

Patient Reported Measures – Measuring what matters

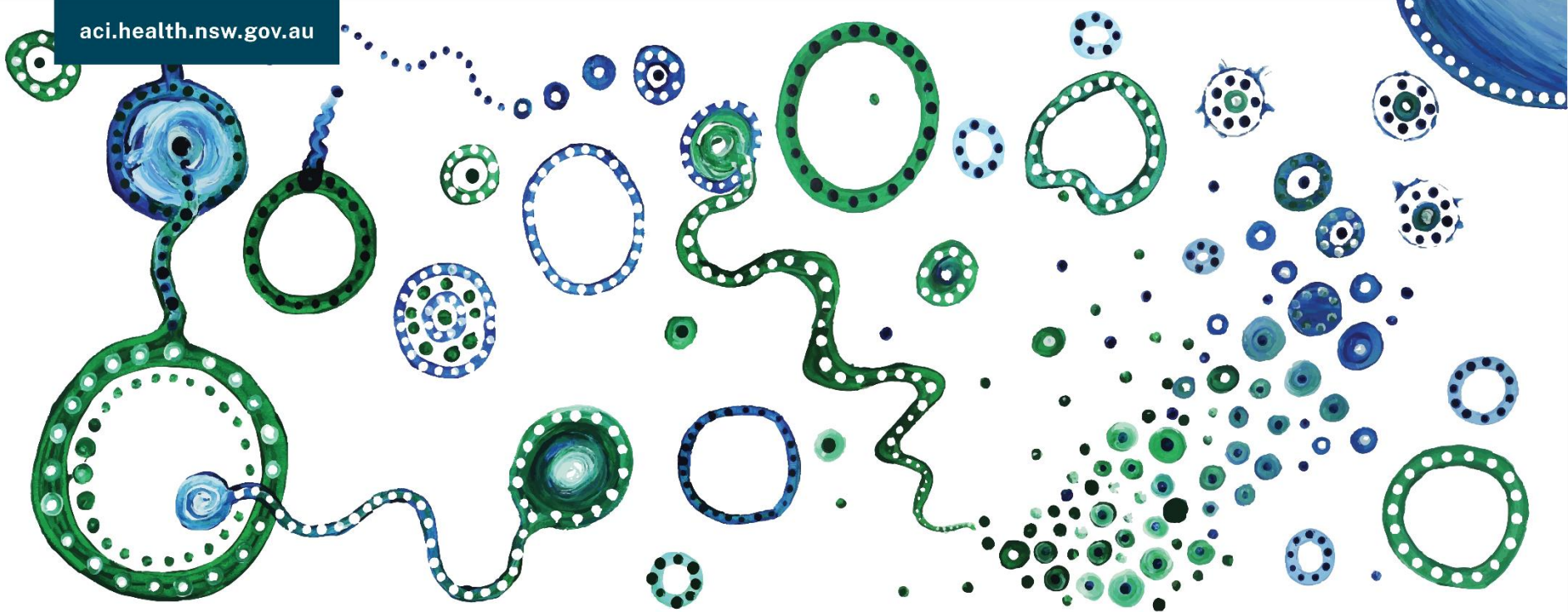
International Forum on Quality and Safety in Healthcare, Melbourne
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Aaron Hall

Stream Lead – Patient Reported Measures
Agency of Clinical Innovation (ACI)



AGENCY FOR
**CLINICAL
INNOVATION**



We acknowledge the traditional custodians of the land that we work on.

We pay our respects to Elders past, present and emerging, and extend that respect to other Aboriginal peoples present here today.

I recognise and appreciate consumers, patients, carers, supporters and loved ones. The voices of people with lived experience are powerful.

Their contribution is vital to enabling decision-making for health system change.



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The NSW Health vision

A **sustainable** health system that delivers **outcomes** that matter to patients and the community, is **personalised**, invests in wellness and is **digitally enabled**, aligned with **people's preferences**.



Patient Reported Measures Program



*Capture the patient's perspectives about how illness or care impacts on their **health and well-being***



Patient Reported Experience Measures

*Capture the patient's perception of their **experience with health care or services***

Individual
Improve quality of care by informing care planning and management



Service
Identify what's working well and areas for improvement



System
Evaluate system outcomes and value

Patient Reported Measures Strategic Framework

- 1. Patient-centred** – PRMs and associated processes are patient-centric and give patients a greater say in their care.
- 2. Iterative co-design approach** – designed with input from patients, carers, clinicians, and decision makers.
- 3. Integrated** – PRMs cover the whole patient journey across all care settings and are integrated to allow a holistic view.
- 4. Fit for purpose and meaningful** – PRMs need to be valued and useful for diverse groups of patients, carers, clinicians, and decision makers.
- 5. Trusted and reputable** – the tools need to be evidence-based, culturally appropriate and easily understood.
- 6. Consistency** – the information collected and systems used allow for comparisons across dimensions of care (core functionality, symptoms and quality of life) and allow flexibility for tailoring to local needs.
- 7. Universal coverage** – PRMs are universal, but need to have adequate variation to distinguish between cohorts.
- 8. Sustainability** – ensure that PRMs support a sustainable health system that delivers effective and efficient care into the future.
- 9. Transparency** – data is available in real time and accessible at multiple levels of the system.
- 10. Staged implementation approach** – supports the incremental adoption of PRMs and ensures adequate change management and resourcing.

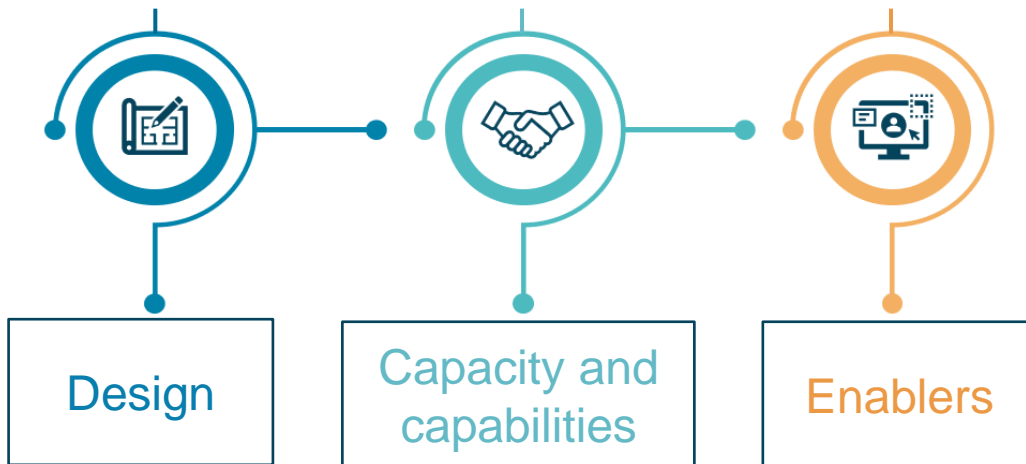
<https://www.health.nsw.gov.au/Value/Documents/prm-framework.pdf>



Patient Reported Measures: Program overview

ACI Patient Reported Measures Program

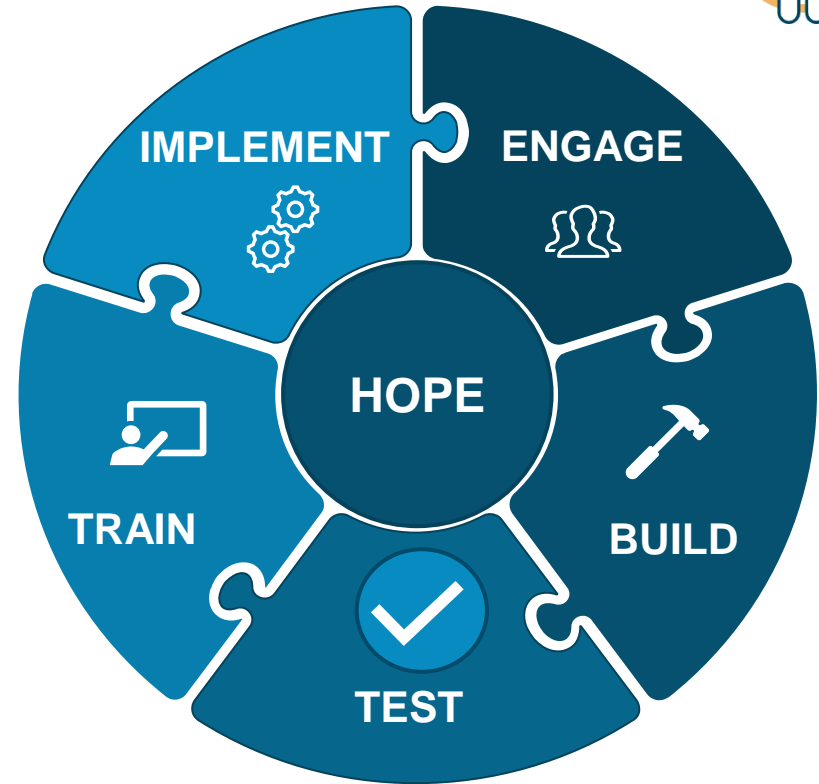
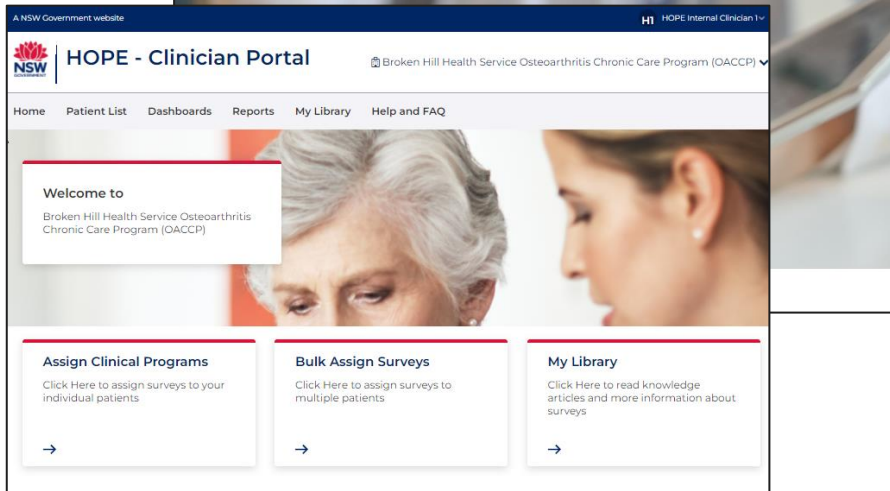
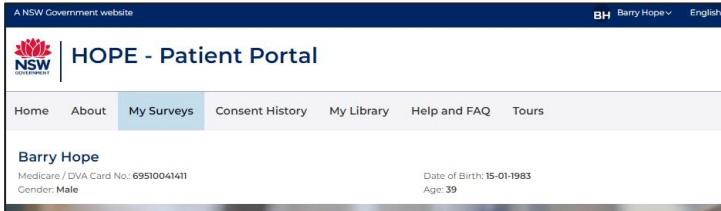
- Centrally coordinated – ACI (eHealth partners)
- Local Health Districts and Specialty Health Networks
- Primary Health Networks and Primary Care



Broader Program areas:

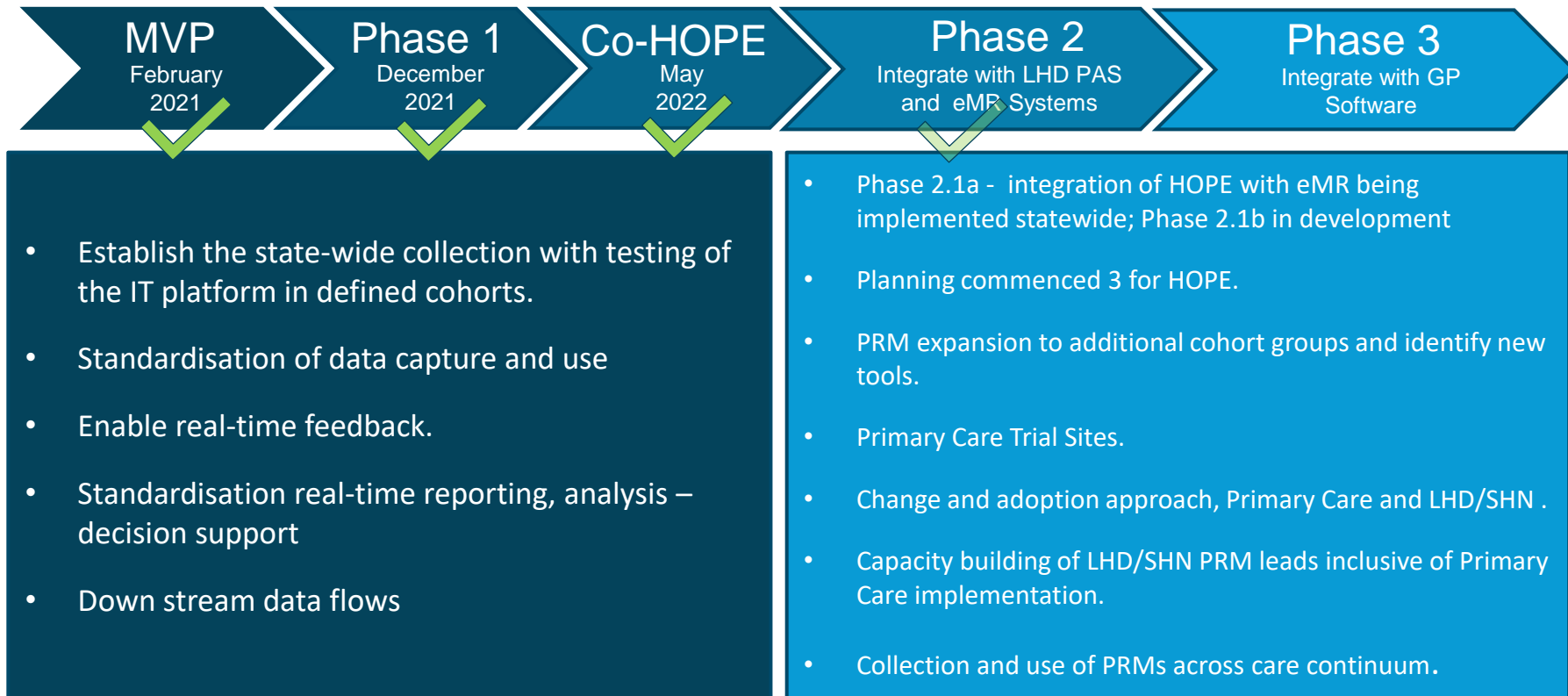
- Decision Support
- Data collection and use
- Change and Adoption
- Systems transformation
- Aboriginal Health Working Group
- Advice for research programs
- Consumer advisory group
- Clinician reference group
- Communities of Practice

Patient Reported Measures: Health Outcomes and Experience Measures (HOPE)



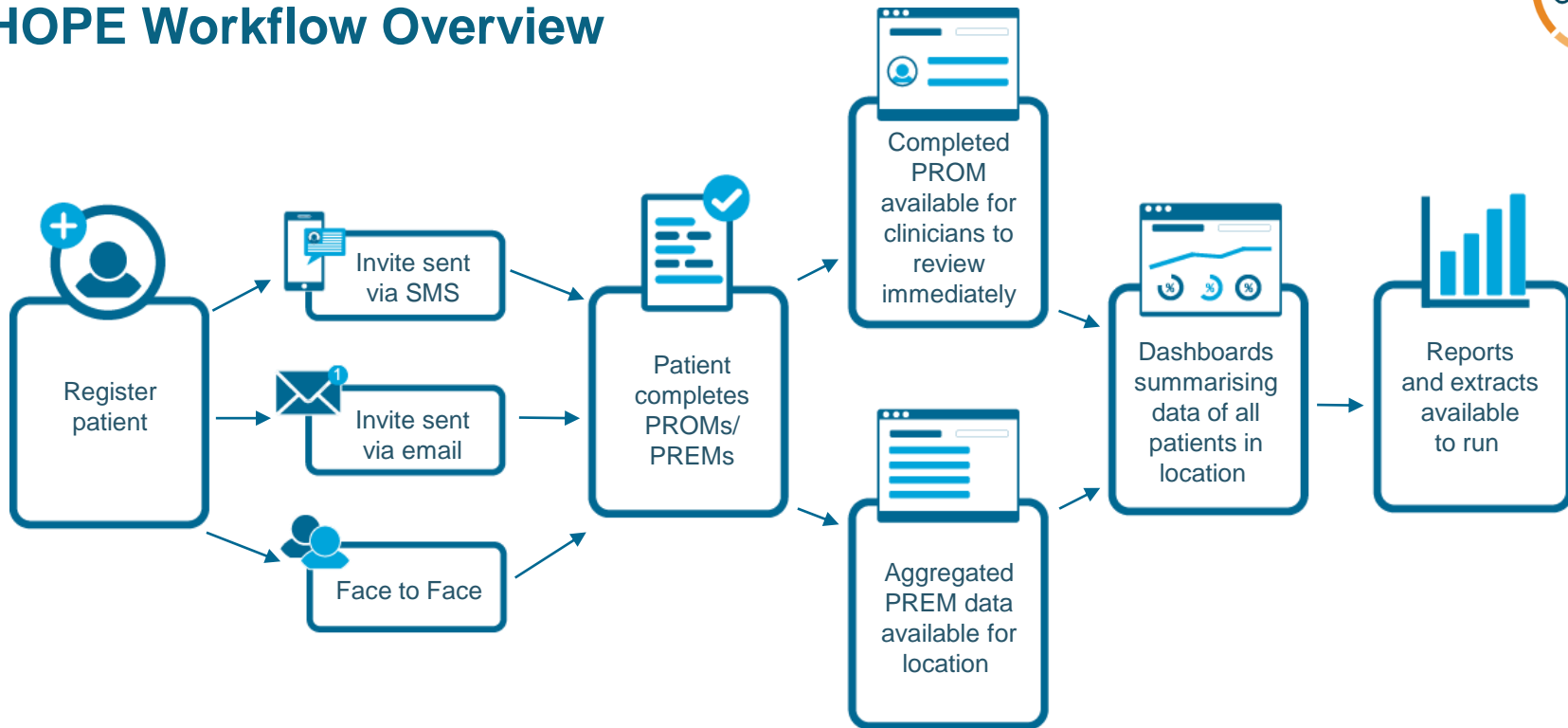


Patient Reported Measures: HOPE - Our roadmap





HOPE Workflow Overview



Survey Results

Scoring reference

Score movement

▲ Upward ▼ Downward – Stable

Reference article

[Decision Support Guide for Clinicians - Promis -29](#)

Consolidated domain score

[Copy to clipboard](#)

Domain	17-04-2023 (This survey)	10-05-2022	27-04-2022	29-03-2022	02-03-2022	01-02-2022
Physical Function	15 T: 40.5 ▼ Mild Declining ↘	17 T: 43.5 Mild	14 T: 39.2 Moderate	13 T: 37.9 Moderate	14 T: 39.2 Moderate	14 T: 39.2 Moderate
Anxiety	13 T: 65.3 ▼ Moderate Improving ↗	14 T: 67.3 Moderate	14 T: 67.3 Moderate	14 T: 67.3 Moderate	11 T: 61.4 Moderate	12 T: 63.4 Moderate
Depression	10 T: 58.9 ▼ Mild Improving ↗	12 T: 62.2 Moderate	8 T: 55.7 Mild	14 T: 65.7 Moderate	11 T: 60.5 Moderate	12 T: 62.2 Moderate
Fatigue	17 T: 66.7 ▲ Moderate Declining ↘	12 T: 57 Mild	13 T: 58.8 Mild	10 T: 53.1 Within normal limits	14 T: 60.7 Moderate	14 T: 60.7 Moderate
Sleep Disturbance	14 T: 57.9 ▲ Mild Declining ↘	12 T: 54.3 Within normal limits	14 T: 57.9 Mild	14 T: 57.9 Mild	13 T: 56.1 Mild	13 T: 56.1 Mild
Ability to Participate in Social Roles and Activities	7 T: 35.7 ▼ Moderate Declining ↘	13 T: 46.2 Within normal limits	12 T: 44.2 Mild	13 T: 46.2 Within normal limits	4 T: 27.5 Severe	12 T: 44.2 Mild
Pain Interference	14 T: 63.8 ▲ Moderate Declining ↘	12 T: 61.2 Moderate	9 T: 57.1 Mild	13 T: 62.5 Moderate	15 T: 65.2 Moderate	14 T: 63.8 Moderate
Pain Intensity	7 T: 7 ▲	6	6	7	6	3

Survey Results

Physical Function

Are you able to do chores such as vacuuming or yard work?

17-04-2023 (This survey) [🔗](#)

With a little difficulty **Declining** ↘

10-05-2022

Without any difficulty

27-04-2022

With a little difficulty

29-03-2022

With a little difficulty

02-03-2022

Without any difficulty

01-02-2022

With much difficulty

Are you able to go up and down stairs at a normal pace?

17-04-2023 (This survey) [🔗](#)

With some difficulty **Declining** ↘

10-05-2022

Without any difficulty

27-04-2022

With some difficulty

29-03-2022

With some difficulty

02-03-2022

With a little difficulty

01-02-2022

Without any difficulty

Are you able to go for a walk of at least 15 minutes?

17-04-2023 (This survey) [🔗](#)

With a little difficulty **Stable** ↔

10-05-2022

With a little difficulty

27-04-2022

With some difficulty

29-03-2022

With a little difficulty

02-03-2022

With some difficulty

01-02-2022

With a little difficulty

Are you able to run errands and shop?

17-04-2023 (This survey) [🔗](#)

With a little difficulty **Improving** ↗

10-05-2022

With some difficulty

27-04-2022

With a little difficulty

29-03-2022

With much difficulty

02-03-2022

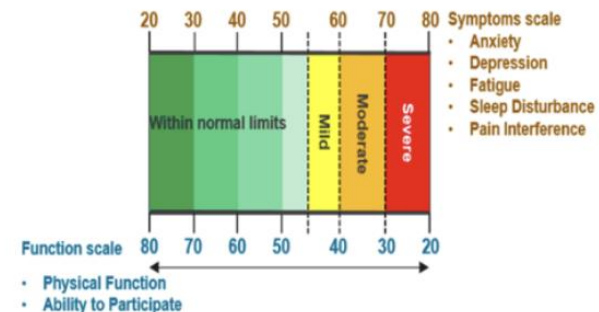
With much difficulty

01-02-2022

With some difficulty

Longitudinal Data

PROMIS-29 T Scores





Statewide Implementation

<p>Patient reported experience measures surveys completed</p> <p>7150</p>	<p>Patient reported outcomes measures surveys completed</p> <p>74683</p>	<p>Patients using HOPE</p> <p>32466</p>
<p>Clinicians using HOPE</p> <p>1454</p>	<p>Sites using HOPE</p> <p>604</p>	<p>Clinical areas using PRMs</p> <p>30+</p>

Current as at 9th October, 2023



Voices from the ground

*“When I was in my early thirties I suffered from depression and struggled to talk about it, having something like this may have been helpful and may have made me realise that it was ok to talk about” – **Wounds patient***

*“It was amazing to see how much I have improved given how sick I was.... It was helpful to be able to see my improvements in my answers as I could not specifically recall how I was when I began” – **Cardiac patient***

*“The majority of older people discharged from our facilities into TACP are telling us that their pain is poorly managed. We didn’t expect to hear that, but now we know we can work together to do something about it – **WNSWLHD CE***

*“Using HOPE in eMR has made things 10x easier for us, no double login or extra window open has been great” – **NSLHD clinician on HOPE in electronic Medical Record (eMR)***

*“I love it. It is so much quicker and I think it is great that everyone has read only access to see the patient's results” – **FWLHD clinician on HOPE in eMR***

*“We can tend to put clients into a box. Using PRMs, my client opened up and was talking quite a bit. We’re engaging our reaction with each question – if it’s about them, it’s not about us. It’s changing how we work with them” – **GP on use of PRMs***

Successes of PRMs in HOPE

- **Co-design** involved clinicians, patients and carers
- **One shared approach** across partner organisations
- **Integration** with electronic Medical Record (eMR)
- Patients are happy to **reflect on their experiences** and health outcomes
- Clinicians **value real-time data** and information
- **Accessible** for everyone (CALD, Aboriginal health)
- Clinicians and healthcare settings are **continuing to use HOPE**

A NSW Government website

HOPE - Clinician Portal

Blacktown Hospital R

Home Patient List Dashboards Reports My Library Help and FAQ Admin

Home / Clinical / Knowledge Base / Decision Support Guides

SEARCH

PROMIS-29 Decision Support Guide for Clinicians

This guide gives clinicians information about how to use and interpret results from the PROMIS-29 survey in HOPE.

Patient Reported Outcome Measures (PROMs) capture a patient's perspective about how the care they receive impacts their health and well-being.

Adding PROMs to your clinical practice can help your patients engage in conversations about their care and treatment decisions, and enable shared decision making. Shared decision making supports patients to make informed choices, and can increase their confidence, knowledge and ability to self-manage and avoid hospitalisations

The Patient Reported Outcomes Measurement Information System-29 (PROMIS-29) is a validated and reliable quality of life survey that assesses seven domains in 29 questions. The domains are:

1. depression
2. anxiety
3. physical function
4. pain interference
5. fatigue
6. sleep disturbance
7. ability to participate in social roles.

Respondents answer four questions in each domain, and an additional question on pain intensity. Most responses are provided using a 5-point rating scale.

Open the expandable boxes below for advice and suggestions.

+ How do I use PROMIS-29 with my patient?

+ How do I use T-scores?

Arabic العربية

简体中文 Chinese - Simplified

繁體中文 Chinese - Traditional

Greek ελληνικά

Italiano

한국어 Korean

Macedonian македонски

Српски Serbian

Español

Tiếng Việt Vietnamese

The implementation approach

ACI's partnership-based implementation approach includes:

- A **whole of system** governance model for the program, alongside local governance
- Working with **executive sponsors** and a patient-reported measures **lead or team at each site**
- A **risk register** completed by ACI and local program lead to triage and resolve issues
- Providing **education, training** and scene setting
- Education around **collecting, understanding and using data**
- **Engaging** with stakeholders and clear communication
- Using change **management principles**
- **Encouraging** participation in testing the HOPE portal at local sites
- Conducting **readiness assessments**
- A **go / no-go** decision made before go-live to ensure the site and staff are ready
- Support to build patient-reported measures into **business as usual**

Implementing at scale: challenges and enablers

Enablers:

- Investing in co-design
- Investing in people and process
- ‘What’s in it for me?’
- Real time data (reports/dashboards)
- Governance
- Executive sponsors and champions
- Readiness assessments
- Harmonisation
- Patients as partners

Challenges

- Changing cultures and norms
- Harmonisation
- Time consuming
- Managing expectations
- Assumptions of consumers inability to use technology
- Delivering at scale – workload
- Managing build cycles, implementation and co-design

Scaling at Pace



Process evaluation: Purpose and questions




Purpose: to track progress, and inform program improvement and investment decisions

Focus Areas for Improvement


 Targeted implementation integrated into Models of Care

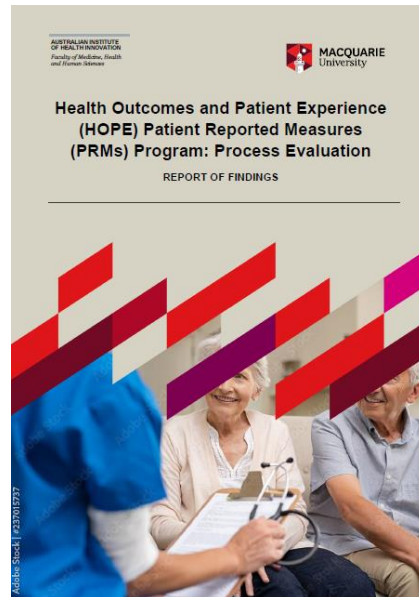
 Tailored methods for PRMs data capture

 Enhancing HOPE reports to support patient care

 Review of existing PREMs

 Clarifying and communicating scope

 Resourcing initial vs sustained implementation



Aaron Hall

Stream Lead, Patient Reported Measures | Agency for Clinical Innovation

Aaron.Hall@health.nsw.gov.au



AGENCY FOR
**CLINICAL
INNOVATION**

1 Reserve Rd
St Leonards NSW 2065

T + 61 2 9464 4666

F + 61 2 9464 4728

aci-info@health.nsw.gov.au

www.aci.health.nsw.gov.au