

Patient Reported Measures Research Collaborative Workshop

16 September 2021

Commission
on Excellence
and Innovation
in Health.



**Health
TranslationSA**
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Workshop Summary

Figure 1. Snapshot of participant themes from Research Collaborative Workshop



Purpose

The purpose of this document is to provide a high-level summary of the Patient Reported Measures (PRMs) Research Collaborative Workshop.

Workshop

The Commission on Excellence and Innovation in Health (CEIH) and Health Translation SA (HTSA) are working to establish a PRMs Research Collaborative. A workshop was held virtually on 16 September 2021 and was attended by 80 participants. The aim of the workshop was to bring together consumers, and people across the health and research sectors to; discuss ideas to enable excellent partnerships and collaboration for PRMs research; and to capitalise on research opportunities to improve the quality and outcomes of the PRMs program and contribute to better patient outcomes.

Presentations

There were three presentations:

- **Jarrard O'Brien.** Executive Director, Human Centred Design and Innovation, CEIH. Jay provided an overview of the Statewide Patient Reported Measures Program.
- **Wendy Keech.** CEO, Health Translation SA. Wendy introduced the work of Health Translation SA and some examples of opportunities to improve translation of research into practice in SA.

- **Jarrard O'Brien**. Executive Director, Human Centred Design and Innovation, CEIH. Jay presented the vision and aims of the PRMs Research Collaborative and considerations to promote excellence in PRMs research in SA.

Why a PRMs Research Collaborative?

In 2022, the CEIH will be implementing a standardised approach to the systematic collection, analysis and reporting of PRMs to clinicians so that they are better equipped to provide patient-centred care. The **Statewide Patient Reported Measures Program** (PRM Program) will make PRMs results available during clinical encounters to enable patients and clinicians to make decisions together. Aggregated data will be available to use as a measure of service quality, and at a system level to drive excellence and innovation and inform value-based health care models.

The expertise in research teams should be integrated into the program. Researchers can work with clinicians, policy makers, consumers and the CEIH project team to support the translation of what we know into practice. Research expertise can be used to inform new methodologies, undertake additional research and evaluate outcomes. Hence, an opportunity to co-design and deliver alongside the program a **PRMs Research Collaborative**.

The Vision of the PRMs Research Collaborative is:

“ Together, let’s create an ecosystem around the Statewide PRMs Program that engages the experience and expertise of the South Australian research community to improve the quality and outcomes of the program while also building research collaborations that can contribute to better outcomes and experience for patients.”

Workshop Participation Sessions

The workshop brought together people from across the health and research sectors, to join a conversation on what would enable excellent partnerships and collaboration for PRMs research. The CEIH and Health Translation SA would consider the information provided and use it to inform the further development of the Research Collaborative and priorities.

Participants provided their input by working in small groups to answer to the following questions:

1. What are the barriers / enablers for partnerships (across research, health and community sectors) working effectively together on PRMs research?
2. What mechanisms will support the translation of PRMs research to improved patient outcomes and experience with measurable impact?

Workshop Participant Input

There were common themes across responses to the questions, providing key considerations in the promotion of excellence in PRMs research. The consolidated information has been interpreted as priorities and actions to and further support the development of the PRMs Research Collaborative.

1. Collaboration and Partnerships

Collaboration at many levels; between research, universities, clinicians, consumers and the community.

What we heard...

- Provide a central point to come together, connect and share ideas; a wayfinding place for clinicians and researchers.
- Leverage existing technology to communicate, integrate and share knowledge.
- Value and respect everyone’s contribution to PRMs research (e.g. clinician and consumer involvement).

- Remain consumer-centred and use co-design from the beginning; together create opportunities to improve patient outcomes and healthcare.
- Enable broad involvement, cross collaboration across sectors, and services and the continuum of care.

The priorities for PRMs Research Collaborative in the area of collaboration and partnerships are to:

- Promote opportunities that will foster partnership and collaboration in our health system, and support collaboration for greater benefit rather than promoting competition.
- Ensure broad and inclusive participation in the PRMs Research Collaborative, where all parties are valued for their knowledge and ideas.
- Ensure consumers are involved in the co-design of the PRMs Research Collaborative from the beginning.

2. Applied research in PRMs

Applied research that ensures clear line of sight to improved patient outcomes and alignment with key principles of the PRMs Program.

What we heard...

- There needs to be a consistent approach to how we collect PRMs data and use information in research.
- Focus on continuous improvement and finding solutions to identified problems.
- Measure only what matters, it needs to be fit for purpose.
- Ensure patient stories and the voice of the consumer is central; including carers and families, from younger people to older people, and representing culturally and linguistically diverse communities.
- Adopt a strategic approach to any new research and build strategic partnerships.
- We need a shared understanding of PRMs collection and usage across organisations for both clinical and research initiatives.

The priorities for the PRMs Research Collaborative in the area of applied research are to:

- Ensure the principles of the PRMs Program are maintained; that any new research must be applied research that clearly connects to improved patient outcomes that benefit the community.
- Strategically prioritise research; to guide selection of new projects and build the research portfolio.

3. Building capability and capacity

Enhance the capability and capacity of researchers to support health practice and drive improvements.

What we heard...

- Resourcing is required with people who have the right expertise to drive research forward; explore funding opportunities.
- Keep informed of what is happening locally and internationally in PRMs research; through knowledge sharing, networking, and working together.
- Build a 'toolbox' and take a skill building approach to support all aspects of research (e.g. from design to evaluation, interpretation of results, how to present and communicate information to various audiences), assisting clinicians to have access to the insights and data they need to provide the best care.

The priorities for the PRMs Research Collaborative in building capability and capacity are to:

- Enhance the capability of researchers to support the health practice and grow the evidence base by working collaboratively and sharing knowledge.

- Build capacity for and retain skilled PRMs research workforce by improving the training and education opportunities for both researchers and health professionals in the evaluation of health service delivery through research.

4. Research translation

Accelerate health system improvement with effective research translation, so learnings have greater potential for impact and improve health care delivery.

What we heard...

- Ensure research and continuous improvement activities are timely and “real-time”.
- An enabler for research translation in PRMs research would be accessibility to data and linkage of data; work to match and link data from multiple sources to reduce duplication.
- Communication and sharing of information in a way that people can easily understand; developing a common language.
- Increase the access to information and the outcomes of research, finding ways to share back into the community and to consumers.
- Leverage different funding models.
- Establish different interest groups.

The priorities for the PRMs Research Collaborative in the area of research translation are to:

- Accelerate health system innovation and improvements by maintaining that PRMs research must be clinically relevant with effective translation, measurable impact, and ability to improve health care delivery.
- Establish ways of connecting people and opportunities to align on clinical themes / projects.
- Communication of information is key to the timely and effective translation of evidence into practice.

5. Governance and Ethics

Effective governance and comply with standards for ethical research and practice, including privacy and sharing of information.

What we heard...

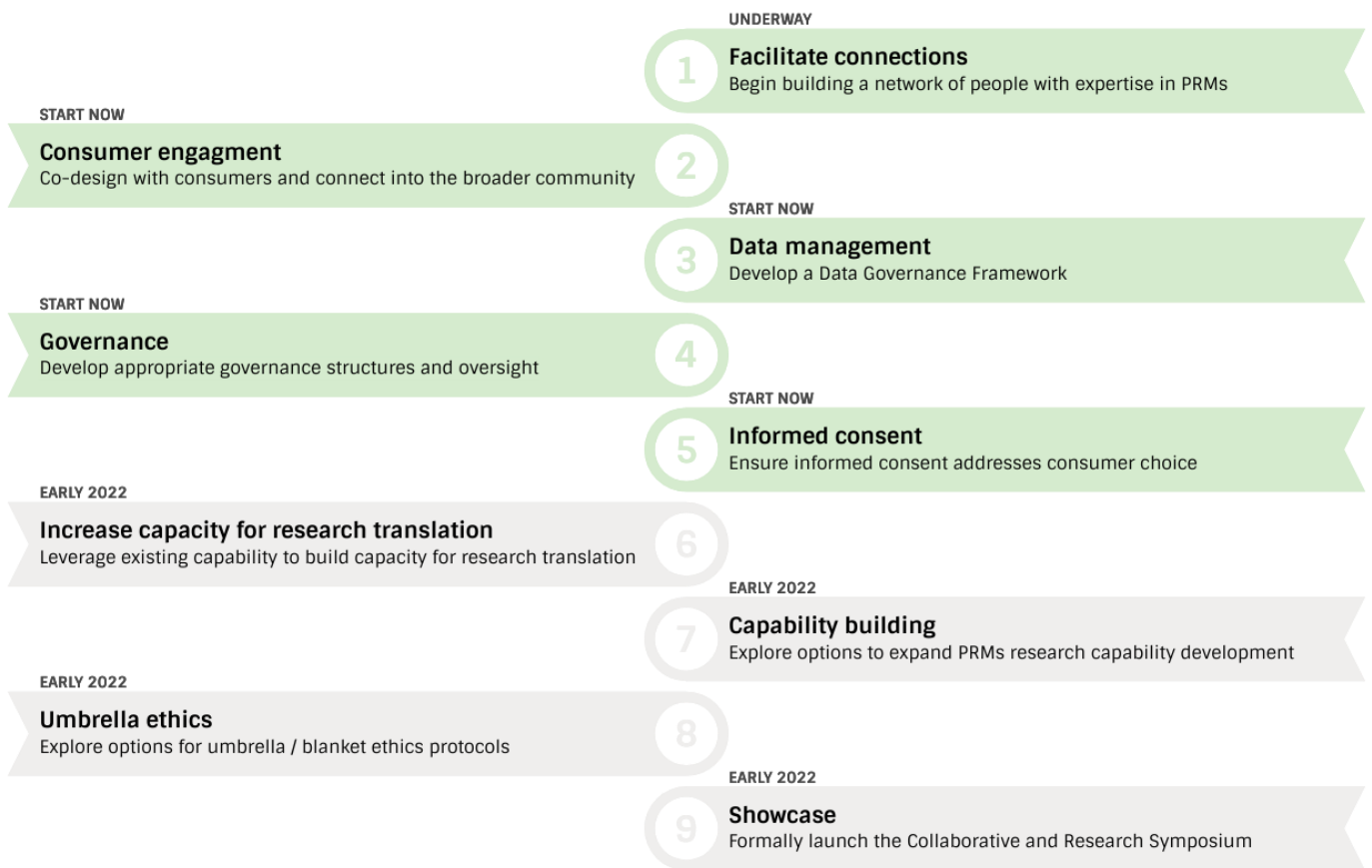
- Provide resources, guidance and support for ethics applications, including acknowledgement of diverse communities.
- Consider examples for overarching ethics across multiple sites.
- Clarity around data governance, ownership, storage, handling and access to data – who and how and why.
- Maintain appropriate standards for patient consent, privacy, and confidentiality, including options to opt-in/out of research.

The priorities for the PRMs Research Collaborative in the area of governance and ethics are to:

- Ensure informed consent, so that people can opt-in/out of sharing their information for research.
- Streamline ethics processes (if possible, at a Program level).
- Comply with the standards for ethical research and practice, including privacy and sharing of information.

Next steps

The CEIH and HTSA will work on the following actions:



Thank you

The PRMs team, CEIH and HTSA would like to thank everyone that gave up their time to come together and help inform the direction of PRMs Research Collaborative. We look forward to continuing to work with the consumer, health and research community in South Australia to improve care and patient outcomes.