

# **Patient-reported outcome measures**

## **Stakeholder interviews**

Prepared on behalf of the Australian Commission on Safety and Quality in Health Care

By Dr Kathryn Williams and Cristina Thompson, Australian Health Services Research Institute, University of Wollongong

This report is based on interviews conducted in mid-2017



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## Preface

This is the third in a three part series of reports presenting current evidence on patient-reported outcome measures (PROMs). It presents findings from systematic analysis of 27 in-depth interviews with Australian and international experts and key stakeholders from each Australian state and territory. The intention was to elicit experiences with, and views on, the use of PROMs to improve the safety and quality of health services. The interviews took place in mid-2017.

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 perceived health status. PROMs help understand which healthcare interventions make a difference to people's lives and in which circumstances.

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 for the Commission by Kathryn Williams and Cristina Thompson at the Australian Health Services Research Institute (AHSRI), University of Wollongong. In this preface, we put the report into context and highlight some of its main messages and potential uses.

### Why was this document commissioned?

The Commission will conduct a program of work at national level to drive and support the consistent and routine use of PROMs for quality improvement and person-centred care. To inform this work, we have analysed three types of evidence: research literature; grey literature (such as policy documents and websites); and the experiences and views of experts in the technical, strategic and practical aspects of PROMs.

Through the expert interviews we gathered rich qualitative information about what experts and stakeholders think about PROMs, their experiences of practical implementation on a large scale, and what has worked or not worked in other countries.

All participants, including Australian state and territory representatives, were asked about the current situation regarding PROMs in their region or country, specifically:

- drivers and current policy for PROMs
- mechanisms and uses
- impacts, both positive and negative
- stakeholder needs and engagement efforts
- future plans and anticipated benefits
- challenges and risks.

In addition, the expert participants from Australia and other countries were asked about:

- lessons learned from large scale implementation, including barriers and facilitators
- effectiveness of current data collection mechanisms
- data reporting issues, including interpretation and translation into quality improvement
- risk adjustment methods
- emerging evidence on impacts of using PROMs
- expected outcomes of PROMs initiatives, and how success should be defined
- fit between PROMs and wider policy initiatives
- links with payment mechanisms.

## What were the main findings and recommendations?

Overall, findings from analysis of the interviews reinforced and elaborated on findings from the environmental scan and literature review. The interview participants also gave us the benefit of their experiences with successful and failed implementations of PROMs in Australia, the Netherlands, the United States, Canada, Sweden and England.

### *Acceptability of PROMs use in Australia*

Echoing the environmental scan findings, there was considerable support among Australian participants for the use of PROMs for safety and quality improvement in Australia. However, the level of PROMs awareness and use varies widely.

There was a high level of support for using individual and aggregated PROMs data to guide shared decision making and person-centred care. Aggregated PROMs could complement administrative and clinical outcome measures to provide the patient's perspective on the value and effectiveness of care. Participants were open to using PROMs for benchmarking against agreed standards. The use of PROMs at a system level – for example, in value-based healthcare or performance reporting – was seen as more challenging and potentially controversial at this early stage of development.

### *Principles for successful implementation*

The interviews reinforced literature review findings that successful implementation of PROMs initiatives relies on equitable access for all consumers, minimising disruptions to the clinical workflow, and maximising data quality and relevance. Challenges include the selection of appropriate measurement instruments; designing systems to collect, store, process and report data efficiently, securely and accurately; and developing sophisticated methods of risk adjustment to ensure fair comparisons among providers. Strong stakeholder engagement at all levels – consumers, clinicians, administration, data managers and policy makers – will be required. This should be built in from the start of any PROMs project with agreement on the purpose, uses and expected impacts of the data, and extend through to managing organisational change and providing guidance on how to use PROMs data for quality improvement.

## How can this document help you?

The Commission intends that governments, researchers, managers, health professionals and consumer groups 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. It also provides a guide to the latest international thinking (informed by practical experience) on the strengths and pitfalls of PROMs for various uses.

Although every effort was made to identify the most appropriate informants in each state, territory, region or country, time constraints meant that not all PROM policy experts could be invited. Interviewees were asked to respond to questions to the best of their knowledge, but it was understood that their knowledge may not be complete or comprehensive, even within their own country, state/province, territory or area of expertise. The views of state and territory government participants do not necessarily reflect those of their respective governments.

## What will the Commission do next?

The Commission has previously released the environmental scan and literature review. We recommend reading the three reports together. The environmental scan captured the current status of PROMs in the Australian healthcare system, mapped activity at various levels, and explored current uses of PROMs data in quality and safety improvement. The literature

review drew on academic and grey literature to put PROMs into a wider, international context. It addressed research questions around the rationale for PROMs, mechanisms for routine collection and aggregation of PROMs data, and the reported uses and impacts at a state/province and national level.

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 of Healthcare Variation*, and the second edition of the National Safety and Quality Health Service (NSQHS) Standards promotes a strong focus on person-centred care. Incorporation of PROMs is also part of our clinical quality registries work.





# Patient-Reported Outcome Measures: Stakeholder Interviews

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Prepared for the Australian Commission on Safety and Quality in Health Care by the Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong

May 2018

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## List of abbreviations / acronyms

ACSQHC	Australian Commission on Safety and Quality in Health Care
DICA	Dutch Institute for Clinical Auditing
ICHOM	International Consortium for Health Outcomes Measurement
NHS	National Health Service
OECD	Organisation for Economic Co-operation and Development
PREM	Patient-Reported Experience Measure
PRO	Patient-Reported Outcome
PROM	Patient-Reported Outcome Measure
PROMIS	Patient-Reported Outcomes Measurement Information System

## Key messages

In this report, we present the findings from analysis of 27 in-depth interviews about the collection and use of patient-reported outcome measures (PROMs) in Australia and internationally. This research is intended to inform the work of the Australian Commission on Safety and Quality in Health Care (the Commission) to develop an evidence-based national approach to PROMs in Australia.

### **Key message 1: there is widespread support for large scale use of PROMs in Australia**

- Overall, the interviews showed that momentum for implementation of PROMs is building rapidly in Australia and internationally. PROMs were widely seen as integral to two important health policy directions: person-centred care, and value-based health care.
- Interview participants believed that systematic assessment and timely use of PROMs could lead to better clinical care and to more efficient use of healthcare resources.
- However, the desired impacts of PROMs will not be achieved automatically. The value of PROMs for the health system relies on genuine engagement of clinicians, consumers and administrators, careful selection of measurement instruments, sufficient resources for implementation, and most importantly a clear rationale for the proposed uses of the resulting data.
- PROMs can be used in the clinical consultation (micro level) to guide shared decision making and consent processes and to track patients' progress over time. Aggregated PROMs data can then be used to introduce patients' perspectives into quality improvement activities and comparative effectiveness research (meso level). Interview participants were enthusiastic about these uses of PROMs.
- PROMs can also be used for performance measurement and as an input to calculations of the relative value of healthcare interventions (macro level). Participants were more cautious about these uses. A few believed PROMs should be linked to payments as an incentive for collection. Most, however, believed that providers will collect PROMs voluntarily if they see convincing evidence of benefits for quality and safety. At this stage linking PROMs with payment incentives may be premature and counterproductive.

### **Key message 2: there is already evidence about how best to implement PROMs**

- Participants believed that PROMs initiatives should be targeted where there is existing interest among clinicians and where there is greatest potential for PROMs to contribute to improvements in safety and quality (that is, where there is unexplained variation in clinical outcomes, or where patient perspectives are most informative and clinical data less so).
- One challenge mentioned by participants is the selection of appropriate instruments from the vast range available. Among Australian stakeholders, there is much interest in working across state borders to introduce a degree of national standardisation in measurement for similar patients, conditions and procedures, with the freedom to supplement this 'core set' with additional questions that serve local purposes.
- Interviewees were aware of organisations such as International Consortium for Health Outcomes Measurement (ICHOM) and systems such as the Patient-Reported Outcomes

Measurement Information System (PROMIS) that have developed standard sets of PROMs. These were generally seen as a possible starting point but not a ready-made solution to the challenge of selecting instruments.

- Change management strategies will be needed to overcome resistance and encourage implementation. Participants suggested that initiatives will not be successful or sustainable without adequate resources including staff, money, training and technology for data capture, analysis and feedback.
- Collection of PROMs should be integrated within processes of routine clinical practice to maximise usefulness to the clinician and minimise disruption to the workflow.
- Measurement instruments and data collection methods must be designed to ensure equitable access to PROMs for all consumers. To avoid introducing bias into datasets, PROMs must be available in community and Indigenous languages and administered via a range of platforms.
- PROMs are most useful in combination with measures of healthcare delivery processes and clinical outcomes. Systems and technology to enable data linkage and data integration (for example, with electronic health records) are required to increase the usefulness of PROMs.
- Infrastructure is also needed to give back data in a timely and meaningful way to those who provided it. Users will need support to interpret PROMs and translate the data into action in terms of clinical decision-making and organisation-level quality improvement.
- Participants were open to using PROMs for benchmarking against best practice standards. This will require sophisticated risk adjustment methodology to ensure fair comparisons between providers.

**Key message 3: there is a need for a national approach to PROMs in Australia**

- Our interviews and the previous environmental scan showed that current work on PROMs in Australia will benefit from national coordination. PROMs have been incorporated into some established health data collections, including state-based clinical quality registries and national collaborations. There are a few promising pilot projects, and some exploratory work that has not yet progressed beyond initial stakeholder consultations. A more systematic approach could involve connecting, facilitating and guiding these areas of activity and encouraging new activity in priority areas.
- A systematic national approach should also include evaluation of PROMs initiatives to build the evidence base, which is currently lacking. Baseline data should be collected and a program logic developed. Ideally, there will be rigorous evaluation of the implementation processes and the impacts of PROMs on patient-provider interactions, clinical decision-making, quality and safety of health care, and the efficiency of the health system.
- Interview participants mentioned a variety of ways in which the Commission could contribute to the wider implementation of PROMs in Australia. These included: providing leadership on policy and standards; engaging stakeholders (such as medical and professional colleges, consumer groups and governments) to promote informed discussion; collating and disseminating information about instruments, implementation and evidence; and strengthening connections between PROMs initiatives, which may

involve linking jurisdictions, supporting the development of clinical networks, or facilitating data brokerage and benchmarking.

- Australian participants would welcome a role for the Commission in promoting and supporting local efforts to collect and use PROMs and working towards a systematic national approach.
- International experts thought that ‘bottom up’ initiatives by healthcare organisations or groups of clinicians are more likely to be successful if supported by ‘top down’ strategic planning, coordination and guidance.
- Without national leadership, there is a risk that PROMs activities in Australia will remain fragmented, with less than optimal implementation. It may be difficult to demonstrate benefits and maintain stakeholder engagement, making these efforts ultimately unsustainable.

## 1 Introduction

Patient-reported outcome measures (PROMs) are tools used to understand health outcomes from the perspective of consumers. They are increasingly seen as an important source of information to guide quality and safety improvement in health care, in conjunction with the more traditional clinician-reported outcomes, measures of healthcare processes, and measures of output, such as the volume of procedures performed by a provider.

The Australian Commission on Safety and Quality in Health Care (the Commission) engaged the Centre for Health Service Development, University of Wollongong, in a program of research to examine how PROMs are being used in Australia and internationally, with a particular focus on the potential purpose and benefits of national-level collation or collection. This work has included an environmental scan of current activity<sup>1</sup> and a review of the academic and grey literature,<sup>2</sup> both of which have been published on the Commission's website.

The Commission is an Australian Government agency that leads and coordinates national improvements in safety and quality in health care. Its mandate is to support the provision of high quality, safe and patient-centred healthcare services. It has taken a national leadership role in developing patient-reported experience measures (PREMs) and has undertaken a program of work in this field over the past five years. The Commission is required to lead and coordinate national improvements in the safety and quality of health care.

This report presents the third component of this program of research: findings from a series of interviews with policymakers from all Australian state and territory government health departments and with Australian and international experts. The purpose of this project was to build on the information available from the environmental scan and literature review. Together, these three pieces of work provide a foundation for the specification of a national program of work to further develop the implementation of PROMs.

### 1.1 Background

This section of the report provides some key definitions and a brief summary of the findings of the environmental scan and literature review, followed by an outline of six principles for the design of PROMs programs, which were derived from these findings.

#### 1.1.1 Key definitions

Patient-reported outcomes (PROs) are reported directly by the patient, 'without interpretation of the patient's response by a clinician or anyone else'.<sup>3</sup> They include a variety of measurable health outcomes including symptoms, quality of life and functional status.<sup>4</sup>

PROMs are the instruments used to measure PROs.<sup>5</sup> In general, PROMs are standardised, validated questionnaires with items that can be combined to represent an underlying construct such as pain, physical functioning, symptom control or psychological distress. PROMs can be generic (applicable across a variety of disease states or conditions), condition-specific (relevant to a particular population group, such as elderly people or those with mental illness) or disease-specific. Whereas generic PROMs often cover multiple dimensions of health status that are relevant to most patients, disease-specific PROMs focus on the symptoms most salient at particular stages in treatment and recovery. In general, analysis of PROMs focuses on the

change in scores following a health intervention.<sup>6</sup> By comparing patients' self-reported health before and after the intervention, the outcomes of the care they received can be assessed.<sup>7</sup>

PROMs are increasingly used as quality improvement tools. Data can be used to monitor outcomes of individual care or to feed into clinical registries that assist in identifying effective healthcare practice and benchmarking the performance of healthcare providers.

### 1.1.2 Environmental scan

The environmental scan<sup>1</sup>:

- Captured the current status of PROMs in the Australian public and private health sector
- Mapped what is going on in Australia in PROMs at the national, jurisdictional and organisational level
- Explored how PRO information is used at an aggregated level to improve quality and safety in health care 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 or implementation of PROMs. Over 100 organisational websites were reviewed.

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

However, there are many initiatives highlighted in the report which show innovative and robust uses for PROMs. 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.

### 1.1.3 Literature review

The literature review<sup>2</sup> had a wider geographical scope than the environmental scan, but was limited to the collection and use of PROMs at the national, state, territory or province level of the following countries:

- Australia
- New Zealand
- United Kingdom
- Ireland
- United States
- Canada
- Western European countries (specifically France, Germany, the Netherlands)
- Scandinavian countries (specifically Finland, Norway, Sweden).

It addressed the following research questions:

- What is the rationale for collecting PRO information?
- What mechanisms are used internationally for the routine collection and aggregation of PRO information at national or state/province level, and are there particular PRO measures and conditions which are more commonly aggregated and reported at this level?
- What are the reported uses of PRO information in terms of quality and safety improvement?
- What have been the reported impacts, benefits and challenges of collection of PRO information at national or state/province level?

The literature review found that the countries most advanced in implementing PROMs at a national or other jurisdictional level are England, the Netherlands, Sweden and the United States, with increasing interest in a national approach in Canada. Perhaps the most striking finding from the review was the wide variety of purposes for which PROMs are now being used, in research, clinical practice and health services management. For example, they are used to promote shared decision making and patients' self-management at the level of the clinical interaction and as indicators of the quality of health care provided by an organisation.

Overall, the review showed that in many of the countries studied, PROMs are integral parts of a movement towards patient-centred systems of structuring, monitoring, delivering and financing health care. Increasingly, quality is being seen as defined by the patient, not just by the clinician or policymaker. It is therefore fitting that PROMs are becoming widespread. The review also reflected on implementation challenges associated with PROMs, and noted that the evidence supporting PROMs is, for some applications, still equivocal.

The findings from the environmental scan and literature review were combined to inform a set of recommendations for the Commission's potential role in helping embed PROMs in Australian health care and its future work on PROMs.

## 1.2 Guiding principles

Evidence from the environmental scan and literature review was presented to the Commission's Board.<sup>8</sup> The paper also requested Board members' endorsement of a proposed position on PROMs for the Commission. This position would be guided by six principles for the design of PROMs programs:

### 1. Principle 1: Embed in policy

To have a meaningful impact, any PROMs program must be seen as an embedded, integral element of a broader policy initiative, not as an isolated 'data' project. PROMs need to be presented as resources to help services achieve broader quality and safety goals, rather than as ends in themselves. They can usefully be seen as tools to support broader policy movements towards (a) person-centred care and (b) value-based (as against volume-based) care.

### 2. Principle 2: Make objectives explicit

Any PROMs program must have explicitly defined objectives related to the policy it supports. As part of the program design, the Commission encourages articulation of a clear



model of the mechanisms by which PROMs are expected to assist quality and safety improvement.

**3. Principle 3: Make data accessible at multiple levels of the system**

The data collected through the routine use of PROMs have potential for use at multiple levels of the health system. The Commission therefore urges the adoption of a ‘collect once, use many times’ philosophy in any PROMs program design. This means that a patient’s responses could be used to inform their own health care and to refine the practice of their treating professionals, and at the same time be aggregated with others’ data to determine the comparative effectiveness of treatments and interventions, to monitor patterns of outcomes and identify outliers, inform policy design, or even to be integrated into reimbursement systems.

**4. Principle 4: Base on the latest evidence**

The Commission recognises that the evidence for some applications of PROMs is currently stronger than for others and that there are methodological and practical challenges to expanding the scope of PROMs. As a result, any PROMs program in Australia must be guided by lessons learnt during implementation and operation of other programs both here and internationally, and by recent and emerging research evidence about the effective and appropriate use of PROMs data.

**5. Principle 5: Support nationally**

Given the increasing interest in implementing PROMs, it is now an appropriate time to establish a level of national coordination and support for health services and governments seeking to make more systematic use of PROMs. The Commission will provide formal guidance on the collection and use of PROMs, an enabling environment for knowledge sharing, or (if warranted) coordination of any activity to achieve national consistency in collection or use of a limited selection of PROMs.

**6. Principle 6: Align with other national programs**

In performing a national role in relation to PROMs, the Commission would ensure close alignment of this work with its other relevant priorities, including setting national standards for person-centred care, prioritisation of clinical quality registries, detecting unwarranted variation in clinical practice, and in reducing the use of low-value interventions and procedures.

The Commission’s Board endorsed the proposed position and the continuing program of work, including the current project.

### **1.3 Structure of this report**

The next section of this report describes the methods of the stakeholder interviews project. Findings are then presented, structured broadly around the sections of the literature review in order to build on previous work. The discussion section is structured around the six principles and explores how these might be adapted, modified or enhanced in the light of the new findings from the interviews. The implications of these findings for the scope and nature of a national role for the Commission are then presented.

## 2 Methodology

### 2.1 Design

This project was the third part of a program of research which began with the environmental scan and literature review in 2016. It was designed to complement these earlier pieces of work by collecting and collating current information from Australian and international experts and Australian state and territory government policymakers on current activity in PROMs, lessons to be learned from existing initiatives, and desired future directions.

Data were collected via semi-structured interviews. It was anticipated that 25-30 interviews would be required to cover all Australian states and territories as well as key international and local initiatives.

We conducted a total of 27 interviews between 22 May and 12 July 2017. Of these, three were conducted by CT and the remainder by KW. All the interviews were recorded and professionally transcribed. Interviewers also took notes during the discussion. The transcription service provided password-protected data storage and staff were bound by confidentiality agreements. Transcripts and audio files were stored on a secure, password-protected drive only accessible to members of the project team.

### 2.2 Participants

A list of potential participants was compiled. This was a purposive sample, based on the need to consult people with the best available current knowledge of PROMs initiatives in Australia and major international initiatives. Australian state and territory government policymakers were selected based on their roles within governments' health departments. The key work areas targeted were person-centred care, quality and safety. Australian and international experts were identified through the literature and using contacts of the Commission and project team members.

Although every effort was made to identify the most appropriate informants in each state, territory, region or country, there was a wide variety of potential participants to choose from and due to limitations on time and budget, not all could be invited (and not all of those invited were able to take part within the time frame). Hence, this should be considered a sample of convenience. Interviewees were asked to respond to questions to the best of their knowledge, but it was understood that their knowledge may not be complete or comprehensive, even within their own country, state, territory or area of expertise. The views of state and territory government participants do not necessarily reflect those of their respective state or territory health departments or agencies.

In the findings presented below, direct quotes from participants are indicated by the use of indented, blue, italicised text. Codes accompanying the quotes can be interpreted as follows: J = jurisdictional, AE = Australian expert, IE = international expert.

### 2.3 Materials

The materials for this project were two semi-structured interview schedules, one for the state and territory government participants and the other for the international experts. Questions were generated from the issues identified in the environmental scan and literature review,

from consultation with the Commission, and were also stimulated by the attendance of KW at the inaugural International Consortium for Health Outcomes Measurement (ICHOM) Australasian Forum on 4 May 2017. No separate schedule was written for the Australian experts; instead there was a more free-ranging discussion drawing on relevant questions from the other two schedules. The interview schedules are available at Appendices 1 and 2.

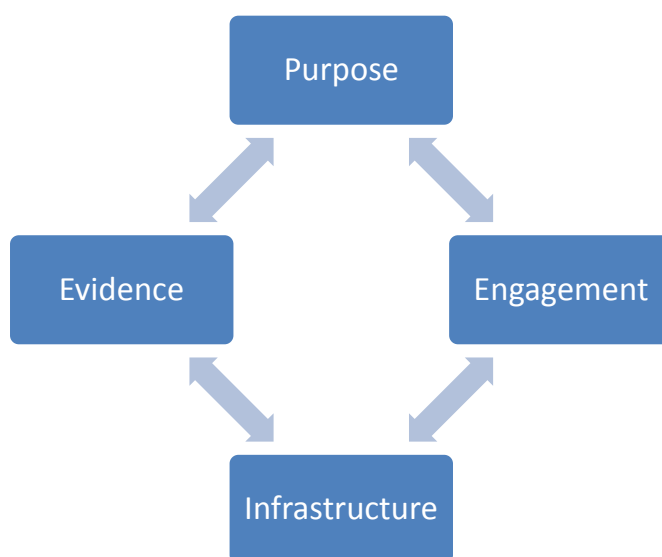
## 2.4 Analysis

Transcripts were imported into NVivo<sup>9</sup> for data management and analysis. A modified framework analysis approach was used initially to organise the data around the interview schedules. This method imposes a structure on qualitative data based on a set of research or evaluation questions and is often used in health services research.<sup>14</sup> The initial coding framework was developed by KW and discussed independently with CT and also with Dr Jennifer Plumb in the early stages of analysis. As coding progressed, the framework was re-shaped iteratively around emerging themes and topics of interest. KW coded all the transcripts. Codes for the Commission's role were then discussed with CT, who refined and simplified this coding around four sub-themes.

### 3 Findings

The first section of this chapter addresses the drivers and policy for PRO collection. The remainder of the findings chapter focuses on future directions for PROMs. The structure is loosely guided by the original research questions about the challenges of PROMs collection and use, implementation of PROMs and evidence of impacts. These have been refined into a conceptual model of the requirements or necessary conditions for a successful PROMs initiative. This model (Figure 1) incorporates the themes of purpose and uses of PROMs; stakeholder engagement and change management; infrastructure and technology; and applying evidence demonstrating the benefits of PROMs.

**Figure 1** Conceptual model of the necessary conditions for PROMs initiatives



To these original areas of focus, a new section presenting the views of interviewees on a potential role for the Commission has been added.

The findings chapter of this report therefore has the following structure:

- Section 3.1: Drivers and policy for PRO collection and use
- Section 3.2: Purpose and uses of PROMs
- Section 3.3: Changing behaviours
- Section 3.4: Designing the infrastructure
- Section 3.5: Building an evidence base
- Section 3.6: Views on the Commission’s role in PROMs.

#### 3.1 Drivers and policy for PRO collection and use

The literature review<sup>2</sup> identified three primary reasons for adopting PROMs:

1. Patients can be most accurate in describing their own symptoms, pain, function and quality of life
2. PROMs can be used in clinical settings to support shared decision making and person- or patient-centred care

3. When collected systematically across multiple healthcare providers (such as via clinical registries), PROMs generate valuable data about treatment effectiveness, adverse events and variations in healthcare delivery and outcomes, all of which can inform efforts to improve quality and safety.

According to the literature, PROMs can help identify and measure the outcomes that matter most to patients. One author has described them as ‘the only direct voice that an individual has in the health decision-making process.’<sup>11 p.329</sup> This information can be used by clinicians to assist in shared decision making with patients, and to assess the efficacy of treatment approaches. PROMs also have an important role in quality improvement efforts at an organisational and system level by informing comparative effectiveness research and payment and incentive schemes. They are seen as an essential part of ‘value-based health care’.<sup>12</sup>

Interview participants largely echoed these findings about the rationale for using PROMs. There was widespread acceptance that patients are the best judge of their own outcomes; that PROMs can be useful to clinicians, helping to inform patient-centred care and shared decision making; and that PROMs are a valuable input into quality and safety improvement efforts.

In their responses, participants spoke about the philosophies and broad policy directions that are currently driving the adoption of PROMs in Australia and overseas, as well as the desired outcomes of PROMs initiatives. These are expanded upon in the next two parts of this section of the report.

The third part of this section describes the policy status of PROMs in various countries and Australian jurisdictions from the perspective of those interviewed.

### **3.1.1 Philosophies and policies driving PROMs**

The major philosophical and policy driver identified by participants was the movement towards person- or patient-centred care. Patient-centred care is ‘an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships between healthcare providers, patients, and families.’<sup>13 p.7</sup>

Interviewees saw PROMs as closely linked with patient-centred care. Both patient-centred care and PROMs have risen in prominence in recent years due, at least in part, to the emergence of more informed and engaged healthcare consumers.

Increasingly, healthcare consumers have high expectations of their providers, their experiences of health care and their health outcomes. One participant spoke about experimental work which demonstrated that anticipated health outcomes are the most important consideration for consumers when selecting a potential healthcare provider.

Particularly among younger consumers, there is a higher level of health literacy than previously, coupled with a greater willingness to share information about themselves if they believe it may contribute to improvements in health care. At the same time, the required technology for measuring and reporting PROs – in the form of validated instruments and electronic data management systems – has become more widespread and sophisticated.

*I think we live in a consumer time at the moment. Our consumers are becoming more educated, health literacy is a thing that, even when I was in medical school in the not so*

distant past, wasn't anywhere near as at the forefront as it is now. And I think actually looking at what are the patient-reported outcomes for this and what is the patient experience? And I think for me it is tying those things together, is something that patients are expecting or starting to expect... They're starting to anticipate that their outcomes, their opinions, what their experience was actually helps inform what happens in our public health sector. (J10)

I suppose it's because there is and has been for a long time now a commitment to patient-centred care and PROMs seem to be obviously common sense, a key aspect of providing patient-centred care. It's bringing the patient voice into the context and now that the research setting has developed good methods... in terms of questions and questionnaires and how to score them and interpret them and modes of administration and... now that technologically we're ready to do electronic data capture, I think all of this has meant that the people in safety and quality are thinking, okay, well we're ready, we're ready now to do things here. (AE5)

And one of the best ways of engaging patients in their care is to proactively ask them how they're doing. (IE2)

Participants believed that PROMs could contribute to patient-centred care in various ways. First, systematic assessment of outcomes could provide valuable information to the clinician and the patient to guide their shared decision making about treatments. Consistent with the literature review, participants stated that there were some things that only patients could know and therefore data collection could not be accurate or complete without incorporating their perspectives. Using a standardised measure would ensure consistent and comprehensive information was collected for all patients. For example, where a patient has a chronic, complex condition or is experiencing a variety of symptoms, a PROMs instrument can be used during or immediately prior to the clinical encounter. Patients can identify their own priorities for care and bring these to the attention of the clinician. This allows the discussion to focus on, for example, the symptoms that are currently most distressing, ensuring that these are addressed in a timely and efficient way.

Second, PROMs were seen as a potentially valuable input into quality and safety improvement efforts at an organisational and system level. For example, when assessing the comparative effectiveness of interventions, there was a general recognition that clinical measures do not provide all the information needed to judge treatment effectiveness. In breast cancer surgery, for example, relevant outcomes include not just the complete removal of the tumour and avoidance of complications, but also the range of movement in the patient's arms and the cosmetic results. Several participants described PROMs as the 'missing piece of the puzzle', while others pointed out that PROMs complement the process measures and clinical outcomes already present in many clinical registries and other data collections.

In terms of quality improvement for health services, very much like the more clinically oriented key performance indicators, I think PROMs could potentially be used in similar ways. It is a reflection of patient-centred care and performance. (J11)

For me the primary benefit is ... about understanding whether the treatments that are being provided to patients are actually providing the outcomes and the benefits that the patients are expecting them to derive ... With some intelligent data analysis it may then be possible to identify whether there are particular types of procedures that are not ... delivering the benefits that they're anticipated to ... it would maybe combine with clinical

outcomes as well as patient outcomes in order to make that assessment. For me it's about understanding whether the health system is delivering what patients are expecting. (J3)

For participants, another important driver of PROMs adoption was value-based health care. This concept is inspired by the work of Michael Porter<sup>14</sup> and proposes that payment for healthcare services should be based on the outcomes they deliver rather than on measures of output such as volume of medical procedures. In Porter's view, 'value should always be defined around the customer, and in a well-functioning healthcare system, the creation of value for patients should determine the rewards for all other actors in the system.'<sup>14 p.2477</sup>

Several participants pointed out the growing costs of health care to governments and individuals, which threaten the sustainability of health systems around the world.

I think there's no other way to proceed with health which will ... gobble up your entire gross domestic product, so we need to look at alternative ways of funding it, and value-based health care... it's not that simple, but it's certainly an inevitable progression from what we are doing at the moment, which is paying for volume. (IE7)

We do not have good outcomes information at the moment. Really the outcomes that we measure systematically are you're either dead, you've got your mortality measure, you're readmitted, or you've got a hospital-acquired complication. So I think certainly there's a recognition that we need to become much more sophisticated, and that's where I think the movement going forward is increasingly seen, a focus on value-based healthcare delivery with the patient outcome really driving the investment. (J13)

Nevertheless, some participants remained sceptical about value-based health care, saying that the expected impacts had not yet been convincingly demonstrated. Others saw value-based payments as a key incentive to drive PROMs collection and use. Both sceptics and converts agreed, however, that PROMs would need to be an essential element of any such initiative implemented in Australia or elsewhere.

In the health system, the only driver is cost saving. They say it's other things, but the really big emphasis is getting people out of hospital, getting people into systems that are funded by the Commonwealth and not by the state, and so on. It is my observation that the honest answer to that question is if you could argue that this saves money, it would get up really quickly. But the policy answer, and the public answer, and certainly the answer of consumer groups, is that people's understanding of what's of value in health care, and the impact of health care, and how decisions are made, is totally inadequate without this kind of thinking. And we welcome a systemic approach to it. (AE3)

What's a good clinical or surgical outcome may not necessarily represent a good patient outcome and from a value point of view we're trying to work out what actually represents a ... good value outcome from both a patient and a clinician's point of view. So I think there's some principles around health care and how to measure health care that are contributing to this. But I also think that it's still new and still evolving and I think that in Australia, like many places in the world, we're starting up a lot of these things, but the value is still to be proven in many instances. (AE2)

To me, the greatest motivation to do this is if you do it, you will make things better. You will make individuals better because people will focus on the outcome that patients are reporting. You'll make groups of patients that are being treated do better, because there'll be groups of physicians who do poorly and others who do well and physicians are



competitive and they'll want to make things better. But I think the magic wand has to be – somebody has to say that payments need to be tied to value and the only way to assess value is to assess outcomes and one key cornerstone of outcome measurement is patient-reported outcomes. (IE2)

### 3.1.2 Desired outcomes of PROMs initiatives

There was a sense among interviewees that momentum for adoption of PROMs in Australia is building rapidly. The Australian state and territory government participants felt it was important to develop, coordinate and promote local PROMs initiatives, or risk being left behind or forced to adopt approaches developed elsewhere that may not fit the local context and priorities. These interviewees wanted to ensure that their jurisdictions were well prepared to take advantage of the expected benefits of PROMs, which they believed would include better health outcomes and more efficient use of health resources.

The prospect of improving health outcomes through better information was a major driver for PROMs, according to those interviewed for this study. The hope is that systematic assessment and timely use of PROMs could lead to better clinical care. According to participants, the use of PROMs in health services research could identify some sources of health inequity, help reduce variation within the system, and improve integration across care settings.

I should mention this, another reason for collecting this data, and there has been research on this in this country, is to investigate the level of inequality between areas as well, so are certain patients groups benefitting more than other patient groups ... are more deprived areas getting worse outcomes for example? So it's not just an efficiency argument or a shared decision-making thing, there's also issues of national policy about not just equity of access but ... equity of outcome as well. (IE5)

And I think the other really important key driver is that as we try to support people living with chronic and complex conditions ... we're now hopefully partnering better with primary health care as well, so that there is that consistency across care settings, that patient-reported measures are collected within the hospital system, but then there's that continuity of care quality collected in primary health care in community settings as well. So, we're normally trying to really strive for improvements for the outcomes of patients. (J12)

The other major desirable outcome of PROMs mentioned by interviewees was more efficient use of health resources. These measures offered an opportunity to better understand the health gain from particular treatments and thus to steer clinicians and consumers towards more effective options. For example, information from the English PROMs program has been used to inform the choice of prostheses for joint replacement. These choices affect not only the health authorities' purchasing decisions, but also the rates of revision surgery for patients. The ultimate goal would be to achieve similar or better health outcomes with reduced costs. There is anecdotal evidence that this is achievable, for example:

I know of a team of orthopaedic surgeons who began collecting these data for a couple of years and they realised that they could reduce the number of post-surgery rehabilitation visits. They had been essentially, prescribing everybody 12 weeks of rehab. And when they started measuring the PROMs, they realised that some patients were done in five or six weeks and some patients needed 10 or 12 weeks. And they could tune the quantity of rehab to the patient's pace of recovery. And they actually now had a metric of when people were functioning at a level that would be considered optimal, post-operatively. So, they



were able to overall, reduce the total number of visits for rehabilitation and still achieve the same or better results. (IE1)

One international participant mentioned an additional benefit of PROMs which was seen as compelling in an environment of increasing regulation in health. That is, valid, reliable PROMs in widespread use may replace other, less efficient measures. Overall, this participant hoped that PROMs may lead to a reduction in the number of process measures required by governments, insurance companies and other authorities for performance reporting.

### 3.1.3 Government policy relating to PROMs

Interviewees were initially asked whether there was any official or formal policy to drive the collection and use of PROMs in their jurisdictions (or, for international participants, their countries). This was followed up by a question about the 'unofficial feeling' regarding PROMs, in order to judge the level of interest and activity. As expected, all those interviewed were aware of PROMs initiatives in their jurisdictions or countries; however, there was less awareness of the existence of formal policies governing PROMs.

#### *Australia*

Participants from six of the eight state and territory governments indicated that their government had not issued a formal policy governing PROMs collection or use. These were: Australian Capital Territory, Northern Territory, Queensland, South Australia, Tasmania and Western Australia. Where there were multiple informants for particular states and territories, these interviewees were consistent in their responses.

Although there was no formal policy to guide activity in these states and territories, it was apparent from the interviews that there is strong interest in PROMs and a high level of awareness of current developments. For example, several of those interviewed had attended the ICHOM forum in May 2017. There was also a keen interest in, and some concerns about, a paper that had recently been presented to the Australian Health Ministers' Advisory Council proposing a national audit of PROMs readiness. Most spoke about PROMs collections in their state or territory, some of which were well established. Efforts to coordinate and support these activities were at an early stage of development. Nevertheless, this was seen as an important new direction in health care.

I think it's a bit of a buzzword at the moment. I don't know if they know the details but they have all started to hear the word. (J2)

So we're still in the initial stages of the PROMs area but very keen to go further down [that] path. (J1)

Interviewees from New South Wales said that support for PROMs was strong and implicit in the Leading Better Value Care Program which began in 2017. This program aims to refocus measurement of value in health care away from outputs and towards health outcomes, patient experiences and 'efficient and effective care'<sup>15</sup>. In her address to the recent ICHOM Australasian Forum, Secretary of Health Elizabeth Koff explained the rationale for this change in focus in terms of benefits for consumers and improved economic sustainability. The ultimate goal of the value agenda in NSW is to link payment models to measures of outcomes rather than volume of procedures.<sup>16</sup>

Interviewees from Victoria said that there had been a consultation process in 2016 about PROMs collection and use in that state and that the aim of this process was to develop a policy. The initiative was linked to reforms aimed at improving safety and quality reporting in the Victorian health system after a review of the system which followed an investigation of paediatric patient deaths at one Victorian hospital.<sup>17</sup>

A consultation paper released by the Victorian Department of Health and Human Services (DHHS) in September 2016 stated that PROMs data would be collected on an ongoing basis from Victorian health services, starting from 1 July 2017.<sup>18</sup> The collection of PROMs was intended to serve the Department's strategic reform directions which include person-centred care and advances in quality and safety. Evidence and data – including PROs – are viewed as enablers of the success of these reforms.

Clinicians, consumer representatives, research bodies and healthcare organisations were encouraged to make submissions during the Victorian consultation process to contribute to the design of the PROMs program. To date, project funding has been made available for inclusion of PROMs in local collections (such as clinical registries) and for pilot projects. Detailed work to design mechanisms for large-scale PROMs collection in Victoria is now underway.

### *International*

Of the five countries represented in the international interviews, only one (the UK) has some kind of national policy to guide PROMs collection and use, while the others (Canada, the Netherlands, Sweden and the United States) do not. Recent work by the Organisation for Economic Co-operation and Development (OECD) to take a 'snapshot' of PROMs across member countries confirms this picture: although there is considerable activity in PROMs, there is little central coordination or direction, with the exception of the UK and some Scandinavian countries. There are some isolated examples of mandatory PROMs collection (for example, for some diseases and treatments in the Netherlands, and for electroconvulsive therapy in Scotland) but no systematic national approaches.

In the UK, PROMs are considered a priority and the national PROMs collection is seen as an important mechanism of health policy. National Health Service (NHS) providers in England are required to collect outcomes data using PROMs in four areas of elective surgery: hip and knee replacement, groin hernia repair and varicose vein surgery. This program, which began in 2009, uses both disease-specific and generic PROMs measures which patients complete before and after their surgery. The data are linked with hospital episode statistics and self-reported demographic data; the casemix-adjusted PROMs for each provider are both reported publicly and used for benchmarking. This program represents one of the largest and most important PROMs benchmarking collections worldwide to date.

PROMs activity in the Netherlands centres on the Dutch Institute for Clinical Auditing (DICA), a non-government organisation which manages 21 clinical registries, 10 of which now include PROMs. DICA was initiated by, and is run on behalf of, clinicians in various specialties. Its main goal is quality improvement; and the inclusion of PROMs in some registries has been led by doctors who have seen the potential of PROMs to inform these efforts. DICA also facilitates public reporting on indicators of care quality generated from registry data; this information is used by health insurers for purchasing decisions. Some of these indicators, which are selected in consultation with groups of clinicians, are now incorporating PROMs.

Canada does not yet have a national policy on PROMs, but there is considerable activity at province level. Discussions between the provinces on national cooperation and coordination have taken place. The Canadian health system has some parallels to the federated Australian system. One of the barriers to a national approach is sensitivity about sending data outside provincial borders for central collation and, potentially, for comparison with other provinces.

In Sweden there is currently no national framework or policy for PROMs. However, PROMs collection is guided by a national framework for performance monitoring of the total healthcare system, which is based on the six dimensions of high quality health care (similar to those developed by the Institute for Healthcare Improvement in the US): safe, knowledge-based, effective, patient-centred, equally distributed and accessible. This framework is supported by legislation.

There are 21 county councils in Sweden and they are independently responsible for health care in their region. A National Board has an advisory and monitoring role. A lot of data is held within the county councils and there are policies which guide indicator monitoring and data collection. The National Board also hosts multiple registers which are mandatory (such as a death register) but does not routinely receive data from any of the Swedish National Quality Registers. It can, however, request data from the registers and helps validate their data collections by comparing their data with national data. Analysis, benchmarking and action on variations in county councils occurs predominantly at the level of the county council where most quality improvement work is based. Data collection occurs at the level of the facility or county council and nationally.

The county councils do not have to implement PROMs, there are no payment mechanisms linked to the use of PROMs and they perceive this would be a mistake (there have been some examples where the government has talked with county councils about linking PREMs to payments). There is some incentivising of the National Quality Registers to incorporate PROMs and if they reach certain levels of certification they get reimbursements from the government.

The US Federal Government has specified reporting requirements for payment programs but most of these are based on processes, not outcomes, of health care. There is no national policy on PROMs. Under the previous administration, legislation was passed which would enable the introduction of value-based healthcare principles into Medicare, which provides insurance coverage for the population aged over 65 years. This would entail greater use of health outcome measures, including PROMs.

### **3.2 Current and future uses of PROMs**

One purpose of the interviews was to gain an overview of any current PROMs activity in Australia and internationally and to understand how participants envisage PROMs being used in the future. These questions were intended to complement the previous work of the environmental scan<sup>1</sup>, which was based on a purposive search of organisational websites in Australia. It was beyond the scope of that project to provide a comprehensive mapping and description of all current PROMs initiatives.

Most interview participants were able to describe PROMs activity that they were involved in (for example, as an advisor or through their roles with state health departments). As well as

data collection activities, they described collaborations or consultations with clinical groups and consumers. Initiatives could be categorised as either well-established programs (of which there were relatively few) or pilot studies and programs in an early stage of development. PROMs are being used in a wide variety of clinical specialties and treatment settings, from surgery to chronic disease to palliative care.

Current activity can be categorised according to three broad uses of PROMs: clinician-patient interactions (micro level); descriptive and analytical studies such as comparisons of treatment effectiveness or understanding variations among providers (meso level); and population surveillance and policy (macro level<sup>19</sup>). These three uses of PROMs are based on the three ‘arenas of application’ of cancer outcomes research, first outlined in a monograph which emphasised the importance of collecting PROs in cancer.<sup>19</sup>

1. **Micro level:** PROMs are used to understand, evaluate and enhance interactions between patients and providers, including the decisions made about treatment. These uses require individual-level data collected in real time from patients and delivered to clinicians in a timely way for use during the consultation. PROMs data aggregated across groups of patients (such as within registries at the meso level) may also be used to inform decision-making.
2. **Meso level:** PROMs are used to understand the factors that influence outcomes. Uses at this level include comparative effectiveness research, studies examining patterns of care variation or service use, randomised controlled trials of intervention efficacy, and clinical modelling, evaluation and priority-setting analyses to aid clinical decision-making. Uses of outcomes data at this level interact with those at other levels. For example, studies at the meso level may illuminate links between processes and outcomes and thus inform clinical practice; or they may test hypotheses suggested by macro-level analyses and thus guide policy making.
3. **Macro level:** PROMs are used to help decision-makers establish and evaluate policies designed to benefit whole populations. This includes population surveillance of trends in outcomes; identifying factors associated with ‘value’ in health care to inform payment models; and informing quality improvement activities at a system level, such as standard setting, adherence to clinical guidelines and performance measurement across healthcare organisations.<sup>19</sup>

The literature review<sup>2</sup> found that PROMs are most commonly used at the meso level, with greater focus on other levels in recent years. However, one data collection – such as PROMs collected by a clinical registry – can have uses at multiple levels.

Participants also referred to these different levels of use for PROMs. Overall, there was more enthusiasm for the micro- and meso-level uses, but some interviewees also emphasised the contribution that PROMs could make to system-level improvements in safety and quality of care and to the more efficient use of health resources, which are macro-level uses.

### 3.2.1 Micro and meso uses

Among interview participants, there was considerable support for the use of PROMs at the micro and meso levels. There are several new initiatives in Australia that are aiming to use individual PROMs data during the clinical encounter. This may be complemented by aggregate

data to assist in shared decision making, which has been described as the ‘pinnacle’ of patient-centred care:

In shared decision making, both parties share information: the clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values. Each participant is thus armed with a better understanding of the relevant factors and shares responsibility in the decision about how to proceed.<sup>20 p.781</sup>

Patients are very interested in other patients’ perspectives on the outcomes of their treatments. Aggregated PROMs data can bring these perspectives into the clinical conversation. The same aggregate data can then be used at the organisation level to highlight where practice could be improved.

I’ve always believed that the real value of PROs is that they can spark the right conversation between patient and clinician. They’re a snapshot. I see their usefulness mostly in terms of screening and being able to identify where there may be some problems that were below the surface. That’s not to say that they can’t be enormously helpful in our understanding where there is an important gap, needs, where we are doing a great job, where we’re dropping the ball. But certainly the idea that this will be data that in and of itself can provide important answers. (IE6)

A few participants specifically referred to the use of PROMs for informed consent. All treatments carry risk, and patients want to know the likelihood that a treatment will be effective in their case: ‘What are my chances?’ When combined with clinical outcomes data, aggregated PROMs can help answer this question.

Researchers at the University of York in England have recently used PROMs data to develop an algorithm to predict outcomes of surgery for the four conditions covered by the UK national PROMs program (hip and knee replacement, varicose veins and groin hernia repair). Similar work is happening in several places in Australia. For example, the Coronary Angiogram Database of South Australia (CADOSA) has a current project to develop an algorithm to more accurately predict the risks of procedures and the patients most likely to benefit.

If we bring it right down to very much at the clinical interface, if patients can be better informed in terms of the likelihood of side effects or particular outcomes, then in theory they should be able to make more personalised treatment decisions in collaboration with their treating clinician. Very much as part of that informed consent and shared decision-making process, PROMs should be able to play quite an important role. (J11)

We’ve gone the next step, we’re trying to use PROMs for clinical decision-making, so with orthopaedics for example, we’ve been able to develop algorithms using functional scores and pain scores – that patients fill out pre-operation ... and at one year post the ... operation to be able to predict their likelihood of having a revision or a contralateral joint done or some complication so we put them on different surveillance trajectories based on their PROMs responses at the time of pre-surgery and ... post-surgery so we actually make it more efficient in how we identify those at higher risk. (J6)

PROMs data from individuals may also be used to track changes over time for patients with chronic illnesses or progress in recovery from surgery. For example, one doctor in England is giving patients access to their own PROMs data so that when they input their post-operative PROMs they can assess their own improvement:

They can see how quickly they are recovering against what might be perceived to be the norm for that kind of procedure. So, as part of putting in the data, they can think through, 'Okay, so do I really need – do I feel that I need a follow-up consultation with my consultant to check on my recovery?' And what he has said is that if people feel fine... then they don't have to come for that follow-up if they don't want to. If they still want to do that, that's absolutely fine ... But it just means that from his perspective, he feels that his patients are more in control and this further enables their recovery, because they're not waiting and worrying 'what's my outcome here and is my shoulder back to normal? Can I carry on with normal life?' They can see for themselves how their recovery is progressing and he's found that to be really effective. (IE3)

That could be really positive therapeutically to say... you might feel like you're not making progress, but here's... your own rated outcome measures, and look how much you've improved, you know, whenever, and that can be to a chronic condition, pain and all sorts of things. (AE4)

Established registry collections have PROMs embedded in routine clinical care. By collecting PROMs regularly, the data can be used to anticipate the patient's care needs and avoid urgent situations or crises where their condition deteriorates rapidly.

I think that the tools and the use of the tools and particularly, the patient-reported outcome measures of that tool, has been evolving, which is a really good thing... it's increasingly being seen as more useful for assessment and care planning. And so, it's not just about that vital signs observation type stuff. It's really about determining, you know, responding... as they change and urgency. So, that's where it definitely meets the needs for real-time care and care planning. (AE1)

With the right motivation and system design, data can then be fed back to a central database and used at the meso level to look at variations in outcomes between organisations (benchmarking) or to compare treatments (comparative effectiveness research). PROMs data can also be used within organisations to evaluate small-scale, clinician-initiated quality improvement efforts.

Where you have treatments that give you similar clinical outcomes, where they also have similar costs, it could be that the key difference would lie in patient-reported outcomes. And that would have a lot of implications for service planning, and also purchasing policies and so forth. (J11)

Because that kind of stuff happens all the time in the hospital where somebody says, 'Oh, why don't we do X?' And then it either doesn't get off the ground or we don't really know. If we use [PROMs] to help us make those decisions around those kinds of simple changes of practice, I think it would be really helpful and it would boost some of that research, kind of the soft research that happens in the hospital to actually have something behind us that carries a bit more weight. (J10)

One participant noted that benchmarking can have different meanings in different contexts. In an accreditation sense, a benchmark is a standard that is required to be met. Using PROMs to set required standards was seen by some participants as quite threatening.

Well, if you want to really alienate your clinicians, that's the fastest way to do it. (IE6)



I think the notion of blame rests heavily over people's sense of any collection and comparability of data. But it should be about, I mean it's how you crunch it up too, isn't it? Does it need to be tracked based on the individual clinician or the role? We need to know what happened, and what the outcomes were for the person, and how those two things interact. We don't need to know what patients thought of their clinician. That's another pathway altogether, it seems to me. (AE3)

In contrast, in quality improvement efforts, a benchmark is an aspirational target which is defined with reference to clinical best practice rather than average levels of performance. This type of benchmark was generally viewed very positively.

Ours are set high, but only, you know, 30 per cent of the services meet them, so that there can be this learning and decrease in variability across [services]... And if everyone's meeting it, then we're going to shift it up. And if everyone's [still] meeting it, then we won't even bother having it, because our work here is done. (AE1)

So I guess it's about – the thing like benchmarking and that sort of stuff, comes in when you're able to collect things for multiple sites, whereas, if you're just a doctor working in a private practice and you administer your own PROMs, you get a sense of things over time but you don't necessarily get a sense of how your [outcomes] benchmark [against other doctors]... and benchmarking has been shown to improve overall outcomes over time. (AE2)

Probably from my perspective design over quality improvement perspective would be the most important and the most interesting, so we would have one particular rehab hospital for example, giving much better patient-rated outcome measures than another. We'd be wanting to look at what they're doing differently for that particular side and then using that to improve other hospitals. (AE4)

### 3.2.2 Macro uses

There was less enthusiasm among interviewees for macro-level uses of PROMs data such as performance monitoring and management. One international participant stated that there was much developmental work to be done before PROMs could be used for international comparisons. Government department participants were wary that comparisons may highlight deficiencies in certain states, regions or organisations without taking into account differences in resources, population and other important factors likely to influence outcomes.

So to us the PROMs main use is at the patient-clinician level. So we don't advocate for any PROMs outcome results to be used for a performance measure. It is very much used for the patient and the clinician to really look at the patient's care and their treatment in real time. I guess we're not looking at rolling out the NHS model, just being reported quarterly, not down to the clinician level but aggregated at a higher level. I don't think we see that. (J2)

However, as one participant pointed out, the perceived threat around performance management was more about the culture of health than PROMs themselves. Instead of viewing safety and quality reporting as punitive, they could use such information positively as an opportunity for service improvement. This would require culture change, starting with a willingness to move away from reactions such as seeking out and blaming individual 'mal-intent' or incompetence and towards evidence around best practice and systemic change.

There was scepticism among Australian and international experts about the extent to which public reporting of PROMs would actually enhance patient choices about their treatment or setting of care. Some pointed out that in the UK, there was no apparent behaviour change by GPs or patients to indicate that publicly reporting PROMs had influenced patient choice of hospital. In contrast, one Australian expert argued that consumers should have access to outcomes data, especially PROMs because those are the outcomes of most interest and relevance to consumers.

Other participants believed that macro-level uses of PROMs have the potential to be influential drivers of system-level change, in quality and safety and in health system efficiency.

You want your driver to be safety and quality outcomes for people. I think scaling up is good, because I think if you can influence clinical practice guidelines or similar, that can be very powerful for people. (AE3)

You can get a little bit of data from benchmarking, but it doesn't permit you to really do value in contracting or information for patients and families. So, to do that, we really need a comprehensive approach, at least in one geography, where all the providers and the cities or regions are being held up to the same measurement standard. That's our strategy right now, is to try to get that done in one or two places and with one or two conditions. (IE1)

The other argument for collecting this data is that there's an efficiency argument, how efficient are hospitals at converting inputs into outcomes? We know how efficient they are in terms of converting inputs into outputs but churning out lots of hip operations may not be a signifier of an efficient organisation. (IE5)

The ultimate goal of the International Consortium for Health Outcomes Measurement (ICHOM) is to enable the value-based care agenda through the development of standardised outcomes data, including patient-reported outcomes. In terms of the three levels of PROMs uses, ICHOM advocates starting with the micro and meso levels and eventually moving to macro-level implementation. At this stage, macro-level uses have not been demonstrated or evaluated. However, there is emerging evidence that using PROMs to guide resource allocation and governance at a system level is feasible and may have benefits for health system efficiency.

So, the ICHOM approach has been to think of three phases. The first phase is clinical adoption for quality and comparison purposes. The second phase is benchmarking and feedback on an aggregate level of comparative performance, but there's no consequences and it's not public, just feedback. And then the third phase is for accountability, public disclosure or payment purposes ... We're now getting to where we have really reliably comparable information at a community-wide or market-wide level as our next challenge. (IE1)

We have a politician board, decides on the budgets... And they use our indicators quite a lot for prioritisation... And then it's used, sometimes it's on a hospital level or a little bit more local level... our reports more and more are documents for the governance, more than for the clinical local improvement work. (IE4)

I had some colleagues who a couple of years ago were able to use the PROMs data to calculate a cost per Quality-Adjusted Life Year (QALY) by hospital for things like hips and knees and hernias so it was a measure of efficiency, if you like, for the hospitals based on this data and that showed some variation which was interesting. (IE5)



### 3.3 Changing behaviours

One of the primary challenges in implementing any new health initiative is obtaining and maintaining the support of the staff whose working lives will be affected. PROMs will inevitably change established ways of working; one participant described them as a ‘disruptive technology’. PROMs will also require the sustained cooperation of thousands of patients. Stakeholder engagement is therefore a key challenge for PROMs implementation.

This section of the chapter focuses mainly on the stakeholder groups mentioned by interview participants: consumers, clinicians, healthcare organisations and payers. It explores their interests and concerns regarding PROMs, and how these might be addressed. The chapter concludes with a more general discussion of issues raised by participants around change management that are relevant to PROMs initiatives.

#### 3.3.1 Consumers

In general, participants believed that consumers would be highly supportive of PROMs if the benefits were explained. Some felt that consumers had already ‘heard the buzz’ around PROMs and there was interest, particularly in advocacy groups which were already ‘sold’ on the idea. PROMs seem to fit with the agenda of achieving greater influence for consumers on quality and safety improvements in the health system. Nevertheless, a number of issues were raised around consumer engagement in PROMs and the necessary conditions for a successful and sustainable collection.

First and foremost, PROMs need to be relevant to consumers. They need to understand the questions and why they are being asked. Face validity is crucial; consumers need to ‘recognise themselves in the questions’ (IE9). But more than that, health services need to be measuring outcomes that are meaningful for consumers, and take into account their preferred uses of the information. Relevant uses for consumers may include:

- Tracking their own progress over time
- Reporting their level of function or symptom interference in relation to their goals (e.g., whether they have been able to resume an enjoyable activity)
- Understanding what improvements might reasonably be expected from a treatment, and how likely they are in their own circumstances
- Making informed choices between treatments or providers.

Feeding back information in a useful form to consumers is an ethical responsibility and is also likely to enhance buy-in and data quality; one participant described it as ‘closing the loop between the people giving the information and the people asking for it’ (IE5). Whether PROMs are reported publicly or fed back privately to individual patients and their clinicians, the data must be presented in thoughtful ways that fit with consumer preferences.

*If patients take the time to fill it out, the patients need to see a benefit. And one benefit is that they can see all their results, their entire history of experience. (J7)*

*But I mean, you'd probably begin with the consumer and asking them what outcomes are they actually interested in. And generally their answers are going to be quite different to the clinicians. Clinicians might want quite specific sort of clinical outcome measures but the*

patient's going to want quality of life indicators so there's going to be that balance, I guess, of trying to integrate both. (J5)

Consumers want a chance to be heard, and to have positive engagement with health services. As one participant pointed out, it is not desirable to have policy and practice shaped only by those patients who are assertive enough to complain. PROMs provide a systematic way to ensure the consumer voice has an influence in the health system.

PROMs are potentially a consumer tool that clinicians will listen to. Unlike a lot of other things that consumers try to get on the agenda of clinicians and policy makers, PROMs make sense for clinicians. (AE3)

However, the level of desired engagement is likely to vary between groups of consumers. Those with chronic illness, such as cancer patients, have a long-term relationship with a healthcare provider and may be more personally invested in the idea of improving treatments and outcomes by providing their input. In contrast, those who visit a health service only once for a procedure or treatment related to an acute condition may be less amenable to providing follow-up data.

Where populations of service users are very mobile, there will be more missing data as people are lost to follow-up. One participant suggested that public messages about the importance of engaging with research might help build support for PROMs among consumers. Although mobile phones and email may seem a good solution to the follow-up issue, another participant warned about being careful not to overuse these methods as there is a risk of annoying consumers if you bombard them with 'spam'. Services should also be aware that consumers do not have equal access to such technology and therefore relying on it may result in disadvantaged groups being under-represented in their datasets.

Survey fatigue was seen as a real problem for PROMs collections. One way to overcome this is to ensure that the patient knows that the data will be used in their own care. Nevertheless, several participants made the point that lengthy questionnaires should be avoided. Service providers should be honest with consumers about how long it will take to complete PROMs and resist the temptation to squeeze in a few more questions. If a tool is too onerous, certain patients may struggle to complete it, particularly those who are the most vulnerable and ill. This may introduce bias into the data collection. Staff or family members may feel they have to answer the questions on the patient's behalf, which can defeat the purpose of PROMs.

So it's got to be short and it's got to be sharp and it's got to give us what we want. (AE2)

Equity of access was an important consideration for participants in the interviews. Several spoke about the needs of Aboriginal and Torres Strait Islander people, in particular, to have the opportunity to provide feedback on the health services they receive. PROMs need to be made accessible to all, including those who speak languages other than English, visually impaired people, and others who may struggle to complete a conventional questionnaire.

The importance of respecting a patient's privacy was also noted. Some participants believed that patients were more likely to be open and honest in a written questionnaire than face-to-face.

Finally, one participant spoke about the value (to consumers) of using standardised PROMs in research, specifically around improving the quality of research to ensure that the information provided by consumers contributes to medical knowledge. This interviewee was critical of 'pointless' research projects that waste consumers' time completing instruments that have not been properly validated for use, or are not comparable with measures used elsewhere. Such projects largely benefited medical students and registrars who were conducting the research to gain their qualifications.

### 3.3.2 Clinicians

Doctors are the main gatekeepers for PROMs. Although patients' willingness to provide their own information is an essential prerequisite, this is more likely to occur if their doctors encourage them to do so. If doctors choose not to be involved, there will be major difficulties with the implementation of PROMs. Even if collection is mandatory or linked to payment, a lack of engagement by doctors can compromise data quality and ultimately threaten the sustainability of a PROMs initiative.

Nurses will also play an important role in PROMs, particularly in hospitals and sub-acute settings such as palliative care, rehabilitation and mental health. However, relatively few participants spontaneously nominated nursing staff as key stakeholders in PROMs. Some allied health practitioners – including physiotherapists and psychologists – were also mentioned.

Participants were virtually unanimous in emphasising the importance of engaging doctors and their representative bodies, such as medical colleges and state-wide clinical networks. Rather than trying to persuade those who were opposed to PROMs, interviewees advised strongly to 'work with the willing'. Ideally, the starting point would be to build on, guide and facilitate clinician-initiated projects. Otherwise, the approach should involve extensive consultation and agreement on shared goals that are meaningful to clinicians.

We take a small sub-group of doctors who have the most affiliation with PROMs and we also ask the specific patients' federation to join these doctors and with them we start the whole process of finding out which dimensions to measure, which questionnaires there already are, which moments in time we should measure the PROMs. So, it's a very intrinsic driven system in which [our organisation] is only a facilitating party and, of course, we have a lot of knowledge in PROMs and we guide them, but we always say that the doctors and the patients are in charge in this whole process. (IE9)

One participant suggested that it was important to consider the 'clinical appetite' for the data. Another contrasted the experience of two projects in which they had been involved: the first, which required mandatory collection of a set of centrally determined PROMs; the second, a more collaborative effort which ultimately produced more successful results.

The difference was that clinicians were much more actively engaged, that was the basis on which they were invited to be involved; they chose ways in which they would use the score... and have been reporting very positive experiences of using it. But it helps them have meaningful discussions with their patients, it helps them discuss with their patient progress over time and it provides evidence of how they are doing - a particular service, a particular clinic - that they can provide to funders and generally a much more positive sense that this is relevant to them and works and actually helps. So the lesson of that is to adopt what I would call a more partnership approach to the use and implementation of PROMs. (IE8)

The concept of intrinsic motivation – willingness to engage in an activity without any external consequence – came through strongly in discussions about engaging clinicians in PROMs. Most participants felt that doctors were intrinsically motivated to make things better and to do things better for their patients. As one participant put it, ‘voluntary action can be associated with quite strong motivation’ (IE8). If this is the case, then one key task for those wanting to implement PROMs is to demonstrate the benefits for safety and quality. Convincing evidence of potential benefits may then motivate clinicians to incorporate PROMs into their own practice.

And then clinicians see that example and go, ‘Oh, right, that makes sense. Yes, that’s got a lot of value, I can see how I can utilise them filling out this questionnaire in being able to help me in being able to help talk to the patient, gauging the patient, make sure that they are tracking in the right way, we can identify issues with them. Okay, it’s got value in terms of how I do clinical practice.’ (J6)

So, when they can truly see the value in it, that’s pretty much the only incentive that they need to say, wow, I never knew that my person with diabetes, for example, had low mobility, or was depressed, or was anxious, because I never thought to ask, because I was always so busy concentrating on their sugar levels. So, we have found that is the biggest motivator and incentive when you can show, the what’s in it for them and the value add, and that they know that actually most of the time it isn’t going to take me any extra time, it’s actually not that added burden. Once we can actually demonstrate that to them, they’re usually jumping to get on board. (J12)

Another key task would be to assist clinicians with the resources and guidance they need to make PROMs a normal part of routine practice. This requires carefully selected instruments and cleverly designed systems to ensure that consistent, rigorous data can be collected without disrupting the workflow.

If you have six or seven minutes, you don’t want to spend three of those for the patient to fill in twenty-one questions. (J7)

If collection is easy and quick, it is more likely to happen. Doctors will, understandably, have concerns that collecting PROMs takes valuable time that could be used more productively. However, there is evidence from current trials that, where these measures are well integrated into the system of care, there is the potential to save time during the consultation.

However, efficient data capture will not be sufficient to engage clinicians in the long term. The data need to be relevant to care, and (ideally) available in real time to assist in decision-making. If the data are immediately useful, clinicians will be more likely to ensure the PROMs are completed and to incorporate this ‘disruptive technology’ into their practice.

When clinicians have immediate feedback in terms of how their patients are feeling, where they're at with regards to key symptoms, then that should really influence the way they approach clinical management. And with the ability to be able to provide real time feedback, then they should be able to see change, depending on what they do. And that would be a really powerful driver in terms of how symptoms are managed. (J11)

I think, it kind of makes sense for us, because what you want as a clinician, with the family and the patient, is to have something that’s uniform, to find out what their problems are and then to work with them to resolve them and then to reassess it. And then kind of,

behind the scenes, we get that data and measure what the outcomes are. So, there's buy-in from the clinicians, if it's just part of what you normally do. (AE1)

I think in the end if clinicians see them as useful in their clinical practice, not if they see them as useful to help the general efficiency of the hospital or some national goals around quality or whatever, that's too distant and too vague, I think they've got to see some almost direct clinical benefit to this information. (IE5)

Data can then be fed into a central repository for other purposes, and fed back in an aggregated form to clinicians and organisations to guide quality improvement. Although aggregate uses of PROMs, such as benchmarking, research and public reporting, may not be as intuitively appealing, some clinicians will support them where the benefits can be demonstrated. Healthcare providers may wish to interact with the dataset creatively, by generating research questions; or they may use PRO data to draw attention to the good outcomes they are achieving.

I mean, just to give an illustration, many of the pilot sites are very positive; they didn't need to be persuaded... just felt that this would show their services in a good light. They were so positive about what they were doing that bringing the lens or the laser of a PROM to bear on their work would just work to their advantage. (IE8)

Aggregate uses of PROMs may, however, create resistance to their use. Participants pointed out that asking clinicians to collect PROMs for their own use is a very different proposition from, for example, 'doing a state-wide survey and looking at performance across local health districts or between hospitals' (J11). Using the data for performance management may be seen as a threat to professional decision-making and autonomy. There may be a temptation to 'fudge' data if it is tied to payment. Risk adjustment methods will be closely scrutinised and challenged if publicly reported data reflect poorly on individuals or organisations.

Some clinicians will question the validity of PROMs. They may see them as an added burden, offering minimal additional value. PROMs may draw attention to errors and prompt complaints, which then will require a response. Doctors may feel that the outcomes covered by PROMs are beyond their capacity to influence, and therefore should not be attributed to their clinical care.

There are, certainly the older generation of clinicians may be, there may be a fair bit of scepticism amongst that generation as to the value of such data. They may see it as subjective, and therefore not of much use at all. They may also not think that it's appropriate to collect patient-reported outcomes if that gets in the way of their natural way of interacting with patients. They're worried about raising issues that it's not within their remit to address, and they're worried about having time for this sort of additional task, and, if those sorts of concerns aren't addressed, then the implementation will fail. (AE5)

It's just my assessment that you could get kick back from people saying what else do you want us to do? How much else do we have to do? I think it would require very strategic and tactical engagement of clinical groups. (AE3)

This kind of resistance has been encountered in some PROMs initiatives overseas, according to some of the international interviewees.

Even though the information is out there and they are seeing some interesting patterns, people are not changing what they are doing at all. And there is a lot of pushback. There is a growing sense of this is a lot of work and a lot of effort and the clinicians feel like the information may not have enough context to be representative and useful and that, if anything, they are more likely to be hurt by this than helped. (IE6)

They might intellectually be interested, but they see it as a risk to their business to have some future accountability for improving people's health. Which actually takes a look into the social, the cultural issues. There's a strong feeling here by the physicians, the doctors in particular, that they should not be held accountable for something they can't control and they don't want to have performance measures or quality measures that are not within their direct span of control. So, a process measure, whether I've prescribed a particular medication or conducted a particular screening test, that, they understand that they could be accountable for that. Whether three months later, a patient's walking well or breathing clearly, they feel like that's too far beyond their responsibility. (IE1)

Several participants spoke about the influential role of the medical and professional colleges, and the possibility of engaging them in selecting appropriate PROMs and endorsing or promoting their use. The extent to which the medical colleges in Australia are already engaged with PROMs was unclear. Overseas, however, clinical registries for medical specialities have been a focus for clinician-led PROMs initiatives. Medical colleges may also have a role to play in responding to PROMs data, for example when it highlights poor performance by an individual clinician.

### 3.3.3 Other stakeholders

The other key stakeholders mentioned by interviewees can be categorised broadly as providers (primary care; hospitals) or payers (health insurers; state/territory and Australian Government agencies). Their interests and concerns are discussed below.

Among the Australian participants, it was seen as highly desirable to engage the primary care sector in PROMs and to find some way of following patients across settings from general practice to inpatient and back again, rather than waiting for them to re-enter the hospital system, possibly via an outpatient clinic.

So I think there is opportunity to bring GPs into this space and for them to be, I guess, a counterpart in helping us to collect things, even if it is about the hospital sector. Because they quite often are the person who sees the patient after they've been in the acute setting... I think if we could engage our GPs in that post-acute setting we could gather a lot better, a lot more rich data. (J10)

I mean the other thing that we are also grappling with is patients where the care isn't always delivered in the hospital or it might be a shared care situation so we do obviously need to think about how PROMs may be utilised or collected at points that aren't necessarily specifically in the hospital space but... we're still very early on in the piece there. (J2)

However, participants acknowledged that state/territory health departments had little influence in primary care and no capacity to fund GPs to collect these measures. With the exception of a few GPs who had a particular interest in measurement or innovation, most had not yet joined the 'conversation' around PROMs. Nevertheless, at least one pilot project had



succeeded in engaging general practitioners in an effort to measure the continuity of care across settings from the perspective of patients.

Hospitals have a key role in collecting PROMs for the treatment of acute conditions, and participants saw hospitals as a focus for the expansion of PROMs collections in Australia. Hospitals and state health departments were identified as being responsible for building the infrastructure for PROMs. State and territory government participants indicated that there was scattered activity in PROMs within hospitals and interest in a more systematic approach. One thing that could facilitate systematic PROMs collection is access to up-to-date information about what measures to use and how to collect them. If PROMs data are to be used for benchmarking, there need to be robust risk adjustment methods. Staff responsible for quality improvement may require assistance with interpreting the data and understanding how it can be used.

I mean I think just like half the hospitals, the health services recognise that... they need to start getting into that space and start collecting PROMs. I think one of the problems is that they don't understand maybe what PROMs are and what the tools are... But I don't think [there exists] a one-stop shop that, if a hospital says okay I'm really interested in PROMs and I would really like to do it for my surgical clinic. What do I do and how do I do it? I don't think that is sort of there, but I might be wrong. (J2)

If I was a hospital and I was towards the bottom end of some distribution of outcomes or something I immediately want to have a whole host of questions to ask about the quality of the data, about are there significant differences, is this just a one-off this year or is it persistent over time and so on, so you still need to put in quite a lot of work to interpret the data. (IE5)

Interviewees with experience in the use of health outcome measures for benchmarking had observed differences between public and private sector providers in terms of their willingness to share good practice with other providers. Whereas in the public sector there appeared to be little sense of competition and more openness about asking for (and providing) advice and assistance on quality improvement, private sector representatives were less apt to be open and enthusiastic contributors to such discussions.

Another participant said they had found that private provider health data in general was not easily available for quality and safety reporting purposes. There was also a perception that private hospitals may want to use PROMs primarily as a marketing tool.

I think some people... are probably using it as a pseudo patient experience, sort of, you know, 20 outpatients... the care we provided was excellent and [...] they only got a sample return of 10% of patients or something like that. And so I think that that sort of use is not going to be high value to anyone, really, that's for marketing and promotional purposes, it's not going to change care or improve care. (AE2)

However, some private healthcare providers have demonstrated a willingness and capacity to use PROMs for quality improvement through public reporting and sharing of best practice, as well as for marketing. For instance, the national PROMs program in England was preceded by an initiative of the large private healthcare provider BUPA Hospitals (now Spire Healthcare). This initiative, which dates back to 1998, has achieved a number of practice improvements such

as changes to care pathways, enhanced communication with patients, and a greater focus on post-operative pain relief following hysterectomy.<sup>21</sup>

The issue of patient follow-up across settings may be more problematic in private hospitals because there is limited opportunity to collect data in pre-admission or outpatient clinics. These providers deal with hundreds of medical specialists and surgeons, each of whom is an independent small business with their own data systems and level of willingness to take part in a coordinated data collection.

So it's great when the doctors all participate, but because of the funding models in private hospitals, the doctors are their own business you know, they're not actually employees of the private hospital. They're a separate contractor, so again it's that sharing of data across the platform that is tricky. (AE4)

In the UK, following a ruling by the Competition and Markets Authority, private hospitals are now required to collect and publicly report PROMs data not just for NHS patients treated in their facilities but for all patients who have one of the four procedures targeted by the national PROMs program. This Authority, which regulates competition law, conducted an investigation into the private health market and concluded that consumers were not being well served by the information that was then being released about their treatment outcomes from private sector healthcare providers. Data collection from these providers is now coordinated by the Private Healthcare Information Network and reported on its website: <https://www.phin.org.uk>.

The issue of how to engage private healthcare providers in broader PROMs initiatives is also highly relevant in Australia, where the private sector provides the majority of certain elective procedures and where state and territory health departments sometimes contract with private hospitals to treat public patients. There are also contractual arrangements between governments in smaller states and those in larger states to perform certain procedures for which there is insufficient volume to maintain the necessary medical expertise in the smaller state or territory. As payers, state health departments have an interest in using PROMs to gauge the value they are obtaining from these contracts.

At the national level, the Therapeutic Goods Administration (TGA) uses data collected from clinical trials and registries to judge the value of new and existing drugs and devices that are or may be included in the Australian Register of Therapeutic Goods. PROMs offer another, potentially valuable, source of information:

So the TGA are very interested in this type of data, because they get reports to them that suggests there may be a problem with a device, and then they'll ask us about our experience of that device, but as PROMs come on board that will form part of the assessment for the TGA. (AE2)

The other payers in the Australian health system (apart from consumers) are health insurance companies. These are also prominent in some other countries, for example, the Netherlands and the United States, although the roles they play in the health systems of different countries vary considerably. Few participants mentioned health insurers as key stakeholders, and there were divergent views on their level of interest and involvement. Two Australian interviewees referred to the existence of joint projects between health insurers and providers or clinical registries, focusing in areas of particular interest to the health fund. One international



participant discussed the ‘business barriers’ to participation by the health funds in their country:

And that is to do with how much money they make in the traditional business model and they’re not really interested in a business model that’s tied to value and tied to management of patients’ health status, unless it goes through them. So, they’ve been very unsupportive, the health plans have, only a couple of exceptions. (IE1)

Another international participant offered a more optimistic assessment of the willingness of health insurers to engage with PROMs. This interviewee described the involvement of health insurers in public reporting, first by taking part in discussions to develop suitable indicators of care quality that might include PROMs, and then by taking PROMs-based indicators into account in their negotiations with healthcare providers. There was also an Australian example of the potential to use PROMs to demonstrate the value of certain treatments or providers to health insurers:

Rehabilitation would be a helpful area for PROMs because we’re getting a lot of pushback from health funds to say that inpatient rehabilitation isn’t actually working, and yet, we’re getting lots of information from our patients that say... my life would have been a misery if I’d gone straight home and I didn’t have my rehab. (AE4)

### 3.3.4 Change management

Participants suggested a variety of strategies to address resistance and facilitate PROMs uptake. These strategies generally involved investing time and resources in managing change. Some of these would involve a long-term investment in lasting change, whereas others would provide short-term solutions to critical problems during the early stages of implementation.

The kinds of approaches mentioned by participants were consistent with theories of change management, incorporating ideas such as identifying change champions, engaging stakeholders in co-designing the initiative, providing support and incentives for participation, giving regular feedback on progress and demonstrating benefits early. It was generally accepted that change would take time, and the process would be complex and would require provision of adequate resources including staff, money, training and infrastructure such as the questionnaires themselves and technology for data capture, analysis and feedback.

Short-term approaches to change management may include providing practical assistance with data collection. For instance, one pilot project included funding for trained assistants to administer PROMs questionnaires. Another short-term strategy is to identify change champions who are ‘passionate and invested’ clinical leaders (J10). Other advice offered by participants was to be realistic about the pace of change and the likelihood of obstacles, and to keep stakeholders informed regularly about progress. This feedback should celebrate successes and acknowledge aspects of the project that have not worked as well, preferably also explaining what was learned from the experience and how the project might be adapted in response to formative evaluation findings.

The anecdotal feedback that has been given to us by the clinicians, the consumers, and the managers, is that there is that short amount of pain upfront as there is when you’re trying to change any process, or introduce anything new. However, once you have invested the

time in really trying to get that right and trying to understand what you're doing, that there are definitely the longer-term benefits and outcomes. (J12)

In order to sustain long-term change, however, PROMs will need to be embedded into 'business as usual' and not depend on the enthusiasm of a project officer or a few champions. A sustainable and systematic approach to PROMs will require a strong commitment to behaviour change among clinical staff and consumers.

I'm also reminded of a literature review that came out of the UK in 2014 on systemic approaches to person-centred care and so on, and it said despite the growing empirical evidence and practice information about person centred-care - these kinds of approaches that value patient-reported experiences and outcomes, it's increasingly in policy, it's increasingly in priorities. But in practice it's just not happening. Like a lot of behaviour change, it's complex. (AE3)

Successful translation of policy to practice has been achieved in some of the well-established health outcomes collections in Australia. Several Australian experts pointed out that embedding PROMs in usual practice is not just about data collection – it's also necessary to ensure the data are used regularly and seamlessly to inform treatment decisions and quality improvement activities. Building these uses into PROMs systems, and providing support for clinicians to understand and act upon the data, will allow the value of PROMs to be realised and demonstrated to clinicians and consumers, providers and payers. This in turn is likely to increase and maintain stakeholder support for the initiative.

You see the thing is about the PROMs enthusiasm is, it's really easy to select some measures and to get some systems in place and collect a whole lot of data, that's the easy bit, but that's also the trap, because if you don't do something with it, people are going to feel pretty resentful of having spent their time and energy collecting those data. (AE5)

One international participant suggested that new initiatives should start in areas where PROMs can make the biggest contribution to understanding health outcomes; fields in which objective biological markers of treatment success may be less useful. This is the principle behind the selection of PROMs as the only health outcomes measures to be collected by the electronic Persistent Pain Outcomes Collaboration in Australia and New Zealand.

Other participants suggested a 'layered approach' starting with rapid feedback of PROMs data to clinicians for quality improvement. Of all the uses of PROMs, this is perhaps the least threatening and has the most obvious direct value to clinicians. After building experience with the PROMs instruments and refining the data analysis and presentation, it may be possible to gain support for other uses in contracting and public reporting. This suggestion is consistent with the approach taken in recent years for the incorporation of PROMs in the clinical registries managed by DICA in the Netherlands.

Attitude and behaviour change may be promoted through education and training of clinicians and consumers. Ensuring that clinicians who complete PROMs-related training are eligible to receive continuing professional development points (or equivalent) will enhance the credibility of these courses as well as providing an incentive to participate. Doctors need to know how to use and interpret the instruments, but they also need to gain an appreciation of the science of psychometrics. This may help avoid situations where doctors modify tools or invent questions for their own monitoring and research purposes, resulting in invalid data.

Clinicians who engage in being able to collect information from patients will typically have no knowledge of psychometrics and they will pretty much barbarise, cut and paste, pull together, create whatever is possible to - and whatever they think is appropriate for what their purpose is and so that's a big problem. (J6)

There is not a lot of experience or comfort with these kinds of surveys, so people might be very comfortable taking a blood pressure, but they're not very comfortable administering a standardised symptom battery. (IE1)

However, changing attitudes and behaviours using in-service training has proven more challenging than anticipated, prompting one international participant to emphasise the importance of 'starting early'. It is vital that undergraduate medical training fosters an appreciation for patient perspectives.

I think there is still reluctance by the clinical community to accept these data as genuinely relevant information for clinical practice, and I think that's also the key barrier, convincing the sceptics who still seem to think that patient experience is about how hot the bread rolls were in the hospital food and things like that, and that PROMs are simply subjective, fuzzy and kind of soft information... They are not aware of the science that's gone into it, into the validation of these tools and measures, and a lot of effort I think needs to be expended in convincing the profession broadly of the value of doing this and also conquering perhaps some of the fears that some of the clinicians may have about having the outcomes of their work exposed so starkly. (IE7)

We've got to be able to train our clinicians and train our other stakeholders on how to use this information and we're going to have to spend a lot more time and effort and begin very early with this training so that it becomes part of the way they think about things. (IE6)

The concept of partnering with patients is now incorporated into standards governing healthcare providers. This provides an opportunity to reward participation in PROMs initiatives by allowing this activity to count as evidence towards accreditation. Patients are, of course, key partners in PROMs as without their willingness to provide data, any initiative will fail. Strategies to engage patients suggested by participants included: having consumer representatives take part in early focus groups and contribute to the design process; education on what PROMs are and how to use them; and communication about the quality improvements achieved as a result of PROMs initiatives.

We have to train the patients, the public, to be our partners in this. They have to see it as part of their job as patients, is to pull out their phones six months after surgery and answer some questions. So, that will take some time and is at least a challenge, if not a risk... If we don't take on that challenge successfully, we will have more incomplete and unreliable data. (IE1)

### **3.4 Designing the infrastructure**

The effective implementation of PROMs requires an investment in infrastructure that supports the objectives of data collection and use. This will include validated, relevant measures; systems for capturing data efficiently and storing it securely; data analysis methods; and reporting mechanisms that meet the needs of various stakeholders.

### 3.4.1 Selection or design of measures

According to the Mayo Clinic, a good PROM is simple and brief; it can be read by a 12-year-old and will take no more than 15 minutes to complete.<sup>22</sup> It must be developed with input from patients. It must also have the essential psychometric qualities of reliability, validity and responsiveness to change; and be easily scored and interpreted.<sup>22</sup>

Almost all participants had something to say about the importance of choosing the right PROMs for the intended purpose. There are many instruments, and a poor choice could undermine the credibility of a PROMs initiative and limit the usefulness of the data.

If people dive into this without thinking about use and thinking about longer term applications and usability and feasibility, then they might end up selecting a tool that they wish they hadn't. (J2)

Nevertheless, many of the experts were optimistic about the availability of suitable instruments. Much of the hard work of development has already been done by those using PROMs for research and there are several established data collections and numerous pilot projects that are currently using PROMs in Australia.

So we do understand, I think better than we ever have, the core components of what a profile of health should look like. And as I say what I've been sort of most struck by in our work is that most of the time the profiles tell you that people are really actually doing pretty good. And once in a while you find things that are unexpected and yet incredibly important. (IE6)

One caveat I would like to just note for the record, is there is a danger in you using the PROMs that have been designed for research use at the clinical level, because they may not have the precision required for managing individual patients and there we have the promise of new computer adaptive testing style approaches to measurement that can be implemented with electronic data capture. But as you aggregate up to the higher policy levels and the benchmarking levels, that problem drops away because you get tremendous precision from the large sample sizes that you get at those levels. (AE5)

It is important to include people with expertise in psychometrics on any team that is choosing and implementing PROMs, to ensure that the selected instruments have measurement properties suited to the required purpose, whether that is individual care or aggregation or a combination of the two. Careful work is needed to define the domains of measurement that are relevant, both to local settings and to quality and safety improvement.

Some state and territory government participants admitted that selecting PROMs was a daunting task and they would welcome some guidance or advice. Those who lack access to expertise in psychometrics are possibly more likely to turn to ready-made solutions such as the ICHOM standard sets. These are appealing because they provide a menu of options that have been selected and validated for use in particular clinical fields. Another major development in PROMs in recent years has been the Patient-Reported Outcomes Measurement Information System (PROMIS) item bank, developed to measure a set of core domains common across a variety of chronic and complex health conditions. Participants' views on these two initiatives are presented below, after a more general discussion of the issues around selection of PROMs. The three dominant issues were ownership, flexibility and the extent to which PROMs should be standardised.

## Ownership

The importance of ‘ownership’ of PROMs initiatives has been discussed above. This applies also to the selection of measures. One expert said that this process had to start by getting ‘everyone in the room’ (AE1). Another said that even when clinicians were wedded to certain tools, it was possible to start conversations around a set of minimum data that might be useful, and these conversations resulted in a surprising degree of consistency and agreement (IE6). Yet another warned that it may not be wise to be too prescriptive; better to allow some ‘wiggle room’ in order to facilitate engagement with providers and patients (IE7).

This alternative approach is messier, more unpredictable. Depending on how it’s done you may be leaving a lot of discretion about which conditions are the focus and which measures are used and how they’re used... So it’s messier, but it may well be that like many other areas of health and health policy, so the incremental progress is better than top-down progress, well, or non-progress. (IE8)

## Flexibility

Even after PROMs have been chosen and used for some time, it may be desirable to revise that choice at some point. One expert described the process of reviewing the instruments used in an established data collection to ensure they were still serving their purpose. In a pilot program, the final set of instruments may be decided via an iterative process. Organisations or jurisdictions that decide to go down a slightly different path can be used as case studies in evaluating the impact of the PROMs initiative. In both cases, the process involves collecting evidence on the extent to which the instruments are capable of detecting variation in outcomes and their sensitivity to changes in practice.

But there’s also an opportunity for that community of practice to come together, to have quite a mature and informed debate, often about the validity of the measure itself. Whether it’s still appropriate, whether it needs changing, whether it needs updating, you know? Whether it’s appropriate across settings. (AE1)

You won’t always get consensus... some people will always just do what they would like to do, regardless of whether there is a statewide, or national approach. And, I suppose, being adaptable ... because lots of people will get caught up in the ifs, and the whats and the buts, but sometimes it’s about let’s just give it go and if it doesn’t work, then we have the option to come back in two months’ time, or whatever it might be, revise it and then move forward from there. (J12)

The disadvantage of such an approach is a lack of consistency and comparability. Collecting different questions for similar patients is a barrier to a systematic approach (IE7). If it is possible to gain early agreement on useful measures, this has advantages in terms of efficiency.

I think ultimately what we’d be looking to do is try and move this nationally, to start to get collaboration, sharing of information and if there’s an opportunity to standardise it early... in terms of the development of a standard set of outcome measures, I think that’s a positive step, so two years down the track or whatever it might be, we’ve already had that similar approach as to what we’re actually capturing. (J4)

## Standardisation

While no-one was in favour of mandating collection of specific measures, there was considerable support for some level of standardisation, both among the experts and the

government participants. Scaling up the use of a particular measure or set of measures within and across organisations was seen as a powerful strategy for collecting information to guide safety and quality improvements. In order to detect unwarranted variation in outcomes, it is necessary to have comparable data (and careful risk adjustment).

I think you've got to have some standardisation. The bigger the population group, the more you've got to have the standardisation because at least it's got some meaning in it. I like the idea of the core, plus you can add some local measures in some ways. I think if you are collecting clinical data about something, then it would be good if your PROMs could be at the same scale, you know? If you're looking at the impact of some kind of intervention, you want to have sufficient quality PROMs data to be considered at the same time. (AE3)

I'd be strongly in favour of a national standardisation... I mean, you know, a hip replacement is a hip replacement, no matter where it is, and I think it's really helpful to know if there's a variable outcome for Darwin versus Tasmania. (AE4)

In addition to core generic PROMs and disease-specific PROMs, organisations or jurisdictions may want to collect local items to enhance buy-in and relevance. One participant referred to this idea as a 'dual core': one national set, and one state- or organisation-based set. However, these extra items need to be subject to the same scrutiny as the core PROMs with regards to validity, acceptability and relevance.

Standardisation has the advantages of being able to pull data and compare it across places and that's important, so I think that there do need to be core datasets and great care needs to be taken in choosing those and they can't be too big, but equally I think it's important to allow local sites to have scope to add additional measures that they might already have been using in their practice and that they find useful in their practice. (AE5)

We all think we're unique. We all think we do things differently, and we all think we do things slightly better than the guy next door. I don't know that we are... I think we basically provide fairly similar services... So I suspect that a lot of questions that if you had a questionnaire in New South Wales and it was validated, that it would be the same for the surgeons in Victoria, that were in Western Australia, that were in Northern Territory. I don't know that there is a whole lot of need to adapt things for local specific treatment or care. (J10)

## **ICHOM**

There was a high level of awareness of ICHOM among the jurisdictional participants, some of whom had attended the inaugural forum in Sydney. Participants could also point to a number of collaborative projects with ICHOM currently under way in Australia. There was interest in the ICHOM standard sets, with the understanding that these may need to be adapted for local contexts.

You can't ignore ICHOM. They've done a lot of work. They're internationally recognised and of course we would look to them to see what they have selected and to see whether that was something that would be applicable locally. (J3)

So people often ask me, 'This is the area that I'm interested in, what PROMs should I collect?' and I say to them, 'Look, don't reinvent the wheel, there's a lot of work already being done by groups like ICHOM to develop standard sets.' So, I think, promoting the use of an international standard set of data is really important... And also, people need to



understand that what ICHOM has put out there is just a minimum set, you can add things onto that if you want, but, I think, it's a good starting point for anyone starting from scratch to see what ICHOM have set up. (J5)

However, there were some concerns from international and Australian experts about the prospects for successfully implementing standard sets of measures. One of the international experts described a conversation with an acquaintance who had decided to go down this path:

And he said, 'Well look, they offer exactly what I need. They come in and they tell you.' He said, 'I don't need to know what is the best measure... I need a menu. I need to put them into my hospitals and I need you to tell me of these 40 conditions, here are the measures you should be using. I don't want to go through making the decisions. I don't want to understand the nuances. I want you to tell me you've done all the work and here it is.' (IE6)

There was a feeling among the experts that the benefits of a standard set of measures and instruments had yet to be demonstrated. Several referred to the experience of the English NHS PROMs program, which in several ways had not had the hoped-for impact on safety and quality.

As I read it and read it now, the goals really were a strong belief, especially by health economists that you could improve productivity, increase quality, reduce unhelpful variations all through generating evidence about outcomes. They would reveal – good outcome data would reveal unproductive services, poor quality services and unnecessary variations in services. And as I'm sure you will have read that didn't really happen. (IE8)

So [ICHOM] is something that has really come out of nowhere in five years. It is a business model that's very clear. It is geared at providing a service. I think that a lot of what they do is very, very attractive. They give you these shelf-ready sets of outcomes... What worries me is, in listening to people like Nick Black and having watched him for the last 10 years, with NHS. And hearing him say we've put a lot of time, a lot of effort and a lot of our hearts behind some core PROs that we thought were going to help us to reshape the NHS. And they are not seeing the benefits that they had hoped. (IE6)

Expert participants raised issues about the ICHOM business model, the selection of instruments and the expertise of the panels conducting validation studies. One government participant said that researchers and clinicians in public hospitals could be involved in validating an instrument but then asked to pay for its continued use after the trial ended. This person questioned whether this was an appropriate model for a publicly funded health system. There was also a concern that the existing expertise in Australia could be overlooked in the hunt for a ready-made solution from overseas.

[ICHOM has] gained momentum and they're developing their datasets and they're implementing them, but they're still – to get to the stage where they've been implemented for a period of time, results have been analysed, fed back, led to improvements, like, you know, we're not quite at that level yet, we're starting to get to that level. So we're really in a very early stage of it, I think, and we're still trying to work out exactly what's the best way to do PROMs the best, what the outcomes are from them, how useful they are, how feasible, how meaningful, all that sort of stuff. (AE2)

I am particularly worried about things like the ICHOM set getting widely implemented quickly. I've spent most of my career trying to convince my colleagues no, no, no. You don't want to collect everything under the sun, trust me. Holding back, collecting smaller limited

datasets but one that will be maximally informative I think is where we need to spend a lot more time and thought. (IE6)

Participants questioned the idea that suitable instruments could be chosen by a small group of experts rather than through a broader consultation process involving consumers and clinicians. Without a genuine consultation and co-design process, consumers and clinicians who have never used PROMs may not see the point. Other clinical groups may be strongly attached to legacy instruments they have used for many years and simply refuse to change over to the new measures.

So, I think from our point of view, it's very much the clinical areas need to decide exactly what it is they want and then why they want to know it and then design the PROM that way, rather than having... standard PROMs just fitted on to all the different areas and maybe collected centrally, but it's not particularly owned by those areas. (IE3)

There are a range of instruments for every condition now, and people and clinicians and managers and academics, will have their preferred one, and I think it may be counterproductive to impose, to mandate the use of a particular one at the expense of – at the risk of losing the support of those devotees to others, so some investment, I think, is wise to be made in mapping across instruments so that you can use the results... into a combined – into a uniform measure. (IE7)

## **PROMIS**

Many participants were in favour of a core set of generic PROMs, complemented by disease- or condition-specific PROMs. While the former would allow comparability, the latter are more sensitive to the changes in symptoms of a particular condition, the effectiveness of a specific treatment, or the potential complications arising from a procedure.

One way to achieve the required precision without making the test excessively long and time consuming is to use an item bank delivered by computerised adaptive testing. The US National Institutes of Health (NIH) PROMIS uses this approach to measure PROs common to a variety of chronic conditions. It uses item response theory to create tests that are tailored to a patient's health status and change dynamically as they are used, but remain valid and reliable.<sup>23</sup> Generic domains covered by PROMIS include physical functioning, fatigue, pain, emotional distress and social role participation.

PROMIS instruments are already being used in some Australian states. Several international participants spoke positively about PROMIS and the approach is currently being emulated in other countries.

We have our national registers who are mainly developing PROMs, and they have developed these measures quite independently, so we have... a whole table full of different kinds of measures, and now the registers are actually working on the project where they want to construct a nationwide item bank for these measures, which means that maybe they will move forward in a more united way in these PROMs. And they are looking very much on the item bank PROMIS in America, the US. So that's actually the development, and we are following this development. (IE4)



PROMIS was funded by the NIH for a 10 year period. Since January 2017, there has been a shift to a cost-recovery model and users have to pay a fee which covers staff time and maintenance of the infrastructure.

### 3.4.2 System design and data capture

Once the measures have been agreed upon, it will also be vital to gain agreement on standard procedures for data collection including the timing of administration and integration into clinicians' workflow and organisational systems. Many participants were in favour of saving time during the consultation by asking patients to complete their PROMs shortly beforehand.

I think... using digital devices more, to let the people... fill in surveys... while they are waiting for the doctor... I think that would be something that could be more developed, because it's very hard to take the time of course for the doctor in the actual patient meeting to try to ask those questions. I think the questions that you want the patient to answer, it has to be done somewhere else than the actual meeting. (IE4)

And maybe that's where part of the role for the GP is, or it's the role of the pre-admission clinic to have people doing things like that while they're waiting to go into see the anaesthetist, or the nurse, or the surgeon. There are potential points I suspect along the patient's trajectory leading up to something where you could do it if you had the way of collecting it. Or you could collect it once and then it would need to be then in a place where all areas could go in and actually extract the bit that they wanted for their area. (J12)

Standard procedures around data capture, assisted by a common platform or information technology (IT) solution, are necessary to ensure that the data are 'robust and accurate' (IE3). However, this relies on all parties having access to basic information such as up-to-date patient contact details, which is not always the case in Australia. One participant noted that this information was actually becoming more and more difficult to obtain. The idea of a unique patient identifier across settings is 'utopia' for those involved in data collection:

But there's also a trend towards reducing the amount of information on a sticker. So one of the hospitals in [State] just has a barcode, a name and a birth date and that's it. So we've then got to ring the hospital to then get each of this information, get that over the phone, get the information transferred over the phone, which has risks of the data being incorrectly transferred, and there's going to be more of a trend toward that, which means following up patients. If you're a third party it's going to be even more difficult going forward. (AE2)

Many participants spoke about the benefits of having purpose-built technology to assist with data capture. The UK PROMs national collection is still largely paper based, which limits the timeliness of feedback to clinicians and organisations. However, there are other collections in the UK that are set up for immediate local use of PROMs in consultation with patients. Electronic data collection enables rapid feedback as well as easier and more accurate transfer into databases.

Everyone would like the ability to have an integrated IT system that was seamless and had a clinician portal, a patient portal, and that we had the ability to view data over care settings. (J12)

There's a bit of IT work that we need to do, but the data is already being collected and collated. What we need to do is to develop IT systems that allow the use of data more

efficiently in real time. So, a lot of the stuff we do now is retrospective analyses which, whilst they're very useful because there's no other data source that can provide clinicians with the detail that we're collecting, well, what happened three months ago, it's probably better to have this information in real time as much as possible. So, I think, that the IT systems are probably about 12 months away from us doing that... that's me being very optimistic. (J5)

One method currently being used by several Australian pilot projects is to send a text message to the patient with a link to a web-based survey. Those who do not respond after several messages are followed up by telephone and eventually by mail. Computer-assisted administration and automatic translation of PROMs questions has the potential to make these tools more accessible to people from different cultural and linguistic backgrounds, and also to Aboriginal and Torres Strait Islander people, and those with visual impairments.

There is a project under way at Monash University to compare response rates from PROMs surveys using paper questionnaires, telephone interviews or online survey platforms, and to examine whether these vary according to the age of the participants. This kind of study can provide valuable information about the best way to reach different types of consumers.

They've got this iPad software that can actually translate into different languages, like if you've got a visual impairment you can listen to the questions, and that sort of stuff, and it's a whole set of PROMs and PREMs on this website that a patient can just enter in on an iPad in the hospital. (J5)

We are the administrators of that application and we push the surveys through the mobile devices or they can have online services. Online surveys as well. So there's a bit of a program happening with that and so I'm trying to capture more people outside of that telephone service because not everybody's sitting at home waiting for the phone to ring obviously, so we're capturing them in different ways. (J1)

While the ideal situation might be a common information technology platform across all users of a set of PROMs, in practice IT systems in health differ in terms of age, design, capacity, original purpose and the extent to which they are capable of being adapted for new uses. This diversity is a limiting factor for wider implementation of PROMs across settings and locations.

However, waiting for a customised IT solution may not be the best way to proceed with PROMs as this can delay the roll-out considerably. It may be better to start with pilot tools on paper and then work with healthcare providers to design an IT system that best suits their needs. Local solutions which prove effective can later be scaled up along with the PROMs initiative.

A variety of commercial IT solutions are available and some of these were showcased at the 2017 ICHOM forum. Participants were aware of these options but tended to be cautious about whether they could be readily applied to the Australian context. Although an off-the-shelf product may be appealing, there is a need to critically appraise these systems to ensure they are suitable for all the envisaged uses of PROMs. A pilot program can provide an opportunity to see exactly how users interact with PROMs and what functionality they would want from an IT system before committing to a particular design.

There are a number of companies, vendors who are developing software solutions to display the information as a dashboard or as a reporting format for clinicians and for

managers. And so, we do keep track of many of the people out there, developing those types of services. So, we don't have one approach we use. (IE1)

I see that there are two aspects involved. One is the thinking behind it. So, what are the principles that we are adhering to? And the other aspect is whatever IT or even paper based system that is involved, do they actually have the capability to be able to deliver what our thinking dictates? That's the big system risk that comes to mind. (J11)

Some of these service providers definitely manage big data, big PROMs data, but it's a path that we've chose not to go down purely because of dollars in the first instance, but it's not necessarily one that, you know, maybe the state wouldn't consider – they would sort of go, let's progress a little bit more. (J4)

REDCap (Research Electronic Data Capture; [www.project-redcap.org](http://www.project-redcap.org)) is a web-based survey tool that can be customised to meet the security requirements of users.<sup>24</sup> It was developed at Vanderbilt University in the USA and is now supported by an international consortium of researchers and other users associated with non-profit organisations. The software is free to consortium members. Several participants mentioned REDCap in the context of data capture methods for PROMs. It provides the common platform for the PROMIS tools.

On the other hand, the research infrastructure REDCap freely provides the [PROMIS] measures. So that, if your institutions - and most of them do in North America quite frankly – if they subscribe to REDCap and there's a very small fee to do that annually, you have free access to all of the Computer-Adaptive Tests (CATs). And the institutional agreements are such that it overcomes that barrier of where the CATs are actually located. So REDCap, when you're using REDCap through your institution, you're using it on your own soil. (IE6)

Some of the barriers that exist, besides physician resistance, have to do with the mechanisms of collecting that data. So, the electronic tools that are out there, in terms of the electronic health records that are the common vendors in the United States, don't do this very well. There are some research solutions. There's one that's pretty widely used for capturing survey data called REDCap and a lot of academic medical centres use that. (IE2)

Whatever technology is chosen, it needs to be supported with adequate resources for roll-out and maintenance. With constrained budgets and the need to balance multiple demands, IT support staff may not regard the PROMs system as a priority:

The docs need their labs long before they need their PROs. And so, by not having had a specific budget set aside to be able to anticipate things like that, we found ourselves in the situation once of going almost three months without being able to collect the data. (IE6)

PROMs data collection systems will also require appropriate policy support and, possibly, incentives for participation. For example, in the UK the requirement to collect PROMs is written into standard contracts between commissioning organisations and healthcare trusts or hospitals. However, the recent OECD scan of PROMs activity internationally found few examples of mandatory collection. Other kinds of incentives may be considered, such as reducing the burden of collecting other indicators that are no longer relevant. Voluntary participation is more likely to be sustained if it is centrally supported and resourced and the system for data collection is simple and efficient.

One thing in terms of solutions that we're very concerned about here is we need to make the implementation process virtually free. There's almost no cost to the healthcare

professionals and their organisations and it's virtually painless, so that it fits in naturally to the flow of how patients visit the clinic and so on. So, simplicity and cost are very high values for success, we think. (IE1)

So if we don't have that system that supports the end user to do outcomes measurements, we will revert back to what we can measure, instead of what we should be measuring. (J12)

Several of the experts advocated a team approach to system design. Involving patients, clinicians and administrators from the beginning may help build shared understandings of the purpose of data collection and the needs of all parties across a variety of sites and settings. Involving a wide variety of stakeholders also increases the breadth of knowledge available, including knowledge of solutions that have already been developed by similar initiatives elsewhere.

As part of the team that is devising the program, there's a very strong clinical component so there are clinicians, both doctors and nurses who are helping work out, design the project and there are also people who have a good understanding of patient-reported outcome measures and they also have as a component of it, IT people who can, who have an understanding of electronic data capture and then synthesising that and converting it into a portal to give feedback in a timely fashion to a clinician so I think that's the key to it as it's very multi-disciplinary and it is very grounded in the clinical practice of a particular group. (AE5)

With any large-scale collection of patient information, there has to be close attention to privacy and data security. System designers will need to gain stakeholder agreement on who gets access to the data, and what protections will be in place to prevent inappropriate uses. These considerations will also inform the choice of an IT system provider. Participants questioned whether offshore storage could meet Australian security requirements. The *USA PATRIOT Act 2001* enables the US Government to gain access to information stored within (or passing through) databases in that country; this means that organisations allowing data to be stored in the US cannot guarantee confidentiality, which presents a problem for patient privacy and ethical approval.

Within Australia, any efforts towards national collections will involve negotiating where the data are stored. State and territory health departments may be reluctant to allow data to cross state boundaries; this has been a contentious issue in Canada, which has a similar federated health system. There are also ethical risks around the collection of data from individuals; for example, using private contact information and asking questions about sensitive health-related issues.

The more information we collect, the more that we have to be mindful that there are privacy issues associated with this. Where do you store that information? Who has access to that information? How is that information being used and reported? It really comes with a whole array of such questions, and it really needs a very considered approach. (J11)

So we're aware that if you send a text message it can be read by someone else; the first few words come up on an iPhone. So we've had – we're getting the balance between being suitably vague, but also trying to tell how important this is. (AE2)

### 3.4.3 Data analysis

Issues raised about data analysis fell into three categories: quality of the data, the capacity to link PROMs with other datasets, and risk adjustment methods for fair comparison.

#### *Data quality*

To be useful, PROMs data must meet basic psychometric requirements of validity and reliability. They must be sensitive to changes in health status which result (at least in part) from changes in healthcare processes and clinical practice. To be credible, they must be collected and processed in ways that are rigorous and transparent. Clinicians accustomed to examining the results of randomised controlled trials will be likely to scrutinise PROMs reports closely, so the data have to be ‘watertight’ (IE3).

We mustn't let people down. We don't want to do it badly, and then people say they're just pathetic. 'That's just people telling stories. It's not rigorous.' And it is possible to be rigorous in this area. (AE3)

The English national PROMs program has demonstrated that very high quality data can be obtained with a highly centralised system of collection and analysis. However, there is a considerable delay between collection and reporting which limits the usefulness for quality improvement. This apparent trade-off between quality and utility may be resolved eventually by clever technology and system design.

Patient engagement will also be crucial for data quality. Asking patients to complete these tools is an imposition, but if they are convinced that the data will contribute to their own care, they may be more inclined to provide thoughtful and honest responses.

I learned when I was a clinician that, if I wanted to get usable data, then I needed to be really, really clear to the patient that I was working with that I was looking at this data and using it with them. Otherwise it becomes an exercise and everybody is trying to get – you know, you open your computer, your email in the morning, and somebody is trying to get you to complete a survey. (IE6)

#### *Data linkage and electronic health records*

Participants considered PROMs to be just one part of a broader infrastructure of outcomes measurement. In order to realise the benefits of PROMs they need to be integrated with good clinical datasets and also with casemix variables.

PROMs in isolation are not terribly helpful. Our view is that PROMs are better combined with the clinical datasets. (AE2)

There is considerable current work to link PROMs with clinical datasets held by registries. Linkage with electronic health records was seen as more challenging, due to the variety of such systems and poor uptake and coverage. This work appears to be at an early stage of development both overseas and in Australia. Nevertheless, participants felt there was much to gain if the challenges associated with connecting PROMs with electronic health records could be overcome.

There are people who are adapting our existing electronic health records to do patient-reported outcomes. But it's not a national institution at this point. It's a desire on the part of a lot of people. But we're not there yet. (IE2)

And also, I think there's some movement now to include this information in electronic health records, pop-ups and so on, and I think that's a very interesting thing to keep track of, again how this is designed and what the interface looks like, is critical; if it's user-friendly then it might have some effect, if not, then well we'll just see it go the way of many other digital innovations in health that we've seen come and go. (IE7)

But if the patients don't see [PROMs], they may not see themselves getting better, so they should be used sort of therapeutically and individually as well and that then requires them to be in the medical record as well as in some databases so that the aggregated results can be used. (AE4)

These views are supported by recent research which demonstrated that embedding PROMs in electronic health records in routine clinical care led to a reduction in missing data in a Learning Health System.<sup>25</sup> Interestingly, teaching doctors to specifically mention the PROMs report to patients ('I looked at your PCM report and...') proved an important part of implementation as it reinforced the value of the information to the clinician.<sup>25 p.8</sup>

### **Risk adjustment**

Patients having similar procedures may have very different starting points in terms of their age, general health, comorbidities and so on. These differences are important because they affect the possible health gain that can be achieved from the procedure. Further, providers will differ in the variety of patients they treat. On average, smaller hospitals may treat less complex cases. Specialist facilities and highly experienced practitioners will receive referrals for the most serious and difficult cases where, on average, the potential health gain is lower. Risk adjustment methods, such as casemix classification, can be used to account for these differences to try to ensure that any comparisons between facilities or providers are fair.

Expert participants agreed that risk adjustment to PROMs data will be necessary if the data are to be used for benchmarking, performance management or public reporting. However, they had divergent views on whether current risk adjustment methods were adequate.

Some participants were optimistic about the prospects for applying methods developed elsewhere to comparisons involving PROMs. These methods involve obtaining a large dataset which includes casemix variables – factors that might need to be taken into account when comparing outcomes, such as age, sex, socioeconomic status, problem severity, previous treatments for that condition, comorbidities and so on. Statistical techniques are then used to derive a model that adjusts outcomes for these known factors.

This process has already been undertaken successfully for the English national PROMs program and the method has been published and replicated elsewhere. It was achieved relatively simply by asking patients to report what other chronic conditions they had, yet it proved reasonably reliable and meaningful. Ideally, medical records would provide more reliable casemix data, but this entails more technical challenges to link the datasets. Currently, Yale University in the US has a project which involves taking joint replacement outcomes data from around 200 hospitals and using this to derive a new risk adjustment model.



Risk adjustment, absolutely, but those methods exist already. I don't see a problem in applying those, the risk adjustment methods we already have compared to the numbers you get out of patient-reported outcome measures... that's not a problem thank goodness. (AE5)

Other participants emphasised the limitations of existing approaches and warned that they may be challenged when the data reflected poorly on individuals or organisations.

The sickest people in the world come to [this hospital]. You can get, I think, some of the very best care in the world. But, if you look at mortality rates, our local community hospitals might have better outcomes in many areas simply because they're not dealing with nearly the same kind of patient. And there is nothing in the way in which outcomes are currently proposed to be used that can really adequately adjust for these kinds of things. (IE6)

In one case described by an international participant, data collections did not include risk adjustment variables apart from age, and more sophisticated techniques were still under development. The influence of contextual factors on outcomes is complex. Some of the experts were dubious that this could all be neutralised somehow using statistical adjustments, and whether this was entirely desirable.

When we have seen some differences in the data, even with controlling for factors like that, we have seen a little bit of pushback, which says 'well, I do the most complicated procedures, therefore the health gains for my patient are going to be lower than the national average'. So, then you get into questions of perception and how data is understood and whether that level of subtlety is applied to the data when a person looks at it and interprets it. So, yes, we can do lots of adjustments for control factors and things like that, but there's always a level of intelligence that I think probably has to come into play as well. Given that these are people that we're talking about and all people are individuals, so it's not rigid. (IE3)

There is a casemix adjustment that's done to the data before it's published, but I have to say that sometimes you have to be careful with some casemix adjustments because you can adjust away precisely the thing that you might be interested in so there may be questions about why certain hospitals get perhaps more difficult or more unhealthy patients and so on, so it's sometimes useful to have the raw data as well as the casemix-adjusted. (IE5)

#### **3.4.4 Data reporting, interpretation and use**

Infrastructure is also needed to give back data in a timely and meaningful way to those who provided it. The importance of making the data useful, particularly at the micro and meso levels, was emphasised by many participants. However, the usefulness depends to a large extent on whether the information is presented in an approachable format and can be easily understood by potential users. The literature review also highlighted the fact that data presentation has been the subject of intense study in recent years.

The use of this information seems to work better, when the people who it affects, so the providers and the patients, are consulted and included in a design of how the information is presented and in what format. (IE7)

The first stage is really just to identify the technical solution that works, and implement that. What hopefully very closely follows that is actually the ability to generate that clinician report. The idea is that the survey will be completed at point of care, and the clinician will receive the report from the patient's PROMs, and that will obviously facilitate that level of engagement, communication and treatment assessment at that point of care. Also, we are planning to produce a longitudinal report, in terms of tracking patient progress over time. And then obviously the third part of that is looking at the data that's coming in here and... compare patient PROMs with treatment protocol to some degree. (J11)

In addition to clarity in reporting, clinicians and organisations are likely to require some assistance to interpret the data. PROMs are complex and the numbers they produce are not intuitively interpretable; it takes psychometric knowledge to derive meaning from these instruments. The task is made more complicated by the application of statistical models to adjust for casemix; this makes the data more remote and increases the likelihood that some people will be 'slightly puzzled' (IE5).

I think looking at data, depending on the person who actually receives it, is quite different as well. So we're going through a process of actually meeting with people to say, 'Well, this is what your data is telling you, anything that's over a certain amount, it is fine if it's within your benchmark. You need to decide what your benchmark is'. But we're finding that you have to actually work with the service units to help them look at what the information is telling them because it does take a degree of analytics. It's not just us providing them with a report and the numbers. We actually expect that they come back to us with their quality improvement plan and what they're going to do following their survey. So there is some need to actually understand what the data is telling them. (J1)

After receiving their PROMs data, clinicians, organisations and policymakers may also need help to translate this knowledge into action at the various levels of use.

I think that the areas that are using it are then using that to help determine how well their lists are going. Have they listed the right people for the right procedures? Are the patients getting the right level of intervention? (J10)

There is really going to be a need for some guidance and support around how to interpret the actual PROMs tools themselves as well as the scores or results that they spit out at the end of the day. And potentially, as well, guidance around... how to interpret that result and identify how that can relate back to direct action at a site level for quality improvement. I think it would be important to have support at that end point... making sure that once the data is collected it's used for something meaningful. (J3)

There are established and emerging systems for reporting outcomes data – including PROMs – and for linking data with knowledge translation and practice improvement. For example, one jurisdictional representative described using the data to drive the design and evaluation of clinical care pathways:

The information for the care pathway may be enough to be able to do a formal testing of the hypothesis around it, so the patient [reported data], even though we're using it for individual decision-making, it's also contributing to be able to test hypotheses at a more aggregated level... So then that becomes part of the knowledge and then it becomes part of the standard care, so it's translated as soon as it can be into the mainstream. (J6)



One established program which includes PROMs is the Palliative Care Outcomes Collaboration (PCOC), which is a national initiative designed to drive safety and quality improvement in both hospital-based and community palliative care services. This program uses change management and continuous quality improvement methodology, including the 'Plan, Do, Study, Act' cycle which is familiar to many in health. PROMs and clinician-assessed patient outcomes are collected as part of routine clinical practice and the data are then fed back to a national database. Participating organisations receive their own patient outcome results compared to the national benchmarks, as well as anonymised feedback on how other organisations are performing in relation to these benchmarks. There are additional, optional data and reports on specific topics that are provided on request. They also receive a suite of tools and resources to assist with quality improvement. Participants are invited to attend benchmarking workshops which are designed to showcase quality improvements and motivate services to improve their outcomes in the future. They may also make facilitated visits to services to learn from them. PCOC facilitates advanced quality improvement workshops for participating services to analyse their data and design activities to improve patient outcomes. The PCOC dataset can also be used to evaluate the impacts of quality improvement efforts by tracking changes in outcomes over time. In these ways, support for quality improvement is integrated into the PCOC program.<sup>26</sup>

### 3.5 Building the evidence base

Building an evidence base is essential not just for scientific reasons but also for sustainability. Clinicians, policy makers and the public will require compelling demonstration of benefits for quality and safety in order to maintain support and resources for PROMs.

As reported in the literature review for this project, the increasing international interest in patient-reported outcomes has resulted in a corresponding growth in academic publications.<sup>2</sup> However, the evidence base about the implementation and evaluation of the impact of PROMs is very much a 'work in progress'.

The sections below present participants' views on the state of the existing evidence and the work that needs to be done to evaluate current initiatives and build an evidence base. It concludes with their views on the potential risks and unexpected consequences that should be considered in any evaluation of PROMs initiatives.

#### 3.5.1 Existing evidence on the impacts of PROMs

It has previously been reported that most evidence about the impacts of PROMs is about the benefits of individual PRO data for the clinician-patient interaction (micro level uses) and the benefits of aggregated data for quality improvement activities (meso level uses) as this is where most evaluation activities have occurred. There is very limited academic literature available regarding impacts on policy (macro level uses) although the grey literature identified some relevant reports.<sup>2</sup> The available evidence about impacts of PROMs is comprehensively outlined in the literature review by Williams and colleagues<sup>2</sup> and more recently by Greenhalgh and colleagues.<sup>27</sup>

The interview findings are generally consistent with the findings in the literature and there was agreement about the application of PROMs at the micro, meso and macro levels and about how their level of application influenced their design. However, interviewees' examples of existing evidence about the impacts of PROMs were small in number and heavily context-specific.

So just highlighting that PROMs can be used at the three levels, at the individual patient level, the unit or organisational level and the system level, and that how you want to use them, for what level, for what purpose, if they're actually going to be used to support individual patient care or going to be used as a measure of overall system performance or whatever, will greatly affect the design of the PROMs. (AE2)

### **Micro level**

The most frequent examples about existing evidence on the impact of PROMs came from the micro level – particularly in relation to the clinician-patient interaction.

I would say that one of their domains might be communication between the patient and the doctor, because this is the area where, so far, what we know from the scientific evidence about PROMs, that having a standardised way of assessing PROMs at the beginning of the consultation can actually improve communication between the patient and the doctor. So that's where the biggest promise lies. (AE5)

There were many examples of clinicians effectively integrating PROMs into their practice but far fewer published evaluations of these examples.

But certainly for collecting a profile, being able to have a snapshot of somebody's health or a profile of their health, these measures just work I think better than anybody had even hoped that they might work. (IE6)

While there are many anecdotal reports of the benefits, a challenge for the future is to robustly capture and publish the evidence that underpins these practice anecdotes.

Our clinicians are saying that they actually aren't spending as much time, so there is that time saving in terms of their clinical consultation... obviously identifying and addressing issues that were previously not met from the patient side of things. So, for example, thinking that patients' moods were low, or they were depressed, or they were anxious, and that being left untreated for a very long time, that's now being addressed much earlier. Things around social satisfaction and social isolation, social relationships are now being talked about where they previously weren't being talked about, so the PROMs are really acting as that conversation starter for number one, around, well, tell me a little bit more about that, because perhaps, as a clinician, I haven't thought to ask you, or as a patient maybe you don't have the words to tell me, or you're not sure how to tell me, so the PROMs is acting as that conversation starter. But then once the conversations are starting, the clinicians and the consumers are both reporting that it is helping them with their clinical care, their referrals, their outcomes, and that in general, patients are feeling better managed, and they're feeling like they're included more in their health care, and their clinicians are actually valuing what matters to them, and looking at them as a whole person instead of their heart, or their brain, or their lungs, or whatever it might be. (J12)

### **Meso level**

There was some experience among interviewees of aggregating data for quality improvement activities (meso level uses) most frequently from involvement with a clinical registry or specific project; in these examples, PROMs are almost always used in tandem with other clinical assessments.

What we know from the research setting is that patient-reported outcomes can actually be much more sensitive. Quite highly correlated with a number of clinical parameters we

collect but more sensitive, and in some cases they're not correlated at all with the clinical parameters but they still tell you something really, really important about how the patient is faring. Now, some of the most powerful evidence of that we have is that patient reported outcomes across a huge spectrum, pain, fatigue, physical function, role function and so on, have very strong predictive value of patient survival over and above clinical measures and there are a number of systematic reviews of this, that have been published. So it's evidence like this that tells us that there's more than a grain of truth in what patients say about how they feel and we should be listening to it. But we can't – it's not a substitute for imaging and blood tests and so forth, it completes the picture in a way that resonates with the notion of patient centred care. (AE5)

Prostate cancer was identified as an example where quality improvements had been achieved across a variety of service providers and institutions.

So my understanding is that sort of information has been fed back for a little bit of time now to the units and it has assisted in reducing some of those rates of complications and side effects. I think there is also a specific project that has looked at where actual individual results have been assessed with patients... offered potentially particular supportive care. (AE2)

So obviously the prostate cancer people have reported benefits to patient outcomes from collecting PROMs, because [with] the PROMs they were able to verify the relative benefits of radical prostatectomy technique versus radiotherapy and other treatments. So there seems to be some evidence from the few consultations that we've had, of the benefits of PROMs. (J13)

### **Macro level**

During the interviews participants were asked whether there was evidence that collection of PROMs had driven any useful changes in safety and quality improvements at the country level. Reference was made to two particular studies that have been written up recently, but the conclusion was that they found no benefit.

Interview participants spoke frequently about the limitations of existing evidence:

I think the quality of the evidence is not great. There are many anecdotal reports of organisations and people who believe that their care has been improved and can tell stories of how it's been improved because they've collected these data. I don't think there's any empirical evidence that justifies that... I don't think you could make a business argument or a policy argument let's say, to a government agency that requiring these data has been shown to produce a benefit. (IE1)

Several interview participants spoke of the association between the collection of PROMs at a national level and improvements in care or organisational performance. They noted that systematic measurement of PROMs on a broad scale was not yet a widespread occurrence so it may not be a case of there being no benefit but rather that it is too early to evaluate.

I'm not sure that there's been a noticeable gain... has there been a move of patients towards hospitals of higher quality, however that's measured, and away from those with lower quality?... I think there wasn't much evidence that had happened, that's not to say it hasn't happened, it's just that... it's not detectable within the national data that they looked at. (IE5)

Systematic measurement of PROMs at this point in time is translating them to mechanisms and intelligence to performance and that could be that it is too early or it could be that there was some ... lack of adjustment and controlling for comorbidities and other defining factors. (IE7)

The other issue raised was that PROMs have only been used in a relatively limited number of interventions on a national scale, so assessment of macro level impacts remains premature.

You have to remember in terms of the PROMs at the moment they're only covering a relatively small group of interventions, hips and knees are two major interventions of course in terms of volumes but they're still only a fraction of what hospitals actually do and just by having that data, which is available to the public... you can compare hospitals using this information, but I'm not sure whether patients are actually using this information so it may not be surprising that we haven't seen much of a change in the patterns of referrals and choices by patients. (IE5)

There were no examples provided where PROMs were referred to in national policy discussions.

I've never seen PROMs being referred to in national policy dialogues or inter-country policy dialogues. (IE7)

### **3.5.2 Evaluation of new PROM initiatives**

The progress in evaluating PROM initiatives is varied and evidence will continue to emerge as wider implementation occurs. Interviewees made it clear that while there is a growing body of evidence around what works when implementing PROMs (the process or formative side of evaluation), there is much less on the impacts of PROMs (summative side). It will be important to ensure evaluation is part of any PROMs initiative.

Several examples of evaluation projects were discussed at both the international and Australian levels. Again there was reference to the large amount of anecdotal evidence about the impact of PROMs but unfortunately less formal evidence of systematic evaluation. Most international examples came from England and Sweden.

There is still uncertainty about how to implement PROMs on a national scale and what approach might deliver the best value. Several issues about the evaluation of PROM initiatives were identified: clarity about the purpose of an evaluation; evaluating implementation; evaluating impact and lessons from the field.

#### ***Clarity about the purpose of an evaluation***

Several interview participants noted that PROMs can be implemented for different reasons and that this intention needs to be reflected in the related evaluation. In their experience, however, this explicit clarity around the intended purpose of the PROMs collection and evaluation is sometimes lacking. As might be expected the purpose of the evaluation might be seen very differently by diverse stakeholder groups, for example consumers or patients may be interested in improving their quality of life; whereas clinicians may be interested in improving the patient/clinician interaction; and administrators may be most interested in reducing unwarranted clinical variation and reducing costs of care.

Equally, if the PROMs were set up for a different purpose in mind, then I suppose that it's really having that kind of evaluation to see whether the intended purposes are being achieved. (IE3)

The added value for us is then you actually get the outcomes. Have you made a difference? Where can you improve? What's not working? (AE1)

Several participants raised the importance of defining the success of a PROM initiative prior to developing an evaluation strategy. There is no international agreement on what success would look like or how it might be measured. For example, if the collection of PROMs is not mandatory, a level of 'sufficient' coverage of instrument administration and data collection needs to be defined according to the purpose of collection.

What percentage of a particular intervention would you think is reasonable, it doesn't have to be a census, it doesn't have to be 100%, a sample could be good enough statistically. So, again, that will go back to what you want to use the data for, over time would you want it to be detailed enough to be able to say something sensible statistically about individual clinicians, but if you want to be able to say something sensible about an individual hospital let's say then you'd need to have a reasonable number of observations... (IE5)

Another example related to identifying unwarranted clinical variation to effect a change in referral patterns. This would require effective public reporting of the outcomes achieved by facilities. A process measure to evaluate the success of such an application of PROMs data could be whether information about varying outcomes for a particular procedure is routinely referred to by patients and doctors when choosing a hospital or specialist.

Ultimately what most stakeholders want to see is continuous quality improvement and improved value; this may be measured through improved patient outcomes and reduced healthcare costs.

I would have two hypotheses, I guess. One is that production and use of this information will lead to continuous improvements in these results. And the organisation collecting these data and using them, will show year on year improvement in patient outcomes. Especially, if there's some incentive attached to improvement. Then people will find interesting and valuable ways to improve quality, if they have these data. That's one hypothesis. The second is that they will find ways to improve their results and they will probably start using approaches which are less expensive to achieve those results. (IE1)

Well, success would have to be defined in terms of an improvement in the provision of things that are considered to be important in quality health care, so deciding what those domains, if we call them domains of quality health care are, would need to be the first stage of the evaluation. What are the domains of quality that matter to patients, what are the domains that matter to clinicians, to doctors, to nurses and any other stakeholders that you think are important in that setting. Having established the domains that matter you then need to make sure that you measure those domains in a sensible way that's going to actually capture them and allow you to measure change in them, and you need to do all of this before you bring your PROMs into the situation as the intervention. (AE5)

## *Evaluating implementation*

It is complex and resource intensive to properly implement PROMs so there is value in monitoring and evaluating implementation. This is where most evaluation activity is occurring and there is significant interest in learning 'how to do it' from the experience of others.

Something that I certainly got from the ICHOM forum was the importance of getting the implementation right. I mean we knew before we attended that not adding burden was important but, listening to some of the speeches in relation to how to facilitate through implementation is really important, and there is a lot of new work coming out around the implementation side of things which we we're keen to learn from. (J2)

So, it's a complicated area but that's why I sort of believe in picking off little vignettes and working with the willing to build up a store of experience is the way to go. (AE5)

There are many evaluation issues to consider, not just around the appropriateness and efficacy of the PROM instruments but also issues such as the optimum points in time for data collection and the most effective methods of data collection. There is also a need to understand the best ways of presenting the data back to both consumers and clinicians.

But we will really need to be driven by the people on the ground because... it has to work for them. It has to work for patients and it has to work for clinicians and it has to work for administrators. If it doesn't it won't add any value and that's all we want to do. We want to add value with PROMs. (J2)

There is a view that process evaluation is the starting point.

I think as a demonstration, the measure of success will be a process measure, really, around uptake and completion rates and coverage of the tools across a population, rather than clinical impact at this stage, or even market impact. I think it's simply to be able to collect comparable data, reasonably reliably and comparably across a good size geographic area. (IE1)

A consistent message from participants is that the implementation of PROMs is still new. Several participants discussed what the starting point might be for evaluation of PROMs, this could begin with a focus on more generic quality of life measures that can be used across diverse populations and health conditions and then progress to focus on more specific condition-related outcomes.

A generic set of questions that relate to - have you functionally improved and that kind of thing obviously in a much more patient-centred language than that... would be the starting point and then as we begin to mature the system we could perhaps look at whether there are specific outcomes related to things like orthopaedic surgery... that could then be developed down the track. (J3)

Consequently there is not enough evidence about best practice and a standard approach to implementing PROMs. This strengthens the need for robust evaluation so that the health system continues to learn and build upon successive evaluation initiatives.

So, it's very interesting to see that people definitely want it and they see the added value and the doctors themselves as well, which I find very fascinating. But it is difficult, I have to admit that as well, because it's so new that we don't have one best practice, like you should

do it in that way if you have that questionnaire or if you implement it in your hospital in that way or discuss it with a patient in a specific way they have got the best results. We are not into that yet, but we are definitely working on getting that to help hospitals with implementation. (IE9)

A recent report on the use of electronic PROMs in seven US programs presents practical lessons from implementation.<sup>28</sup> This series of case studies highlights the importance of stakeholder collaboration, careful planning and integration into clinical workflow, consistent with the views of interviewees in the current study. The report is an example of how data from formative evaluation could be presented in a format that might be useful to those seeking to implement PROMs and wishing to learn from others' experiences.

### **Evaluating impact**

The language of 'health outcomes' is synonymous with evaluating impact, as achieving outcomes for patients implies a higher order impact or health gain has been achieved. The difficulties in evaluating the impact of PROMs mirror those of evaluating complex healthcare interventions more generally. Linking the measurement of PROMs with an impact, in terms of practice change and ultimately health gain requires a causal link. Like most interventions, isolating cause and effect is extremely difficult in the diverse clinical settings where PROMs may be used.

A fundamental issue raised by experts was the importance of establishing a baseline to measure change and that this needs to be completed prior to implementing PROMs. Investment is necessary to ensure sustained implementation of PROMs. Without these preconditions it is impossible to meaningfully evaluate the impact of PROMs.

...we need to have a decent base line period where it's not done, and again that's one of the big dangers in barreling forward and just doing stuff. You don't get good baseline data first. (AE5)

Often there is a temptation to 'pick the low hanging fruit' or to start with an issue that might deliver 'early wins'. International experts cautioned against this as it may result in selecting procedures or conditions where there is not actually significant unwarranted clinical variation between providers. Historically the focus has been on surgical procedures but there is an increasing interest in the application of PROMs in the management of chronic disease.

Robust evaluation requires resources and this is most likely to come from Australian Government and state or territory departments of health. Government may direct evaluation efforts by funding them.

In my hypothetical example I put to you a minute ago, of... states saying we'd like to see some experimental use of PROMs in... chronic disease, let's say, and what the state would offer would be some minimal level of infrastructure support... IT and survey costs... so that groups could feel they were going to produce... something that was at least sustainable for a two year experiment. (IE8)



### *Lessons from the field*

There were consistent views expressed about the iterative nature of PROMs introduction and the importance of involving consumers and clinicians in evaluation activities, to capture impacts from diverse perspectives.

Genuinely and completely having consumers in governance, working out how to frame this, in professional associations. I think if the community can be in conversation with people, it would help. That will take a long time. So the best thing I guess to do is to make it an iterative process, and make sure the evaluation of introducing PROMs, and its impact, is monitored by consumers as well as clinicians. And written up, and the positives are not just clinical positives. The stories begin to be told. (AE3)

The most common means of engaging consumers and clinicians in the evaluation of PROMs was through the feeding back of collected data.

So, I think, just feeding back data is the key thing at the moment, and then showing how we can use those PROM responses to improve the patient... health outcomes, I guess, that's the tricky part, because it's one thing to measure, but being able to use PROMs to improve health outcomes. I mean, that's the ICHOM ethos, but how does that actually happen in practice, I think... there's quite a bit of work to do still in showing... how measuring PROMs can actually improve practice. (J5)

The people who contribute to the PROMs should hear about what was learnt, by setting that system up. And we should find out whether they think it was worth their time to contribute. And the clinicians should be able to tell us whether it influenced their practice, and if not, why not? And if yes, why? In summary there is a long way to go. (AE3)

Engaging these groups in the generation of new knowledge and the dissemination of evaluation lessons was raised by several participants. The impacts of PROMs on clinicians' practice and on consumers' perceptions of their care are two evaluation issues that could be further explored.

We're trying to get that translation to have a greater take up, better traction within the clinical process... and we don't know as we ask patients and they start to see that it has an implication in terms of the way they cared, you may see their response will change, and we're still testing all that out and that's... what's slowing its adoption, people have to understand that it is translatable and they are robust and it still has to be demonstrated. (J6)

The concept of a clearinghouse is discussed further in Section 3.6 on the potential role of the Commission. Such a facility could also provide a repository for evaluation evidence and methods.

It's been quite difficult to keep track of all of the initiatives that are taking place and I think if you were to set up that kind of overview function, through which local initiatives could be started, really robust feeding back in terms of progress... Establishing the purpose, measurements, so that if it goes really well and it achieves the intended outcome and you have a cracking dataset at the end of it, then that dataset is going to stand up to scrutiny. And I suspect having some national scrutiny of those projects, which means that you're not going to miss the lessons learned and the revisions to approaches and the rationale will help collect a really good body of knowledge as to what works for different conditions, different segments of the population. (IE3)



### 3.5.3 Risks and unexpected consequences

Negative impacts associated with using PROMs are examined in the literature. Wolpert<sup>29</sup>, although an advocate for PROMs, notes, with reference to recent approaches to national collection of PROMs in the UK, how little is known about the psychometric properties, impact or utility of many measures being used.

Interview participants also mentioned the risk of not capitalising on the current interest in PROMs in an effective way. Some suggested this might be mitigated by increased reporting about local experiences of the use of PROMs. A variety of evaluation risks relating to data collection and use were also identified.

#### *Data collection risks*

Collecting PROMs is perceived to be expensive and resource-intensive. This can be a deterrent to their use particularly if the data collection requires independent information systems and cannot be integrated into existing information technology infrastructure.

Well I think one thing to know is that collecting patient reported outcomes is very expensive... resource intense... an expensive part of any data collection. So I think it is important to try and do it where there is some evidence of benefit and we've probably got existing infrastructure and processes in place. Hence aligning it with registries or with some sort of other suitable data collection... if you've got no registry potentially it can be very expensive. (AE2)

Another data collection issue is the difficulty in ensuring consistency when PROMs are being collected, not only in terms of data quality but also to consistent administration of PROMs and questionnaire completion. This then created difficulties for their analysis and the interpretation of findings.

We found from similar projects in the past that it's very hard to get everybody... collecting the same information and even if you get the collection done, then there are important variations in completion rates. There's a lot of bias in who does and doesn't respond. A lot of difficulties in getting the post-treatment follow up measures. Most patients are not necessarily in clinic anymore. So, I think there are some important logistical challenges we have to solve. (IE2)

#### *Data use risks*

There were two key risks identified about data use which are not unique to PROMs. These were collecting but not using/acting on the data, and inappropriate use of the data. There was a healthy degree of scepticism that data generated by PROMs would be used and if so, used for the intended purpose.

Another potential risk is going back to what I was talking about before. That we're simply collecting information for the sake of that and nothing is actually done with the information. The whole point of doing PROMs is to improve the quality of care and patient outcomes. So how do we make sure that the information is being used in such a way? And importantly, that we have the measures in place to be able to demonstrate that. (J11)

Several interview participants spoke of the importance of providing data to clinicians for use in 'real time'. If PROMs cannot be reported in real time, the capacity for the information to be

meaningfully used in clinician-patient interactions is lost. This should be considered as a factor for monitoring during implementation of PRO initiatives.

The risk for PROMs going forward is that if it isn't implemented in a way that enables clinicians to get their data back in real time, so they can actually change clinical care... it does just become another data collection system, and it's not adding value to that clinician and consumer interaction [or] allowing services to modify the way that they're currently doing things to better meet and improve the outcomes and experience of care for patients. I think that's a very big risk. (J12)

Systems need to be in place to handle and act on the information that emerges when a patient completes a PROM questionnaire. These are needed to manage complaints that arise as a result of patients realising there were problems with their care, to detect and appropriately refer patients who require follow up, and to respond to data that may highlight the poor performance of an individual clinician. An evaluation of PROMs will need to include a mechanism to capture these unexpected consequences of PROMs implementation. In addition, systems will be required to act on the information that arises from PROMs, such as the need for prompt referrals to appropriate services.

You might unearth problems that patients don't want to talk about; you might [complicate] the relationship between the providers of care and the patients on that front. Or it might also reveal to patients that maybe they should be aware that there's an issue that they're not aware of, and that hasn't been told to them. (J7)

Once you begin to screen for depression you must have referral sources in place. You must have real time monitoring. You can't be asking people about their mental status and then not follow up on it. (IE6)

Any sort of PROMs collection necessarily involves you changing your model of care, not just locally but across the system... So if the patient reports that they're terribly suicidal, what onus is there on the survey collector or the registry to follow up on that? Or do you simply say, 'thank you very much,' and then hang up? (J13)

Using aggregated PROM data on a national scale particularly for comparative evaluation purposes was perceived to be much more difficult than using it at the level of a clinician, unit or single facility. There was reference particularly to the challenges of risk adjustment.

It's so much harder to do on the national level, and then also to try to make a judgment on, okay, this hospital has this result and this hospital has another result, what does that really mean when it comes to quality? It's something I think that we don't really have the methods for doing that kind of analysis yet, and that's something that we really want to work with... we have a project where one of the main things is to learn how to analyse data on a more analytical level than on a clinical level. (IE4)

There were concerns about the risk of punitive use of data, referring to using data for purposes other than those originally disclosed at the start of data collection. There was a strong view that such a practice will irretrievably impact data quality because it will change the way people report and result in a loss of confidence in the integrity of the PRO system.

You would have to show that there was some evidence that doing this is actually going to be of some benefit in some way to either the patients and or to the clinicians, hopefully to

both. I suppose you'd have to also have to convince them that the data wasn't going to be used punitively, because I think that's another fear. (AE5)

This issue was not to be confused with the risk of dealing (or not dealing) with poor performance of individual clinicians that might be identified, in part, through the collection of PROMs.

If you've got a problem with a surgeon, who's having very bad outcomes, and we haven't dealt with this problem yet, but there's an outlier or an escalation plan of what are we going to do if there's someone who has terrible, terrible patient satisfaction. You've got to check whether that's – whether the data is correct, whether there's a problem with the way the data was entered or conveyed by the patient. Is it a particular cohort of high risk patients? And then you've got to make the decision are you going to tell the surgeon, are you then going to tell the College of Surgeons and what role are they going to take? So they're issues that we haven't dealt with, but certainly you need to be aware of; if you're going to collect data what are you going to do with the data? (AE2)

It may be necessary to provide support to early adopters of PROMs with data analysis and reporting to provide examples of the effective use of PROMs.

This is a time when we don't know the right thing to do, and research has to be conducted but in parallel with using PROs. And this is a big ask, because most clinical settings, they're already stretched to the limit doing what they do. So, that's why in order for this application of PROs to progress on the basis of evidence there needs to be some support for creating that evidence in terms of analysing data and reporting on it...In order to get value out of analysing data, you have to start off with a carefully thought out analysis plan which is guided by some specific questions... (AE5)

The introduction of new initiatives, such as PROMs, will inevitably generate unexpected findings. Several insights were gathered about these from both the Australian and international experience. These included the realisation that some procedures selected for monitoring with PROMs and other clinical indicators did not actually warrant investigation as there was in practice relatively little difference in outcomes between service providers. The introduction of PROMs in itself can also raise issues that were unexpected, for example in the case of surgical procedures the issues may not be with outcomes of care but rather about the timing of surgery.

As with implementation, participants highlighted the risks of top down strategies for evaluation and the importance of early engagement consumers and clinicians.

### **3.6 Views on the Commission's role in PROMs**

The views provided by interview participants about what role the Commission could or should play in relation to PROMs were thematically analysed. There were four major dimensions of this role: leadership, engagement, guidance, and facilitation. Each dimension is discussed in more detail below.

#### **3.6.1 Policy leadership**

There was a clear view among interviewees that national leadership is required to facilitate the adoption and implementation of PROMs within Australia. National leadership does not need to be prescriptive but is necessary to avoid some of the difficulties experienced by other countries, such as Canada, that have taken a more evolutionary approach to the introduction of PROMs.

There were several consistent messages from participants about how the Commission might provide this leadership through actions such as: the development of a national framework or strategy; setting the policy agenda; and/or identifying priorities for investment in PROMs.

The Commission's previous experience in the development of a framework for Australian clinical quality registries was referred to by several participants.<sup>30</sup> This experience could be leveraged and adapted to inform a national approach to PROMs. The Commission was perceived to have already demonstrated leadership in the clinical registries area and to have an informed understanding of important issues such as the ethics of data collection and use and security of information. In addition, the work that the Commission has already undertaken in PROMs means that the organisation understands the conditions and prerequisites for PROMs collection. There was particular mention of the Commission's consultative approach in the development of the framework for Australian clinical quality registries with the inference that a similar consultative process would be needed to develop a national approach to PROMs.

The Commission was seen as a logical leader in the development of a national framework. This might start by clarifying the objectives of a national framework and then identifying the overarching principles and policies to prioritise investment in PROMs. This investment may come from the Commission or other organisations. A clear statement about priorities was seen as useful in stimulating engagement by other organisations and generating resources for implementation of PROMs.

I think the Commission has developed this list of prioritised clinical domains for clinical quality registries last year and so it would seem to me that it would be appropriate to have the same sort of concept for PROMs. Because it's the same sort of thing, you know, it's again going to be population level data presumably related to the appropriate conditions where you'll get the most benefit collected by an organisation that knows how to manage the ethics and security of information, all that sort of stuff... I would have thought that it would be appropriate for the Commission to identify similarly the sorts of conditions and prerequisites for PROMs collection. (AE2)

I think a lot of thought needs to go into what can the data tell us and how might we use it. (IE5)

The framework might also describe what a core set of PROs would be and provide a starting point for discussion about a consistent set of measures that could be adopted by the healthcare sector.

I think we have had quite a bit of bottom up [PROMs development] in Australia and we really need to have a bit more top down, obviously the two have to meet but I think that the top down approach has to be something that – I'm sure it is, but it has to be some kind of framework that makes sense to the clinicians. And just coming up with a framework that is really superficial to clinical practice then this distant thing, you send data off and then three years later you get a result, I don't think that is going to help either so I think they have a bit more of a roadmap. (J6)

Several international participants discussed the importance of clinician and patient or consumer engagement.

We think you should have a bottom up perspective on this and not a top down perspective. We think that this development should come from the clinicians themselves and from the patients and we think it's a bad idea to decide anything from a national point of view and then try to implement it. We don't think that's the way to do it actually. (IE4)

There was also an argument put forward that introducing PROMs may reinforce the importance of the consumer perspective in informing quality and safety in health care and that PROMs provide a way to capture this.

I think what PROMs offers us from a quality and safety perspective is ... being able to access the consumer's voice that is valid and reliable and can be utilised to identify positive and negative experiences, and those experiences can be related to circumstances within the healthcare system, whether they're interventional or whether they're organisational, systematic, those sort of things, so I think that's one thing that the Quality and Safety Commission can be doing, it can be really highlighting the role of PROMs in the bigger picture. (J6)

Participants advised against adopting a heavy handed or overly prescriptive approach to a national framework; there was not support for a mandated approach but rather one that generated engagement and buy-in. Several participants discussed the importance of clinical leaders and working with those who already have a vision about what PROMs can contribute. This would rely on encouraging the spread and adoption of PROMs through mechanisms other than nationally mandated data collections.

One imagines that a national framework would be useful, but one imagines a light touch approach would be preferable to kind of a heavy handed regulatory approach, so a light touch approach which is more... encouraging rather than dependent on more force of the technique. (IE7)

In a federal system like Australia, the role of central government would be to encourage and to enable rather than to enforce or regulate. (IE7)

The National Safety and Quality Health Service (NSQHS) Standards were perceived as a highly useful mechanism for stimulating implementation of PROMs as they provide a nationally consistent and uniform set of measures of safety and quality for application across a wide variety of healthcare services<sup>31 p.4</sup>. The NSQHS Standards were seen as a 'carrot' and have encouraged hospitals to engage in quality improvement initiatives and to engage with clinical registries. They could therefore be used to facilitate collection of PROs. Establishing some form of link between the NSQHS Standards, accreditation and the implementation of PROMs would 'incentivise' organisations.

I guess the most obvious would be for a way to actually build those into the core standards so that there is an expectation that within the core standards for different things PROMs will be part of that, and will be collected, and evidence from those will be expected as part of a review process for the national standards. So I guess that would be one of the big ways that the Commission could get involved. (J10)

I think development of evidence, development of a collaborative approach, development of standards, development of consistent approaches, consistent questions, and generic questions. I think that is a very important role they've played or role the Commission has played. (J9)

The Commission is responsible for setting accreditation standards and clinical care standards. In the future, when this work is far more developed, we start to incorporate PROMs measured as a component of either a national standard or clinical care standard. (J9)

Clearly a lot of work, but I think that's where the Commission really does, in my experience, play an enormous role. They're setting standards and expectations... I think that is particularly where its value is. (J9)

This view was also expressed in a slightly different way in that the Commission may be able to demonstrate a connection between PROMs and other policy imperatives such as personalised care or shared decision making.

How do PROMs support other policies that represent the direction the Commission wants to go in? (IE3)

The Commission's reputation for independence and relationships with all governments position it well for the leadership role, as it has the capacity to formally liaise with jurisdictions through existing mechanisms such as the Inter-jurisdictional Committee. This leadership may also include framing the policy agenda for discussion between the Australian Government and state and territory health departments. One participant emphasised the importance of linking PROMs to a policy of strategic importance that is relevant to patient care, for example policies about unwarranted clinical variation have been linked to safety, quality, performance effectiveness and efficiency outcomes. If clinicians and health services can see that collecting PROs will support personalised care or shared decision making there is likely to be much better clinician buy-in.

I think it would be really, really good for the Commission to take this role. I know this isn't quite what you said - you wanted to know what they could do, but I just wanted to say that I think what they already do is they're positioned really well, being funded by all governments and reporting to the ministers. Their agenda is independent, safety and quality. There's some issues. It's hard work they do, but I can't think of anyone better placed to do it. (AE3)

I think the Commission's role is to make the link between the policy conversations and to actually influence the Australian Government in terms of the development policy and its application and then after that support the enactment of that policy, so they have to be an advocate on one hand but then also think of the future in terms of if this is likely to be policy, it's got to be policy implemented to act, scale and pace that's relevant to the current service providers and therefore in terms of enabling that change, the Commission potentially has a role... both in terms of raising awareness but also in terms of developing and supporting the application and then evaluating, 'Has this made a difference?' (J8)

There are various ways in which the Commission might provide leadership, for example producing a strategic plan outlining the preferred strategic approach and priorities over an extended (five year) timeframe. A national strategy was generally perceived to be of great value. One participant questioned whether the strategy should be about PROMs or whether it should really be about something larger such as patient-centred care and the application of PROMs in improving patient care.



Not every jurisdiction has to do the same stuff, but together you can implement a strategic plan that starts to build practice, and pick a couple of seminal projects. What is something there's an appetite for and funding for to do across the nation, in a priority area? ... I think a priority setting strategic approach that brings together senior bureaucrats, obviously consumer representatives. I still would have some researchers at the table. I'm not a researcher, but I think it's good to have that frame around what you do as well. (AE3)

There were two key examples provided from international participants where clear strategic direction and priorities for the use of PROMs were not established, resulting in slow and fragmented implementation. This was perceived as a particular risk for Australia and it was seen as preferable to achieve some consistency of focus and approach across the various states and territories.

Well, the thousand flowers blooming has gotten us into our current healthcare situation and I think it – you know, I don't wave a magic wand, nor is anybody going to in this political environment... I have a friend who likes to say these things need to happen organically... not quite sure I believe it. I'd rather there is a magic wand, because I think these things, if you wait for them to evolve, the evolution will be very slow. (IE2)

The Commission was seen to have the capacity to recommend a minimum standard for comprehensively assessing PROs. While there was strong endorsement of the Commission's role in supporting standardisation, equally there was recognition of the importance of some local adaptation. The difficulty of achieving consensus for a national approach was discussed with consensus seen as an iterative process that would progress over time with appropriate engagement.

As long as they're asking the 'right' questions at the 'right' time so that there can be the scope to report and benchmark at a jurisdictional or perhaps even national level. That's probably what I see the Commission's role as. Rather than working with hospitals step by step to make PROMs happen. (J11)

I think, for the Commission, it would be very good for them, as they have been doing, to keep their eye nationally, and to really try and standardise the way that we are collecting and using PROMs, looking at the various different care settings, care groups, conditions, looking at the PROMs that are used, how they're used, trying to make sure that we are always using validated tools. (J12)

The Commission has the capacity to articulate the value proposition for involvement by clinicians, clinical registries and healthcare facilities in PROMs. Participants expressed the importance of being prepared to start the conversation at a higher level about 'is this the right direction?' Several participants spoke about the need to be explicit about the strategic intent of the Commission and how important it was to clearly explain what the information will be used for and why it should be collected.

I think the Commission would have that role at a national level to promote the utilisation of PROMs alongside other measures to reflect on quality and safety. Align it with the standards so that we use this as a way to measure if good quality care is being provided and deal with homogenisation work where it needs to happen, really. (J7)

What's the value proposition for the Commission in that space where everybody would be involved in PROMs? (J7)

The strongest view amongst participants was for a framework that provides principles and potentially describes the core or minimum desirable set of patient-reported outcomes. One suggested starting point was a basic PROM such as a generic quality of life measure which applies to all care conditions and all patient populations. Another view commonly expressed was to start with clinical registries. This was closely followed by the need for implementation support.

If we're trying, from a national perspective to have a consistent set of measures, I think it is the Commission's role to facilitate the establishment also with the various stakeholders. That'd be the starting point... getting the agreement on what should be measured. (J3)

I think one of the biggest questions that the Commission needs to be addressing is how can data collected in hospitals and clinics be used, what's going to be the purpose of the data, and who are they going to be used for? (AE5)

One participant argued that PROMs have an important role in assessing value for money.

So how then does the Commonwealth know and the states know that they're getting value for money? Well the only way they know that is by measuring PROs, or measuring outcomes and PROMs being part of that and PREMs being part of that. (J8)

### 3.6.2 Engagement with stakeholders

The Commission is seen as having two potential roles in engagement. First, the Commission could act as a stimulus or catalyst for change throughout the healthcare sector, to increase interest and engagement in the implementation of PROMs. This would include articulating the rationale for the use of PROMs and their potential value for patients, clinicians and the broader health system. The second proposed role is in bringing together the diverse stakeholder groups with an interest in PROMs and coordinating the discourse at a national level.

Previous sections of this report have identified the healthy scepticism that exists amongst many clinicians and influential stakeholders as well as the challenges organisations face when confronted with disruptive change. There is a role for the Commission in presenting the case for change for the implementation of PROMs. There was a strong desire amongst participants from states and territories to understand why PROMs should be used and how they might add value.

I think if the Commission had some evidence to show that there were some PROMs out there that were very helpful in helping units or sections, or divisions, or whatever; however that is broken down, that what they're doing is helpful, or isn't it helpful? That would be great. So I think one of the reasons that they might not be picked up as much as they can is that there isn't anybody out there really, in the kind of public domain saying that these are helpful and this is how to use that information to help drive what care you're giving and how you're giving that care within your health service. (J10)

Not so much the details of how to implement PROMs, but more the 'why should an organisation do it', and if one does sign up to it, how that information can be used. More at a framework or principle level, rather than saying here is a prescriptive set of instructions; that should a hospital choose to collect PROMs, here's what they do. I don't think that's the level that the Commission needs to go into... It's more like a minimum standard for comprehensively assessing patient reported outcomes, I guess. (J11)



I think there are definitely lots of ways it can be done, I don't think that we're anywhere near a healthcare system that can do that as yet, but I think consultations need to be held broadly, and so I think broadly is the key for this... But I do think at least in the initial stages, having that broad consultation with people gathering ideas, even if it is to say from the various jurisdictions, bring along some case studies on what's currently happening, and they're bringing along some that's worked well, and some that haven't worked so well, how is that happening, what does it look like, even if you're comparing those across jurisdictions as a start. And then maybe some jurisdictions who aren't even up to that stage as yet, and that's absolutely fine, because once again it's that leveraging off what other people have done so that you can fast track your, I suppose, design process or implementation around outcome measurements, and that we can all move towards the same starting point. Because, again, unless we're starting conversations around this everyone will just do what has been mandated to them by their state government, or jurisdictional body, so, I do think that would be really important. (J12)

Participants saw the Commission as a highly reputable and influential organisation and thought that this positioned it well to demonstrate how PROMs can add value from the perspective of the patient, clinician and broader health system. Other advocacy-type roles might be raising awareness about PROMs, taking an educative role within the health sector, disseminating evidence about the benefits and limitations of PROMs and/or showcasing the application of PROMs within the Australian context.

I think that would be great to learn from what's already working and working well. And using PROMs in routine practice and being able to show that link for collecting, you know, patient reported problems in routine practice and using them for quality improvement... we've got examples of how that works well. I think the Commission could be promoting what happens in Australia currently... (AE1)

Several participants referred to the work the Commission had previously completed on the economic evaluation of clinical quality registries. This assessed the cost-effectiveness of five Australian clinical quality registries and demonstrated that these registries have delivered significant value for money when correctly implemented and sufficiently mature.<sup>32</sup>

We need to show examples of where measuring PROMs actually results in an improvement in value for the patient, does it reduce costs? I don't have any of that data available, and, I think, we need to be able to show data that shows the value of investing and measuring PROMs, so similar to the economic analysis of the registries, I think, that was a really powerful piece of work, maybe something similar for PROMs, does actually measuring PROMs, is there a benefit in terms of saving money down the track, that sort of stuff, I think that would be a very valuable piece of work. (J5)

I think it's the clear articulation of the potential benefits and the limitations of the benefits. Because I think there is a lot of thought that this is going to be the be all and end all, and just to be really clear that yes, it is a powerful tool, but it's a powerful tool for doing different things, and if you want to do the different things, what you need to be careful of and what you need to pay attention to; and that it's not going to do everything for everyone. (J7)

The national profile of the Commission meant it was well-placed to showcase the application of PROMs, providing a stimulus for change. The challenge of behaviour change around PROMs has been comprehensively addressed in Section 3.3. The key message from interview participants

was that the Commission can take a national leadership role by presenting the rationale for the use of PROMs.

I think first of all you need to showcase the application, because you need to be able to influence people to get them to recognise that there is a role for PROMs and that's influencing people at multiple levels for the service delivery side but also the funding policy makers side... because I think if people don't first of all understand what PROMs are, how they're important and then how people are applying them, they won't be in the right mindset to consider whether or not they should be doing it themselves. (J8)

Where I think we need to be absolutely clear is that where we are going is guided by evidence. I think the Commission has put a lot of information out there about evidence, so that's what we'll be guided by I think as being standard. (J9)

Be the catalyst more than the director. That's what I would suggest to the Commission... (J7)

The second role for the Commission in 'engagement' relates to its capacity to generate buy-in through working with key stakeholder groups. The Commission has the ability to coordinate its activities with other state and territory jurisdictions. It was perceived to have the necessary gravitas to engage with professional associations and medical colleges. The Commission has a track record of ensuring clinicians are consulted and would be able to identify and engage with organisations already collecting PRO data.

But the clinicians, I don't think they are really there right now, and to force it on them I think is a bad idea. I think it's better to try to implement, try to improve, help them to see that this is something that they really can use in their work. (IE4)

Starting small is incredibly important in building on successes and showing people how this is not an exercise. This is not more work for you but this is actually a way to help you be more efficient and do your work more effectively and understand your patients more quickly. (IE6)

One international expert referred to the sensitivities that may be required when setting standards, referring particularly to health insurers and private healthcare providers. The importance of engaging those already working in the PROMs area was a recurring theme throughout the interviews. The Commission was seen as an appropriate body to navigate a path through these sensitivities and engage diverse stakeholders.

Whether the Commission could act as that – it's more of an informed focus for the experiences, as you put it, it's not like you're starting from zero [where] nobody's doing anything. Different people are doing different things and different organisations are doing different things, it's how you marshal that experience because it will be valuable. (IE5)

I think what has proven to be most unifying and most motivating has been just getting the right people in the room talking from across the country and starting to have a conversation. I have really kept my expectations and my hopes deliberately slim but I have been pleasantly surprised by what we're finding and how we are able to move ahead and what's really useful is to find some champions in which it really, really works. (IE6)

Ensure that the framework is designed in such a way to not make those places that have already have their own systems up and running, their own programs up and running, to demolish those and have to start again, that would be a real momentum killer. (IE7)

### 3.6.3 Guidance in implementation

A variety of comments were provided about the Commission's role in providing 'guidance' or support for implementation. This was most frequently expressed as a need for guidance about a national standardised approach, particularly how PROMs align or integrate with national quality and safety standards. There were also frequent references to the importance of the Commission collating and disseminating evidence relating to the use of PROMs.

I think development of evidence, development of a collaborative approach, development of standards, development of consistent approaches, consistent questions, and generic questions. I think that is a very important role the Commission has played. ...And I think the other thing is in the future, the Commission is responsible for setting accreditation standards and clinical care standards. (J9)

Guidance is needed about the application of PROMs across all settings, how to identify conditions and pre-requisites for the collection of PROs as well as the available tools and how to use them. There is a tension between the use of generic and condition specific measures. One participant referred to this as finding 'the common thread' that can work across all initiatives, whether this is an agreed minimum dataset or PROM.

Say an individual hospital wants to start collecting more information, PROMs type information, where do they go to find out everything from the basics, from what instruments to use, which ones have been tested, how to do it technically, how the administration of it should work and so on? If there isn't a single place to do that then there should be really. (IE5)

That might be where there's a space for the Commission. Providing some guidance on best practice in use of those things as well and how to integrate that in different levels, different processes and guidelines. Obviously the Commission having that clear mandate for guidelines and standards. (J7)

Within Australia, health service providers require support not only in the development of appropriate outcomes frameworks but also in the application of these frameworks. One suggestion included the development of a handbook about implementing PROMs similar to the one developed by the Commission for clinical registries. Information about barriers to and enablers of PROMs collection would be useful. Several state and territory participants discussed the need for guidance with the interpretation of the data generated by PROMs, how to interpret results and how the data can be used by organisations for quality improvement. The importance of ensuring that once data are collected they are used for something meaningful was a recurring theme.

One of the Commission's roles is coming up with measures and things, and I think there's a risk that they will come up with a tool, but that they won't come up with the guidance around using the tool well and that's something that we saw with the patient experience side of things, it was very much, here is the tool, and we don't want to discuss the methodology of collection... So I think there's more than just coming up with the measure, it's kind of, there needs to be guidance around how to use that appropriately as well. (J7)

Perhaps developing a handbook... on implementing PROMs, a reference source that people can go to where you talk about things like ethics, technology, those sorts of things. I found the Commission's handbook on registries fantastic; it really helped us when we were setting things up. I think, just being a voice for promoting this across the country. (J5)

The Commission might take on a 'clearinghouse' role and act as a point of reference for stakeholders who want to learn more about using PROMs for safety and quality improvement. The example of the Mapi Research Trust, which provides a clinical outcome assessment portal, was cited.

It could be a clearinghouse and a body facilitating exchanges between states so that the states as a collective come with the best tools, because they've not been very successful so far creating tools for everyone. (J7)

There are lots of methodological and logistical issues that they have not maybe got their heads around in some places. And I guess that's an area to look at moving forward, is that guidance... but we also need to know a bit, whatever people are going to use it's going to be like relevant to their context and to their population. (J2)

The Commission's *Australian Atlas of Healthcare Variation*<sup>33</sup> was mentioned by several participants as a potential mechanism that could be copied or adapted in some way to provide guidance for states and territories in the implementation of PROMs. There was interest in how PROMs could be used to improve health service providers' understanding of clinical variation.

I don't know what the IT capability would be like, it might be independent IT platforms which could be informed by something central and then similar to the Atlas they produced where you would be able to start to get an understanding of the measures, PROMs as they vary region-by-region, you know, to give more of a comprehensive snapshot of the activity that's going on. (J4)

I guess that the next part for me would be around the Atlas of Variation. So we've got really good data around where there is variation and I really think that states should be using PROMs to help identify some of those issues around why there's variation, because the Atlas really tells us that there is variation and I think that we could potentially use PROMs as a way of looking into that variation a bit more... So there may be ways that the Commission can actually promote PROMs and the use of PROMs in line with the Atlas... there isn't anybody out there really, in the kind of public domain saying that these are helpful and this is how to use that information to help drive what care you're giving and how you're giving that care within your health service. So if they could, I guess in a way, validate that some of these are really helpful - and put those out into the public domain you may find that other areas are happy to pick up on it because they see there is value add, and it's been validated, and that might be a role for the Commission. The work that comes out of the Commission is quite often regarded very highly. (J10)

#### 3.6.4 Facilitation of networks

The Commission is also seen to have a vital role in facilitating networks to support development, implementation and evaluation of PROMs in the health sector. This includes advocacy for infrastructure and research funds to advance PRO initiatives across Australia.

This facilitation might focus on strengthening linkages between states and territories, supporting the development of clinical networks and/or facilitating data brokerage and

benchmarking. Data brokering was explained more as facilitating the links between states and territories; this could be for benchmarking purposes or to more effectively monitor outcomes for patients who live close to state and territory borders and may move between different hospital facilities in two different jurisdictions.

The possibility of benchmarking is limited if there is no coordination amongst jurisdictions about the instruments and methods used to collect PROs. The plethora of instruments available was reported as a barrier to a systematic approach to benchmarking. The Commission was perceived to have a role in driving states and territories and healthcare providers towards convergence in best practice.

It feels like now is the time for both national authorities and even international bodies such as the OECD to start doing some work and trying to achieve consistency and work in this area to try and bring some standardisation to the questions asked, clearly there are problems of comparability... (IE7)

But there are some really good examples of where that's happening and working well. And it'd be good to look at what are some common elements across those programs that are successful and be able to replicate them. (AE1)

I think to me then ideally there'd be some way of coordinating with the states too, so for the Commission to then understand what the different states are doing and maybe working to share information from what the different states are doing or to provide academic forums where people who work in PROMs get together and share – that sort of learning and facilitating, whether there's ability to have a website dedicated to PROMs information or consolidating PROMs related information together. (AE2)

I guess the Commission is about supporting best practice across the country, especially for public services. So I guess it's about – the thing like benchmarking comes in when you're able to collect things for multiple services, whereas, if you're just a doctor working in a private practice and you administer your own PROMs, you get a sense of things over time, you don't necessarily get a sense of your benchmarks.... benchmarking has been shown to improve overall outcomes over time. (AE2)

Participants discussed the usefulness of pilot projects as a starting point for bringing stakeholders together. The Commission could facilitate implementation research to build on the lessons from successful PRO pilot projects.

I think you have to start with pilot projects, so I don't think it's a good idea to start with the top down. I mean maybe something that the Commission can do is to get examples from people who are actually currently doing things and seeing and learning from those, and show...here's an example of where PROMs were used and they were on the balance better than not having PROMs...There needs to be some implementation research done so that the evidence collected by people doing pilots and so forth is collected in a scientifically robust way, and, importantly, is reported...I don't know if the Commission is in a position to provide some assistance with that sort of thing...in ensuring that the people who are conducting successful pilots are given some support in writing those up and reporting them and sharing them...Facilitating connections and communication and sharing of lessons learnt, what worked and what didn't work. (AE5)

International experience has demonstrated the usefulness of working with healthcare organisations to facilitate the selection of PROMs, determine the timing of measurement, and

identify the appropriate measurement system and how the data is reported back to the organisation.

What I often say to doctors that besides discussing the results of the MRI or the blood results, it should be normal to also look at differences in the PROMs measures ... they need to get into making it a normal aspect of care which should also be discussed and which is just as important as the blood results. So, it is definitely a cultural change for doctors as well. (IE9)

The Commission potentially has a role in advocating for infrastructure support. The effective implementation of PROMs requires resources and without “overarching infrastructure support” most healthcare providers struggle to see how to incorporate PROMs into existing clinical care processes and information management systems. References to infrastructure were not just about funding but giving healthcare providers the resources to integrate PROMs into their routine work and existing patient care processes. The Commission could have a role in either developing infrastructure around PROMs or influencing others to do it.

...I think of the infrastructure in terms of giving them the time, the resources to build that into their routine work. (IE7)

The example of ICHOM was raised in the context of it providing a model for collaborating around the implementation of PROMs.

One thing I took from ICHOM is you work with the willing. So, if there are people that are willing and busting to have a go at this, for them to be supported in that way, to work with other like-minded people and to have them potentially behind it because it will require effort...if you think PROMs are a good thing and you want them to work then we need to get them wins, don't we? And that we learn from it (J2)

...a degree of support for implementation ... to actually collect the information and that kind of thing would be the early stages for me. (J3)

The Commission may have a role in facilitating access to research funding streams. This could come from various sources such as the NHMRC or the Commission itself. The importance of investment in the implementation of PROMs and building the evidence base was a consistent message.

National funding bodies like the NHMRC really need to rethink their strategies as well about how they distribute funding, very little goes to health services research, because we try to put grants to these national bodies knowing that over 50% of basic research - a huge chunk of funding goes to basic research, and very little goes to this type of work that we're doing. But if there could be a dedicated pot of money that could be reserved for this type of health service research grant, or whatever you want to call it, and I don't know if the Commission could have a voice in that respect, I think, that's a really important priority for the future. Because at the moment, we try and do all of this stuff just whenever we've got a bit of spare time, but it's really hard when you haven't got enough dedicated health service researchers to get the data out there. (J5)

Well, you could help fund some of it. Everybody wants money. Well, I think the Commission has – you fund things and that's great, we love funding. (J6)



I don't think necessarily it would be about the Commission collecting the data or anything like that, but I think it could be about academic forums, where people who collect PROMs in relation to certain things can get together and compare their data or their findings. But it can certainly be about also providing some investments for registries or those that are working with those sorts of PROMs, providing some national investment and then providing opportunities for that information to be shared generally as well as between the sciences. (AE2)

International experts perceived that Australia had much to contribute in the arena of PROMs to research translation.

There doesn't seem to be much evidence at the moment that they believe PROMs could lead to system improvement and so I think Australia could contribute at an international level to fill in that gap by focusing from the very outset on how the data can be applied because it seems that if you simply collect it and publish it not a lot seems to happen. (IE7)

The Commission could have a role in facilitating conferences and workshops which would allow various stakeholders to share their experiences. These were seen as a valuable opportunity to promote particular models or outcome measures and reduce duplication of effort. The value of bringing people together was identified by several participants.

If the Commission were to set up a program of workshops and conferences over a couple of years to really give people who are interested a platform to share their experiences, that might then form the basis of knowing whether or not there's enough knowledge, collective knowledge and experience to combine into guidelines. (AE5)

And then I think that they could play a role in ongoing workshops after that, about best practice. If you want to set up PROMs this is the way to do it and once they start collecting that sort of – someone, somebody needs to have an overview of all of this and I guess the Commission is in a pretty good position to do that, and once there was emerging some common understanding of what works in what circumstances and why and what doesn't work, then you might start to get an idea of what an over-arching program, national program might look like... (AE5)

I went to a patient experience symposium ...a couple of weeks ago... there was a bit of emphasis and a few presentations about PROMs. And one of the best parts of that symposium was meeting with the leads from all the other jurisdictions that attended who were the leads on patient experience on the patient-reported matters. Most of them look after the patient experience surveys and we could see from meeting with each other that the states are all at very different levels and different journeys with PROMs. (J2)

One jurisdictional participant best summed up how the Commission can contribute to the implementation of patient reported outcomes in Australia through its policy leadership, engagement with stakeholders, guidance in implementation and facilitation of networks, resulting in system-wide practice change and quality improvement.

I think to me what the Commission does really well, is standardise and converge towards better practice. I think that for me is what I think the Commission does extremely well. Standardisation, convergence towards best practice, is where I think the Commission can really play a big part. (J9)



## 4 Discussion

This discussion chapter has two main sections. In the first, the discussion focuses around the six principles for the design of PROMs programs presented to and endorsed by the Commission's Board in April 2017.<sup>8</sup> This is an opportunity to reflect on these principles in the light of new lessons from the interviews.

In the second section of this chapter, the discussion focuses on options for the Commission's role, with recommendations informed by the interviews as well as earlier stages of this project.

### 4.1 Principles for PROMs programs

The principles below were developed in response to the findings of earlier stages of this project: the environmental scan<sup>1</sup> and the literature review.<sup>2</sup> They also align with the findings of a more recent review.<sup>27</sup> In the next sections we draw on data from the interviews and some relevant, recent publications and summarise this new information around the principles.

#### 4.1.1 Embed in policy

This principle acknowledges that PROMs are not an end in themselves, but a means to achieving policy objectives. They are tools which can serve broader safety and quality goals.

Stakeholders agreed that PROMs initiatives would need to be backed by policy commitment and continuity if they were to have any chance of a positive impact on quality and safety. They nominated person-centred care and value-based health care as the two dominant policy directions in health care at this time. PROMs are seen as integral to both. It seems self-evident that efforts to reshape clinical care around patients' values and needs should involve systematically collecting information from patients about their experiences and outcomes. Perhaps less obvious, but no less important, is the need to incorporate patient perspectives in any assessment of the 'value' of health care for the purposes of performance measurement or reimbursement.

Interviewees tended to place more emphasis on person or patient-centred care as a driver of PROMs initiatives. They believed that PROMs could serve this policy direction in two main ways: by providing information to aid shared decision making and informed consent; and by providing input into safety and quality improvement efforts. In the clinical setting, the use of a PROM can help focus discussion on the patient's concerns and priorities. Clinical measures cannot provide all the necessary information to judge the patient's health status or the outcomes of treatment. PROMs complement the information already available in many clinical registries and other data collections.

To have a meaningful role in patient-centred care, PROMs need to be relevant to patients. Consumers need to be able to see why they are being asked these questions, and they also need the data fed back to them in a form that can be easily understood. They may wish to use this information to track their own progress, to report their health status in relation to their goals, to shape their expectations about the outcomes of a treatment, and to make informed choices between treatments or providers.

Consumers will be more likely to complete PROMs if their doctors encourage them to do so. Doctors are more likely to engage with PROMs if the collection method is efficient and the data

can be used immediately to guide care. Clinicians may also be interested in using aggregated PROMs data for research purposes such as evaluating innovations in care or comparing the effectiveness of alternative treatments. Several interviewees believed that clinicians would be 'intrinsically motivated' to collect high-quality PROMs data and would 'engage creatively' with the data if given the opportunity.

Most of the interviewees placed less emphasis on value-based health care as a driver for PROMs adoption and use in Australia. Nevertheless, there was interest in using PROMs in ways that could contribute to greater efficiencies in the health system; for example, to understand the health gain from particular treatments and thus to steer clinicians and consumers towards more effective options. The hope is that inclusion of PROMs in comparative effectiveness studies and evaluations of quality improvement interventions could lead to both better outcomes and reduced costs.

Value-based care has been proposed as a way to refocus the health system on outcomes that matter most to patients, as well as to clinicians and funders. At this stage only a minority of Australian and international interviewees are strong advocates for using PROMs in calculating the value of health care. There was a sense that this country is not yet ready to use PROMs in performance measurement or as a component of reimbursement formulae. There is, as yet, little convincing evidence of effectiveness for these uses of PROMs. However, several interviewees acknowledged that it will continue to be necessary to find ways to direct healthcare budgets to where they will have the most beneficial impact. Patient perspectives should be taken into account in those considerations.

#### 4.1.2 Make objectives explicit

This principle requires any PROMs program to have objectives that are explicitly defined in relation to the policies that guide it. It also requires articulating the mechanisms by which those objectives will be realised through the program.

##### *Clarity of purpose*

International experts strongly advised that the starting point for a PROMs initiative must be a clearly stated, mutually agreed purpose for the collection. It is vital to consult with stakeholders around what information to collect and how it will be used. Without a clear purpose, it will not be possible to define and measure the expected impacts of the initiative. If stakeholders are not able to see meaningful benefits, it will be difficult to sustain the necessary support from clinicians, consumers and those providing resources for the collection.

Australian stakeholders have very clear ideas about how they would like PROMs to be used. First and foremost, they believe that PROMs can and should be used to guide conversations around shared decision making and informed consent during the clinical encounter. These conversations are at the heart of patient-centred care<sup>20</sup>. Patients are very interested in other patients' perspectives on their treatment outcomes and will use this information to help answer their key question, 'What are my chances?'

There is also considerable interest in using aggregated PROMs data to explore unexplained variations in treatment and outcomes, and to identify high- and low-value procedures. Benchmarking against best-practice standards will allow providers to target their quality

improvement activities where they are most needed, to learn from better-performing organisations, and to demonstrate their successes and strengths.

Using PROMs at the system level is more controversial. Some international experts believe that providers will not collect PROMs without a financial incentive to do so; others argue that providers will voluntarily collect PROMs if they can see convincing evidence of benefits for quality and safety. In part, these different views arise from the structure of the various health systems and the ways in which health care is funded. In the highly regulated US healthcare market, providers must submit data in order to receive reimbursement. Currently most of the data relate to outputs; the value-based healthcare agenda is driven by a desire to move towards more meaningful data collections, based on outcomes including PROMs.

In Australia, the drivers are somewhat different. There is no appetite for mandatory PROMs collection. There is, however, some willingness to consider a level of national standardisation. For example, stakeholders who want to collect data from similar patients may see the advantages of using the same measures across jurisdictions, as long as there is some flexibility and freedom to adapt the collection for local needs. Movement towards a more systematic approach will require careful ground work to identify key stakeholders and negotiate shared understandings and upfront agreement on how the data will be used.

There are pockets of interest in using PROMs to inform payment models, although this mainly applies to NSW, where the use of PROMs is implicit in the *Leading Better Value Care Program*. Other states do not yet have the clinical buy-in, resources or infrastructure to support this use of PROMs. At this stage, any attempt to mandate the use of PROMs for the purposes of value-based payment is likely to be counterproductive.

### **Program logic**

One way to articulate the mechanisms through which the objectives of PROMs may be realised is to develop a program logic (sometimes called a program theory). This evaluation technique was recently employed in two realist reviews of the literature on the impacts of PROMs.<sup>27</sup> By reviewing the literature and consulting with consumers, clinicians and policy makers, the reviewers developed a taxonomy of the ideas and assumptions about: (1) how publicly reported aggregate PROMs data might lead to improved patient care; and (2) how PROMs used in the clinical consultation might support patients to raise their concerns and/or support clinicians to become more aware of, and willing to discuss, patients' concerns. Logic models were developed for each of these questions.

Providers were seen as more likely to respond to performance data if the data were credible and provided in a timely and easily interpreted way, with information on the causes of poor care.<sup>27</sup> External incentives or sanctions were also influential. Improved patient care was one possible outcome of reporting; however, there were other, less desirable possibilities such as ignoring the data or engaging in 'gaming'. The mechanisms by which performance data might lead to outcomes were:

- Fear of losing market share
- Protection of professional reputation
- Desire to be as good or better than peers

- Intrinsic desire to provide high-quality care.<sup>27 p. 57</sup>

The logic model for PROMs in the care of individual patients consisted of a series of processes by which the use of PROMs might influence decision-making, treatment and health outcomes. These processes or mechanisms mainly pertained to communication between the consumer and the clinician, for example:

- The patient raising concerns during the consultation
- The clinician reviewing PROMs feedback
- The clinician discussing PROMs with other clinicians
- Actions taken to address concerns.

The program theories developed by Greenhalgh and colleagues<sup>27</sup> provide a rigorous starting point for developing similar logic models for PROMs initiatives in Australia.

#### **4.1.3 Make data accessible at multiple levels of the system**

This principle refers to the three levels of use – micro, meso and macro – discussed above. Data collected at the first level can be used at all three levels, avoiding duplication of effort and maximising the value of the collection.

Stakeholders largely endorsed this concept of ‘collect once, use many times’ on the understanding that all uses would be agreed up front. There was some mistrust and suspicion that data collected ostensibly for one purpose, such as quality improvement, could eventually be used for other purposes, such as performance reporting and pricing. Any such ‘surprises’ should be avoided as they are likely to undermine stakeholder support for PROMs, compromising the quality of the data and its effective use.

PROMs are not seen as a stand-alone solution but are most useful when integrated with relevant clinical data. One of the major technical challenges, which has not yet been satisfactorily solved either in Australia or elsewhere, is linking PROMs collection with electronic health records. Australia is not alone in facing the challenge of linking PROMs with electronic health records and there is considerable effort currently to find a solution. It will be important to keep up with rapid developments in this field by examining the literature and maintaining contact with international and local researchers and software developers.

Resources and infrastructure will be needed in order to: collect the data accurately and quickly without disrupting work flow; provide individual patient data in real time to clinicians; aggregate and link the data with other data collections; and assist consumers, clinicians and healthcare organisations to make the best use of the data.

To gain and sustain stakeholder support, PROMs initiatives will need to be designed to meet clinicians’ wishes for rapid feedback and the capacity to track patients longitudinally. Clinicians and healthcare organisations will need information in a form that can be easily interpreted and translated into action. Different stakeholders will need access to the data for different purposes. For example, PROMs data might be used by a hospital or local health district to evaluate the impact of clinical guidelines, care pathways or other innovations in care processes; to prompt discussions around competency and training needs; or to compare outcomes against agreed best practice benchmarks or quality indicators.

One idea that came through very strongly in the interviews is that PROMs initiatives must ‘add value’. By this, interviewees meant that in design and implementation such initiatives must facilitate the use of data to improve quality, safety and efficiency at all levels of the system.

Several international experts from various countries pointed to the NHS England PROMs program as an example of an initiative that has largely failed to have the expected impacts on quality and safety. Although it has produced high quality datasets that can be used at the system level (for example, to guide purchasing of prostheses for hip or knee replacements), there has been relatively little change in consumer or clinician behaviour in relation to selecting hospitals or procedures. This was attributed to a perceived lack of consultation in the early stages of the program. The system was designed to allow universal (mandatory) participation and ease of collection, but there appeared to be little consideration of making the data easily and quickly accessible to clinicians and hospitals.

This approach can be contrasted with that of established Australian collections and some more recent initiatives which have high levels of voluntary participation and keen interest in using the data for quality and safety improvement. Good examples include the PCOC and ePOC national collections hosted by the Australian Health Services Research Institute, the recent Agency for Clinical Innovation Patient-Reported Measures project in NSW, and the consultative approach to inclusion of PROMs into some clinical registries in the Netherlands.

#### 4.1.4 Base on the latest evidence

This principle acknowledges that although PROMs have been used in research (particularly clinical trials) for many years, their other potential uses are still at an early stage of development and there is a lack of evidence for some applications of PROMs. The literature review conducted at an earlier stage of this project found there is some evidence of benefits in the clinical encounter and for quality improvement uses of aggregated PROMs data but little evidence of system-level impacts<sup>2</sup>.

Since that work was completed, the NHS National Institute for Health Research has released a review that comprehensively examined impacts of:

- Publicly or privately reported aggregated PROMs data
- PROMs as a tool to support patients in raising or sharing concerns with clinicians
- PROMs as a tool for raising clinicians’ awareness of patients’ concerns.

This work by Greenhalgh and colleagues<sup>27, p. 228</sup> concluded that there was a ‘paucity of evidence evaluating the use of PROMs as a tool to improve patients care’. PROMs appear to help patients to raise issues with their clinicians, but do not substantially change clinicians’ communication practices. In order to act upon PROMs, clinicians need timely feedback and easy access to data through electronic health records. Using the data for both individual care and organisation- or service-level quality improvement remains a challenge. Providers require more support on how to interpret the data, identify causes of problems, and integrate PROMs with broader performance data to assess and improve their performance.<sup>27</sup>

Because there was so little research into feedback of aggregated PROMs to providers, the reviewers also drew on evidence from interventions with similar program theories and

discussions with consumers, clinicians and policy makers. Their conclusions are therefore influenced to some extent by the specific experience of the UK national PROMs program.

The experts interviewed for the current study readily acknowledged the limited evidence base for these broader uses of PROMs, beyond the research sphere. Several experts emphasised the need to continue building the evidence base by building in formative and summative evaluation into any new PROMs initiatives. Ideally this would be guided by some kind of program theory or logic model, as discussed above. A central repository of evaluation evidence – especially lessons about implementation – was seen as potentially useful.

There is relatively strong evidence around the psychometric properties of PROMs, particularly for well-known generic instruments. It will be important for new initiatives to draw on this established bank of knowledge to guide the selection of instruments. Project teams should include people with expertise in psychometrics. There is a need to educate clinicians about the science of psychometrics to inoculate them against the temptation to alter or adapt the tools or, worse still, to devise their own questions. If the resulting dataset is to be at all useful, the tools must be valid, reliable and sensitive to changes in health status (which presumably result from changes in care delivery). As discussed above, some standardisation of measures across units, organisations or even jurisdictions is desirable if the data are to be used for comparison and benchmarking against best practice. Where there is a choice of suitable tools or where clinicians are heavily committed to ‘legacy’ tools, some flexibility may be needed to accommodate local preferences and needs.

Evidence from national and state collections of quality and safety data could also help in deciding where to target PROMs initiatives. Ideally, initiatives will be implemented where there is most scope for improvement. For example, policy makers and program developers may wish to examine data around unexplained clinical variation to identify particular procedures or conditions that might benefit from the use of PROMs. In some conditions, such as chronic pain, patient perspectives are particularly informative and more ‘objective’ clinical measures are less so. Another way to prioritise PROMs initiatives, suggested by interviewees, might be to look at areas of greatest resource use, such as chronic and complex care, where there is potential to improve both efficiency and health outcomes.

#### **4.1.5 Support nationally and align with other national programs**

This principle concerns the potential role for the Commission in establishing national coordination and/or support for the use of PROMs in Australia. There is considerable interest in PROMs and appears to be an appetite for information and guidance on how they can best be implemented within health services and jurisdictions. In providing national support, the Commission has opportunities to align PROMs with its other priorities, such as setting national standards for person-centred care, providing guidance for clinical quality registries, detecting unwarranted variation in clinical practice, and reducing the use of low-value interventions and procedures.

Interviewees confirmed that a level of national coordination and support for PROMs is warranted, and many stated that the Commission would be an appropriate organisation to take such a role. This role might include providing leadership on policy and standards; engaging with stakeholders (such as medical colleges, consumer groups and governments) to promote informed discussion; collating and disseminating information about instruments,



implementation and evidence; and strengthening connections between PROMs initiatives, which may involve linking jurisdictions, supporting the development of clinical networks, or facilitating data brokerage and benchmarking. These points are discussed in the next section.

## 4.2 Potential roles for the Commission

The primary role for the Commission is about policy leadership. However, the approach to achieving this has to be consultative and developmental and not a mandatory and ‘top down’ driven solution.

The benefit of policy leadership is that this will facilitate coordination of the ‘bottom up’ initiatives that are already in train. This increases the potential for standardisation, learning from the experiences of others and engaging various jurisdictions in a consistent policy direction. The experience of other countries is that without a strategic framework or agreement to guide development of PROMs, efforts may be scattered and transitory. This type of leadership role is best undertaken by a national agency that is respected and has existing mechanisms to work with all jurisdictions and inform policy development.

Several interviewees referred to the Commission’s previous work in developing guidelines for clinical registries and saw this providing a model that could be used to educate and guide future implementation strategies for PROMs. There is also potentially alignment of PROMs initiatives with the Commission’s National Safety and Quality Health Service Standards and associated accreditation practices.

The Commission might start by clarifying the objectives of a national framework and then identifying the overarching principles and policies to prioritise investment in PROMs. The framework might also describe what a core set of PROs would be and provide a starting point for discussion around a consistent set of measures that could be adopted by various entities. It was clear from the interviews that there is no consensus about the highest priority procedures or conditions for PROMs development. Therefore a useful starting point may be to identify areas of unexplained clinical variation where PROMs might best inform quality and safety improvement efforts. The Commission’s work on the Australian Atlas of Healthcare Variation demonstrates expertise in this area. There is currently high investment in the area of chronic and complex care and there was strong interest among interviewees in using PROMs in this context. Another useful way to target PROMs may be to consider where there is clinical appetite for their use.

The Commission’s role in engagement is two-fold. First, the Commission has an important role in providing a stimulus or catalyst for change throughout the healthcare sector increasing interest and engagement in the implementation of PROMs, such as the rationale for the use of PROMs and their potential value for patients, clinicians and the broader health system. Second, it is about engaging the diverse stakeholder groups that have an interest in PROs and coordinating the discourse at a national level.

The Commission has the capacity to engage in international PROMs developments through the OECD and collaborations such as ICHOM and PROMIS. Within Australia it has well-established links with all state and territory jurisdictions, clinical registries, medical and professional colleges and national data collections. These networks position the Commission to generate



informed discussion around the uses of PROMs and facilitate shared understandings of how to progress at national level.

There is a need for transparent discussion about the resources required to realise the benefits of PROMs as well as the limitations of their use. The national profile of the Commission means it is well-placed to showcase the application of PROMs and provide a realistic assessment of what can be achieved.

Interviewees frequently referred to the importance of the Commission collating and disseminating evidence relating to the use of PROMs. One of the key principles for PROMs programs is to make objectives explicit and to articulate the logic of how PROMs activities link to expected program outcomes. This is another area where the Commission will lead the development of logic models for PROMs initiatives in Australia.

Within Australia, health service providers require support not only in the development of appropriate outcomes frameworks but also in the application of these frameworks. There is currently limited guidance for jurisdictions and organisations wishing to implement PROMs. This extends to not only instrument selection and implementation but technical solutions relating to electronic health records, privacy and sharing data across jurisdictional and organisational boundaries.

The Commission is also seen to have a vital role in facilitating networks to support development, implementation and evaluation of PROMs in the health sector. This includes advocacy for infrastructure and research funds to advance PRO initiatives across Australia. This facilitation might focus on strengthening linkages between states and territories, supporting the development of clinical networks and/or facilitating data brokerage and benchmarking. The possibility of benchmarking is limited if there is no coordination amongst jurisdictions about the instruments and methods used to collect PROs.

The Commission might also facilitate implementation research to build on the lessons from successful PRO pilot projects. Advocating for infrastructure, research grants and translation of research into practice are other roles that might be adopted. References to infrastructure were not just about funding but giving healthcare providers the resources to integrate PROMs into their routine work and existing patient care processes. The Commission could have a role in either developing infrastructure around PROMs or influencing others to do it.

In summary, the twin policy drivers of person-centred care and value based care are already generating considerable interest and activity in PROMs across Australia. This activity will remain scattered and most likely unsustainable without coordination and leadership. The Commission will contribute, on the behalf of the Commonwealth, states and territories, to the implementation of patient-reported outcome measurement in Australia through its policy leadership, engagement with stakeholders, guidance in implementation and facilitation of networks, with the goal of system-wide practice change and quality improvement.

#### **4.2.1 Recommendations**

The following recommendations arise from the expert interviews. These are consistent with the evidence produced through the environmental scan and literature review which were earlier stages of this project.

It is recommended that the Commission:

1. Develops a national strategic framework for PROMs that identifies potential priorities for collaboration, principles to guide data collection and use and research translation.
2. Supports evidence-based approaches to the implementation of PROMs through promotion of ongoing research and evaluation and monitoring international developments.
3. Provides opportunities for interested stakeholders to meet and progress the PROMs agenda in relation to quality and safety.
4. Maintains a database of PROMs initiatives implemented in all states and territories to facilitate information sharing and reduce duplication of effort.
5. Investigates how technical barriers might be overcome to facilitate the use of PROMs, particularly in relation to use of the electronic health record.
6. Facilitates quality and safety improvements through supporting organisations to interpret and use PROMs data.

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## Appendix 1 Interview schedule for state and territory government participants

This interview is in two parts. The first part asks about the situation in your jurisdiction with regard to current and planned activity related to PROMs. The second part asks about what you believe an appropriate role for the Commission would be to support or catalyse the use of PROMs in your jurisdiction and elsewhere in Australia.

### Part 1: Your jurisdiction

1. Does [your jurisdiction] have a formal position or policy on PROMs?
2. What is the unofficial feeling about PROMs within your jurisdiction, whether in the department or among stakeholders? (This will not be attributed back to you or your jurisdiction)
3. What are the drivers for the use of PROMs in [your jurisdiction]? (prompt: e.g., the National Safety and Quality Health Service Standards)
4. How are PROMs being used currently and in what contexts (and at what scale)?
5. Have any positive or negative impacts been demonstrated? (prompts: for patients, for providers, for the health system)
6. Which stakeholders are most likely to influence PROMs implementation in [your jurisdiction]? (prompt: e.g., clinical registries often led by professional groups or research groups)
7. Do you have a sense of how engaged those stakeholders are with the idea of PROMs?
8. What do you think their concerns and information needs might be? (prompts: form/type of information, risk adjustment, concerns about using PROMs as a performance management tool for individual providers, beliefs about validity of PROMs, costs versus benefits)
9. How do you see PROMs being used in the future in [your jurisdiction] and what benefits for healthcare quality do you hope this will bring?
10. What are the key challenges and risks? (prompts: selecting measures; data collection infrastructure; consumer participation; provider buy-in; relevance and adaptability to local systems)

### Part 2: The role of the Commission regarding PROMs

11. What do you think a national organisation such as the Commission should do to support PROMs uptake, implementation and use in Australia? (Prompts: producing a National PROMs strategy or framework; facilitating forums for sharing best practice; promoting a standardised set of 'Core PROMs' for consistent collection all over Australia; developing a supporting infrastructure ...)
12. When it comes to the Commission's future role, what do you see as the ideal balance between creating national standardisation of PROMs instruments, collection and use and the scope for local innovation and adaptation to the needs of [your jurisdiction]?
13. Ideally, what guidance and/or practical support would be available at a national level to facilitate your jurisdiction's current and planned future use of PROMs?

14. What does your jurisdiction consider to be the priority (conditions/processes) for the use of PROMs?

## Appendix 2 Interview schedule for international experts

1. Is there a national policy or framework to guide PROMs collection in [your country]?
2. What are the drivers for the use of PROMs in [your country]? (prompt: are there policy principles relating to health differentials/health inequalities; driving more patient-centred health care or personal control by patients through the use of people-centred metrics; what about the role of PROMs in health technology assessment; are there principles relating to health data governance etc.?)
3. What parts of the health system collect PROMs? Is collection voluntary or mandatory?
4. How are responsibilities and roles for PROMs uptake, implementation and use shared between national and local/state/provincial agencies? How is this working and what would you change in an ideal world?
5. What are the major mechanisms for PROMs collection? (prompt: generic vs condition or disease specific measures; timing and circumstances of collection; infrastructure for data collection)
6. How well is this approach to data collection and analysis working, and what would you change if you could?
7. What have been the barriers to implementation and how have you overcome these?
8. An important principle in PROMs is ‘collect the data once, use many times’. But different users have different needs. How can these be balanced in practice?
9. How are PROMs data reported? (prompts: has real-time reporting during the clinical encounter been achieved?)
10. What is your approach to risk adjustment? How acceptable has this been to stakeholders? What issues still need to be resolved?
11. What are the main ways in which PROMs data are used now? What future uses for PROMs data collections are envisaged?
12. Are there any links between PROMs and payments mechanisms or for funding allocations to promote QI and patient-centred care? (prompt: investigate if/how PROMs might be used to incentivise service improvements)
13. Is there evidence that PROMs collection has driven any useful changes in safety and quality improvement in [your country]?
14. What are the risks of PROMs? Have there been any unexpected consequences?
15. Is there any international agreement on how to define and measure ‘success’ of PROMs initiatives? How would you define ‘success’? (prompt: explore experience/capacity for inter-regional/jurisdictional comparisons as well as international comparisons using PROMs)
16. The Commission is seeking to define its role in relation to PROMs. Currently, PROMs use here is patchy but there is considerable interest and there is an opportunity to develop a national strategy or framework. If you were in this situation, knowing what you do now about the experiences in your country, what would you do to support and promote PROMs? What would be the first and second things you would do? (prompts: focus on the measures themselves, getting them consistent; focus on scaling up and sharing local



initiatives; focus on infrastructure; focus on 'selling' PROMs as a part of a wider value-based healthcare movement)

17. How do PROMs fit into wider policy initiatives? What other changes are needed in the system to facilitate their optimal uptake and use? What other policy imperatives need to be aligned?

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