



# Commission on Excellence and Innovation in Health.

## OVERVIEW

## STATEWIDE PATIENT REPORTED MEASURES PROGRAM

January 2021

# SUMMARY

The quality of the South Australian health system is largely measured by clinical outcomes and key performance indicators that are typically process type measures, such as how long a patient waited for a service.

Whilst these measures are important, they don't tell us about the quality and value to the patient of the services we are delivering. To truly understand quality and value, and deliver patient-centred care, we need to understand patients' perspectives of their own health. The program of work described in this document seeks to empower patients to tell us about the impact of their health condition on their life, what quality of life they are aiming for, their experience of the health system and whether what we do actually makes a difference to their lives.

Generally, there are two ways health systems across the world are capturing the patient's perspective – referred to collectively as Patient Reported Measures (PRMs). The first, Patient Reported Outcome Measures (PROMs) capture, at a point in time, a person's perception of their own health through questionnaires which enable patients to report on their quality of life, daily functioning, symptoms, mental and emotional wellbeing, and other aspects of their health and wellbeing – outcomes that matter to patients. There are three general types of PROMS<sup>3</sup>:

- Generic - measure aspects of health that are common to most patients, such as physical functioning, role functioning, psychological symptoms, and pain
- Condition specific – include questions which provide complementary information that directly relate to specific health conditions and their associated treatments
- Population specific – instruments that are designed to measure health within particular populations, e.g. PROMs have been designed specifically to be used with children.

PROMS are used for the following broad purposes:

- Clinician and consumer decision making - enhancing individual clinician-patient interactions and care; and enable tailoring of services to provide the care that the patients need and want
- Quality improvement – e.g. comparing the effects of different treatments, and for understanding unwarranted clinical variation
- Population-level surveillance and planning, and informing policy and funding models.

Internationally, such routine and consistent measurement is already embedded in the health systems of several Organisation for Economic Co-operation and Development (OECD) countries. Countries most advanced in implementing PROMs at a national or jurisdictional level are England (referred to as the NHS), the Netherlands, Sweden and the United States, and an increasing interest in a national approach in Canada.

The second, Patient Reported Experience Measures (PREMs), are psychometrically validated questionnaires used to obtain patients' views and observations on aspects of services they have received, such as their views on accessibility and physical environment, and aspects of the patient-clinician interaction (e.g. whether procedures were clearly explained or questions responded to in a way that they could understand).

In 2020 the Commission on Excellence and Innovation in Health (CEIH) undertook a snapshot analysis of PROMs-PREMs implementation in South Australia (SA). Results showed considerable variation in data collection and reporting, and that their use is within a narrow range of settings.

A subsequent workshop in June 2020 was attended by 76 stakeholders from the Department for Health and Wellbeing (DHW), each Local Health Network (LHN) (management and clinical), consumers, South Australian Health and Medical Research Institute (SAHMRI), Universities, CEIH - staff, Advisory Committees and Statewide Clinical Networks.

The consensus from these key stakeholders was that there should be a systematic approach across the state, and that data should be available in real-time to inform clinician and consumer decision-making. A vision statement and guiding principles were formulated during the workshop. A workshop summary is available. An Aboriginal Health Impact Statement was also developed and approved by DHW Aboriginal Health.

The implementation of a standardised approach would support the systematic collection, analysis and timely reporting of PROMs and PREMs to clinicians so that they are able to provide the best care to patients. Results would be available during clinical encounters to enable patients and clinicians to make decisions together. Aggregated data would also be available to use as a measure of service quality, and at a system level to drive excellence and innovation and inform value-based healthcare models.

$$\text{Value} = \frac{\text{outcomes that matter to patients}}{\text{cost per patient}}$$

*“The ultimate measure by which to judge the quality of a medical effort is whether it helps patients (and their families) as they see it. Anything done in health care that does not help a patient or family is, by definition, waste, whether or not the professions and their associations traditionally hallow it.”*

- Berwick 1997

A Technical Reference Group was convened to oversee and advise on the functional, technical and financial requirements of a statewide program. The current SA Health information technology landscape requires that we consider 3 different pathways for implementation, which are:

1. Integration with Sunrise Electronic Medical Record (EMR)
2. Integration with other EMRs (e.g. for private and primary care providers)
3. Implementation in sites without an EMR.

Market research was conducted to seek indicative pricing. The approach to market included consideration of sustainability, whereby the vendor would provide a train-the-trainer program to provide skills and capability within LHN implementation teams.

## **Program Strategic Elements**

The use of PRMs is core to health system sustainability, and there is strong evidence to support these programs. We have also been fortunate to learn from the experience of international models and from other Australian states, in particular New South Wales and Queensland. Several Australian states are in various stages of statewide implementation, and the Australian Commission on Safety and Quality in Health Care (ACSQHC) are supporting states in implementation and sharing international evidence.

Successful PRMs programs have five core elements:

- Program Governance:
  - Data sovereignty; ownership
  - Change management
  - Implementation; training
  - Communications; stakeholder engagement strategy.
- Generic quality of life measures (e.g. EQ-5D) – enabled by an IT solution
- Service specific PROMs – enabled by an IT solution
- Resource library – validated tools (in line with ACSQHC)
- Research program (local validation of international surveys).

The significant consumer, clinical, service and system benefits of implementing a PRMs program, enabled by a system-wide IT solution, are summarised below.

Implementation of a PRM program in SA aligns with the vision in the SA Health and Wellbeing Strategy, the Digital Health SA strategy, and the National Safety and Quality Health Service Standards. Additionally, it will enable outcomes data to inform value-based healthcare models and align with the development of an activity-based management (ABM) portal.

A PROMs utility and evidence background paper prepared by the Institute for Innovation and Improvement, Waitemata District Health Board, New Zealand<sup>11</sup>, refers to ideology behind PROMs in following the ideal of a patient-centred healthcare system, stating “The purpose of healthcare is to improve quality of life – that is, to help patients achieve the health-related goals and results that truly matter to them”.

It continues to state: “Accepting that patients, rather than clinicians, are the best judges of the impact of treatment on their lives, the ‘value’ of healthcare provided should therefore be defined by patient reported outcome measures”. This is the school of thought underlying ‘value-based healthcare’ which, “sees outcomes as the true measure of quality; how well did the patient actually do in a holistic sense relative to how much did it cost to deliver those outcomes?”

## Benefits

The benefits of implementing a patient reported measures program, enabled by a system-wide IT solution, are outlined below.

Consumers	Clinicians	Service	System
Informed decision making with clinicians to achieve personalised care	Clinical decision making tailored to patient needs based on the patient's self-reported outcomes and experience	Enable services to understand consumer needs	Population-level service planning and funding
Self-monitoring/tracking over time	Predictive analytics to inform decision-making	Aggregate data to inform continuous quality improvement	Health economic analysis*, e.g. does health budget improve quality of life?
Increased engagement and participation	Interoperability with other personalised health data (e.g. phones, wearables, IOT)	Health economic analysis* to ensure value for money and best outcomes	Reduction in unwarranted clinical variation and associated costs
Improved health literacy	Data set available for clinical research	Reduction in unwarranted clinical variation	Aligns with the vision and supports delivery of the SA Health and Wellbeing Strategy 2020-2025.
Improved quality of care, outcomes and experience			
Reduced length of stay			Aligns with the vision and purpose and supports delivery of the SA Health Digital Strategy
Reduced morbidity and mortality			
Choices based on aggregate PROMs/PREMs data Predictive analytics to inform decision-making			
Interoperability with other personalised health data e.g. phones, wearables, IOT)			

\* NB: It is crucial that DHW invests in an ABM portal to achieve this.

# Implementation in SA

Figure 1 provides a map that depicts the implementation program flow, including solution integration across different systems and sites, and the clinical services in which PROMs would be implemented.

Service implementation rationale entails identifying clinical services provided across multiple sites, enabling widespread implementation, and whereby a currently validated PROM tool is available and/or PROM collection is already established.

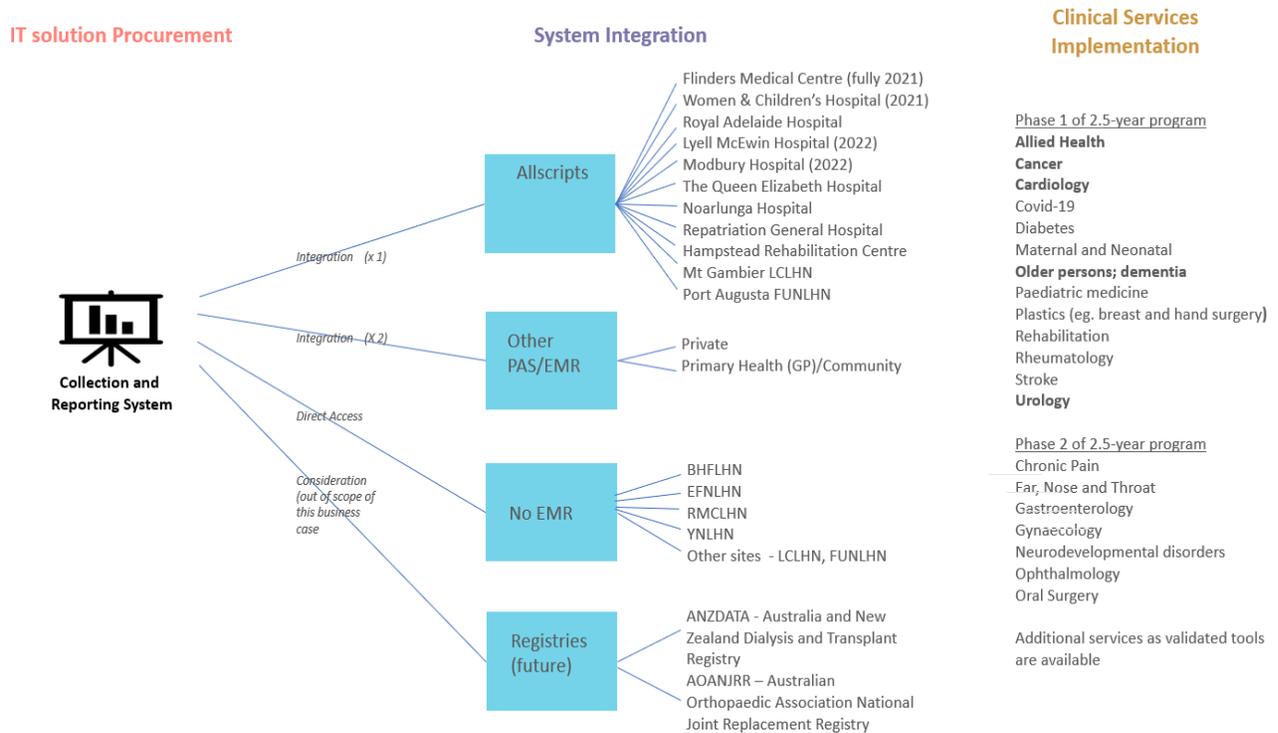


Figure 1: Implementation map showing how the PRMs solution will be integrated across different systems and sites.

A high-level implementation approach is outlined below.

<b>Implementation Stage 1: 2021-22</b>
<ol style="list-style-type: none"> <li>1. Establish Statewide Governance Committee</li> <li>2. Develop a data governance framework</li> <li>3. Establish Statewide PROM-PREM Program Team and Implementation Working Groups</li> <li>4. Co-design a detailed implementation plan (including current-state mapping, evaluation and reporting framework)</li> <li>5. Undertake open procurement process</li> <li>6. Contract selected provider</li> <li>7. IT system configuration, implementation, integration, testing and training (train-the-trainer)</li> <li>8. Commence PROM implementation per implementation plan</li> <li>9. Stage Gate review and evaluation after year 1</li> </ol>
<b>Implementation Stage 2: 2022-23 to 2023-24</b>
<ol style="list-style-type: none"> <li>1. IT system additional testing and customising</li> <li>2. Ongoing staged roll-out per Implementation Plan including additional training/train-the-trainer, monitoring and reporting</li> <li>3. PREM implementation (proposed)</li> <li>4. Annual evaluation</li> </ol>
<b>Implementation Stage 3: Project closure (2024) and transition to sustainability model</b>
<ol style="list-style-type: none"> <li>1. Post implementation governance and support frameworks finalised</li> <li>2. Identification of and handover to operational team (ongoing support)</li> <li>3. Formal project closure</li> <li>4. Post implementation review and evaluation</li> </ol>

**Figure 2:** High-level implementation approach for the three implementation stages over the next three years.