey*. The survey was run by the **Population Research and Outcome Studies Unit (University of Adelaide)**, included eighty health-related questions, using some PROMs (e.g. SF-1, SF-12, K6).<sup>46</sup>

The **SA Health Omnibus Survey** is a user pays population health survey in which normative data for commonly used PROMs can be collected. It was used to collect Australian normative data in 2004 for the SF-36V2<sup>47</sup> and by the Population Research and Outcomes Studies Unit in 2008.

### **Victoria**

The **Department of Health and Human Services** released *Health 2040: A discussion paper on the future of healthcare in Victoria* in September 2015. In this discussion paper, six broad themes are identified as starting points for further exploration of healthcare reform direction. At the heart of these themes is the idea that the healthcare system should be designed from the perspective of the people who use the system. These themes include 'A person-centred view of healthcare' and 'Improving people's health outcomes and experience.' The paper notes that:

*'...Patient experience of some types of care is measured in Victoria, but this is not done comprehensively and generally applies only to a single episode of care (such as an admission to hospital for elective surgery), rather than people's experience as they move between services and different types of care.'*<sup>48 (p 18-19)</sup>

PROMs are identified as a possible way to influence the performance of providers to ensure they are achieving the outcomes that matter to their patients. The report identifies one of the benefits of this approach is that it does not focus on a single treatment, but covers all the care a person is likely to receive over time for a particular disease or injury.<sup>48</sup> The report also refers to

the work of ICHOM and its aim to develop 50 standard measurement sets incorporating PROMs.

The importance of PROs and patient-reported experience is evident in the Health Innovation and Reform Council's *Health Outcomes and Well-Being Framework*, which responds to the *Victorian Health Priorities Framework 2012-2022: Metropolitan Health Plan* priority area of 'increasing accountability and transparency' and consists of two high-level outcomes:

- Outcome 1: Optimised healthy life, (e.g. reduced days of disability and years of life lost, health quality as well as length of life and patient experience of care).
- Outcome 2: Optimised system outcomes, productivity, and sustainability (value for money).<sup>49</sup>

The *Victorian Healthcare Experience Survey* will be expanded to new setting types in 2015-16. This survey identifies areas in which the patient experience can be improved and what aspects of care are enhancing person- and family-centred care. The survey results provide health services with actionable results. It is unclear whether this survey includes PROMs as survey questions are not readily available.

The Department of Health and Human Services through the **Victorian Comprehensive Cancer Centre** (VCCC) and other partners has been actively engaged in implementing PROMs in cancer care. In 2014, fieldwork was completed for a statewide *Patient-reported Outcome Measures (PROMs) Survey* that aimed to assess the quality of life of cancer survivors in Victoria with five different cancer types and at three different time points since diagnosis. The UK National Health Service (NHS) PROMs questionnaires for breast, bowel, prostate cancer and non-Hodgkin lymphoma were used, and in addition the VCCC developed a fifth questionnaire for survivors of melanoma. Eligible participants were identified and recruited through the Victorian Cancer Registry and the survey data is currently being analysed. The data will be used to assess the contribution that demographics, disease-related and other factors have on quality of life to inform future programs. In addition the VCCC has implemented the VCCC cancer patient experience survey with information from patients used to drive quality improvement initiatives and better models of clinical care.

The **Peter MacCallum Cancer Centre** has implemented a project *Survivorship Connections: A Pilot Model of Post Treatment Shared Survivorship Care for Adolescent and Young Adult (AYA) Cancer Patients in Victoria*. This project included several patient-reported outcome measures including: the AYA Survivorship Screening Tool, AQoL-6D, SF-12 and Psychological Evaluation Questionnaire (PEQ).

A large number of clinical quality registries are based at **Monash University** several of these have a state focus and are collaborative projects involving Monash University and the Victorian Department of Health and Human Services. Examples of these have already been briefly described in Section 4.2.2 with additional detail included in Appendix 2 and Appendix 3.

### **Western Australia**

There was limited information about PROMs accessible using the **Western Australian Department of Health** website. The Department has conducted surveys of patient satisfaction. The *Western Australia Strategic Plan for Safety and Quality in Health Care 2013 -2017* explains



the approach to measurement and reporting of safety and quality measures across the WA Health system and includes a strategy to learn from consumers' and carers' experiences.<sup>50</sup>

Research is occurring at the **University of Western Australia** about the use of patient-reported outcome measurement instruments in several fields, for example multiple sclerosis,<sup>51</sup> oncology,<sup>52</sup> and orthopaedics.<sup>53</sup>

**Edith Cowan University's Survey Research Centre** undertakes the *Patient Evaluation of Health Services (PEHS) Survey* in Western Australia. This is an annual survey of patients following a hospital admission funded by the Western Australia Department of Health. It contains non-condition-specific questions about functioning and quality of life, but also questions about the person's experiences of their care episode.

### **Tasmania**

The **Department of Health and Human Services in Tasmania** does not currently have any information relating to PROMs available on its website. The Department does periodically conduct population health surveys.

### **Australian Capital Territory (ACT)**

The **ACT Health** Population Division conducts population surveys, for example, *Health and Wellbeing of Older Persons in the Australian Capital Territory* that include some self-reported health status and psychological distress items.<sup>54</sup> It collaborates with local universities such as the Australian National University, in reports including *Mental Health and Wellbeing in the ACT: Results of the Personality and Total Health (PATH) Through Life Project*, which included a variety of self-reported health status and PROM style measures (e.g. depression, coping styles, resilience).<sup>55</sup>

Some ACT research centres undertake health outcomes research using PROMs, for example the **Centre for Advances in Epidemiology and Information Technology**. A main focus of this centre has been the creation of a sustainable growth model for knowledge generation in healthcare. Known as Turning Research into Practice (TRIP), the program has a three-tier approach incorporating:

- the research process;
- generation of predictive models to improve individual patient outcomes; and
- a focus on efficient service delivery using an evidence-based model.

An IT model developed at the Centre was developed into a commercial IT system called DiscoverQuick, which can be used for monitoring patient health outcomes in routine practice and in real time. It was used as the web platform in a multi-site national field trial about aged care assessment (patient-reported measures) across Australia.<sup>56</sup>

This recent work evolved from an important early ACT study, the Care Continuum and Health Outcomes Project by Shadbolt and colleagues.<sup>57,58</sup> This study examined both service utilisation and patient-reported HRQoL outcomes (e.g. SF-36 and symptom measures) and remains one of the few large scale Australian studies, which tested the feasibility of collecting PROMs data from hospital admission through the trajectory of recovery and thus remains relevant today.

The Centre for Advances in Epidemiology and Information Technology cooperates with the Australian Health Outcomes Collaboration based in the Australian Health Services Research Institute at the University of Wollongong on health outcomes research and training activities.

ACT Health supports activity in trauma and orthopaedic research and the **Trauma and Orthopaedic Research Unit (TORU)**, which is founded within the **Australian National University Medical School**. TORU recently collaborated with the Centre for Advances in Epidemiology and Information Technology in a study that indicated that Oxford hip and knee scores were predictors of subsequent joint outcomes. The iFracture data collection system is supporting the longitudinal measurement of PROs for fracture trauma cases presenting to the Canberra Hospital. Outcome measures, which are integrated into various research projects, include, the general health self-reported outcome measures (AQoL – quality of life) and disease-specific outcome measures.<sup>59</sup>

### **Northern Territory**

The website of the **Northern Territory (NT) Department of Health** does not include information about the use of PROMs on a jurisdictional or health district level. This does not necessarily mean that activity is not occurring in the implementation of PROMs. For example the Department has a long history of work relating to Aboriginal and Torres Strait Islander health outcomes and the NT Department of Health's Epidemiology Unit has undertaken population health surveys, which may have included some PROM type items. The **Menzies School of Health Research** has a Masters elective in Health Outcomes Measurement and Management, in their Masters of Public Health program, run in conjunction with the Australian Health Outcomes Collaboration. The NT Prostate Cancer Registry also collaborates with the SA Prostate Cancer Registry.

### **4.3.2 Private healthcare providers**

A small number of private healthcare providers using PROMs were identified through the web searches.

**Ramsay Health Care (RHC)** is Australia's largest private hospital operator. In August 2015 RHC announced a strategic alliance with ICHOM. Patients' outcomes will be measured according to the recommendations of the ICHOM Standard Sets. The results of their care will be monitored for a year or more, during and after treatment, through surveys and interviews, for example on quality of life and self-sufficiency. Ramsay's first areas of focus with ICHOM will be prostate cancer, low back pain, and depression and anxiety.

The organisation also monitors patient-reported satisfaction and has recently started a pilot project that is providing data from five of its facilities to a research project that aims to develop nursing sensitive outcome measures. The project is being conducted by researchers from the Faculty of Science, Medicine and Health in collaboration with the Australian Health Services Research Institute at the University of Wollongong. RHC publishes annual *Patient Safety & Quality Reports* and provides detailed patient safety and quality performance results for core indicators on its website.<sup>60</sup> An organisation-wide patient satisfaction survey is conducted by an independent company every two years, providing a snapshot satisfaction report.

**Healthscope** is Australia's second largest private hospital operator, with 46 hospitals. Healthscope publishes the results of its clinical performance and health outcomes on its

website. One PRO was identified, the MHQ-14 (Mental Health Questionnaire), which includes questions about symptoms of fatigue, anxiety and depression and the impact of those symptoms in daily life. The organisation also uses the Functional Independence Measure clinical rating scale for rehabilitation services.

**Epworth HealthCare** is Victoria's largest not-for-profit private healthcare group. No specific documentation about PROs was identified on the Epworth website. However, Epworth participates in the Prostate Cancer Registry (PCR). The PCR's role is to monitor and allow benchmarking of quality of care by institutions and individual surgeons and radiation oncologists in the care of prostate cancer patients. Information collected includes patient response to a quality of life questionnaire at 12 and 24 months post diagnosis, from a follow-up phone call to the participant.

#### 4.4 Organisations actively promoting the use of PROMs but not collecting data

##### 4.4.1 Health-related advocacy organisations

Websites for health-related advocacy organisations were searched for evidence of the use of PROMs. Many of these organisations actively promote the use of PROMs by sponsoring research or data collection through clinical registries; however none are engaged directly in the collection of data.

The **Consumer Health Forum** (CHF) is Australia's peak health consumer group. In 2013, CHF produced a *Literature and Practice Review: Capturing, analysing and using consumers' health experience*. CHF was involved in a joint presentation on *Real People, Real Data* at the 2016 *International Forum on Quality and Safety in Healthcare* in Gothenburg, Sweden. The presentation included discussion about both PREMs and PROMs.

Among the other advocacy organisations, the strongest interest in PROMs was found in the area of oncology. For example, **Bowel Cancer Australia** has co-sponsored the *ICHOM Standard Set for Colorectal Cancer Reference Guide* (a complete overview of the ICHOM Colorectal Cancer Standard Set, including definitions for each measure and selected PROM instruments, time points for collection, and associated risk factors).

The **Movember Foundation** contributes funding to the Victorian Prostate Cancer Outcomes Registry - Australia and New Zealand (PCOR-ANZ). It has recently funded a project implemented by ICHOM that focuses on assisting providers and registry leaders to select appropriate tools for PROMs collection. It aimed to establish guidelines and identify key attributes for electronic PROMs tools, develop a decision framework for selecting the right tool in a given context, and summarise information on the most popular tools to facilitate comparison and selection. The Foundation is also funding the *Irish Prostate Cancer Outcomes Research Project* (implemented by the Irish Cancer Society) and includes a PROMs database.

**Cancer Council Australia** partnered with the University of Adelaide in the *20/20 Vision for Cancer Project (2012-2015)*. This online survey aimed to further understanding of quality of life and the significance of existential wellbeing for those affected by cancer. The PROM used for this project was the 12-item Spiritual Well-Being Scale (FACIT-Sp-12).

PROs, including HRQoL, will be measured as part of a current drug trial funded by **Asthma Australia**. The trial is evaluating the safety and tolerability of the drug dupilumab.

#### 4.4.2 Peak national bodies

The **Australian Healthcare and Hospitals Association (AHHA)**, the peak national body representing health professionals / healthcare organisations, has information supporting the routine collection of PROMs. For instance, a key recommendation of their recent *Submission to the Senate Select Committee on Health* is that ‘health outcomes are measured using patient-reported outcome measures (PROMs) and patient-reported experiential measures (PREMs)’.<sup>61</sup>

The **Australian Medical Association (AMA) Clinical Indicators Position Statement**, released in 2012, does not specifically refer to PROMs, but does recognise that clinical indicators are tools used for measuring a process or outcome. They emphasise that the introduction of any formal set of clinical indicators in health care should be for the sole purpose of improving safety and quality.

The **Private Mental Health Alliance (PMHA)** consists of several organisations including the AMA, Private Healthcare Australia representing private health insurers, the Australian Private Hospitals Association representing private hospitals with psychiatric beds and the Australian Government. The Alliance has established a national PMHA Centralised Data Management Service to improve the quality of information and enable benchmarking within the private hospital sector and it manages the implementation of a *National Model for the Collection and Analysis of a Minimum Data Set with Outcome Measures for Private Hospital-based Psychiatric Services*. Under the national model, participating hospitals collect two measures of a patient’s clinical status. These include:

- A 12-item clinician-completed rating scale, developed by the Royal College of Psychiatrists in the UK and known as the Health of the Nation Outcome Scale, or the HoNOS; and
- A 14-item patient-completed questionnaire, which is known as the MHQ– 14.

Currently all private facilities with psychiatric beds across Australia participate; a listing of services is available on the AMA website.<sup>62</sup>

The **Australian Rheumatology Association (ARA)** is an association of rheumatologists in Australia that is a specialty society of the **Royal Australian College of Physicians**. The ARA database holds detailed information about patient treatment and PROs (quality of life) over time. Further detail about the data collection is included under the AIHW entry in Section 4.3.1.1.

#### 4.4.3 Private health insurers

The **Hospital Contribution Fund Research Foundation** was originally established with a donation from **The Hospitals Contribution Fund of Australia Limited (HCF)**. The HCF Research Foundation now operates independently. In 2016 the HCF Research Foundation announced a partnership with ICHOM to develop two new Standard Sets (oral health, pregnancy and childbirth) to better measure health care results in these areas throughout Australia. The HCF Research Foundation is also funding the implementation of the *ICHOM Standard Set for Hip and*

*Knee Osteoarthritis* at Royal Melbourne Hospital. HCF releases an annual survey of its members' hospital experience.

The **Medibank Health Research Fund (MHRF)** funds innovative health-related research projects throughout Australia. The MHRF 2015 Research Grant Projects included a project based at Monash University titled *Improving the measurement of patient-reported outcomes*. The project is funded for \$600,000 over three years and will measure the quality of hospital-based care experienced by patients. Important outcomes for this project will be: establishing and validating PROs; use of the data in establishing benchmarks for quality care in hospitals; identifying new and better ways to report results to clinicians, patients and funders; and improved quality of care and clinical effectiveness for Australian patients.

## 5 Discussion

The environmental scan highlights existing and emerging trends in the collation and use of PROMs to improve safety and quality at a national, jurisdictional and/or organisational level.

### 5.1 Current status of PROMs in the Australian health sector

There is a high degree of interest across the health sector generally about the application of PROMs to safety and quality improvement; however there is no consistent national approach with each jurisdiction determining its own practice. The approach to PROMs appears to be somewhat 'ad hoc'.

Some of the most significant advances have occurred when there is a high level of clinician engagement as evidenced by a willingness to integrate PROMs into existing clinically based data collection systems (particularly clinical registries). While there are a plethora of disease-specific and condition-specific PROMs that may be used, several clinical registries also include more generic quality of life measures.

Generic PROMs that assess health status and/or HRQoL are included in various state based population surveys, burden of disease studies, in clinical studies along with disease-specific measures and in patient surveys that are predominantly about patient satisfaction and patient experience.

### 5.2 PROMs data collection and aggregation

A number of organisations across Australia are engaging with the ICHOM standard sets particularly clinical researchers supporting disease-specific and condition-specific clinical registries, groups of clinicians and hospitals. NSW Health is providing access to the PROMIS suite of measures but to use these in dynamic mode (computerised adaptive testing) rather than the static mode (standard questionnaires) requires the use of sophisticated methods and technologies that may not, as yet, be routinely available.

The paucity of detail available from organisational websites relating to the use of PROMs prevents any in depth exploration, within this environmental scan, of how PRO information is used at an aggregated level to improve safety and quality in health care in Australia. The forthcoming literature review<sup>6</sup> may well cast more light on this aspect. The developments with Ramsay Health Care provide an example of interest in using PROMs to achieve safety and quality improvements. Research interests have been a strong driver for data collection systems that comprise PROMs.

Generic instruments (e.g. health status measures such as the SF-36, also commonly referred to as PROMs) may be used in health population surveys but when they are used in clinical settings they are used with disease-specific measures and/or condition-specific measures. A general health status measure can be completed by anyone, regardless of their disease or condition, and are often used to provide an estimate of the burden of the particular disease or condition compared to others. For this reason they are quite commonly used in diverse settings.

Disease-specific and condition-specific measures, however, can only be completed by patients that have the disease or condition specified. These patient-reported instruments provide more

detailed information about the symptoms of the disease or condition before and after treatment and the impact of symptoms for a particular condition.

There are some PROMs instruments that contain generic and disease-specific items in the one measure but these are generally not preferred because of concerns over their psychometric adequacy and the limitations placed about the potential comparisons that can be made. A modular approach using separate instruments to capture these elements is generally preferred.<sup>20</sup>

### **5.3 Gaps in the collection and use of PROMs in Australia**

In summary, there is interest by many organisations in using PROMs but actual benchmarking applications of PROMs data are relatively few. There are examples of promising approaches, for example inclusion of PROMs data by some clinical registries and some interest at the state and territory level in moving toward international benchmarking by the use of standard sets for a range of conditions and diseases (e.g. ICHOM standard sets). There is considerable expertise in national aggregation and benchmarking of data observed in consortia and collaboratives such as the Palliative Care Outcomes Collaboration. These promising approaches could be encouraged by organisations such as the Commission.

This interest in PROMs is extending to the private sector with health-related organisations either funding research into PROMs or engaging with the ICHOM standard sets. The work of the Private Mental Health Alliance provides an interesting comparative approach to the work of Australian Mental Health Outcomes and Classification Network.

While several states and territories are progressing work in this area, significant effort has been invested in the domains of integrated care (NSW) and cancer (Victoria and NSW). There are isolated examples of Local Health Districts or groups of organisations testing and trialling the collection of PROMs in either disease-specific or condition-specific areas. Efforts to integrate this data collection with the patient's electronic health record are being conducted on a small scale in individual clinical specialties or hospitals. There is support within most state and territory health departments for the use of PROMs as evidenced by their inclusion in several statewide population based patient surveys, in clinical registries and in funded research projects. Overall however, there is little information available about the practical uses of PRO information.

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## Appendix 1 Examples of search results

Search terms & results	Examples of organisation	Suggested classification
'patient-reported outcome measures' and 'Australian organisations' (limited number of hits)	Sax Institute	Academic institution / research centre
	Ear Science Institute Australia	Not-for-profit organisation engaged in health care, health research
	Clinical Oncology Society of Australia	Peak national body representing health professionals / healthcare organisations
'patient-reported outcomes' and 'health care' (high number of hits)	NSW Health – Agency for Clinical Innovation	Government department/entity
	Commonwealth Fund	Private foundations and/or charitable organisations
	Diabetes Australia Cancer Council Australia	Health-related advocacy organisations
	Monash University	Academic institution / research centre
	Australian Medical Association	Peak national body representing health professionals / healthcare organisations
	Movember Foundation	Private foundations and/or charitable organisations
'patient-reported outcome data' and Australia	University of Western Australia University of Sydney (Patient-reported Outcomes Special Interest Group) University of New South Wales (Simpson Centre for Health Services Research; Centre for Big Data Research in Health) Grattan Institute, University of Melbourne NHMRC Centre for Clinical Eye Research, Flinders University	Academic institution / research centre
	Australian Government Department of Health NSW Health – Cancer Institute NSW Australian Institute of Health and Welfare	Government department/entity
	Healthscope Limited	Private healthcare providers

Search terms & results	Examples of organisation	Suggested classification
	Illawarra Cancer Care Centre, Illawarra Shoalhaven Local Health District	Public sector healthcare providers
	Royal Australian College of General Practitioners	Peak national body representing health professionals / healthcare organisations
'patient-reported surveys' and Australia	Australian New Zealand Clinical Trials Registry	Not-for-profit organisation engaged in health care, health research
	University of Newcastle	Academic institution / research centre

## Appendix 2 Patterns of collection of PROMs in Australia

The information included in the following table is ordered alphabetically by 'Area/Geography'. All entries are also available in a companion file provided in Excel that includes filters to facilitate easier searching by typology, geography, PROMs specific information and comments.

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
<b>National organisations</b>						
Australian Commission on Safety and Quality in Health Care (ACSQHC)	Government department/entity	National	NA	NA	Organisation concerned with quality and safety in health care in Australia; numerous reports related to health outcomes assessment (e.g. variation, guidelines, clinical registries, PREMs, funding a scoping exercise about PROMs currently). In 2015, the ACSQHC released the first 'Australian Atlas of Healthcare Variation'. Significant variations in surgical intervention rates across Australia were identified. The recommendations noted that variation in the delivery of health care could be augmented by routine, nationally consistent use of PROMs for four particular conditions and procedures which included radical prostatectomy, lumbar spine surgery, knee pain and cataract surgery.	<a href="http://www.safetyandquality.gov.au/">www.safetyandquality.gov.au/</a>
Asthma Australia	Health-related advocacy organisation	National	NA	Trial evaluating the drug dupilumab includes an evaluation of the effect of dupilumab in improving patient-reported outcomes including health-related quality of life.	Asthma Australia and member Asthma Foundations provide advocacy and education services and funding to support basic science and population health research. An example of research is a current trial evaluating the safety and tolerability of the drug dupilumab. This trial includes an evaluation of the effect of dupilumab in improving patient-reported outcomes including health-related quality of life. The PROM is not specified and the trial is in the recruitment phase.	<a href="http://www.asthmaaustralia.org.au/national/research/participate-in-asthma-research/asthma-research-trials/evaluation-of-dupilumab-in-people-with-persistent-asthma">http://www.asthmaaustralia.org.au/national/research/participate-in-asthma-research/asthma-research-trials/evaluation-of-dupilumab-in-people-with-persistent-asthma</a>
Australian Council on Healthcare Standards	Peak national body	National	NA	NA	ACHS are Australia's leading health care assessment and accreditation provider. ACHS works with health care professionals, consumers, and government and industry stakeholders to develop and continually review health standards. No documentation specific to the collection of PROMs was	<a href="http://www.achs.org.au/about-us">http://www.achs.org.au/about-us</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
					identified.	
Australian Healthcare and Hospitals Association (includes the Deeble Institute)	Peak national body	National	NA	NA	No documentation on collections identified, although several quotes in support of use of PROMs found. For example, AHHA's Submission to the <i>Senate Select Committee on Health</i> (8 December 2015) suggests that health outcomes are measured using PROMs and PREMs.	<a href="http://ahha.asn.au/system/files/docs/publications/ahha_submission_to_senate_select_committee_on_health_8_dec_2015.pdf">http://ahha.asn.au/system/files/docs/publications/ahha_submission_to_senate_select_committee_on_health_8_dec_2015.pdf</a>
Australian Bureau of Statistics	Government department/entity	National	NA	Normative data for health status and psychological distress instruments.	The ABS has included a number of health status instruments such as the SF-36V1 health status survey (Australian Health Survey, 1995) and the Kessler 10 psychological distress scale in national surveys (1997 and thereafter), providing Australian normative data for these commonly used generic and condition-specific PROMs.	<a href="http://www.abs.gov.au">www.abs.gov.au</a>
Private Mental Health Alliance	Peak national body	National	Outcome benchmarking for private mental health	The MHQ-14 (Mental Health Questionnaire, 14 item version) is a patient self-report measure consisting of items that capture symptoms of fatigue, anxiety and depression.  PMHA Centralised Data Management Service (CDMS) to improve the quality of information and enable benchmarking within the private hospital sector.	Private Mental Health Alliance consists of AMA, PHA, APHA and Australian Government. PHMA Update (2016) reports on the outcome benchmarking for mental health being conducted by PHMA - similar to AMHOCN but private sector -implementation of a National Model for the Collection and Analysis of a Minimum Data Set with Outcome Measures for Private Hospital-based Psychiatric Services. Uses HoNOS (clinical rating) and patient-reported MHQ-14. The PHMA Centralised Data Management Service produces annual reports related to activity and outcomes including PROMs	<a href="https://ama.com.au/psychiatrists-newsletter/private-mental-health-alliance-pmha-update-4">https://ama.com.au/psychiatrists-newsletter/private-mental-health-alliance-pmha-update-4</a>



Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Health Services Research Association of Australia and New Zealand	Peak national body	National	NA	NA	HSRAANZ supports and promotes the conduct and dissemination of applied research to improve the delivery and organisation of health services in Australia and New Zealand. It has a wide range of individual and corporate members from universities, research centres, government departments, independent government agencies, and consumer groups. The Association tries to bridge the gap between research and policy, as well as reflecting consumer issues. It holds a biennial conference, which include some papers on health outcomes and PROMs but it does not have a major focus on PROMs.	<a href="http://www.hsraanz.org/">http://www.hsraanz.org/</a>
Australian Health Services Research Institute	Academic institution / research centre	National	Benchmarking and quality improvement	<p>The Symptom Assessment Scale (SAS) used by PCOC is a patient-reported assessment of distress, pain and other factors in palliative care.</p> <p>All adult and paediatric pain service questionnaires used by ePPOC are patient rated.</p>	<p>Australian health services research centre with a number of sub-centres (e.g. AHOC, AROC, CHSD, PCOC, ePPOC) that undertake health outcomes information dissemination, education, research and outcome benchmarking activities.</p> <p>Palliative Care Outcomes Collaboration (PCOC) is a national program that uses standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care.</p> <p>electronic Persistent Pain Outcomes Collaboration (ePPOC) is a new program that aims to help improve services and outcomes for patients suffering with chronic pain through benchmarking of care and treatment.</p> <p>Australasian Rehabilitation Outcomes Centre (AROC) is a joint initiative of the Australian rehabilitation sector (providers, funders, regulators and consumers). With the support of its industry partners, AROC has been established by the Australasian Faculty of Rehabilitation Medicine of the Royal Australasian College of Physicians. Since 2002 it has been concerned with the outcomes benchmarking of rehabilitation services in Australia and NZ and there are 372 participating services. AROC has recently received funding to develop a patient experience survey for sub-acute rehabilitation services.</p> <p>Australian Health Outcomes Collaboration (AHOC) is concerned with education and information dissemination about the health</p>	<p><a href="http://ahsri.uow.edu.au/index.html">http://ahsri.uow.edu.au/index.html</a></p> <p><a href="https://ahsri.uow.edu.au/chsd/index.html">https://ahsri.uow.edu.au/chsd/index.html</a></p> <p><a href="https://ahsri.uow.edu.au/pcoc/index.html">https://ahsri.uow.edu.au/pcoc/index.html</a></p> <p><a href="https://ahsri.uow.edu.au/ahoc/index.html">https://ahsri.uow.edu.au/ahoc/index.html</a></p> <p><a href="https://ahsri.uow.edu.au/aroc/index.html">https://ahsri.uow.edu.au/aroc/index.html</a></p> <p><a href="https://ahsri.uow.edu.au/eppoc/index.html">https://ahsri.uow.edu.au/eppoc/index.html</a></p>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
					outcomes approach (including advice re PROMs) and which has undertaken numerous outcomes research projects. It has connections with international groups such as ICHOM and the Mapi Research Trust. It was responsible for the Dementia Outcomes Measurement Suite and is involved in the ICHOM dementia working group to develop a standard set of measures for dementia including PROMs.	
George Institute for Global Health	Academic institution / research centre	National	NA	NA	The Institute has released the report, <i>Putting the consumer first: creating a consumer-centred health system for a 21st century Australia. A health policy report, April 2016</i> One recommendation of the report is to ensure that consumer experience drives the health system by routinely measuring and benchmarking patient experiences and outcomes across the health system, and making this information publically available to allow informed decision-making.	<a href="http://www.georgeinstitute.org.au/projects/areas/putting-the-consumer-first-creating-a-consumer-centred-health-system-for-a-21st">http://www.georgeinstitute.org.au/projects/areas/putting-the-consumer-first-creating-a-consumer-centred-health-system-for-a-21st</a>
Australian Institute of Health and Welfare	Government department/ entity	National	NA	Reports on some PROMs used in population health survey data. Holds relevant data collections (Australian Hospital Morbidity Database and National Death Index) relevant for linkage studies	The publication <i>Australia's Health 2014</i> is a biennial report mainly concerned with health indicators rather than PROMs, but includes some wellbeing indicators and some global indices of health status / health-related quality of life (e.g. PROMs items).	<a href="http://www.aihw.gov.au/publication-detail/?id=60129547205">http://www.aihw.gov.au/publication-detail/?id=60129547205</a>
Cancer Australia	Government department/ entity	National	NA	NA	Cancer Australia has a relevant national project in progress about the development of a National Cancer Control Indicator framework to facilitate national-level reporting of key cancer control indicators. The Quality of Life (QOL) Office is funded by Cancer Australia as part of the Support for Clinical Trials Program. The QOL Office is Directed by the Cancer Australia Chair in Cancer Quality of Life (QOL Chair), Professor Madeleine King, and is based at the University of Sydney. There are links to the NHS <i>Quality of Life of Cancer Survivors in England</i> PROMs study from the Cancer Learning survivorship page.	<a href="http://cancerlearning.gov.au/topics/survivorship/toolbox-providing-cancer-survivorship-care">http://cancerlearning.gov.au/topics/survivorship/toolbox-providing-cancer-survivorship-care</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Australian Medical Association	Peak national body	National	NA	NA	AMA reports on the outcome data collection and analysis for mental health being conducted by PHMA - similar to AMHOCN but private sector implementation of a National Model for the Collection and Analysis of a Minimum Data Set with Outcome Measures for Private Hospital-based Psychiatric Services. Uses HoNOS (clinical rating) and patient reported MHQ-14. The PHMA Centralised Data Management Service produces annual reports related to activity and outcomes including PROMs. Also see pages relating to <i>Clinical Indicators Position Statement</i> which concludes: 'Clinical indicators must be relevant, evidenced-based and easily measured so as to ensure that limited resources are efficiently directed and the data gathered worthwhile.'	<a href="https://ama.com.au/position-statement/clinical-indicators-2012">https://ama.com.au/position-statement/clinical-indicators-2012</a>
Australian Mental Health Outcomes and Classification Network (AMHOCN)	Consortium/ collaborative	National	The purpose of outcomes measurement is to improve the quality of mental health services through better understanding and use of information about the outcomes for consumers.  Data is used to continue to improve mental health services.	The Kessler 10 is a short measure of non-specific psychological distress based on questions about the level of nervousness, agitation, psychological fatigue and depression.  BASIS-32 is a symptom and behaviour scale completed by clients of mental health services in ACT, Tasmania and Victoria	AMHOCN was established by the Australian Government in December 2003 to provide leadership to the mental health sector to support the sustainable implementation of the <i>National Outcomes and Casemix Collection</i> (NOCC) as part of routine clinical practice. AMHOCN manages the NOCC on behalf of the Australian Government. The scope is all inpatient, ambulatory and 24-hour community residential mental health services, nationally. A significant component of the initiative included upgrading current information systems to support the collection.  AMHOCN was established to work collaboratively with the states and territories and others in the mental health sector to implement routine outcome measurement in public mental health services. AMHOCN consists of three components: a data bureau responsible for receiving and processing information; an analysis and reporting component providing analysis and reports of submitted data; and a training and service development component supporting training in the measures and their use for clinical practice, service management and development purposes.  Under the Australian Health Care Agreements (AHCAs), introduction of routine consumer outcomes measurement in	<a href="http://www.amhcn.org/">http://www.amhcn.org/</a> <a href="https://www2.health.vic.gov.au/mental-health/practice-and-service-quality/service-quality/measuring-outcomes-in-mental-health">https://www2.health.vic.gov.au/mental-health/practice-and-service-quality/service-quality/measuring-outcomes-in-mental-health</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
					<p>mental health services was introduced nationally. For example, South Australia has received Australian Government funds to enable it to deliver on this initiative. Similarly, under the <i>National Mental Health Plan</i>, all clinical mental health services in Victoria must routinely submit consumer outcome ratings through a national collection protocol known as the NOCC. The NOCC provides a coherent picture of mental health outcomes in each state and territory, which can be used to measure clinical effectiveness across different service sectors and age cohorts.</p> <p>Improving mental health service outcomes is a primary goal of the National Mental Health Strategy. To advance this, the strategy emphasised the need for consumer outcomes to be reviewed on a regular basis. The collection of routine outcomes measures allows mental health services to begin to answer questions about the effectiveness of treatments that are delivered.</p>	
Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)	Academic institution / research centre	National	The purpose of the AOANJRR is to define, improve and maintain the quality of care of individuals receiving joint replacement surgery.	NA	AOANJRR collects a defined minimum data set that enables outcomes to be determined on the basis of patient characteristics, prosthesis type and features, method of prosthesis fixation and surgical technique used. The principal measure of outcome is revision surgery which identifies the need for further intervention. Combined with a careful analysis of the timing and reasons for revision this can be used as an accurate measure of the success or otherwise of a procedure. The AOANJRR also monitors mortality rates. It does not routinely collect PROMs but some data collections by participant surgeons also include PROMs.	<a href="https://aoanjrr.sahmri.com/background">https://aoanjrr.sahmri.com/background</a>
Australian and New Zealand Intensive Care Society (ANZICS) Centre for	Academic institution / research centre	National	ANZICS CORE provides audit and analysis of intensive care data to contribute to peer review,	NA	<p>ANZICS CORE comprises four data registries:</p> <ul style="list-style-type: none"> <li>-Adult Patient Database</li> <li>-ANZICS Paediatric Intensive Care Registry</li> <li>-Critical Care Resources Registry</li> <li>-Central Line Associated Bloodstream Infection Registry</li> </ul> <p>The Centre researches the availability and utilisation of critical</p>	<p><a href="http://www.anzics.com.au/Pages/CORE/About-CORE.aspx">http://www.anzics.com.au/Pages/CORE/About-CORE.aspx</a></p> <p><a href="http://www.anzics.com.au/Downloads/ANZICS%20APD%2">http://www.anzics.com.au/Downloads/ANZICS%20APD%2</a></p>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Outcome and Resource Evaluation (CORE)			quality assurance and research		care resources, patient outcomes, mortality, disease patterns and the effectiveness of critical care interventions.  Benchmarking of outcomes and quality of care against comparable units and international standards occurs. The ANZICS Outlier Management Policy specifies the appropriate action required if performance of a unit falls outside expected norms (this includes notification of the relevant jurisdictional health authority).	<a href="#">0Dictionary%20V4.1 Basic.pdf</a>  <a href="http://www.anzics.com.au/Downloads/Outlier%20Analyses%20Policy.pdf#search=policy">http://www.anzics.com.au/Downloads/Outlier%20Analyses%20Policy.pdf#search=policy</a>
Australian New Zealand Clinical Trials Registry (ANZCTR)	Academic institution / research centre	National	NA	Quality of life questionnaires and PROMs used in some trials.	The ANZCTR is an online registry of clinical trials being undertaken in Australia, New Zealand and elsewhere. Trial details are provided on this website and can be searched. Trials cover health-related matters and use a wide variety of relevant measurements, including some patient-reported ones such as quality of life measures e.g. RCT to evaluate effectiveness of telephone, mail or email approaches to collecting PROMs data using Prostate Cancer Outcomes Registry-Victoria (PCOR-VIC).	<a href="http://www.anzctr.org.au/">http://www.anzctr.org.au/</a>
Australian Private Hospitals Association (APHA)	Peak national body	National	NA	NA	Links to the ACSQHC publication 'On the Radar' were found, which referenced two articles discussing PROMs (2012/2103).	<a href="http://www.apha.org.au/">www.apha.org.au/</a>
Australian Rheumatology Association (ARA)	Peak national body	National	NA	Quality of life measures	The ARA is an association of rheumatologists in Australia that is a specialty society of the Royal Australasian College of Physicians. The AIHW note (in 'Assessment of the ARAD for national population health monitoring', 2014) that the ARA Database holds detailed information about patient treatment and patient-reported outcomes (QOL) over time.	<a href="http://rheumatology.org.au/">http://rheumatology.org.au/</a>
Bowel Cancer Australia	Health-related advocacy organisation	National	NA	Bowel Cancer Australia co-sponsored the <i>ICHOM Standard Set for Colorectal Cancer Reference Guide</i> (a complete overview of the ICHOM Colorectal Cancer	Bowel Cancer Australia is a community-funded charity working in prevention, early diagnosis, research, quality treatment and care.	<a href="https://www.bowelcanceraustralia.org/optimal-care-pathway">https://www.bowelcanceraustralia.org/optimal-care-pathway</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
				Standard Set, including definitions for each data element and selected PROMs, time points for collection, and associated risk factors).		
Cancer Council Australia	Health-related advocacy organisation	National	To further understanding of quality of life and the significance of existential wellbeing for those affected by cancer.	The 20/20 Vision for Cancer Project re: QOL and spirituality  FACIT-Sp-Ex / Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being; The 12-item Spiritual Well-Being Scale or the FACIT-Sp-12	Cancer Council Australia and its members have a broad spectrum of roles, including advocacy. Cancer Councils do not directly collect PROMs, but are independent funders of cancer research in Australia. As an example, the Cancer Council Australia partnered with the University of Adelaide in the <i>20/20 Vision for Cancer Project (2012-2015)</i> . This online survey aimed to further understanding of quality of life and the significance of existential wellbeing for those affected by cancer. The PROM used for this project was the 12-item Spiritual Well-Being Scale (FACIT-Sp-12).	<a href="http://www.cancer.org.au/health-professionals/research/2020vision/">http://www.cancer.org.au/health-professionals/research/2020vision/</a>
Clinical Oncology Society of Australia (COSA)	Peak national body	National	NA	NA	COSA is active in four main areas: education, networks, advocacy and research. The culmination of these activities occurs at the Annual Scientific Meeting. No specific documentation relating to the collection of PROMs was identified. Professor Currow mentions PROMs in speech receiving Tom Reeve Award, and presentations at COSA 2015 related to PROMs.	<a href="https://www.cosa.org.au/grants-awards/tom-reeve-award/2015-david-currow-oration.aspx">https://www.cosa.org.au/grants-awards/tom-reeve-award/2015-david-currow-oration.aspx</a>
Australian Government Department of Health	Government department/entity	National	NA	NA	The Australian Government Department of Health is associated with several organisations that are investigating the potential to integrate PROMs into existing data collections e.g. the Australian Mental Health Outcomes and Classification Network.	<a href="http://www.health.gov.au/">http://www.health.gov.au/</a>
Australian Government Department of Veterans' Affairs (DVA)	Government department/entity	National	NA	WHOQOL-BREF Hospital Anxiety and Depression Scale (HADS) Dimensions of Anger Reactions Scale (DARS) Dyadic Adjustment Scale	DVA funds treatment for veterans with Post Traumatic Stress Disorder (PTSD) at centres accredited by the Australian Centre for Post-traumatic Mental Health and PROMs and clinical rating measures are collected in these programs. There are 11 participating centres that contribute outcome-related and PROMs information to a central collection point, which enables some comparisons about the effectiveness of programs to be	<a href="http://www.dva.gov.au/">http://www.dva.gov.au/</a>  <a href="http://at-ease.dva.gov.au/professionals/assessment-and-treat/ptsd/">http://at-ease.dva.gov.au/professionals/assessment-and-treat/ptsd/</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
					made.  Client surveys (satisfaction with DVA services, including time to open and settle claims) are collected by DVA.  DVA also has systems in place to monitor the servicing and claiming patterns of health care providers. DVA uses this information, in addition to best practice guidelines from professional regulatory and/or representative bodies, to establish internal benchmarks for the future delivery of services and to identify possible instances of overpayment resulting from administrative error, inappropriate-servicing or non-compliance.	
Consumer Health Forum (CHF)	Health-related advocacy organisation	National	NA	Peak consumer group in Australia with some focus on PROMs e.g. Patient Reported Outcomes to Accelerate Change (from the International Forum on Quality & Safety in Healthcare, 13 April 2016).	As part of the <i>Real People Real Data</i> project funded by the Australian Government Department of Health CHF produced a ' <i>Literature and Practice Review: Capturing, analysing and using consumers' health experience</i> ' in 2013. CHF was involved in a joint presentation on <i>Real People, Real Data</i> at the 2016 International Forum on Quality and Safety in Healthcare in Gothenburg, Sweden. The presentation included discussion about both PREMs and PROMs.	<a href="https://www.chf.org.au/">https://www.chf.org.au/</a> <a href="https://chf.org.au/sites/default/files/rep-1142-literature-review-using-consumer-narrative-to-inform-better-health-outcomes_0.pdf">https://chf.org.au/sites/default/files/rep-1142-literature-review-using-consumer-narrative-to-inform-better-health-outcomes_0.pdf</a>
Dementia Collaborative Research Centres	Consortium/ collaborative	National	DOMS aims to tackle issues related to a rapidly growing population with dementia / Alzheimer's disease, creating a common	Web page adaptation of DOMS (AHOC; AHSRI)	Information pages about measures used for assessment and health outcomes monitoring of people with dementia - based on the Dementia Outcomes Measurement Suite (DOMS), an Australian Government Initiative (Sansoni et al., AHOC).	<a href="http://www.dementiaresearch.org.au/">http://www.dementiaresearch.org.au/</a> <a href="http://www.dementia-assessment.com.au/">http://www.dementia-assessment.com.au/</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
			assessment language for use by all professionals.			
Diabetes Australia	Health-related advocacy organisation	National	NA	<p>National Evidence Based Guideline for Patient Education in Type 2 Diabetes - discusses some PROMs.</p> <p>Outcomes and Indicators for Diabetes Education: A National Consensus Position also discusses PROMs.</p>	Diabetes Australia is the leading diabetes advocacy organisation in Australia. In addition to the Diabetes Australia Research Program, Diabetes Australia works with the National Health and Medical Research Council (NHMRC), The Royal Australian College of General Practitioners and The Royal Australian College of Physicians as research partners. No specific documentation relating to the collection of PROMs by Diabetes Australia was identified. However, Appendix 1 (Indicators and measurement tools for diabetes patient education) of the 'Outcomes and Indicators for Diabetes Education - A National Consensus Position' (Diabetes Australia, 2007) provides information about the Patient-Reported Outcomes and Quality of Life Instruments database (PROQOLID).	<a href="https://www.diabetesaustralia.com.au/">https://www.diabetesaustralia.com.au/</a>
Ear Science Institute Australia (ESIA)	Health-related advocacy organisation	National	NA	Disease specific PROMs in some research projects.	<p>The primary aim of clinical research at ESIA is to improve the quality of care for people with hearing loss. Current projects include assessing outcomes after hearing implantation including speech perception tests, bone conduction implants, and quality of life measures.</p> <p>One publication located: Hinton-Bayre A, Friedland P. 'Let's get dizzy: a statistical method to evaluate individual changes in vertigo patient reported outcome measures.' Australian Society of Otolaryngology Head and Neck Surgery Annual Scientific Meeting (ASOHNS), Brisbane, 29 March – 1 April 2014. Little documentation specific to the collection of PROMs was identified.</p>	<p><a href="https://www.earscience.org.au/">https://www.earscience.org.au/</a></p> <p><a href="https://www.earscience.org.au/sites/www.earscience.org.au/files/field/pdf/annual_report_2014.pdf">https://www.earscience.org.au/sites/www.earscience.org.au/files/field/pdf/annual_report_2014.pdf</a></p>



Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Hospital Contribution Fund Research Foundation	Private health insurance organisation	National	NA	Implementation trial of ICHOM standard set for Hip and Knee Osteoarthritis which includes PROMs	The HCF Research Foundation operates independently and has a specific focus on funding health services research to benefit Australians. In 2016 the HCF Research Foundation announced a partnership with ICHOM to develop two new outcome Standard Sets (Oral Health, Pregnancy and Childbirth) to better measure health care results in these areas throughout Australia. The Foundation is also funding the implementation of the ICHOM Standard Set for Hip and Knee Osteoarthritis at Royal Melbourne Hospital to help improve outcomes for Australians with hip and knee joint pain. HCF also releases an annual survey of members' hospital experience.	<a href="https://www.hcf.com.au/">https://www.hcf.com.au/</a>  <a href="https://www.hcf.com.au/pdf/media-releases/2016/HCF_MEDIA_RELEASE_02052016.pdf">https://www.hcf.com.au/pdf/media-releases/2016/HCF_MEDIA_RELEASE_02052016.pdf</a>
Healthscope	Private healthcare provider	National	NA	One patient-reported outcome was identified, the MHQ-14 (Mental Health Questionnaire), which asks questions about symptoms of fatigue, anxiety and depression and the impact of those symptoms in daily life. Also uses the FIM (clinical rating scale) for rehabilitation services.	Healthscope is Australia's second largest private hospital operator, with 46 hospitals. Healthscope publishes the results of its clinical performance and health outcomes on its website.	<a href="http://www.healthscopehospitals.com.au/quality/my-healthscope">http://www.healthscopehospitals.com.au/quality/my-healthscope</a>
Movember Foundation	Health-related advocacy organisation	National	Establish Guidelines and Key Attributes for Electronic Patient-Reported Outcomes Measurement (ePROM) Tools	Movember Australia provided funding for the project implemented by ICHOM: 'Establish Guidelines and Key Attributes for Electronic Patient-Reported Outcomes Measurement (ePROM) Tools' (Lippa et al., 2014). Monash: Prostate Cancer Outcomes Registry - Australia and New Zealand	This project sought to establish guidelines and identify key attributes for providers and registry leaders to consider when selecting an electronic tool for collecting data directly from patients about their health (i.e. PROMs), to develop a decision framework for selecting the right tool for a given setting and/or context, and summarise information on the most popular tools to facilitate comparison and selection	<a href="https://au.movember.com/">https://au.movember.com/</a> <a href="https://au.movember.com/report-cards/view/id/2805">https://au.movember.com/report-cards/view/id/2805</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
				(PCOR-ANZ)  Quality of life questionnaire		
Movember Foundation	Health-related advocacy organisation	National	IPCOR - Irish Prostate Cancer Outcomes Research	The Irish Prostate Cancer Outcomes Research (IPCOR) is a project currently funded by Movember and implemented by the Irish Cancer Society. The two IPCOR databases, the clinical database at the National Cancer Registry and the PROMs database have been developed and have undergone testing. The databases will ultimately be merged using a unique patient identification number to form the IPCOR registry.	Movember Foundation provided funding for the project, 'To establish a clinically-led, population-based, prospective, longitudinal, prostate cancer disease registry, which will capture high-quality information from newly diagnosed men with prostate cancer in the Republic of Ireland.'  IPCOR will generate robust data on several important clinical outcomes in men with prostate cancer and assess processes, consistency and quality of care. By providing evidence-based data and recommendations to clinicians, hospitals, decision-makers and the National Cancer Control Programme, IPCOR will promote equity of access and improvements in care nationally.	<a href="https://au.movember.com/uploads/files/2013/Report%20Cards/ePROM-White-Paper.pdf">https://au.movember.com/uploads/files/2013/Report%20Cards/ePROM-White-Paper.pdf</a> <a href="https://au.movember.com/report-cards/view/id/2521">https://au.movember.com/report-cards/view/id/2521</a> <a href="http://www.socialventures.com.au/sva-quarterly/movember-changing-a-system-collaboratively/#sthash.wirOU5AJ.dpuf">http://www.socialventures.com.au/sva-quarterly/movember-changing-a-system-collaboratively/#sthash.wirOU5AJ.dpuf</a>
Patient-Reported Outcomes Safety Event Reporting (PROSPER) Consortium	Consortium/ collaborative	National	NA	NA	The PROSPER Consortium was convened to improve safety reporting by better incorporating the perspective of the patient. PROSPER comprises industry, regulatory authority, academic, private sector and patient representatives, interested in the area of patient-reported outcomes of adverse events.	<a href="http://www.ncbi.nlm.nih.gov/pubmed/24092596">http://www.ncbi.nlm.nih.gov/pubmed/24092596</a>
Public Health Association of Australia (PHAA)	Peak national body	National	NA	NA	The Public Health Association of Australia is recognised as the principal non-government organisation for public health in Australia and works to promote the health and well-being of all Australians. The Association seeks better population health outcomes based on prevention, the social determinants of health and equity principles.	<a href="https://www.phaa.net.au/">https://www.phaa.net.au/</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Medibank	Private health insurance organisation	National	Important project outcomes are listed in the comments section.	Testing PROMs as measures of hospital care.	<p>The Medibank Health Research Fund 2015 Research Grant Projects included a project run headed by Professors John McNeil and Just Stoelwinder at Monash University titled 'Improving the measurement of patient-reported outcomes'. The project is funded for \$600,000 over 3 years and will measure the quality of hospital-based care experienced by patients. The project is aimed at improving the way this data is recorded and presented, and ultimately how it might assist clinicians and lead to improved processes in hospital settings. Important project outcomes will be: establishing and validating PROs; use of the data in establishing benchmarks for quality care in hospitals; identifying new and better ways to report results to clinicians, patients and funders; and improved quality of care and clinical effectiveness for Australian patients.</p> <p>Medibank has also funded the development of a patient experience survey for sub-acute rehabilitation patients by the Australasian Rehabilitation Outcomes Centre.</p>	<p><a href="https://www.medibank.com.au/">https://www.medibank.com.au/</a></p> <p><a href="https://www.medibank.com.au/content/about/corporate-responsibility/sponsorships/jcr%3Acontent/mainContentArea/download_6/file.res/Summary-table-2015-Grants-MHRF.pdf">https://www.medibank.com.au/content/about/corporate-responsibility/sponsorships/jcr%3Acontent/mainContentArea/download_6/file.res/Summary-table-2015-Grants-MHRF.pdf</a></p>
Ramsay Health Care (RHC)	Private healthcare provider	National	NA	Ramsay Health Care publishes annual <i>Patient Safety &amp; Quality Reports</i> . An organisation-wide patient satisfaction survey is conducted by an independent company every two years, providing a snapshot satisfaction report.	<p>In August 2015 RHC announced a strategic alliance with ICHOM. Patients' outcomes will be measured according to the recommendations of the ICHOM Standard Sets. The results of their care will be monitored for a year or more, during and after treatment, through surveys and interviews, for example on quality of life and self-sufficiency. Ramsay's first areas of focus with ICHOM will be prostate cancer, low back pain, and depression and anxiety.</p> <p>The organisation also monitors patient-reported satisfaction and has recently agreed to provide data from 20 of its facilities to a research project that is seeking to develop nursing sensitive outcome measures. The project is being conducted by researchers from the Faculty of Science, Medicine and Health in collaboration with the Australian Health Services Research</p>	<p><a href="http://www.ramsayhealth.com/Businesses/Australia">http://www.ramsayhealth.com/Businesses/Australia</a></p>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
					Institute at the University of Wollongong.	
Royal Australian College of General Practitioners	Peak national body	National	NA	NA	The RACGP website provided a link to the journal article 'Quality of care measures in multimorbidity' (Neurology, 2014, 43(3):132-136). This systematic literature review included 'patient-rated measures'.	<a href="http://www.racgp.org.au/Home">http://www.racgp.org.au/Home</a>
<b>New South Wales organisations</b>						
NSW Ministry of Health	Government department/entity	NSW	NA	NA	The use of PROMs is recommended in the Independent Pricing and Regulatory Tribunal's 'Framework for performance improvement in health' (2008).	<a href="http://www.health.nsw.gov.au/">www.health.nsw.gov.au/</a>  <a href="http://www.ipart.nsw.gov.au/files/sharedassets/website/trimholdingbay/framework_for_performance_improvement_in_health_-_final_report_-_september_2008_-_apd_website.pdf">http://www.ipart.nsw.gov.au/files/sharedassets/website/trimholdingbay/framework_for_performance_improvement_in_health_-_final_report_-_september_2008_-_apd_website.pdf</a>
NSW Health - Agency for Clinical Innovation (ACI)	Government department/entity	NSW	Patient-Reported Measure program - Part of the NSW Health Integrated Care Program	Overview of PROMs and PREMs with a particular focus on the <i>NSW Integrated Care Strategy</i> written by Jack Chen, Simpson Centre for Health Services Research, UNSW. This literature review pointed strongly to PROMIS for the PROMs question sets, for the purposes of the pilot program. PROMIS 10 is used – a validated 10 question generic HRQoL	The ACI is responsible for managing the Patient-Reported Measure component of the <i>NSW Health Integrated Care Strategy</i> . The Patient-Reported Measures program is inclusive of up to ten proof-of-concept sites within NSW, working with ACI to implement patient-reported measures as part of business. There are three Integrated Care 'Demonstrators' – led by Western Sydney, Central Coast and Western NSW Local Health Districts (LHDs).  Also see Chen, Simpson Centre report commissioned by ACI as key resource ' <i>Integrated Care: Patient-reported outcome measures and patient-reported experience measures, a rapid scoping review</i> ' for Integrated Care Advisory Committee, NSW Agency for Clinical Innovation.	<a href="http://www.aci.health.nsw.gov.au/">http://www.aci.health.nsw.gov.au/</a> <a href="https://www.aci.health.nsw.gov.au/data/assets/pdf_file/0009/281979/ACI_Proms_Premis_Report.pdf">https://www.aci.health.nsw.gov.au/data/assets/pdf_file/0009/281979/ACI_Proms_Premis_Report.pdf</a>

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				tool.	ICHOM has announced a new strategic alliance with the ACI.	
NSW Health - Clinical Excellence Commission (CEC)	Government department/entity	NSW	NA	NA	See Service Compact between NSW Health and CEC (2015-16) for PROMs as key priority.  CEC noted growing interest in PROMs in 2010.	<a href="http://www.cec.health.nsw.gov.au/_data/assets/pdf_file/0005/258215/CEC-Service-Compact-2014-15.pdf">http://www.cec.health.nsw.gov.au/_data/assets/pdf_file/0005/258215/CEC-Service-Compact-2014-15.pdf</a>
NSW Health - Cancer Institute NSW	Government department/entity	NSW	NA	Has commissioned reviews about the use of PROMs and indicators of patient experience.	Manages NSW Cancer Registry, NSW Pap Test Register, Australian Mesothelioma Registry, Breast Screen NSW, Heredity Cancer Registry, NSW Prostate Cancer Registry. CI NSW also commissions research around PROMs e.g. history of PROMs work. Mentions Prostate Cancer Outcomes Registry re inclusion PROMs data. Has a Patient-Reported Experience Program Advisory Committee and has recently commissioned a report on Patient Experience Indicators for Cancer Care (AHSRI).	<a href="https://www.cancerinstitute.org.au/">https://www.cancerinstitute.org.au/</a> <a href="http://www.cancerinstitute.org.au/media/144048/2011-1-31_factsheet_using-patient-reported-outcome-measures-in-cancer-setting.pdf">http://www.cancerinstitute.org.au/media/144048/2011-1-31_factsheet_using-patient-reported-outcome-measures-in-cancer-setting.pdf</a>
NSW Health - Bureau of Health Information (BHI)	Government department/entity	NSW	NA	Some patient surveys contain four PROM style items	The role of BHI is to prepare and publish regular reports on the performance of the NSW public health system, including the safety and quality, effectiveness, efficiency and responsiveness of the system to the health needs of the people of NSW. Much of the work of BHI is concerned with health outcome related performance indicators that may be used in benchmarking the performance of hospitals in NSW and for international comparisons (Commonwealth Fund Survey). It also reports on the NSW Patient Survey program, which reflects on patients' experience of care and a number of surveys include items about PROs.	<a href="http://www.bhi.nsw.gov.au/">www.bhi.nsw.gov.au/</a>

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NSW Health – Illawarra Cancer Care Centre, Illawarra Shoalhaven Local Health District	Public healthcare provider	NSW	PROMPT Care (PROMs for Personalised Treatment and Care)	eHealth platform using PROs. An example is the use of the Distress Thermometer and Checklist and Edmonton Symptom Assessment Scale.	An integrated eHealth platform, using PROs to enable cancer survivors to achieve and maintain improved health and wellbeing and better cancer outcomes. Integrated with hospital's EMR. Funding: Cancer Institute NSW & Bupa Health Foundation. Governance: South Western Sydney Local Health District, Illawarra Shoalhaven Local Health District and the Cancer Institute NSW, cross-LHD Advisory Groups.	<a href="http://www.islhd.health.nsw.gov.au/Cancer_Services/ICC/default.asp">http://www.islhd.health.nsw.gov.au/Cancer_Services/ICC/default.asp</a>
NSW Health – South Eastern Sydney Local Health District	Public healthcare provider	NSW	St George Knee Clinic	Oxford knee score	The St George Knee Clinic has a knee arthroplasty database with prospective outcome measurements including patient demographics, Oxford knee scores and x-rays. This database has been running since 1998 and comprises over 1,500 patients.	<a href="http://www.stgeorgekneeclinic.com.au/neville-j-rowden.html">http://www.stgeorgekneeclinic.com.au/neville-j-rowden.html</a>
NSW Health – Hunter New England Health	Public healthcare provider	NSW	NA	NA	<i>Patient-reported Outcome Measures in Speech Pathology</i> is nominated for the Hunter New England Excellence Awards 2016.	<a href="http://www.hnehealth.nsw.gov.au/Pages/home.aspx">http://www.hnehealth.nsw.gov.au/Pages/home.aspx</a>
NSW Health – Western Sydney Local Health District	Public healthcare provider	NSW	NA	Working on a demonstration project re use of PROMs.	Currently working with ACI to implement Patient-Reported Measures program.	<a href="http://www.wslhd.health.nsw.gov.au/">http://www.wslhd.health.nsw.gov.au/</a>

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Sax Institute	Academic institution / research centre	NSW	45 and Up Study aims to answer important health and quality of life questions and help manage and prevent illness through improved knowledge of conditions such as cancer, heart disease depression, obesity and diabetes.	45 and Up Study includes PROMs such as health status (e.g. SF-36 items) and function.	<p>The report <i>'The impact of routine collection of Patient-Reported Outcome Measures on patients, providers and health organisations in an oncologic setting: a rapid review'</i> discusses issues about the routine collection of PROM data in oncological settings</p> <p>The Sax Institute <i>HARC Forum: Patient experience and patient reported outcome measures</i> - The HARC partners recently welcomed Mr Dan Wellings, Head of Insight and Feedback at NHS England. Mr Wellings spoke about the NHS approach to patient experience and PROMs. His presentation was followed by presentations from Dr Jean-Frederic Levesque, Chief Executive of the Bureau of Health Information and Dr Karen Luxford, Director, Patient Based Care of the Clinical Excellence Commission.</p> <p>The 45 and Up Study has recruited 250,000 NSW men and women into a longitudinal study on ageing. The study allows for data linkage with other databases about health service utilisation and mortality. Similar approach to the Australian Longitudinal Study of Women's Health (ALSWH).</p>	<p><a href="https://www.saxinstitute.org.au/">https://www.saxinstitute.org.au/</a></p> <p><a href="https://www.saxinstitute.org.au/wp-content/uploads/REPORT_PROMS-1.pdf">https://www.saxinstitute.org.au/wp-content/uploads/REPORT_PROMS-1.pdf</a></p>
Australian Institute of Health Innovation, Macquarie University	Academic institution / research centre	NSW	NA	NA	See <i>'Final Report: Performance indicators used internationally to report publicly on healthcare organisations and local health systems'</i> . Mainly concerns health indicators rather than PROMs but recommends bolstering patient experience indicators, calling for National Health Performance Authority's adoption of more PROMs.	<a href="http://www.nhpa.gov.au/internet/nhpa/publishing.nsf/Content/A2BC636E366C7FAFCA257C7800189056/\$File/Final%20Report%20NHPA%20International%20Performance%20Indicators%20AIHI.pdf">http://www.nhpa.gov.au/internet/nhpa/publishing.nsf/Content/A2BC636E366C7FAFCA257C7800189056/\$File/Final%20Report%20NHPA%20International%20Performance%20Indicators%20AIHI.pdf</a>

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University of Newcastle (Faculty of Health & Medicine, School of Medicine and Public Health)	Academic institution / research centre	NSW	NA	Development And Validation Of The First Patient-Reported Outcome Measure (PROM) For Severe Asthma Patients	At present there are no PROMs developed specifically for patients with severe asthma. This project will develop a PROM that can be used in clinical and research settings to assess the impact of severe asthma on patients' lives. It will also provide a valid and reliable tool that can be used by clinicians and researchers to assess response to novel treatment interventions in severe asthma.  Also involved in the Australian Longitudinal Study on Women's Health.	<a href="http://www.newcastle.edu.au/about-uon/governance-and-leadership/faculties-and-schools/faculty-of-health-and-medicine/school-of-medicine-and-public-health">http://www.newcastle.edu.au/about-uon/governance-and-leadership/faculties-and-schools/faculty-of-health-and-medicine/school-of-medicine-and-public-health</a>
Centre for Big Data Research in Health (University of New South Wales)	Academic institution / research centre	NSW	NA	Some 'big data' sets will include health status measures and PROMs	'Big data' refers to datasets whose size or complexity is beyond the ability of traditional methods and tools to capture, store, manage, and analyse e.g. large scale electronic datasets that can link various data collections such as medical service claims, hospital records, registry data, large scale survey data (which in some collections will include PROMs data). Their Health Services and Outcomes Unit undertake research to identify variations and disparities in the use, outcomes and costs of health services, investigates the factors that drive these, and evaluates the outcomes of health policies and programs.	<a href="https://cbdrh.med.unsw.edu.au/">https://cbdrh.med.unsw.edu.au/</a>
Simpson Centre for Health Services Research (University of New South Wales)	Academic institution / research centre	NSW	NA	NA	Centre which undertakes some health outcomes and PROMs related research in Australia including a review of PROMs, the 45 and Up Study and the Longitudinal Study of Australian Children - see ACI and Sax Institute entries.	<a href="https://swscs.med.unsw.edu.au/group/simpson-centre-health-services-research">https://swscs.med.unsw.edu.au/group/simpson-centre-health-services-research</a>



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Centre for Social Research in Health (University of New South Wales)	Academic institution / research centre	NSW	NA	Addiction related PROMs	In 2016 the Centre for Social Research in Health (UNSW) hosted seminar on PROMs and addiction with Prof Jo Neale from King's College - discussed the development of two new addiction-related PROMs (one on recovery and one on sleep) and using PROMs to understand the experiences of people with drug or alcohol problems.	<a href="https://swscs.med.unsw.edu.au/group/psycho-oncology-research-group">https://swscs.med.unsw.edu.au/group/psycho-oncology-research-group</a> <a href="https://csr.h.arts.unsw.edu.au/event/addiction-related-patient-reported-outcome-measures/">https://csr.h.arts.unsw.edu.au/event/addiction-related-patient-reported-outcome-measures/</a> <a href="https://ndarc.med.unsw.edu.au/blog/development-patient-reported-outcome-measures-proms-addiction-science">https://ndarc.med.unsw.edu.au/blog/development-patient-reported-outcome-measures-proms-addiction-science</a>
Cancer Research Network - Patient Reported Outcomes Special Interest Group (University of Sydney)	Academic institution / research centre	NSW	NA	These groups provide advice about the use of PROMs relating to cancer care.	<p>The University of Sydney hosts the Cancer Australia QOL Chair, QOL Office, the Psycho-Oncology Co-operative Research Group (PoCoG) and the Patient-Reported Outcomes Special Interest Group (PRO-SIG).</p> <p>PoCoG was established in 2005, in response to a recognised need to develop the capacity and coordinated collaboration to conduct large-scale, multi-centre psycho-oncology and supportive care research. PoCoG is a member of the Cooperative Clinical Trials Groups of the Clinical Oncological Society of Australia, and is jointly funded by Cancer Australia and the Cancer Institute NSW, and is located in the School of Psychology, University of Sydney. Membership is open to researchers and health professionals from Australia and New Zealand. In 2013, the team was awarded Cancer Institute NSW funding to develop and implement an integrated e-health platform to support and enable cancer survivors to achieve and maintain improved health</p>	<a href="http://www.pocog.org.au/">http://www.pocog.org.au/</a> <a href="http://www.pocog.org.au/content.aspx?page=qoloffice">http://www.pocog.org.au/content.aspx?page=qoloffice</a> <a href="http://sydney.edu.au/cancer-research/intranet/interest_groups/prosig.php">http://sydney.edu.au/cancer-research/intranet/interest_groups/prosig.php</a>

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					<p>and wellbeing and better cancer outcomes.</p> <p>The PRO-SIG aims to provide a forum and focus for discussion of HRQoL/PRO-related issues and methods among Cancer Research Network members.</p> <p>It aims to:</p> <ul style="list-style-type: none"> <li>- facilitate the development of understanding and expertise in the measurement, analysis, interpretation and application of a broad range of PROs, including HRQoL among CRN members;</li> <li>- foster excellence in methodology for HRQoL/PRO endpoints in the research of CRN members;</li> <li>- foster cross-disciplinary collaborations within the CRN, bridging medical, psychological, behavioural and biostatistical disciplines;</li> <li>- mentor early career researchers from a range of disciplines in various aspects of HRQoL/PRO methodology; and</li> <li>- develop a critical and sustainable mass of HRQoL/PRO expertise within the CRN. The CRN includes some world leaders in various aspects of HRQoL/PRO assessment.</li> </ul>	
Arthroplasty Clinical Outcomes Registry (ACORN)	Academic institution / research centre	NSW	NA	Disease specific - Oxford Hip Score and Oxford Knee Score; generic EQ-5D, NHS satisfaction and success items.	ACORN was established in 2012 and as of 2014 had 6 participating hospitals in NSW. It aims to improve the quality and effectiveness of arthroplasty surgery, by monitoring, evaluating and reporting clinical outcomes (including generic, disease specific PROMs and satisfaction) and it routinely undertakes a 6 month follow-up of patients following surgery.	<a href="http://www.acornregistry.org/">http://www.acornregistry.org/</a>

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University of Sydney (Save Sight Institute)	Academic institution / research centre	NSW	The initiative seeks to promote improved outcomes for patients and organisations, particularly in the treatment of wet age-related macular degeneration, diabetic macular edema and keratoconus.	ICHOM data set including PROMs.	Save Sight Institute's Registries online platform analyses real life treatment outcomes globally. The first two modules were for macular degeneration and diabetic retinopathy, and a third module, keratoconus, has been added to the registries framework. The keratoconus module will collect and analyse real time clinical data and patient outcomes from current and emerging approaches to managing keratoconus. Collagen cross-linking will be the first treatment examined, making the module the world's first large-scale assessment of collagen cross-linking. Clinical Professor Stephanie Watson, who heads the keratoconus module, is Sydney based. Although PROMs are used no details are provided. The Centre for Eye Research also collaborates with Save Sight Institute on the Australian Keratoconus Registry. Various patient-reported outcome questionnaires are documented related to eye / vision / ophthalmology.	<a href="http://www.savesightinstitute.org.au/">http://www.savesightinstitute.org.au/</a> <a href="http://www.optometry.org.au/blog-news/2016/1/5/collagen-corneal-cross-linking-registry/">http://www.optometry.org.au/blog-news/2016/1/5/collagen-corneal-cross-linking-registry/</a> <a href="http://sydney.edu.au/medicine/eye/news/2014-keratoconus-registry.php">http://sydney.edu.au/medicine/eye/news/2014-keratoconus-registry.php</a> <a href="http://www.savesightinstitute.org.au/news/save-sight-registries-set-global-benchmark-for-research/">http://www.savesightinstitute.org.au/news/save-sight-registries-set-global-benchmark-for-research/</a> <a href="http://www.savesightinstitute.org.au/news/world-first-in-fight-against-corneal-disease/">http://www.savesightinstitute.org.au/news/world-first-in-fight-against-corneal-disease/</a>
University of Technology Sydney (Centre for Health Economics Research and Evaluation)	Academic institution / research centre	NSW	NA	Uses generic and multi-attribute utility measures in research and evaluation studies.	Their research is largely health economic evaluation focused but with a number of PROMs related projects - Developing MAU instrument weights (a type of PROM used in economic evaluation e.g. SF-6D, EQ5D, AQL), Economic evaluation of falls project, CREST-liaison with Cancer Australia QOL office, an HRQoL Prostate project where PROMs measures are used.	<a href="http://www.uts.edu.au/research-and-teaching/our-research/health-economics-research-and-evaluation">http://www.uts.edu.au/research-and-teaching/our-research/health-economics-research-and-evaluation</a>

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<b>Victorian organisations</b>						
Deakin University (Centre for Quality and Patient Safety Research)	Academic institution / research centre	VIC	NA	No specific information on PROMs was identified.	The Centre for Quality and Patient Safety Research is based within the Faculty of Health. The Centre focuses on translational research in clinical care, quality and risk management. The Centre has a particular interest in investigating patients' and family members' experiences of health services.	<a href="https://www.deakin.edu.au/research/qps">https://www.deakin.edu.au/research/qps</a>
Deakin University (Australian Centre on Quality of Life)	Academic institution / research centre	VIC	NA	Generic and condition specific measures. Various projects are conducted using QOL instruments.	The Australian Centre on Quality of Life facilitates research into quality of life. It has a primary focus on overall quality of life and well-being and the Director, Prof Robert Cummins has developed patient-reported measures of this type. It has an instrument resource page which provides links to recent articles about leading QOL/HRQoL/ PROMs measures. Prof Richard Osborne at Deakin University (Public Health) also has a long track record of outcomes research concerning using PROMs and other measures, and papers concerning response shift effects in the measurement of PROMs.	<a href="http://www.acqol.com.au/">http://www.acqol.com.au/</a> <a href="http://www.acqol.com.au/instruments/">http://www.acqol.com.au/instruments/</a>
Dental Health Services Victoria	Government department/ entity	VIC	NA	NA	The <i>High-performing health services: Victorian health service performance monitoring framework 2015–16</i> (mentioned elsewhere in this table) applies to Dental Health Services Victoria	<a href="https://www.dhsv.org.au/">https://www.dhsv.org.au/</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Department of Health and Human Services	Government department/entity	VIC	NA	Refer to particular centres supported by the Department of Health and Human Services with a focus on PROMs.	<p><i>High-performing health services: Victorian health service performance monitoring framework 2015–16</i> notes current state of PROMs and planned future use.</p> <p>An overview of the Health Innovation and Reform Council's tool to report on the health and wellbeing outcomes of Victorians is available. The Framework responds to the <i>Victorian Health Priorities Framework 2012-2022</i> priority area of 'increasing accountability and transparency'. Within the Framework, the two higher-level outcomes have a number of component parts, each of which has one or more interim indicators reported against it. The Framework includes the measurement of patient experience, health outcomes (with a specific focus on quality and safety), efficiency and effectiveness.</p> <p>The Department of Health and Human Services released <i>Health 2040: A discussion paper on the future of healthcare in Victoria</i> in September 2015. In this discussion paper, six broad themes are identified as starting points for further exploration of healthcare reform direction. At the heart of these themes is the idea that the healthcare system should be designed from the perspective of the people who use the system. These themes include 'A person-centred view of healthcare' and 'Improving people's health outcomes and experience.'</p>	<p><a href="https://www2.health.vic.gov.au/">https://www2.health.vic.gov.au/</a>  <a href="http://dhhs.vic.gov.au/">http://dhhs.vic.gov.au/</a></p>
Department of Health and Human Services	Government department/entity	VIC	Victorian Cancer Survivorship Program - Phase I	A variety of PROMs were used to measure project outcomes.	The project <i>Positive Change for Life cancer survivorship pilot</i> (part of Victorian Cancer Survivorship Program at The Alfred) included PROMs, which were recorded at baseline and following 6 and 12 months of project participation and included quality of life scales, fatigue assessments, self-efficacy scores, physical activity and nutrition questionnaires.	<p><a href="https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-survivorship-program">https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-survivorship-program</a></p>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Department of Health and Human Services – Victorian Comprehensive Cancer Centre	Government department/entity	VIC	Measuring quality of life after cancer	<p>The five PROMs questionnaires contained 58 common questions and between 9-24 additional questions, depending on cancer type, drawn from existing validated tools.</p> <p>In 2014, conducted a quality of life survey for people living with and beyond cancer in Victoria in collaboration with the Cancer Council Victoria (CCV) Victorian Cancer Registry (VCR).</p>	<p>In 2014, fieldwork was completed for a state-wide PROMs survey, which aimed to assess the quality of life of cancer survivors in Victoria with five different cancer types and at three different time points since diagnosis. The NHS PROMs questionnaires for breast, bowel, prostate cancer and non-Hodgkin lymphoma were used, and in addition the VCCC developed a fifth questionnaire for survivors of melanoma. Eligible participants were identified and recruited through the Victorian Cancer Registry and the survey data is currently being analysed. The data will be used to assess the contribution that demographics, disease-related and other factors have on quality of life to inform future programs.</p>	<p><a href="https://www.victorianccc.org.au/our-work/living-with-cancer/">https://www.victorianccc.org.au/our-work/living-with-cancer/</a></p>
Department of Health and Human Services – Victorian Comprehensive Cancer Centre	Public healthcare provider	VIC	Patient information will be used to drive quality-improvement initiatives and better models of clinical care. This is part of the VCCC's commitment to reduce the burden of cancer and ensure patient needs are met.	<p>Uses the NHS questionnaire that is cancer specific and spans the care trajectory, from diagnosis and treatment through to follow-up care.</p>	<p>Under the <i>Living with Cancer Program</i>, the VCCC have initiated a cancer patient experience survey to track progress in future years. The survey is based on that used in the UK and will allow benchmarking against the UK as a whole and against UK institutions specifically. The study on PROMs will also enable benchmarking and document patient quality of life.</p>	<p><a href="http://www.vcccproject.vic.gov.au/">http://www.vcccproject.vic.gov.au/</a></p> <p><a href="https://www.victorianccc.org.au/our-work/living-with-cancer/">https://www.victorianccc.org.au/our-work/living-with-cancer/</a></p>

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Department of Health and Human Services – Monash Health	Public healthcare provider	VIC	NA	Uses PROMs relevant for hip and knee replacements	<p>Monash Health Department of Orthopaedics is undertaking a project: <i>Enhanced Recovery after Surgery (ERAS) Program for Hip and Knee Replacements</i>.</p> <p>Tran T; Mutalima N. Outcome: Improvement of management of primary hip and knee replacements leading to better patient pain management, reduced length of stay and improved patient-reported outcomes.</p>	<p><a href="http://www.monashhealth.org/">http://www.monashhealth.org/</a>  <a href="http://www.monashhealth.org/index.php?option=com_page&amp;controller=page&amp;task=download_document&amp;node_id=187917">http://www.monashhealth.org/index.php?option=com_page&amp;controller=page&amp;task=download_document&amp;node_id=187917</a></p>
Department of Health and Human Services – Peter MacCallum Cancer Centre	Public healthcare provider	VIC	Program aims to develop, implement and evaluate a pilot model of survivorship care for young people diagnosed with cancer between the ages of 15-25 in Victoria.	This project included several PROMs including: AYA Survivorship Screening Tool, AQL-6D, SF-12 and PEQ.	The <i>Survivorship Connections: A Pilot Model of Post Treatment Shared Survivorship Care for Adolescent and Young Adult (AYA) Cancer Patients in Victoria</i> Program aims to develop, implement and evaluate a pilot model of survivorship care for young people diagnosed with cancer between the ages of 15-25 in Victoria.	<p><a href="http://www.petermac.org/">http://www.petermac.org/</a>  <a href="https://www.petermac.org/sites/default/files/media-uploads/Survivorship%20Connections%20Final%20Report-%20VCSP%20Final%20Report.pdf">https://www.petermac.org/sites/default/files/media-uploads/Survivorship%20Connections%20Final%20Report-%20VCSP%20Final%20Report.pdf</a></p>
Department of Health and Human Services – The Royal Melbourne Hospital	Public healthcare provider	VIC	To help improve outcomes for Australians with hip and knee joint pain.	Hip and knee related PROMs.	The HCF Research Foundation is funding the implementation of the <i>ICHOM Standard Set for Hip and Knee Osteoarthritis</i> at Royal Melbourne Hospital.	<a href="https://www.thermh.org.au/">https://www.thermh.org.au/</a>

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Epworth HealthCare (Epworth Knowledge Bank)	Private healthcare provider	VIC	NA	Quality of life questionnaire	Epworth HealthCare is Victoria's largest not-for-profit private health care group. No specific documentation about PROMs identified on the Epworth website, however, Epworth participates in the Prostate Cancer Registry (PCR). The PCR role is to monitor and allow benchmarking of quality of care by institutions and individual surgeons and radiation oncologists in the care of prostate cancer patients. Information collected includes patient response to a quality of life questionnaire at 12 and 24 months post diagnosis, from a follow-up phone call to the participant.  Several journal articles on PROMs authored by Epworth clinicians / researchers were identified.	<a href="http://knowledgebank.epworth.org.au/epworthjspui/about.jsp">http://knowledgebank.epworth.org.au/epworthjspui/about.jsp</a>
Grattan Institute	Academic institution / research centre	VIC	NA	NA	Includes link to Duckett's essay: <i>The need for a regulatory rethink: a perspective from Australia</i> . This essay argues for the wider use of new instruments including PROMs.	<a href="https://grattan.edu.au/news/the-need-for-a-regulatory-rethink-a-perspective-from-australia/">https://grattan.edu.au/news/the-need-for-a-regulatory-rethink-a-perspective-from-australia/</a>
Melbourne Institute (University of Melbourne)	Academic institution / research centre	VIC	NA	NA	Institute members (particularly Professor Anthony Scott) have published about options for supporting value-based health care in Medicare using value-based payment models. Values-based health care is increasingly associated with the use of health outcome indicators and PROMs.	<a href="https://www.melbourneinstitute.com/downloads/economic_forums/June2015/Scott_Tony_30June15.pdf">https://www.melbourneinstitute.com/downloads/economic_forums/June2015/Scott_Tony_30June15.pdf</a> <a href="http://benews.unimelb.edu.au/category/institute/">http://benews.unimelb.edu.au/category/institute/</a>



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Monash University (Victorian State Trauma Outcomes Registry Monitoring Group - VSTORM)	Academic institution / research centre	VIC	The aim of the registry is to collect information about all patients from every hospital and health care facility managing trauma patients in Victoria.	VSTORM: Adults SF-12, EQ-5D-3L, Glasgow Outcome Scale – Extended (GOS-E), Numerical rating scale for pain, Return to work and work disability questions, Paediatric King’s Outcomes Scale for Closed Head Injury (KOSCHI), Pediatric Quality of Life Inventory (PedsQL), Linkage Coroner’s data, State deaths registry, TAC claims data, Department of Health data.	The Department of Human Services (now Department of Health) commissioned the Victorian State Trauma Registry (VSTR) in 2001 in collaboration with the Transport Accident Commission Health Research. The registry provides a mechanism to monitor the system to inform service provision and development with an aim to reduce preventable deaths and permanent disability from major trauma. Changes to systems of care are monitored to ensure outcomes are improving including the reduction in deaths and disability over time.	<a href="http://www.med.monash.edu.au/sphpm/creps/">http://www.med.monash.edu.au/sphpm/creps/</a> <a href="http://www.med.monash.edu.au/epidemiology/traumaepi/traumareg/">http://www.med.monash.edu.au/epidemiology/traumaepi/traumareg/</a> <a href="http://www.med.monash.edu.au/assets/docs/creps/2015/proms2015_belinda_gabbe.pdf">http://www.med.monash.edu.au/assets/docs/creps/2015/proms2015_belinda_gabbe.pdf</a> <a href="http://www.med.monash.edu.au/sphpm/honours/projects-2015/prostate-cancer-study.html">http://www.med.monash.edu.au/sphpm/honours/projects-2015/prostate-cancer-study.html</a>
Monash University (Faculty of Medicine and Centre of Research Excellence in Patient Safety)	Academic institution / research centre	VIC	NA	NA	The Centre of Research Excellence in Patient Safety (CRE-PS) was established in late 2005. Their research focuses on four main areas: the use of data to monitor quality of care, improving information transfer, reducing medication error and patient safety. CRE-PS is a part of the School of Public Health and Preventive Medicine. They have hosted a conference concerning PROMs: <i>Patient-Reported Outcome Measures (PROMs): new horizons in health-related quality of life improvements</i> (25-26 June 2015) and also have a project in MNHS Research Project database: Patient-reported outcome measures in multiple myeloma.	<a href="http://www.med.monash.edu.au/">http://www.med.monash.edu.au/</a> <a href="http://www.med.monash.edu.au/sphpm/creps/">http://www.med.monash.edu.au/sphpm/creps/</a>

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Monash University (Clinical Quality Registries)	Academic institution / research centre	VIC	The primary purpose of a clinical registry is to monitor patient outcomes and report on the quality of the care for a medical disease or condition, or for an area or specialisation of health service provision.	Registries currently collecting PROMs <ul style="list-style-type: none"> <li>• VSTORM –trauma EQ5D measuring <ul style="list-style-type: none"> <li>– usual activities</li> <li>– Mobility</li> <li>– pain/discomfort</li> <li>– personal care</li> <li>– anxiety/depression</li> </ul> </li> <li>• Victorian Cardiac Outcomes Registry-EQ5D</li> <li>• Victorian Lung Cancer Registry-SF12 * no short form disease-specific tool</li> <li>• Prostate Cancer Outcome Registry-Australia and New Zealand</li> </ul>	Clinical registries are large databases that are managed and analysed to: <ul style="list-style-type: none"> <li>– Identify variation in treatment and outcomes (including PROMs)</li> <li>– Monitor appropriateness of treatment</li> <li>– Identify deficiencies in access to treatment</li> <li>– Provide an early warning system if care deteriorates</li> <li>– Facilitate research to improve quality of care.</li> </ul> <p>The primary aim of the Prostate Cancer Outcomes Registry - Australia and New Zealand (PCOR-ANZ) is to improve the quality of care provided to men with prostate cancer. Information from the registry will be used to monitor diagnosis, treatment, complications, and long term quality of life outcomes. This information will be used to help identify trends and whether gaps exist in service provision. Appears to be under construction, will include some PROM data.</p>	<a href="http://www.registries.org.au/cqr.html">http://www.registries.org.au/cqr.html</a> <a href="http://www.med.monash.edu.au/assets/docs/creps/2015/proms2015_sueevans.pdf">http://www.med.monash.edu.au/assets/docs/creps/2015/proms2015_sueevans.pdf</a>
Monash University (Victorian Orthopaedic Trauma Outcomes Registry)	Academic institution / research centre	VIC	The registry collects information about orthopaedic injuries, treatment, complications and outcomes based on admissions to adult Major Trauma Service hospitals in Victoria.	VOTOR includes measures of pain and HRQoL (uses EQ-5D).	The <i>Injury Burden and Outcomes Program</i> of VOTOR is to facilitate and conduct research focused on quantifying the burden of orthopaedic trauma, and validating and improving methods for measuring burden and outcomes (including health-related quality of life).	<a href="http://www.votor.org.au/">http://www.votor.org.au/</a> <a href="http://www.med.monash.edu.au/epidemiology/traumaepi/orthoreg.html">http://www.med.monash.edu.au/epidemiology/traumaepi/orthoreg.html</a> <a href="http://www.registries.org.au/registries/votor.html">http://www.registries.org.au/registries/votor.html</a>

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Centre for Eye Research Australia	Academic institution / research centre	VIC	NA	Various PRO questionnaires are documented related to eye / vision / ophthalmology.	Collaborates with Save Sight Institute on the Australian Keratoconus Registry.	<a href="http://www.cera.org.au/pro-questionnaires/">http://www.cera.org.au/pro-questionnaires/</a> <a href="http://sydney.edu.au/medicine/eye/news/2014-keratoconus-registry.php">http://sydney.edu.au/medicine/eye/news/2014-keratoconus-registry.php</a>
Transport Accident Commission, (TAC) Victoria	Government department/ entity	VIC	To understand and measure client outcomes.	Generic health status and psychosocial factors.	The TAC's goals have evolved to include monitoring performance in relation to the client experience, and to a broader focus on understanding and measuring client outcomes. A comprehensive internal program of research has been developed to inform continuous improvement against client experience, and to support the TAC's understanding of client outcomes. The most recent development in this program was a longitudinal client outcome study. The study developed and implemented by the TAC was a multi-cohort longitudinal study that tracked the experience and outcomes of clients as they returned to health (and work, where relevant) following a transport accident. Clients were interviewed four times over a two-year period post-accident. The questionnaires used in the study covered pre-accident health and vocational status to accident circumstances and injury characteristics to post-accident health, vocational status, psycho-social factors and environmental considerations.	<a href="https://www.tac.vic.gov.au/">https://www.tac.vic.gov.au/</a> <a href="http://www.tac.vic.gov.au/about-the-tac/our-organisation/research/tac-neurotrauma-research/targeted-initiatives">http://www.tac.vic.gov.au/about-the-tac/our-organisation/research/tac-neurotrauma-research/targeted-initiatives</a>
Worksafe Victoria	Government department/ entity	VIC	NA	Kessler 10, Patient-Specific Functional Scale etc.	Outlines patient-reported and clinician reported health outcomes scales for health professional use; refers to similar material from Transport Accident Commission, Australian Physiotherapy Association, UK National Centre for Health Outcome Development, Centre for Outcome Measures for Brain Injury.	<a href="http://www.worksafe.vic.gov.au/health-professionals/treating-injured-workers/outcome-measures">http://www.worksafe.vic.gov.au/health-professionals/treating-injured-workers/outcome-measures</a>

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SA-Vic Prostate Cancer Registry	Consortium/ collaborative	VIC and SA	Development of South Australian-Victorian Prostate Cancer Health Outcomes Research Dataset.	Disease specific PROMs for prostate cancer.	A total of 13,598 de-identified records of men with prostate cancer diagnosed and consented between 2008 and 2013 in South Australia and Victoria were merged into the SA-VIC PCHORD. SA-VIC PCHORD contains detailed information about socio-demographic, diagnostic and treatment characteristics of patients with prostate cancer in South Australia and Victoria. Quality of life / PROMs data is also included but different historical approaches to data collection currently prevents the PROMs data from being merged, the EPIC-26 measure will be used in the future.	<a href="http://dspace.flinders.edu.au/xmlui/handle/2328/36179">http://dspace.flinders.edu.au/xmlui/handle/2328/36179</a>
<b>South Australian organisations</b>						
Flinders Centre for Ophthalmology, Eye and Vision Research, Flinders University	Academic institution / research centre	SA	NA	EUREQUO (European Registry of Quality Outcomes for Cataract and Refractive Surgery) database measures related to vision outcomes.	Measuring vision specific quality of life: loss of eyesight affects 500,000 Australians and costs the country nearly \$10 billion a year in health and community support. While eye disease is the focus of considerable clinical research, the overall impact of the disease and treatment on the patient's quality of life needs further exploration. The Flinders team is undertaking research to develop more effective ways of evaluating medical treatments from the patient's perspective. The project is using new technology to develop an internet-based measurement system that is adaptable and far more accurate than current questionnaire programs. The aim is to make it valid for use across the English-speaking world.	<a href="http://www.flinders.edu.au/medicine/sites/ophthalmology/research/">http://www.flinders.edu.au/medicine/sites/ophthalmology/research/</a>
Population Research and Outcome Studies Unit, Discipline of Medicine, The University of Adelaide for SA Health Safety and Quality Unit	Academic institution / research centre	SA	The results from the SACCESS are used to guide policy development, help SA Health reach and exceed its benchmarks and ultimately	Uses generic and disease or condition specific measures in research surveys and projects.	This unit has now moved to the University of Adelaide from the SA Health Department. It aims to provide the best available epidemiological evidence on the impact of, and outcomes relating to, both established and emerging relevant health and wellbeing priorities and to provide epidemiological information on priority chronic diseases/conditions and their determinants. Has used the South Australian Health Omnibus Survey to provide latest norms for SF-36V2 instrument which is a commonly used generic PROM.  The South Australian Consumer Experience Surveillance System	<a href="http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/safety+and+quality/safety+and+quality+reports">http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/safety+and+quality/safety+and+quality+reports</a>  <a href="http://www.safetyandquality.gov.au/w">http://www.safetyandquality.gov.au/w</a>

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			improve health outcomes for all South Australians.		(SACCESS) has a PREMs focus, surveys conducted in 2013, 2014, 2015 with a representative, randomly selected, monthly sample of South Australian adults, aged 16 years or more who have received inpatient care. CATI used.	<a href="p-content/uploads/2012/03/Dr-Kerena-Eckert.pdf">p-content/uploads/2012/03/Dr-Kerena-Eckert.pdf</a>
International Centre for Allied Health Evidence, University of South Australia	Academic institution / research centre	SA	NA	iCAHE Outcome Calculators	The International Centre for Allied Health Evidence website houses five outcome calculators: basic outcomes calculator, musculoskeletal, neurological disorders, incontinence and chronic disease measurement. The outcome measures contained within the iCAHE Outcomes Calculator Version 5 have been selected on their psychometric properties (validity, reliability, sensitivity to detect change over time and clinical utility for patient populations with peripheral joint disorders). The outcome measures represent several aspects of functioning and / or disability, which are measured at the level of body functions / structure, the individual and society, as defined by the International Classification of Functioning. (Commercial tools developed by Sansom Institute for Health Research).	<a href="http://www.unisa.edu.au/Research/Sansom-Institute-for-Health-Research/Research/Allied-Health-Evidence/Resources/OC/">http://www.unisa.edu.au/Research/Sansom-Institute-for-Health-Research/Research/Allied-Health-Evidence/Resources/OC/</a>
Royal Adelaide Hospital (Immunology Unit)	Public healthcare provider	SA	NA	NA	A scoring system for PROs that incorporates both the Urticaria Activity Score (UAS) and daily medications used.	<a href="https://www.sahealth.sa.gov.au/wps/wcm/connect/4d9d1880477dd3418e67bedd1460951d/Omalizumab_severe+urticaria_final_web+summary_2014.pdf?MOD=AJPERES&amp;CACHEID=4d9d1880477dd3418e67bedd1460951d">https://www.sahealth.sa.gov.au/wps/wcm/connect/4d9d1880477dd3418e67bedd1460951d/Omalizumab_severe+urticaria_final_web+summary_2014.pdf?MOD=AJPERES&amp;CACHEID=4d9d1880477dd3418e67bedd1460951d</a>

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Coronary Angiogram Database of South Australia (CADOSA)	Consortium/ collaborative	SA	To improve the quality of care provided to cardiovascular patients.	CADOSA collects 12-month PROMs. The data is collected from the four public hospitals in Adelaide with catheterisation labs (if an angiogram is performed) – the Royal Adelaide Hospital, The Queen Elizabeth Hospital, Flinders Medical Centre, and Lyell McEwin Hospital.	CADOSA is a statewide quality improvement clinical registry program. The CADOSA Project was established in 2011, and has been collecting consistent hospital-based data since 2012. A similar program in the United States called the National Cardiovascular Data Registry has aided as a model framework for the development of the CADOSA registry. In addition, CADOSA collects the data recommended by the ICHOM which includes both health outcome related indicators and PROMs data. Undertakes data comparisons with a similar Victorian registry.	<a href="http://www.cadosa.org/wordpress/">http://www.cadosa.org/wordpress/</a> <a href="http://www.phcris.org.au/events/docs/summary_reducing_gap_wshop2016.pdf">http://www.phcris.org.au/events/docs/summary_reducing_gap_wshop2016.pdf</a> <a href="https://www.health.qld.gov.au/publications/clinical-practice/engagement/qcs-pp-1603-beltrame.pdf">https://www.health.qld.gov.au/publications/clinical-practice/engagement/qcs-pp-1603-beltrame.pdf</a>
SA Health (Clinical Data Steering Committee)	Government department/ entity	SA	NA	NA	Committee is accountable for Streams 2 and 3 of the <i>SA Health Clinical Data Strategy</i> . Committee underpinned by SA policy <i>Transforming Health, which emphasises the importance of patient-reported outcomes, patient clinical outcomes and system outcomes for quality of care.</i>	<a href="http://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Clinical+resources/Clinical+Data+Strategy/">http://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Clinical+resources/Clinical+Data+Strategy/</a>
South Australian Health Omnibus Survey	Academic institution / research centre	SA	NA	<i>A Population Profile of Quality of Life in South Australia (2009) - generic, disease and condition specific PROMs - population health surveys - provision of normative data re PROMs.</i>	A user pays population health survey in which normative data for commonly used PROMs can be collected. It was used to collect Australian normative data in 2004 for the SF-36V2 (Measuring Incontinence in Australia, 2006) and in 2008.	<a href="http://www.harrisonresearch.com.au/health_omnibus.php">http://www.harrisonresearch.com.au/health_omnibus.php</a>
SA Health	Government department/ entity	SA	NA	HRQoL measures listed for Chronic Idiopathic Urticaria (CIU).	PRO tools for measuring HRQoL in CIU are listed in an evaluation summary (omalizumab for treatment of severe idiopathic urticaria).	<a href="http://www.sahealth.sa.gov.au/">http://www.sahealth.sa.gov.au/</a> <a href="https://www.sahealth.sa.gov.au/wps/wcm/connect/4d9d1880477dd3418e6">https://www.sahealth.sa.gov.au/wps/wcm/connect/4d9d1880477dd3418e6</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
						<a href="http://7bedd1460951d/Omalizumab_severe+urticaria_final_web+summary_2014.pdf?MOD=AJPERES&amp;CACHEID=4d9d1880477dd3418e67bedd1460951d">7bedd1460951d/Omalizumab_severe+urticaria_final_web+summary_2014.pdf?MOD=AJPERES&amp;CACHEID=4d9d1880477dd3418e67bedd1460951d</a>
South Australian Prostate Cancer Clinical Outcome Collaborative (SA-PCCOC)	Consortium/ collaborative	SA	Clinical audit, monitoring outcomes of care for men with prostate cancer in South Australia	Outcomes measured include biochemical recurrence, prostate-specific death and death from any cause, pathology, treatment outcomes and complications. Patient-reported symptoms and quality of life data is also collected.	The South Australian Prostate Cancer Clinical Outcome Collaborative (SA-PCCOC) is a disease -specific registry that is a collaborative venture of the University of Adelaide, Flinders University, The Queen Elizabeth Hospital, the Royal Adelaide and the Repatriation General Hospital.	<a href="http://www.sapccoc.com/">http://www.sapccoc.com/</a>
<b>Western Australian organisations</b>						
Department of Health WA	Government department/ entity	WA	<i>Measuring Patient Satisfaction in Western Australia : Overview of 2005 - 2006 Survey Results (March 2007)</i>	Patient-satisfaction. Touch screen use.	There was limited information about PROMs accessible through the Western Australian Department of Health website. The Department has conducted surveys of patient satisfaction. The <i>Western Australia Strategic Plan for Safety and Quality in Health Care 2013 -2017</i> explains the approach to measurement and reporting of safety and quality measures across the WA Health system and includes a strategy to learn from consumers' and carers' experiences. In addition, Chen (2011) notes 'In a small study, Halkett and colleagues (2010) evaluated the use of a touch-screen system in comparison to written questionnaires in a large tertiary hospital in Western Australia.'	<a href="http://ww2.health.wa.gov.au/">http://ww2.health.wa.gov.au/</a>  <a href="http://ww2.health.wa.gov.au/Reports-and-publications/Western-Australian-Strategic-Plan-for-Safety-and-Quality-in-Health-Care">http://ww2.health.wa.gov.au/Reports-and-publications/Western-Australian-Strategic-Plan-for-Safety-and-Quality-in-Health-Care</a>
University of Western Australia	Academic institution / research	WA	NA	NA	The University of WA research repository identifies several researchers interested in PROMs.	<a href="http://research-repository.uwa.edu.au/en/">http://research-repository.uwa.edu.au/en/</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
	centre					<a href="http://research-repository.uwa.edu.au/en/publications/achieving-valid-patientreported-outcomes-measurement-a-lesson-from-fatigue-in-multiple-sclerosis(27e061c8-f522-411a-bf4f-0d446685b6d8).html">http://research-repository.uwa.edu.au/en/publications/achieving-valid-patientreported-outcomes-measurement-a-lesson-from-fatigue-in-multiple-sclerosis(27e061c8-f522-411a-bf4f-0d446685b6d8).html</a>
Edith Cowan University (Survey Research Centre)	Academic institution / research centre	WA	Patient Evaluation of Health Services (PEHS) survey	NA	Western Australia - for patients following a hospital admission. It contains non-condition-specific questions about functioning and quality of life, but also questions about the person's experiences of their care episode. Conducted annually using CATI.	<a href="http://www.ecu.edu.au/faculties/health-engineering-and-science/research-activity/research-centres/survey-research">www.ecu.edu.au/faculties/health-engineering-and-science/research-activity/research-centres/survey-research</a>
<b>Queensland organisations</b>						
Queensland Health	Government department/ entity	QLD	Results of statewide surveys will be used in monitoring and evaluating the quality of health services provided and to assist in quality improvement	NA	Statewide CATI surveys (with PREMs focus) in settings including general surgery, specialist outpatient clinics, maternity and orthopaedic specialist outpatient clinics, ED and small hospitals.	<a href="https://www.health.qld.gov.au/">https://www.health.qld.gov.au/</a>  <a href="https://www.health.qld.gov.au/system-governance/performance/patient-experience/">https://www.health.qld.gov.au/system-governance/performance/patient-experience/</a>



Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
			activity planning at the facility and statewide levels.			
Queensland Health	Government department/entity	QLD	NA	NA	<p><i>Compendium of Clinical Measures for Community Rehabilitation:</i> outcome measures relevant to community rehabilitation services were identified.</p> <p>Queensland Health also employing a 'Principal Project Officer, Survey and Audit' - the purpose of this role is to develop, coordinate and implement strategic statewide patient safety and quality survey and audit measurement programs and initiatives, using project management methods for programs or initiatives such as Patient Experience Surveys and PROMs.</p>	<p><a href="https://www.health.qld.gov.au/ghcrw/docs/clinical_measure.pdf">https://www.health.qld.gov.au/ghcrw/docs/clinical_measure.pdf</a></p> <p><a href="https://smartjobs.qld.gov.au/jobtools/b_fileupload.proc_download?in_file_id=15750875&amp;in_servicecode=CUSTOMSEARCH&amp;in_organi d=14904&amp;in_sessionid=0&amp;in_hash_key=61FE8E6588DA711E3DC9FE0FAC846E7E">https://smartjobs.qld.gov.au/jobtools/b_fileupload.proc_download?in_file_id=15750875&amp;in_servicecode=CUSTOMSEARCH&amp;in_organi d=14904&amp;in_sessionid=0&amp;in_hash_key=61FE8E6588DA711E3DC9FE0FAC846E7E</a></p>
Queensland Health (Queensland Clinical Senate)	Government department/entity	QLD	NA	NA	Meeting on 17-18 March 2016 'Value based healthcare—shifting from volume to value' had components about PROMs and ICHOM standard sets. Dr Soderlund presentation (from Health Outcomes Australia, associated with ICHOM) to Queensland Health ('Value in Healthcare – Some Global Perspectives') discussed value in health care, outcome-related benchmarking using health outcome related indicators and PROMs, and associated roles of clinical registries and ICHOM datasets.	<a href="https://www.health.qld.gov.au/publications/clinical-practice/engagement/qcs-meeting-report-201603.pdf">https://www.health.qld.gov.au/publications/clinical-practice/engagement/qcs-meeting-report-201603.pdf</a>
Metro South Health	Public healthcare provider	QLD	NA	NA	Metro South Health's <i>Integrated Health Strategy 2015-2017</i> mentions implementing the use of PROMs and PREMs.	<a href="https://metrosouth.health.qld.gov.au/sites/default/files/integrated_health_strategy_-">https://metrosouth.health.qld.gov.au/sites/default/files/integrated_health_strategy_-</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
						<a href="#">internal_020915.pdf</a>
Centre of National Research on Disability and Rehabilitation Medicine (CONROD)	Academic institution / research centre	QLD	NA	Measures of pain, function, health status.	CONROD recently changed its name to the Recover Injury Research Centre. It is a joint initiative of the University of Queensland, Griffith University and the Motor Accident Insurance Commission established in 1997. It was home to the Queensland Trauma Registry until 2012 (when it merged with the Australian Trauma Registry) and it undertakes research on disability and rehabilitation, which often includes the use of PROMs (e.g. pain, function, health status.)	<a href="http://www.conrod.org.au/cms/">http://www.conrod.org.au/cms/</a>
University of Queensland (in collaboration with University of Newcastle – Australian Longitudinal Study on Women’s Health)	Academic institution / research centre	QLD	Assessment of women’s physical and mental health.	Numerous PROMs style instruments have been included in the survey and included in sub-study research projects.	The Australian Longitudinal Survey of Women’s Health (ALSWH) is a longitudinal survey of over 58,000 women in three age cohorts and surveys began in 1996. Using PROMs and other items ALSWH assesses women’s physical and mental health, as well as psychosocial aspects of health (such as socio-demographic and lifestyle factors) and their use of health services. ALSWH has provided data about the health of women across the lifespan, and helped to inform government policies across numerous issues. Although population health focused numerous sub-studies, including data linkage studies with mortality and health service utilisation databases reflect on quality of care e.g. falls, angina, depression.	<a href="http://www.alswh.org.au/">http://www.alswh.org.au/</a>
<b>Tasmanian organisations</b>						
Department of Health and Human Services (Tasmania)	Government department/ entity	TAS	NA	NA	The Department of Health and Human Services in Tasmania does not currently have any information relating to PROMs available on its website. The Department does periodically conduct population health surveys.	<a href="http://www.dhhs.tas.gov.au/">http://www.dhhs.tas.gov.au/</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
<b>Northern Territory organisations</b>						
Department of Health (Northern Territory)	Government department/entity	NT	NA	NA	The website of the Northern Territory (NT) Department of Health does not include information about the use of PROMs on a jurisdictional or health district level. This does not necessarily mean that activity is not occurring in the implementation of PROMs. For example the Department has a long history of work relating to Aboriginal health outcomes and the NT Department of Health's Epidemiology Unit has undertaken population health surveys, which may have included some PROM type items. The Menzies School of Health Research has a Masters elective in Health Outcomes Measurement and Management (coordinated by Associate Professors Senior and Sansoni of the University of Wollongong), in their Masters of Public Health program. The NT Prostate Cancer Registry also collaborates with the SA Prostate Cancer Registry.	<a href="http://www.health.nt.gov.au/">http://www.health.nt.gov.au/</a>
<b>Australian Capital Territory organisations</b>						
ACT Health	Government department/entity	ACT	NA	NA	<p>The ACT Health Population Division conducts population surveys, for example, Health and Wellbeing of Older Persons in the ACT, that include some self-reported health status and psychological distress items. It collaborates with local universities, for example the Australian National University, in reports such as 'Mental Health and Wellbeing in the ACT' (Morris et al. 2011), which included a variety of self-reported health status and PROM style measures (e.g. depression, coping styles, resilience).</p> <p>ACT Health supports activity in trauma and orthopaedic research and the Trauma and Orthopaedic Research Unit (TORU), which is founded within the Australian National University Medical School. The iFracture data collection system is supporting the longitudinal measurement of patient-reported outcomes for fracture trauma cases presenting to the Canberra Hospital.</p>	<a href="http://www.health.act.gov.au/">http://www.health.act.gov.au/</a>  <a href="http://www.health.act.gov.au/healthy-living/population-health">http://www.health.act.gov.au/healthy-living/population-health</a>  <a href="http://www.health.act.gov.au/datapublications/research/trauma-and-orthopaedic-research/toru-projects">http://www.health.act.gov.au/datapublications/research/trauma-and-orthopaedic-research/toru-projects</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Centre for Advances in Epidemiology and Information Technology (CAEIT)	Academic institution / research centre	ACT	NA	Researchers from this Centre have used generic (e.g. SF-36), symptom and disease-specific PROMs (vary by disease) in research applications and has developed a real time system for PROMs data collection.	The main focus of the Centre for Advances in Epidemiology and IT has been the creation of a sustainable growth model for knowledge generation in healthcare. Known as Turning Research into Practice (TRIP), the program has a three-tier approach incorporating: 1) the research process; 2) generation of predictive models to improve individual patient outcomes; and 3) a focus on efficient service delivery using an evidence-based model. An IT model developed by CAEIT was developed into a commercial IT system called DiscoverQuick that is useful for monitoring patient health outcomes in routine practice and in real time.	<a href="http://health.act.gov.au/sites/default/files/ACT%20Health%20Research%20Review%202011-2012%20Part%202.pdf">http://health.act.gov.au/sites/default/files/ACT%20Health%20Research%20Review%202011-2012%20Part%202.pdf</a>  <a href="http://health.act.gov.au/sites/default/files/ACT%20Health%20Research%20Review%202011-2012%20Part%201.pdf">http://health.act.gov.au/sites/default/files/ACT%20Health%20Research%20Review%202011-2012%20Part%201.pdf</a>
<b>International organisations</b>						
International Consortium for Health Outcomes Measurement (ICHOM)	Consortium/ collaborative	International	NA	NA	ICHOM has developed a number of standardised data sets for health outcomes measurement across a range of diseases ( e.g. prostate cancer, dementia), which include various PROMs. ICHOM aims to promote 'value based health care' (which implies the use of PROMs) and also aims to promote international benchmarking using such datasets. A number of Australian organisations have some links with ICHOM including, the Agency for Clinical Innovation NSW, Australian Health Outcomes Collaboration, Australian Women's and Children's Health Network, Bowel Cancer Australia, Clinical Ophthalmology and Eye Health at the University of Sydney, CADOSA, DVA, Health Outcomes Australia, Hospital Contribution Fund, Movember Australia, Optometry & Vision Science at Flinders University, Ramsay Health Care, Royal Melbourne Hospital and the Victorian Prostate Cancer Registry. Representatives from some of these organisations have participated in the development of the ICHOM datasets. Approximately 40 Australians attended the recent ICHOM conference in London.	<a href="http://www.ichom.org/">http://www.ichom.org/</a> <a href="http://health-outcomes.org/">http://health-outcomes.org/</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
Child Outcomes Research Consortium (CORC)	Consortium/ collaborative	International	CORC aims to foster the effective and routine use of outcome measures in work with children and young people (and their families and carers) who experience mental health and emotional wellbeing difficulties.	Standardised patient self-reported outcomes data.	<p>CORC is a collaboration of mental health specialists from over 70 Child and Adolescent Mental Health Services (CAMHS) across the UK and beyond. CORC is primarily involved in collecting and analysing patient-reported outcomes. CORC members collect questionnaire responses from the children and families they work with. A central team of 10 researchers and support staff process the (anonymised) data centrally and provide ongoing support to members. National anonymised outcome information analysis is then provided that can inform services' thinking generally.</p> <p>CORC developed UPROMISE training – <i>Using Patient-Reported Outcomes to Improve Service Effectiveness</i> (in collaboration with the Evidence Based Unit, University College London, YoungMinds and Hertfordshire Partnership Trust).</p> <p>CORC aims to achieve its aims through collaboration with its members, academic consultants, and learning partners; sharing ideas and good practice.</p>	<a href="http://www.healthissuescentre.org.au/images/uploads/resources/Person-centred-care-around-world.xlsx">http://www.healthissuescentre.org.au/images/uploads/resources/Person-centred-care-around-world.xlsx</a>
International Society of Quality of Life Research (and Australian Special Interest Group)	Consortium/ collaborative	International	NA	ISOQOL recommends minimum standards for PROMs used in patient-centred outcomes and comparative effectiveness research.	<p>ISOQOL is a non-profit society to advance the scientific study of health-related quality of life and other patient-centred outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations. ISOQOL fosters the worldwide exchange of information through: scientific publications, international conferences, educational outreach, and collaborative support for health-related quality of life initiatives. ISOQOL is an international society with activities focused on promotion of high quality research in the science of health-related quality of life (HRQoL) measurement and patient-reported outcomes. An Australian Special Interest Group (SIG) has been initiated.</p> <p>The Australia SIG brings together Australian-based researchers in the field of quality of life research. Given geographical</p>	<a href="http://www.isoqol.org/about-isoqol">http://www.isoqol.org/about-isoqol</a>  <a href="http://www.isoqol.org/special-interest-groups/sig-overview">http://www.isoqol.org/special-interest-groups/sig-overview</a>

Organisation	Typology	Area / Geography	Purpose of collection	PROMs specific information*	Comments**	Websites
					remoteness of Australian quality of life researchers from colleagues in the northern hemisphere, the SIG aims to support local researchers by facilitating communication and opportunities for collaboration and exchange of ideas.	
The Cochlear™ Paediatric Implanted Recipient Observational Study (Cochlear P-IROS)	Consortium/ collaborative	International	Prospective international patient-outcomes registry for children who have implanted one or more hearing devices.	Quality of life and health-related utilities.	A prospective international patient-outcomes registry for children. To date, the Cochlear P-IROS has recruited implant clinics across Australia, China, India, Indonesia, Turkey and Vietnam. Australian site: Hear and Say (Brisbane, Australia).	<a href="http://bmcearnosethroatdisord.biomedcentral.com/articles/10.1186/1472-6815-14-10">http://bmcearnosethroatdisord.biomedcentral.com/articles/10.1186/1472-6815-14-10</a>

\* PROMs specific information includes instruments used, generic or condition-specific measures, frequency, sample, mode of administration, if information available

\*\* Comments include current and / or planned future use, if information available

## Appendix 3 List of clinical registries

Listing of clinical registries - Australia
<b>CARDIAC ARREST</b>
Victorian Cardiac Arrest Registry
Western Australian Pre-Hospital Care Database
<b>CARDIAC SURGERY/CARDIOLOGY</b>
Australasian Cardiac Outcomes Registry (ACOR)
Australian Cardiac Procedures Registry (ACPR)
Australian and New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS) Cardiac Surgery Database Program
Melbourne Interventional Group (MIG) Registry
Rheumatic Heart Disease Data Collection System
Victorian Cardiac Outcomes Registry (VCOR)
<b>CLINICAL CANCER</b>
Australian Comprehensive Cancer Outcomes and Research Database (ACCORD)
Bi-National Colorectal Cancer Audit (BCCA)
Breast Surgeons of Australia and New Zealand Quality Audit
Myeloma and Related Diseases Registry (MRDR)
National Breast Cancer Audit (NBCA)
NSW Clinical Cancer Registry Program
Prostate Cancer Outcomes Registry – Australia and New Zealand (PCOR - ANZ)
Prostate Cancer Outcomes Registry – Victoria (PCOR – Vic)
South Australian Cancer Registry
South Australian Prostate Cancer Registry
Upper Gastrointestinal Cancer Registry
Victorian Lung Cancer Registry (VLCR)
<b>INFECTION CONTROL</b>
South Australian Infection Control Surveillance database
Victorian Infection Control Nosocomial Infection Surveillance System (VICNISS)
<b>INTENSIVE CARE</b>
Australian and New Zealand Intensive Care Society Centre for Outcome and Resource Evaluation (ANZICS CORE)
<b>OBSTETRICS</b>
Australasian Maternity Outcomes Surveillance System (AMOSS)
<b>ORTHOPAEDIC</b>
Arthroplasty Clinical Outcomes Registry (ACORN)
Australian and New Zealand Hip Fracture Registry
Australian Orthopaedic Association (AOA) National Joint Replacement Registry (NJRR)
Victorian Orthopaedic Trauma Outcomes Registry (VOTOR)
<b>PAEDIATRICS</b>
Australian Paediatric Surveillance Unit
<b>REHABILITATION</b>
Australasian Rehabilitation Outcomes Centre (AROC)
<b>RHEUMATOLOGY</b>
Australian Rheumatology Association Database (ARAD)
<b>SCREENING</b>
Breast Screen Australia
Cervical Cytology Registry

Listing of clinical registries - Australia
National Bowel Cancer Screening Program
National Familial Hypercholesterolaemia Registry
<b>SPECIFIC DISEASES</b>
Australian Bleeding Disorders Registry (ABDR)
Australian Cystic Fibrosis Data Registry
Australian Genetic Heart Disease Registry
Australian Mitochondrial Disease Patient Registry (MITO Registry)
Australian Motor Neurone Disease Registry (AMNDR)
Australian National Creutzfeldt Jacob Disease Registry
Australian Psoriasis Registry
Bariatric Surgery Registry
Haemostasis Registry
National Diabetes Audit
Registry of Kidney Diseases (ROKD)
Save Sight Registries (Macular Degeneration, Diabetic Retinopathy and Keratoconus)
<b>TRANSFUSION</b>
Massive Transfusion Registry (MTR) – Australia and New Zealand
Neonatal Alloimmune Thrombocytopenia (NAIT)
Thrombotic Thrombocytopenic Purpura (TTP)
<b>TRANSPLANTATION</b>
Australian Bone Marrow Transplant Recipient Registry (ABMTRR)
Australia and New Zealand Organ Donation Registry (ANZOD)
Australian and New Zealand Cardiothoracic Organ Transplantation Registry (ANZCOTR)
Australian and New Zealand Dialysis and Transplantation Registry (ANZDATA)
Australian and New Zealand Liver Transplantation Registry (ANZLTR)
Australian Corneal Graft Registry
<b>TRAUMA</b>
Burns Registry of Australia and New Zealand (BRANZ)
National Trauma Registry Consortium (NTRC)
New South Wales Trauma Registry
Northern Territory Trauma Registry
Queensland Trauma Registry - CONROD
South Australian Trauma Registry (SATR)
Trauma registry, Royal Perth Hospital
Victorian State Trauma Registry (VSTR)
<b>VASCULAR SURGERY</b>
Australian Stroke Clinical Registry (AuSCR)
Australian and New Zealand Society for Vascular Surgery (ANZSVS) Australasian Vascular Audit
Melbourne Vascular Surgery Association (MVSA) Audit

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Australian Commission on Safety and Quality in Health Care

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**AUSTRALIAN COMMISSION**  
**ON SAFETY AND QUALITY IN HEALTH CARE**