

# Aboriginal Health and Patient Reported Measures Stakeholder Engagement in South Australia

● Commission  
on Excellence  
and Innovation  
in Health.

I would like to acknowledge the Traditional Owners and Custodians of the land on which we meet today, the Peoples of the Kulin Nation, and I respect their spiritual relationship with their country.

I pay my respects to Elders past, present and emerging.

I would also like to acknowledge the importance of the voice of Aboriginal people in health care, not just within the PRM program, but throughout all aspects of our health system.



**Together, let's create  
better healthcare for  
South Australians.**

Commission  
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## Our vision for healthcare in South Australia:

Imagine a health system where people are truly at the centre. Imagine a health system where:

- Everyone has access to the latest evidence and data to make the best decisions
- Innovation is encouraged and it is safe to think big and try new things
- No task is done in isolation but instead achieved through partnership and collaboration.

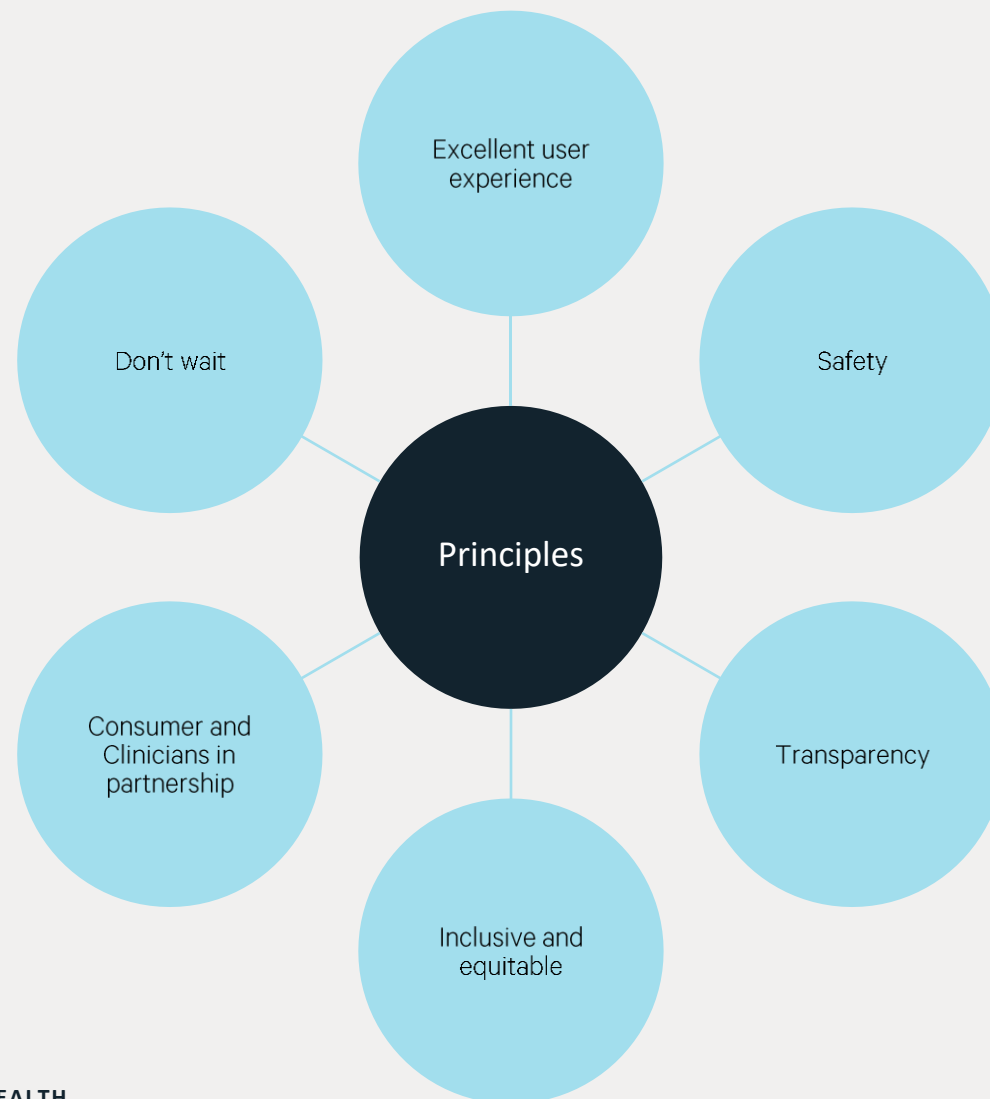
**Together, lets create better healthcare for South Australians.**

# Patient Reported Measures Program

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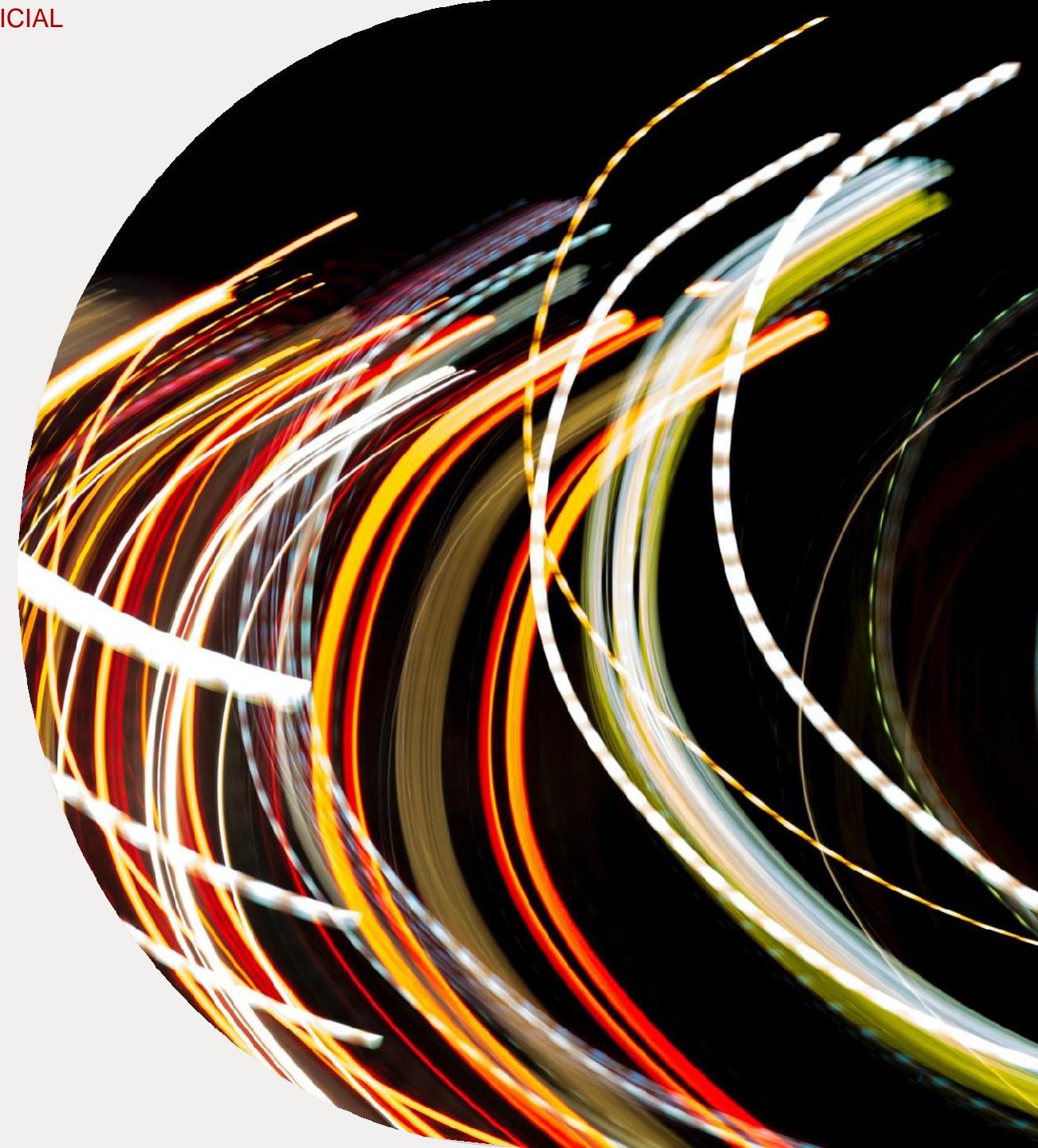


# PRM Program Principles



# PRM Program Vision

A health system that recognises patient reported outcomes and experiences as vital; where feedback is available in real time for clinical and consumer decision-making and information is used at health service and system levels to drive excellence and innovation



# Implementation Approach

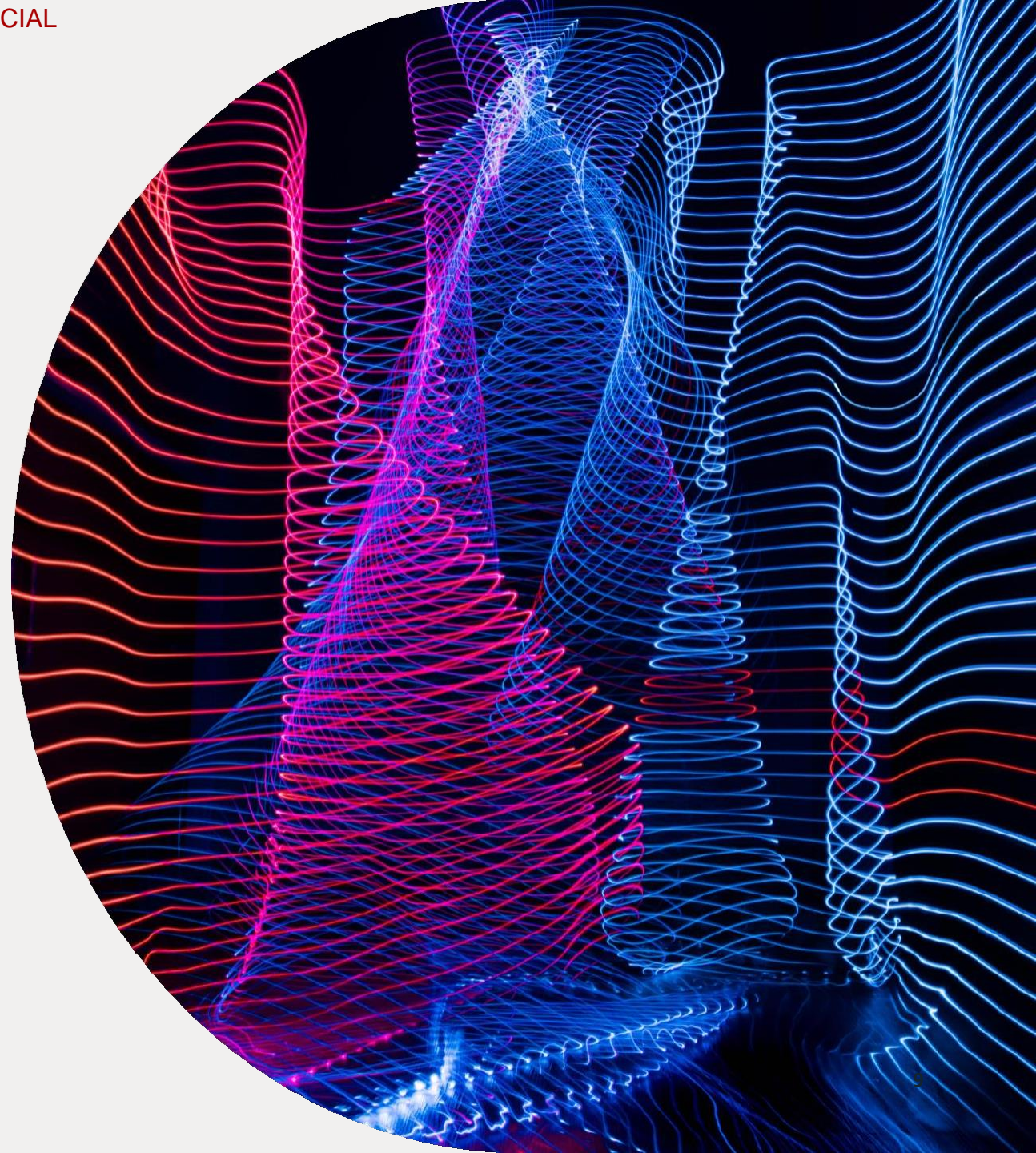
- Initial three year program across selected SA Health sites/services
- Staged implementations commencing 2023
- Work initially with services/sites already collecting PROMs or PREMs (Stage 1)
- Work with LHNs to identify in-scope services
- Use validated PRM instruments initially; then support clinical services to develop new measures if needed



# Patient Reported Measures (PRMs)

Patient Reported Outcome Measures (PROMs)

- Generic or Condition specific
- Assess quality of life, symptoms, functioning
- Usually repeated over time
- Data held as part of patients' medical record



# Patient Reported Measures (PRMs)

## Patient Reported Experience Measures (PREMs)

- Seek to understand a patients' experience with a health service
- Usually a single survey linked to an encounter
- Data is separate to medical records, often de-identified

## Patient experience

Patients who report better experiences also have better health outcomes

## Patient-reported outcomes

Measuring a patient's outcomes from their own perspective helps health services tailor care to their needs.

## Staff experience

Good staff experience translates to better patient experience and outcomes.

## Clinical outcomes

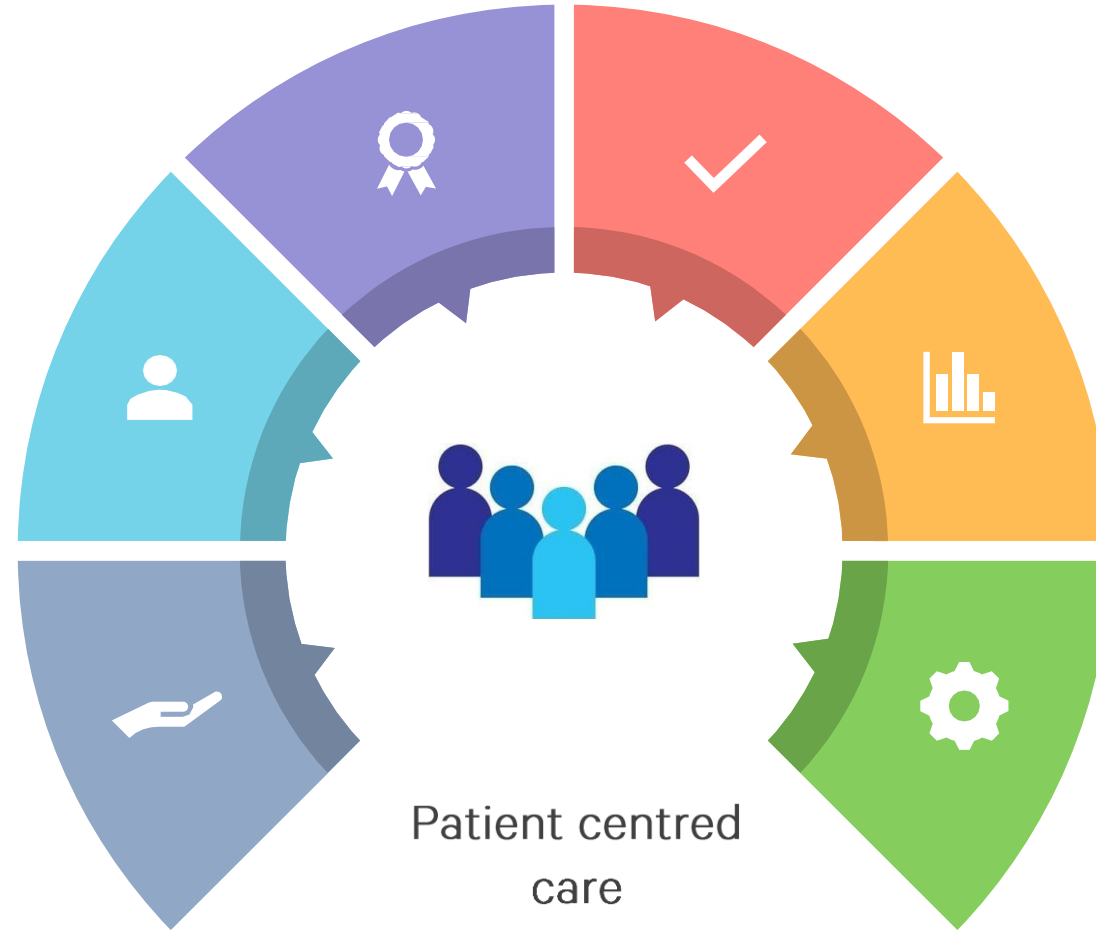
Measuring clinical changes in health is critical to informing decision-making and ongoing care and treatment.

## Value-based healthcare

Measuring health outcomes against the cost of delivery equals better care.

## Efficiency data

Data-driven decision-making for improved efficiency and better patient care.



Patient centred care

# Aboriginal Health Context

- Commission on Excellence and Innovation in Health.
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# Background



Reference: pg, 6. User Guide for Aboriginal and Torres Strait Islander Health, NSQHS Standards

- Few PRMs specifically developed or validated for use by Aboriginal peoples
- Culturally appropriate PRMs do not exist; or are currently under development
- PRMs provide health services with the opportunity to address the 6 actions of the NSQHS Standards

**Diagram 1: A Model of Social and Emotional Wellbeing<sup>16</sup>**

© Gee, Dudgeon, Schultz, Hart and Kelly, 2013

# Emerging Measures

## What Matters to Adults Wellbeing Measure<sup>1</sup>

Preference based-measure of wellbeing  
Considers individual preferences, culture and value systems

## Good Spirit, Good Life<sup>2</sup>

QoL tool for people aged over 45 years  
Measuring 12 factors of a “good life”  
(e.g., health, culture, Elder role, respect, Country, Spirituality...)

## Mayi Kuwayu Survey (MK-K5)<sup>3</sup>

Short-screen for psychological distress  
Modified version of K10  
Developed to be culturally sensitive

## VOICE<sup>4</sup>

Developing a PREM for Aboriginal and Torres Strait Islander people accessing primary health care

## References:

<sup>1</sup>Howard, K. et al., (2020). What Matters 2 Adults: a study protocol to develop a new preference-based wellbeing measure with Aboriginal and Torres Strait Islander adults (WM2Adults). *BMC Public Health*, 20 (1739)

<sup>2</sup>Smith, K. et al. (2020). Good Spirit, Good Life: A Quality of Life Tool and Framework for Older Aboriginal Peoples. *The Gerontologist*. V. 61 (5), e163 – e172.

<sup>3</sup>Brinckley, M-M., Calabria, B., Walker, J., Thurber, K., and Lovett, R. (2021). Reliability, validity, and clinical utility of a culturally modified Kessler scale (MK-K5) in the Aboriginal Torres Strait Islander population. *BMC Public Health*, 21:1111

<sup>4</sup>VOICE -Validating Outcomes by Including Consumer Experience. Developing a Patient Reported Experience Measure for Aboriginal and Torres Strait Islander people accessing primary health care, Passey M, Walke E, Bailie R, Matthews V, Department of Health (Federal)/MRFF - Indigenous Health Research Fund.

# Indigenous Data Sovereignty

The rights of Aboriginal peoples to govern the creation of data collections, ownership, definitions and application of their data.

Relevance for collection of PRMs:

- Who controls the data story?
- How data is used to evaluate the impact of programs and health care services
- Applying an Aboriginal lens to the design, use, interpretation, evaluation and dissemination of data



# Insights

## Measuring Consumer Experience Report – 2022

- Aboriginal consumers may be interviewed as part of the AHPEQS
- AHPEQS does not currently contain culturally appropriate or specific questions for Aboriginal consumers



**Reference:** SA Health, Aboriginal and Torres Strait Islander, Measuring Consumer Experience 2022 Snapshot

# Completed Engagement

- Department for Health and Wellbeing (DHW) Aboriginal Health
- Metropolitan LHNs – Northern Adelaide, Southern Adelaide, Central Adelaide and Women’s and Children’s Health Network
- Regional LHNs – Eyre and Far North, Limestone Coast, Riverland Mallee Coorong, Barossa Hills Fleurieu
- SA Aboriginal Chronic Disease Consortium (within SAHMRI)
- ACI (NSW Health)
  
- Engagement occurred in 2022

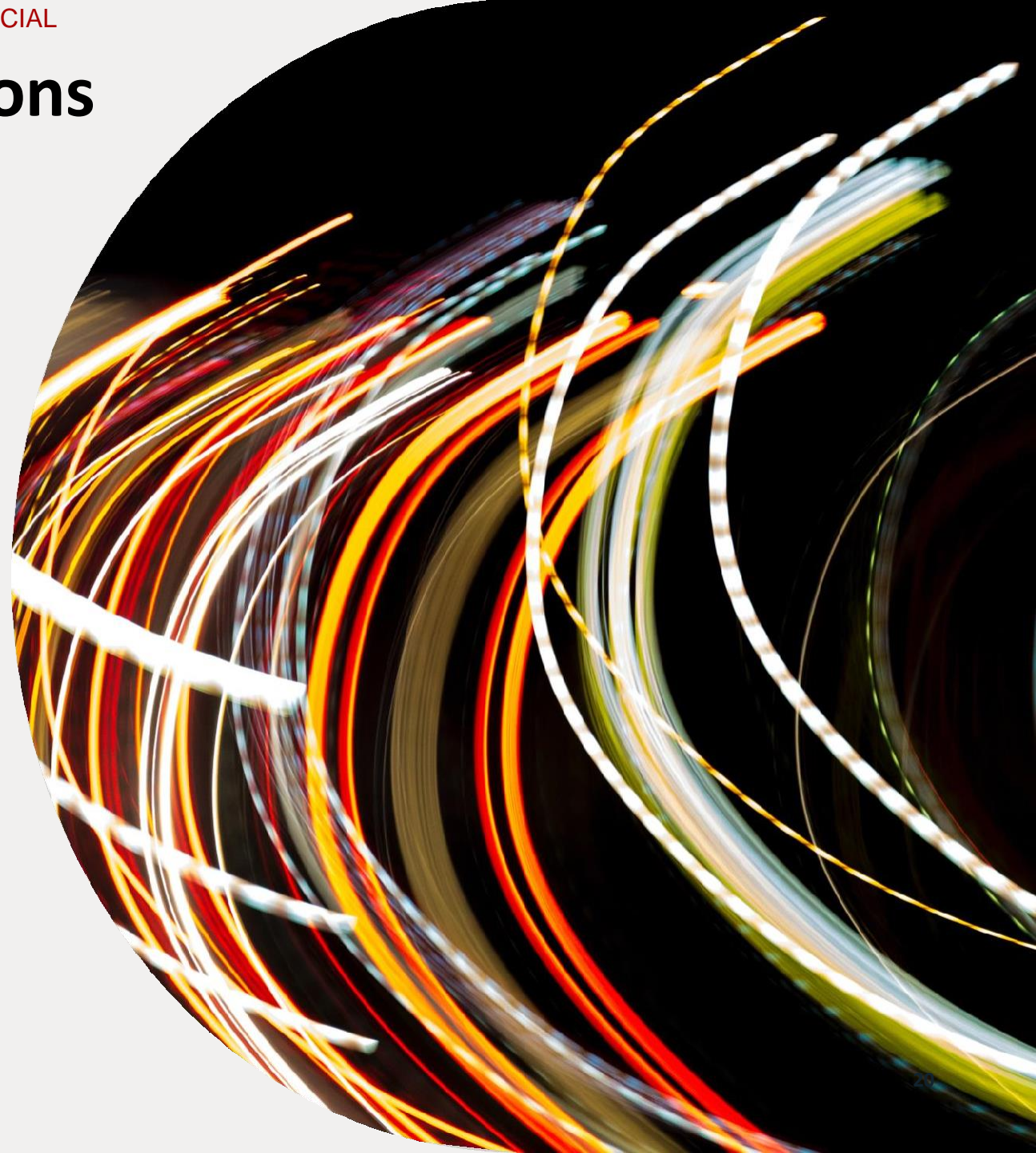




- Aimed to answer the following questions:
- What would the key measurement areas for PRMs be?
- What are the potential areas for community engagement?
- What are the recommendations for:
  - future engagement?
  - program/subcommittee governance?
  - language/translation options?

# Summary of Recommendations

- A need for a better way to capture the voice of Aboriginal peoples and the patient perspective of healthcare, including support for a culturally validated PREM, specifically for Aboriginal peoples, across the system
- Translation of PRMs and associated resources in Aboriginal languages, exploring and utilising a mix of methods
- Collecting PRMs in alignment with existing or planned priority programs, such as mental health, chronic disease and maternal and infant health





- Governance and development of an Aboriginal PRM Reference Group
- Recommended future engagements with additional stakeholders
- Importance of resourcing and training to ensure interpretation of PRMs data by non-Aboriginal staff is culturally appropriate

# Next Steps

- Ongoing aim: meaningful collaboration and partnerships with community
- Utilising co-design principles to best address local cultural context and health service needs



## Personal Learnings

- Indigenous Data Sovereignty Concepts
- Engagement takes time (and this is a good thing!)
- Consultation fatigue





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