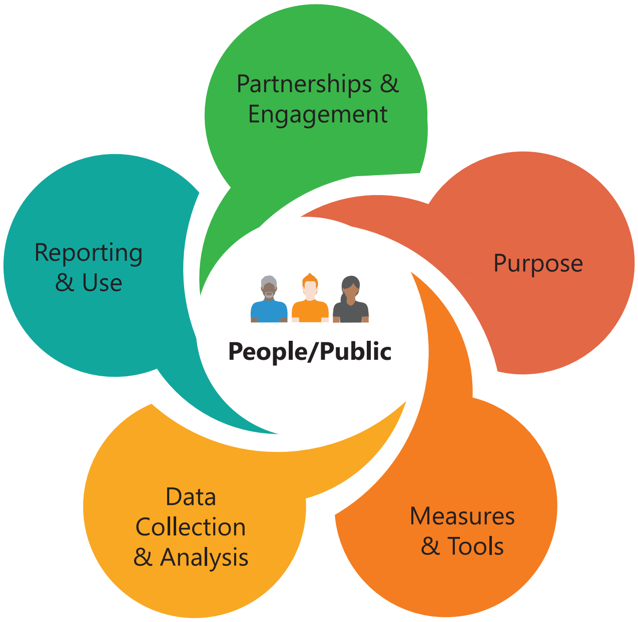
GEORGE & FAY YEE
Centre for Healthcare Innovation

Engaging People with Lived Experience in Patient-Reported Measurement Initiatives



A Resource to Support Health System Partners

PRMs use patient feedback to improve our health system

Patient-reported measures (PRMs), such as patient-reported outcome (PROMs) and patient-reported experience (PREMs), are standardized, validated questionnaires for collecting information directly from patients about whether the care we are providing is meeting their needs. PRM data provide timely feedback about outcomes and experiences that are important to patients and provide a structured and consistent method to capture and use patient feedback in real time.

Manitoba's patient-reported measurement strategy

The authors of the PRM strategy

The Provincial PRM Strategy is the result of a year-long collaboration led by the George & Fay Yee Centre for Healthcare Innovation (CHI), with input from CHI's Public and Patient Engagement Collaborative Partnership (PPECP), health care stakeholders, community members, and people with expertise collecting and using PRMs.

Purpose of the strategy

The strategy supports the collection, analysis, reporting and use of PRMs in Manitoba. It is the first step in a coordinated provincial approach where data are collected from patients and made readily available to guide continuous quality improvement, support clinician-patient decision making, and inform health transformation and policy decisions as part of a learning health system.

Purpose of this document

Engaging people with lived experience is a key component of our Provincial PRM strategy. The PPECP developed this resource to support our health system partners to engage patients and the public in PRM initiatives.

Why Engage People with Lived Experience

Engaging people with lived experience is a key component of our Provincial PRM strategy. The PPECP developed this resource to support our health system partners to engage patients and the public in PRM initiatives.

People with lived experience can provide valuable input

1. To achieve a shared understanding of the purpose for collecting PRM data
2. In the selection of PROMs and PREMs tools
    - Ensuring patience acceptance (e.g., cultural appropriateness, response burden, appropriate literacy level, and the real-world context in which people with lived experience and their families live, work, and play)
    - Striving for tools that are validated and available in multiple languages
    - Confirming that PRM content addresses health outcomes for experiences that are relevant to patients and captures these in a comprehensive and easy to understand matter
3. In the creation of data collection strategies
    - Providing input into data collection strategies such as paper-based or electronic questionnaires or the use of proxies or telephone surveys
    - Identifying barriers and contributing to solutions to ensure that voices traditionally marginalized are heard
    - Contributing to communication strategies to enhance participation and completion rates
4. In establishing reporting outcomes
    - Identifying potential barriers and contributing to developing solutions to ensure that results are reported in meaningful and appropriate ways
    - Ensuring results are reported using plain language prior to dissemination
    - Contributing to communications and KT strategies that will enhance the use of PRM data by clinicians, patients, and administrative and health systems leaders

PRMs require shared understanding and goals

Patient-reported data can be effectively used only where patients are willing and able to provide data. The routine collection of PRMs must, therefore, be carried out in ways that patients understand, are uncomplicated, and create value for patients.

Methods of Engagement

There are a range of methods and levels of engagement to choose from when working with public partners and people with lived experience. One method of engagement that is commonly used when developing a patient-reported measurement strategy is an **Advisory Group**.

Advisory Group

Advisory groups are a participatory method of engagement that involves regular meetings to help provide direction and advice for different aspects of the program. This might involve people with lived experience meeting regularly to provide specific input as a group, or see them participate within a larger Advisory Committee of partners. In either case, public participants must feel welcomed to the group, and be provided with a clear understanding of their role and the purpose of the group. Within Advisory Groups, the team can choose a participatory method to use to come to a consensus on decisions (Delphi process, participatory decision-making, etc.).

Understand and address barriers to participation

Depending on the sector of care in which you work, individuals with lived experience will be variably affected by their illness or condition, which may impact their ability to provide feedback. Some people have experienced significant and sometimes traumatizing life changes—managing chronic pain, a loss of mobility and physical functioning, a loss of status and livelihood, and a loss of trust are just a few examples. Furthermore, inclusivity means engaging people from a range of backgrounds, socioeconomic statuses, ethnicities, education levels, and more. The potential sensitivities and vulnerabilities present for those being engaged must be addressed and understood.

Strategies to use when facilitating advisory committees

- Use anti-oppressive and trauma-informed approaches. It is highly recommended for the research team to participate in critical reflexive practices in advance.
- Create safe spaces by i) setting ground rules for respectful communication and ii) offering a range of meeting locations, including video conferencing and options to meet in the community away from hospitals or clinics.
- Co-develop a shared set of expectation by creating a Terms of Reference for your advisory committee.
- Consider a committee size of between eight to twelve members. A committee of this size is large enough to offer a variety of ideas and expedriences, but also allows enough time for each member to contribute in a meaningful way. Facilitation of a larger group can make it challenging to come to a consensus and taxing for the members. Additionally, a group that is too small may not be representative of diverse experiences, making it difficult to accomplish goals.
- Adopt a strengths-based approach to group work that recognizes the strengths and expertise of participants using language that is non-judgemental, inclusive, and future-oriented. This approach may be especially important when engaging youth, people with lived experience of mental health or additictions, or immigrant, refugee, and/or newcomer populations.
- Recognize that not everyone will feel comfortable speaking up in a group or may require time to process information. Try i) using different participatory approaches, such as arts-based methods, to enhance engagement and participation, ii) creating opportunities to provide feedback through private messaging or email, or iii) leaving time for a roundtable or to circle back to quiet members during the meeting.
- Consider paying patient/public partners. Compensating patient partners for their time, insights, and contribution to the work recognizes the value of people's input and can increase the diversity of participants.
- Consider covering the expenses such as transportation costs, parking costs, caregiving, food and drinks, long-distance calling cards, tablets, internet access, etc. to help support people's ability to engage meaningfully. More information is available at www.chimb.ca/resources

When and Advisory Committee is not the best approach

Age, socioeconomic status, ability, health status, and spoken language represent some of the real barriers to participation on an advisory committee. It may be necessary to consider other approaches to engaging people with lived experience to ensure diverse and inclusive input. A description of other methods of engagement can be found here and within the resources below.

Additional resources

Learn more about patient and public engagement strategies.

- Methods of Engagement: The George & Fay Yee Centre for Healthcare Innovation (CHI)
- Patient Engagement Lunchtime Learning Series: CHI
- Introduction to Patient Engagement: An eight-part blog series by CHI
- Choosing Methods for Patient Engagement: Health Quality Ontario (HQO)
- Engagement Guiding Principles: Canadian Foundation for Healthcare Improvement
- A Toolkit for Applying Patient Engagement Principles and Practices: Health PEI

Advisory committees

- Best Practice Checklist for Chairing Meeting with Patient and Caregiver Advisors: HQO
- Creating an Effective Terms of Reference: HQO
- Working with Patient and Families and Advisors: Implementation Handbook: Agency for Healthcare Research and Quality

Consider whether to pay your patient and public partner

- A Decision Tool and things to think about when considering compensation: The Change Foundation
- Patient Engagement Budget Builder: CHI

Tools for engaging online

- Pre-Assessing Needs for Includes Online Patient Engagement: CHI