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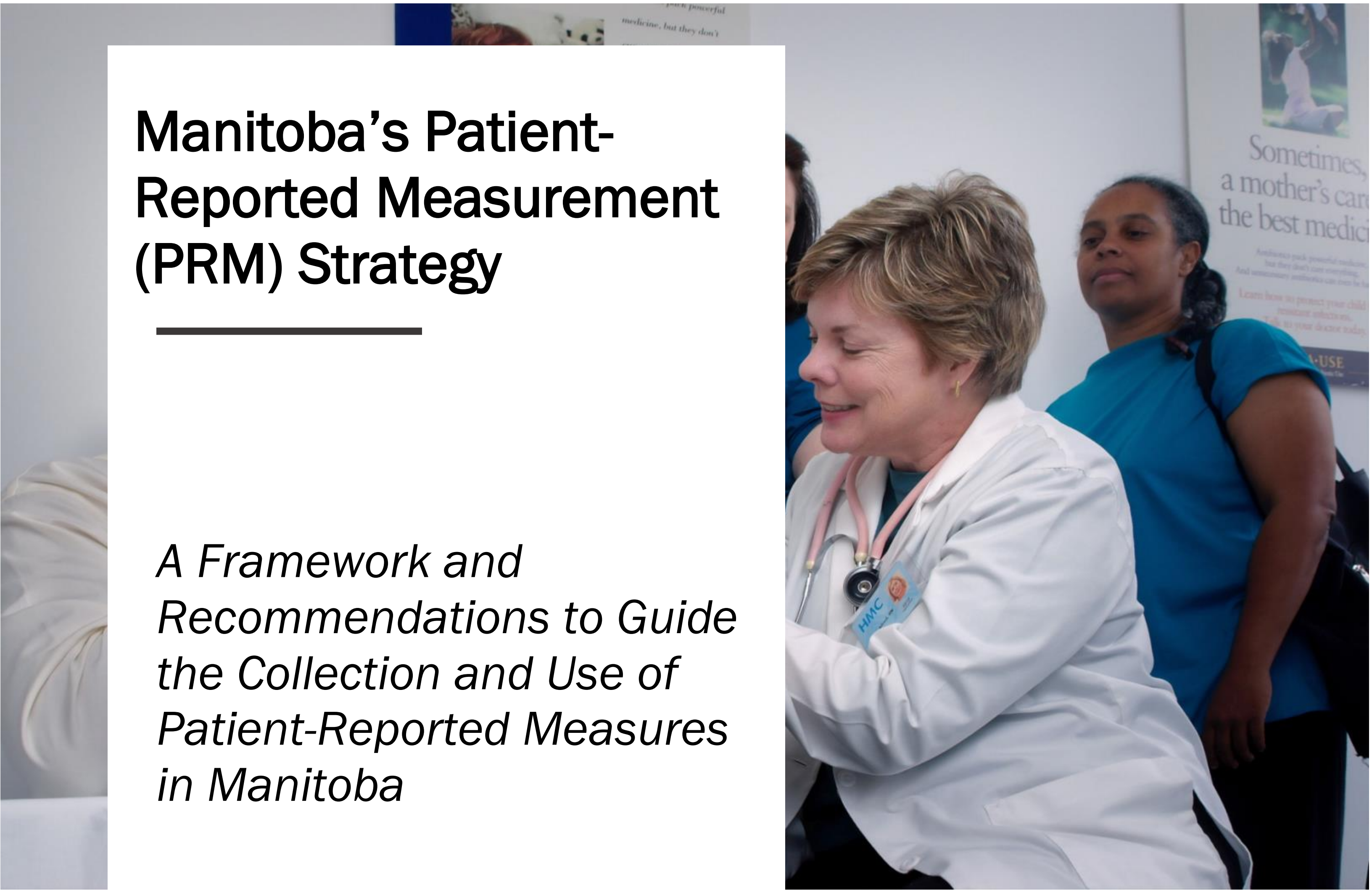

Manitoba's Patient-Reported Measurement (PRM) Strategy

A Framework and Recommendations to Guide the Collection and Use of Patient-Reported Measures in Manitoba

Version 1.0

Provincial Patient-Reported Measurement Advisory Committee

May 14, 2022

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Contributions

This document was developed by members of the Provincial Patient-Reported Measurement Strategy Advisory Committee. The committee was created in December 2019 and included health system leaders and policymakers, people with lived experience, clinicians, and researchers. Regular meetings over the course of one year culminated in the development of a conceptual framework and set of recommendations to facilitate the use of patient-reported measures (PRMs) in Manitoba. The Centre for Healthcare Innovation (CHI) would like to thank all the members of the committee for their input and guidance and their commitment to this work.

Committee Member	Affiliations	Title
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The framework and recommendations drew from resources developed and shared by the Canadian Institute for Health Information's PROMs and PREMs program and resources.

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Shared health
Soins communs
Manitoba

Foreword by Shared Health

Improving the health outcomes of patients, while providing a positive patient experience of care, reflects the very foundation of a healthcare delivery system and Shared Health is working diligently with our partners to do just that. We are working together to deliver a patient-centred, accessible, and responsive provincial health system that people can count on. We recognize that to achieve these objectives, we need to measure more than clinical outcomes and health system activities – we need information about the quality and outcomes of care from the patient's perspective.

Patient-reported outcome (PROMs) and experience measures (PREMs) are key components of patient-centred care. These data provide us with important information about how our healthcare system is performing from the perspective of the people accessing care.

We are pleased to share Manitoba's Patient-Reported Measurement (PRM) Strategy to support the broader use of PROMs and PREMs in order to enhance the delivery of high quality, patient-centred care in Manitoba. As we move forward with the implementation of Manitoba's Clinical and Preventive Services Plan, this data will be essential in measuring health service delivery improvements and overall health system performance.

We look forward to continued engagement with our partners across the health care system as we test the accompanying framework and implement the recommendations outlined in this strategy. While this won't happen overnight, we recognize this as an important first step in ensuring that the patient remains central to the way we deliver healthcare in Manitoba.

Dr. Brock Wright
Chief Executive Officer
Shared Health

Manitoba
Health and Seniors Care
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Foreword by Manitoba Health and Seniors Care

Manitoba Health and Seniors Care is committed to ensuring Manitoban's have access to a healthcare system that provides safe, efficient, affordable and sustainable services. To support these efforts and to create a patient-centred health data environment, we are embarking on a strategy to integrate our many data sources to create one provincial integrated data repository.

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), add an important dimension to our provincial data sets by providing information from the perspective of patients. They provide us the information we need to better match service delivery with needs of patients. PROMS/PREMS further allows Manitoba to make service and resource allocation decisions aimed at achieving health outcomes that matter to patients.

The Provincial Patient-Reported Measurement Strategy is an important first step to enhance the collecting of patient-reported measures (PRMs) in Manitoba. The ultimate measure of our success however, will not be in simply collecting PRMs but how we use this information to advance health system goals.

To support this effort, and our movement toward a provincial integrated data platform, we are collaboratively leading a series of demonstration projects to document and evaluate the application of an integrated health data platform, augmented with PRMs, to support a patient-centred learning health system. Through MindSet (Manitoba INtegrated Data Set), a partnership between the Manitoba Health and Seniors Care, clinician-scientists, and patients, we are launching three high priority projects to demonstrate the innovative capability and ultimate utility of collecting PRMs as part of an integrated data platform. Our eventual aim is to transform how Manitoba uses health data to inform decision-making and ensure the patient's voice is central to the way we measure health outcomes in Manitoba.

Manitoba Health and Seniors Care is a proud partner in the development of our Provincial Patient-Reported Measurement Strategy. We look forward to working with the implementation team to create the integrated data solutions necessary to enable the province-wide collection and use of patient-reported measures to better understand relevant health outcomes and optimize future system investments in Manitoba.

Sincerely,

Dan Skwarchuk, CPA, CGA
Assistant Deputy Minister and
Chief Financial Officer

GEORGE & FAY YEE
Centre for Healthcare Innovation

Foreword by the George & Fay Yee Centre for Healthcare Innovation

The George and Fay Yee Centre for Healthcare Innovation (CHI) supports and promotes patient-oriented research as an integral part of a responsive, learning health system. As Manitoba's Support for Patient-Oriented Research (SPOR) SUPPORT Unit, we engage with patients every day, knowing they are best positioned to determine the health outcomes and experiences that matter most to patients. Working together, we gather input that builds a more informed and accountable healthcare system for Manitobans.

CHI is pleased to lead Manitoba's Patient-Reported Measurement (PRM) Strategy to advance the use of patient-reported outcome and experience measures (PROMs and PREMs) across the healthcare system. In partnership with Manitoba Health and Seniors Care, as well as Shared Health, we have been working with healthcare professionals and people with lived experience to develop a framework and key recommendations to support the collection, analysis, reporting, and use of PRMs across the province. As we continue our journey of health system transformation, PRMs offer an essential means for incorporating patient, family, and caregiver feedback directly into the way we deliver care and how we measure the performance of our health system.

CHI is committed to supporting the PRM Strategy through expertise within our organization and through the development of tools and resources, partner engagement and pilot projects. We had the privilege of co-developing the patient engagement component of this strategy alongside CHI's Public and Patient Engagement Collaborative Partnership, and they will continue to be involved in the development of resources to support patient engagement and implementation efforts.

CHI is partnering on large, system-wide projects such as Manitoba's Integrated Data Set (MindSet) to pilot the implementation of PRMs in Manitoba's healthcare system. Projects like these will provide an important testing ground to resolve methodological and implementation challenges. Further, they will allow us to demonstrate how PRMs, when linked with other data sets, can facilitate the systematic inclusion of patient-reported data into health system measurement.

We look forward to building partnerships with patients, caregivers, health care providers and system leaders as we work together to implement this strategy and improve patient care in Manitoba.

CLeggett

Dr. Terry Klassen
Scientific Director
George & Fay Yee Centre for Healthcare Innovation

Carly Leggett
Interim Executive Director
George & Fay Yee Centre for Healthcare Innovation

Summary and Key Recommendations

Balancing the optimal use of health care resources while providing high-quality, patient-centred care, is a top priority of Manitoba's health system transformation[1]. To achieve this, we need to understand whether our health care services are providing value to patients. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are key metrics of patient-centred care that complement other health data with information about how our healthcare system is performing from the perspective of those who use it.

Developed in collaboration with partners across the healthcare system, this document presents a framework and recommendations to guide the collection, analysis, reporting, and use of PROMs and PREMs 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 system policy decisions as part of a learning health system.

Key Recommendations

Partnerships & Engagement

- Engage people with lived experience at every stage of PRM initiatives.
- Involve a multidisciplinary team early and in all stages of PRM initiatives.

Manitoba's PRM Framework

Purpose

- At the start of a project, establish the purpose and objectives for collecting PRMs, the setting where they will be collected, the patient population to which they will apply, and their characteristics.

Measures & Tools

- Choose specific PRMs that demonstrate appropriate measurement properties and meet the needs of patients and providers. Selection should be guided by the literature and the Provincial Checklist for Patient-Reported Measurement Selection.
- Where possible, use the EQ-5D-5L to collect generic PROMs because the EQ-5D is widely used in other healthcare systems and will allow comparisons across health sectors provincially and nationally.
- Use both generic and condition-specific PROMs together whenever possible, as they provide complementary information.

Data Collection & Analysis

- Where possible, use electronic data collection tools that integrate with electronic medical records and provincial data assets for the collection of patient-reported data to ensure an efficient and sustainable provincial approach.
- Prior to collecting PRM data, provide patients with a simple statement in their language of choice that describes how their data will be used.
- Prior to data collection, consider the clinical context and the resources available at each data collection occasion. Use a census-based approach whenever possible. If using a sample-based approach, consult a biostatistician.
- Include data linkage with provincial clinical and administrative databases in both the data collection and analysis plans. The suggested minimum data set (Appendix F) for collecting PRMs in Manitoba and the accompanying data dictionary (Appendix G) will support linkage with provincial databases.

Reporting & Use

- In the planning phases, create reporting strategies that reflect the input and experience of a multidisciplinary team, including people with lived experience. Provide clarity and guidance around how to interpret the results.
- Plan tailored knowledge translation and dissemination strategies that communicate the results of PRM data to health care providers, patients, health system leaders and policy makers in ways that are understandable, encourage uptake, and are in keeping with the stated purpose and objectives.

Next Steps

By building on our strengths, local expertise, and partnerships, Manitoba can increase the use of PRM data to improve patient-centred care. Our immediate focus will be on developing infrastructure and training opportunities to address methodological and operational challenges. In addition, we will focus on demonstrating the feasibility and value of PRM data to inform health system decisions through pilot projects where we will identify methodological and implementation challenges that will inform a future and comprehensive approach.

Immediate Next Steps (2021 – 2024):

1. Create a provincial implementation team to share PRM implementation experience and help set priorities for implementation across the healthcare system.

2. Build system wide PREM capacity through partnerships with teams currently exploring PREM collection and use.

3. Establish a province-wide, digital data collection platform that is interoperable within and between provincial health data systems.

4. Demonstrate the value of PRMs to support clinical care decisions, continuous quality improvement, and the evaluation of health care services by pilot testing PRM collection and reporting through project currently underway within the health system.

5. Build on and support established PRM processes to improve methodological and province-wide implementation challenges and to demonstrate utility and feasibility.

6. Develop resources and training opportunities to address implementation challenges and support the interpretation of PRM data.

Background

Patient-centred care[a] is a key priority of Manitoba's health system transformation, the fundamental goals of which are to improve the quality, accessibility and efficiency of health care services across Manitoba[1]. The Manitoba Quality and Learning Framework (MQLF) was created to guide these transformation efforts[2]. The framework embodies the attributes of high performing health systems and aligns with the Institute for Healthcare Improvement's quadruple aim objectives:[3]

- Improving the patient experience of care (including quality and satisfaction)
- Improving the health of populations
- Reducing the per capita cost
- Improving the work life of health care providers[4]

The quadruple aim provides a guide to health system quality improvement, recognizing that while we strive to make improvements in one area, we must not regress in others - a concept that is fundamentally important as we move toward improving the performance of our healthcare system[5]. For example, improvements in the efficiency of health care delivery must not negatively impact patients' experience, satisfaction, or quality of care. Routine collection of information in all four of these areas is therefore required to ensure that our transformation efforts are indeed leading to improvements.

To support our health system transformation goals, MHSC is implementing a Provincial Information Management and Analytics shared service to operationalize the creation and integration of a provincial health data platform to support "timely, accurate and relevant information as well as innovative analysis"[6,p15]. By linking our extensive, clinical, and administrative data sources, such a platform will significantly improve our ability to measure transformation efforts, and to support broader health system planning, quality improvement, funding, policy development, performance management, and operations at provincial, regional, and local levels. An integrated provincial data platform will provide us with clinical health data such as medical and surgical outcomes, wait times, adherence to standards of care, hospital-acquired infections, and patient adverse events related to drugs or devices. While meaningful, these types of health data will importantly *not* provide indicators of how the healthcare system is performing from the perspective of the patient. Understanding whether our health care services are impacting patients' health status and quality of life is an essential component of patient-centred care. To meet the goals of health system transformation, we must collect data that are relevant, actionable, and correspond to what matters most to patients.

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[a] Patient-centred care refers to an approach where the patient's specific health needs and desired health outcomes are the driving force behind the health care decisions and quality measures

Patient-Reported Measurement (PRM) Tools

Health outcomes are conventionally measured from a clinical and health care provider perspective. Was the treatment a success? Has the wound healed? Are laboratory indicators within the desired range? At a systems level, efforts to measure health outcomes that are a result of the health services we deliver currently either focus on utilization metrics such as number of doctors' visits and prescriptions filled or rely on the measurement of adverse outcomes such as hospital readmission rate, hospital-acquired infections, or length of stay. These metrics, while important, do not measure all that is important to the patient. Did the treatment achieve the goals I hoped for? Was my health care encounter respectful? Can I function optimally at work and in my personal life? These are referred to as patient-reported measures (PRM) and they move beyond using system utilization and adverse events to provide uniquely patient-centred information about whether the care we are providing is meeting the needs of those who use our health system[7]. Measuring patients' perceptions of their outcomes and experience of care can be achieved using patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). PROMs and PREMs are standardized, validated questionnaires for collecting information directly from patients without interpretation from a health care provider or anyone else[7,8].

Patient-Reported Experience Measures (PREMs)

Patient-reported experience measures are tools that ask patients to provide information about their experience of receiving health care. They are focused on questions related to service delivery and processes of care, such as cleanliness of waiting rooms, bedside manner, or whether a patient feels they were adequately involved in important care decisions[8,9]. They are primarily used to measure and monitor service quality[9].

Patient-Reported Outcome Measures (PROMs)

Patient-reported outcome measures ask patients to provide information about aspects of their health (e.g. symptoms; function; physical, mental, or social health) that are relevant to their quality of life and provide insight into the effectiveness of care from the patients' perspective[7]. They can be designed to assess general health-related quality of life, or they can solicit information specific to a particular condition or disease.

> **Generic PROMs** ask general questions about the well-being of a patient. They allow comparisons within and between disease states and sectors of care. They can be used for comparisons with reference to population norms and generally produce utility scores that can be leveraged in cost-effectiveness analyses. While they facilitate comparisons across different patient populations, they are less sensitive to health outcomes that are pertinent to a specific disease, disability or intervention[7].

Condition-specific PROMs ask questions that are specific to a particular disease or sector of care. They are more sensitive to change over time and differences between groups of people who have the same condition. They generally do not produce utility scores and do not facilitate the comparison of health outcomes with those of the general population or across different clinical conditions[7,8].

Because generic and condition-specific PROMs provide complementary information, it is recommended that they are used together.

How are Patient-Reported Measures Used?

Internationally, PRMs are used variably to evaluate health care effectiveness from the individual to the service and health systems levels[7,9-11].

It is widely recognized that PROMs and PREMs are essential components of measuring patient-centred care, that patients' are the best judges of the impact of treatment on their health status and quality of life, and that the systematic collection of PRMs provide important information to support quality improvement efforts[7,9,12]. Despite this understanding, routine collection of PRMs at the health system level is established in only a few parts of the world. The National Health Service (NHS) in the United Kingdom (UK) is the most advanced in implementing PROMs at a national level, followed by Sweden, the Netherlands, and parts of the United States of America[9].

Individual Patient Level (Micro)

At the individual level, PROMs data can be used to enhance patient-provider communication, informing the care pathway for patients and encouraging shared decision making[7,9,11]. For example, at the Pan Am Clinic in Winnipeg, PROMs data are used to support clinical decision-making and to support communication between the surgeon and patient (Appendix A). In the UK PROMs have been regularly collected since 2009 for certain surgeries to support health services evaluation and to inform patient treatment choices[13]. Patient-reported measures are also used within the NHS's Outcomes Framework to enhance the quality of life for people and maximize health care experiences for patients with chronic conditions[7].

Health Service Level (Meso)

At this level, aggregate PRM data can be used to guide quality improvement efforts for outcomes as well as patient safety[11]. When linked with traditional, clinical-based outcomes, these data provide a more comprehensive understanding of outcomes and effectiveness[7] and can be used to identify gaps in care, evaluate health programs, assess and monitor outcomes of a group of patients over time, and evaluate the impact of health care services. This level of data provides valuable patient-centred information to help measure our provincially targeted practice improvement projects by helping us understand the impact of redesign initiatives from the perspective of patients[5].

Health System Level (Macro)

At the health systems level, PRM data can be used to help decision-makers establish and evaluate policies meant to benefit a given population[9]. This includes comparing outcomes over time, locally, regionally and provincially; informing quality improvement activities at a system level, such as adherence to clinical guidelines; and comparing performance measurement across organizations[7]. Aggregate PRM data, therefore, provides important information to support evaluations of the impact of health system transformation changes. PROMs data can also be used to support "value-based care," – making service and resource allocation decisions to achieve health outcomes that matter to patients[14].

The Use of Patient-Reported Measures in Canada

In Canada, the collection of PROMs and PREMs has been identified as a health system policy imperative by the Canadian Institute of Health Information (CIHI) providing national leadership in facilitating a standardized approach to collection and reporting [12]. In 2013, CIHI developed the first ever pan-Canadian patient experiences survey for inpatient care (CPES-IC). The CPES-IC is a standardized survey patients use to provide feedback about the quality of care they received during their most recent stay in a Canadian acute care hospital. These data are collected within CIHI's Canadian Patient Experience Reporting System (CPERS) and can support quality improvement efforts, as well as provide a platform for national comparisons and benchmarking for the measurement of patient experience[15].

In 2016, CIHI hosted a pan-Canadian PROMs forum and formed a National PROMs Advisory Committee. At the forum, hip and knee replacement, and chronic renal care were identified as priority areas for initial PROMs collection and reporting. As a consequence of the forum, PROMs data collection standards have been developed to support PROMs collection in hip and knee arthroplasty[16].

With some exceptions, PRMs are not yet typically collected as part of routine clinical practice within Canadian provinces[5]. It is, nonetheless, largely recognized that PRM data are a central part of health system measurement[10,12]. Several examples of provincial commitments to the systematic collection and use of PRM data exist. For example, in British Columbia, the measurement of PROMs and PREMs is a provincial strategic objective and efforts are in place to implement a provincially coordinated approach to collecting and reporting PRM data[17]. The Alberta PROMs and EQ-5D Research and Support Unit provides support and guidance for the use of PROMs in Alberta in order to enhance their use within the province. In 2016, Health Quality Ontario and the Local Health Integration Networks launched the provincial Ontario Patient Experience Measurement Strategy aimed at improving the measurement of patient experience across the health system.

PROMs are a central component of value-based healthcare, an approach that strives to achieve the best possible health outcomes or the best possible care at the lowest cost. It focuses on achieving health outcomes that matter to patients relative to the cost of achieving those outcomes[14]. As the concept of value-based healthcare grows in Canada, the ability to measure and act upon PROMs will become paramount[18].

The Use of Patient-Reported Measures in Manitoba

In Manitoba, PROMs and PREMs are predominantly collected and used to support independent research projects; the systematic collection and use of PRMs for health system performance and quality improvement is in the early stages of development and consideration.

The Manitoba Joint Replacement Registry and the CPES-IC are two notable exceptions where PROMs and PREMs data respectively, are routinely collected and used. In the Manitoba Joint Replacement Registry, generic (EQ-5D-5L) and specific (Oxford Hip/Knee Score) PROMs data are routinely collected pre-operatively and one year post-operatively and are used for clinical decision-making, quality monitoring, and research[19]. For example, PROM's data are incorporated into individual surgeons' performance reviews along with intraoperative information related to diagnoses, surgical techniques and implant details, and patient self-reported data about complications and satisfaction. The results of this audit and feedback process have led to improved outcomes for patients and improved patient satisfaction rates[19]. They have also led to a decrease in resource utilization, including a decrease in transfusion rates, length of stay, complications, and revision rates[19].

Manitoba was one of the first provinces in Canada to start routinely collecting PREMs data, beginning in 2013 through the implementation of the CPES-IC. The CPES-IC is mailed out to a cross sectional, random sample of patients who received inpatient care in hospitals across Manitoba. Data are reviewed quarterly in the Winnipeg Regional Health Authority to support quality improvement efforts. Province-wide data will be available to view in 2022, through the CPES tool for hospitals.

Appendix A provides a summary of provincial and site-specific PROMs and PREMs initiatives in Manitoba.

A Vision for Manitoba

In December 2019, the George and Fay Yee Centre for Healthcare Innovation (CHI) formed the Provincial Patient-Reported Measurement Strategy Advisory Committee with the aim of developing a vision and framework to guide the collection and use of patient-reported data to enhance the delivery of high-quality, patient-centred care in Manitoba. The Manitoba Quality and Learning Framework (MQLF) served as the foundation for this work. The experience of other jurisdictions informed the recommendations. The framework and recommendations were developed iteratively over the course of a year with input from CHI's Public and Patient Engagement Collaborative Partnership, health care stakeholders, community members, and people with expertise collecting and using PRMs. The framework and recommendations developed will serve to guide the collection, analysis, reporting, and use of PRMs in Manitoba. It is the first step in developing 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. With this vision in place, and a framework established, it is therefore critically important that health care providers, patients, and people with lived experience work together to collaboratively design, implement, and use of patient-reported data.

A Framework and Recommendations to Guide the Collection and Use of Patient-Reported Measures in Manitoba

Figure 1: Conceptual Framework for Collecting & Using PRMs in Manitoba

Partnerships and Engagement

The implementation of PRM initiatives is inherently a multidisciplinary endeavor that requires input and advice from a range of health care professionals, researchers, information technology experts, biostatisticians, communications consultants, patients, and individuals with lived experience [11,20-22]. Sufficiently diverse patient and provider input will contribute unique expertise and experiences that will provide both population and disease-specific content and cultural context when selecting PRM tools. For example, the early inclusion of methodologic and statistical experts will ensure the data collected can be appropriately analyzed according to the intended purpose. Data collection strategies might be enhanced by input from nurses and clerks who are often involved in collecting data from patients. Information technology experts are required to support electronic data collection strategies, and knowledge translation (KT) experts can inform strategies that enhance the dissemination and uptake of PRM data[9,23].

Engaging People with Lived Experience

Patients and people with lived experience, including caregivers and family members, are key partners in successful PROMs and PREMs initiatives world-wide[9,20]. Involving people who have lived with a particular health condition informs our understanding of its day-to-day impact and effects on quality of life. These individuals bring a unique perspective and knowledge to the planning table.

Patient-reported data can be effectively utilized only if patients are first 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.

Instances where people with lived experience can provide valuable input include

1. Developing a shared understanding of the purpose for collecting PRM data

2. Selecting PROMs and PREMs tools
    - Ensuring patient 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 or experiences that are relevant to patients and captures these in a comprehensive and understandable manner

3. Creating 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. 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

Appendix B provides guidelines and resources for engaging people with lived experience. Additional information can be found here, or by contacting us.

Purpose

Patient-reported measures have value across the healthcare system from the individual patient level to the health system level [9,11,21]. For example, PRMs can be used to enhance individual care in a clinical setting, or they can be aggregated to make decisions about the quality of care provided within a health system[7]. Understanding why PRM data are being collected and how these data will be used is a fundamental first step that will guide all subsequent decisions, including the selection of PRM tools; the timing, frequency, and mode of data collection; data analysis; and how data will be reported and used[7,11,21]. Understanding each partners' motivation for using PRM data can enhance implementation and encourage buy-in[21].

Table 1 itemizes the various ways PRM data can add value to a healthcare system, from the individual patient to the health service and health system level. Ideally, PRMs will be systematically collected and stored within Manitoba's provincial data repository to support measurement across our healthcare system. To reach this goal, we must first build the foundation by starting with smaller, focused initiatives that allow us to develop operational strategies and address implementation challenges.

Table 1: Value of Patient-Reported Measures to Healthcare Users[7,9,11,20]

Level of Use	PRM User	Shared Value of PRMs
Individual Patient Level (Micro)	Patients Health Care Providers	• Enhance patient-provider communication • Provide opportunity for patients to provide direct feedback about whether treatment is delivering satisfactory outcomes • Create an opportunity for people to provide direct feedback about their experience with care • Inform clinician performance comparisons • Support shared decision-making and patient-centred care • Advise patients of expected quality of life outcomes, helping patients decide on the optimal treatment for them
Health Service Level (Meso)	Healthcare Institutions	• Support quality and safety improvements; monitor aggregate patient outcomes and experiences to compare against best practices and other benchmarks to identify areas for improvement
Health System Level (Macro)	Health system Policymakers	• Support health services' resource allocation decisions and optimize health care value by measuring

	Funders Health System Managers	outcomes relative to costs and utilization (value-based care) • Facilitate improvements in population health by identifying disparities and allocating resources accordingly • Compare outcomes over time, locally, regionally, provincially, or between regions or geo-political boundaries • Inform quality improvement activities at a system level, such as adherence to clinical guidelines or performance measurement across organizations

Measures and Tools

There are several factors that will affect the selection of PRMs depending on their purpose. For example, if the objective of collecting PRMs is to influence individual patient care, then a PROM that is acceptable, meaningful, and sufficiently sensitive to treatment effects must be selected. While providing important insights into general aspects of health, a generic PROM, such as the EQ-5D-5L, SF-36 or HUI-3, will not be sensitive enough to assess changes related to a specific condition or disease. However, if the objective is to measure the impact of changes to the delivery of health services, then a PREM may be the optimal tool. PROMs and PREMs can be complementary and are sometimes used together to measure both the patients' perceptions of the outcome and process of their care[12,24].

There are currently hundreds of validated PROM and PREM tools available for use around the world. The Patient-Reported Outcome and Quality of Life Instruments (PROQOLID) data base, for example, provides descriptions and validation results for over 700 PROMs instruments[25]. When selecting a PRM, there are several considerations that will guide decision-making. In addition to ensuring a selected PRM serves the identified purpose, the instrument must demonstrate adequate measurement properties, such as validity, reliability, and responsiveness, in the population they intend to be used. Practical considerations include the length of the survey, the cost of licensing, and validation in languages that will serve the target population.

Table 2 is a checklist developed by the Provincial PRM Advisory Committee to help guide the selection of PROM and PREM tools. Meeting the criteria on the checklist will require a review of the literature to identify validation studies of PRM tools, as well as systematic reviews appraising the available evidence for the selected tool.

Table 2: Checklist for Selecting PROMs and PREMs[7]

☐ Level of psychometric evidence (reliability, validity, responsiveness)[7,20,26]

☐ Track record of widespread use and successful implementation[7]

☐ Questionnaire content such that questions will provide the right data to respond to a specific objective; when selecting a PROM, both generic and condition-specific PROM should be used together[7,9,20]

☐ Patient acceptance (cultural appropriateness, response burden, appropriate literacy level)[11]; selection of the questionnaire content should consider clinician and patient needs[26]

☐ Validated in multiple languages[7,27]

☐ Feasibility (licensing fees, data reporting requirements, costs to implement, administration time and resources, and patient response burden)[7,11]

☐ Potential for Canadian normative comparisons and international comparability; benchmarks available to guide interpretation[7,28]

☐ Clinical and health system applicability[7]

☐ Patient engagement in development[28]

Generic PROMs: The EQ-5D-5L

The EQ-5D-5L, Health Utility Index (HUI), Patient Reported Outcomes Measurement Information System (PROMIS) Global Health Instrument and Short Form (SF) family of instruments are the most commonly used generic PROMs internationally[7]. While all four of these tools include questions that cover a range of health domains, there are differences in the extent to which these domains are covered and the overall length of the questionnaires. For a comparative review of these commonly used generic PROMs tools, see Table 4 of CIHI's PROMs Background Document[7].

The EQ-5D-5L is an instrument that measures health in terms of five domains: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression[28]. It is one of the most widely used health utility PROMs in the world and has been validated in over 200 languages. It is CIHI's recommended generic PROM for use in national PROM data collection for hip and knee arthroplasty[16] and is the generic PROM of choice in Alberta, where it has been adopted by Alberta Health, Alberta Health Services, and the Health Quality Council of Alberta[29]

After taking into consideration several important features, such as patient acceptance, ease of administration, and psychometric properties (Appendix C), the Provincial Patient-Reported Measurement Strategy Advisory Committee recommends the EQ-5D-5L as Manitoba's generic PROM of choice. In different disease sectors and populations, there may be limited evidence of the validity of EQ-5D-5L and other generic PROMs may be more commonly used. This recommendation does not preclude the use of other generic PROM tools. However, we strongly encourage the administration of the EQ-5D-5L to facilitate comparisons within and across different diseases, health sectors and populations within Manitoba.

More information about the EQ-5D-5L can be found here, including user guides and sample surveys. A copy of the EQ-5D-5L is included in Appendix D.

When it comes to selecting PROMs, generic and condition-specific PROMs provide complementary information and are often collected together[7]. For example, condition-specific PROMs measure outcomes that are specific to a particular disease or intervention and are often sensitive enough to detect changes before and after an intervention. They do not allow for comparisons of health outcomes in other disease areas or other populations[7,20]. Generic PROMs are designed to assess general aspects of health that are not specific to a particular condition or disease. They are useful for comparing different patients across different health conditions[7,20]. Some generic PROMs provide utility scores that support cost-effectiveness analyses[7,20].

Data Collection and Analysis

Modes of Data Collection

PROMs and PREMs have been traditionally self-administered in a paper-based format at home or in the clinic. They are occasionally administered in-person by a nurse or other health care professional[7,9,30]. While paper assures accessibility to all patients and is attainable for most programs, there is an increasing number of advantages to using electronic data collection methods for the administration of PRMs[31,32]. Compared to paper-based approaches, electronic data collection strategies can reduce the data entry time, administrative burden[31,32], and errors[33]. Electronic data collection methods are generally preferred by patients (including older adults) over other methods[9,34]. Electronically collected PROMs can be directly incorporated in the electronic medical record (EMR), providing data that can be linked in a privacy-appropriate manner to other data sources such as clinical, administrative, and hospital data[7].

In Manitoba, we are examining the feasibility and acceptability of electronic platforms through pilot projects. These platforms include telephone options, recognizing that internet accessibility is not all-inclusive in Manitoba. While not the panacea of data collection, digital platforms offer an efficient and accessible method of data collection to minimize the burden on patients and health care providers and are viewed as a facilitator of PRM implementation in health care organizations[9,21,22].

Ultimately, the choice of data collection method depends on a range of practical considerations, including the target population. It requires considering the advantages and disadvantages of various data collection approaches. To ensure a consistent and sustainable provincial approach to the collection and use of PRMs, it is recommended that electronic data collection tools be used for the collection of patient-reported data.

Regulatory Considerations

When collecting PRM data as part of a research project, ethical approval is required, and an appropriate patient consent strategy must be considered. When PRM data are collected and used in the course of routine care, for quality improvement or health care delivery management, ethical approval and patient consent may not be required. However, providing patients with information about why and how their personal health information is being used is still an important privacy consideration and can be an opportunity to talk to patients about the value of PROM data to guide patient care and improve the quality of care provided[20]. A simple consent process has been shown to be associated with higher follow-up PROM completion rates[11].

Appendix E offers a standardized privacy statement endorsed by the Provincial PRM Strategy Advisory Committee for use when collecting and using PRMs in a specific context. Provincial health interpreters can provide interpreter services in person or over the phone in 32 languages, including some Manitoba-specific Indigenous languages.

Timing and Frequency of Data Collection

The timing and frequency of data collection will depend on the purpose for data collection, the clinical context, and the resources available. When considering the frequency of data collection, successful PRM initiatives take into consideration the burden of data collection on patients and health care professionals. Approaches that integrate data collection into existing processes as much as possible have higher success rates than those that do not[20,35].

PROMs and PREMs can be collected pre-post intervention, longitudinally, and cross-sectionally[7]:

Pre-post intervention is primarily used to measure the effectiveness of a health care program or service or the impact of a treatment or intervention. Used in this setting, a patient fills out a PRM before and then after the intervention, generating a change score. For example, Manitoba's Cataract Surgery program and Manitoba's Joint Replacement Registry collect PROMs pre- and one-year post surgery and use these data to help measure the impact of surgery on the patients' health status and quality of life. Pan Am Clinic also collects PROMs data pre- and post-surgery, but the *frequency* of data collection post-surgery is increased to three, six, and nine months and 1 year post operatively. This frequency helps patients and providers understand the impact of a given intervention from a patient's perspective. Pre-post PRMs do not easily apply to situations such as chronic care, where a series of complex, ongoing interventions often employed[7].

Longitudinal approaches collect PRM data at multiple points over time. They may be used to inform clinical care or measure changes in health outcomes over time. A longitudinal approach may be most applicable in chronic care situations where no single intervention (such as surgery) applies, but rather a series of interventions over time are anticipated[7]. For example, CancerCare Manitoba integrates the collection of PRM data into each clinic visit to monitor symptoms and quality of life, and the data are then used to inform treatment and care plans at the individual patient level.

Cross-sectional approaches are used most often for the collection of PREMs[20]. These approaches provide data that represents a snapshot in time. They are often used as part of health surveillance programs or as part of population health research. The CPES-IC survey gathers feedback from a sample of patients about the quality of care they received during their most recent inpatient acute care hospital stay. The information supports national comparisons and benchmarking for inpatient care[15].

When administering PRMs pre-post intervention or longitudinally it is most common to sample the entire population of patients receiving the health service or intervention (census-based approach). This approach is taken especially when using PRM data to inform patient care or clinical decision-making. Occasionally, PRM surveys are administered to a random sample of the patient population (sample-based approach). If this approach is selected, it is recommended to consult a biostatistician in order to develop an appropriate random sampling strategy.

For additional support planning PRM administration or for biostatistical input, contact info@chimb.ca or info@cpe.umanitoba.ca.

Analysis

Analysis of PRMs will depend on the purpose for data collection and will be influenced by the PRM tools selected, as well as the mode of data collection. Analytic plans should be formulated upfront with input from members of a multidisciplinary team including patients and clinicians. Biostatisticians play an important role on these teams because they can provide solutions to methodological challenges that are common when analyzing routinely collected PRM data. Methodological challenges to consider include but are not limited to; case-mix adjustments, response shift, differential item response, attrition, and missing data.

Data Linkage

Linking PRMs to existing data sources can help understand the impact of our current health services, procedures, and transformation efforts on the health status, quality of life, and experience of patients.

In Manitoba, we have a rich source of existing data. The Manitoba Centre for Health Policy (MCHP) houses a comprehensive repository of administrative, registry, survey, and other data about residents of Manitoba[36]. These data, while linkable at the person level and over time, provide information at a population level, as well as important outcomes related to hospital readmission rates, pharmacy prescriptions, emergency department visits, and more[37]. Manitoba also has a comprehensive collection of clinical data, and efforts are underway through the Provincial Information Management and Analytics shared service to integrate these data into one provincial repository that can provide near real-time information to support measurement priorities across our healthcare system[6,38].

The linkage of PRM data to clinical and administrative data repositories helps reduce the amount of information asked of patients and can substantially improve the quality of the analyses conducted[7]. For example, case-mix adjustments can be easily facilitated by linking to other data repositories. Case-mix adjustments take into account patient characteristics such as age, sex, presence of comorbidities, and the intervention itself, allowing for more accurate comparisons between providers, centres, or regions[39]. Patient demographic information allows for descriptive analyses providing important information about how health services and interventions are impacting different groups within the larger population[7].

Appendix F provides a strongly suggested minimum data set for consideration when collecting PRM data in Manitoba to ensure data can be linked with other provincial data sets. Appendix G was developed to support the creation of data dictionaries for PRM data collection. Data dictionaries are used to provide detailed information about the contents of a data set, such as the names of measured values, their data formats, and text descriptions. Data dictionaries must be developed for each PROM or PREM survey tool used. For examples of data dictionaries or more information on how to build a data dictionary, contact info@chimb.ca.

The CHI can provide methodological and analytic support for the development of PRM analytics plans and the linkage of clinical, administrative, and other data sources. Contact info@chimb.ca.

The Information Management and Analytics Branch of MHSC can provide advice to support the linkage of PRM data to clinical and administrative data sets, as well as the development of analytic tools for reporting purposes. Contact Information.analytics@gov.mb.ca for more information.

Reporting and Use

The success of a PRM program lies not only in the successful collection and analysis of data but also in how this information is translated into knowledge and used to advance patient care and health system goals. This work includes determining the target audience of the information gathered from the PRM program. The reporting and use of PRM data require that decisions relating to how the data will be used be made early on in the planning phase.

Appendix H provides a summary of some of the barriers and facilitators to the reporting and use of PRM data[9,20-22,40]. The two primary challenges can be divided into two categories: 1) trust in the accuracy of the data; and 2) the presentation of the data in an easily interpreted, useable form. Early, transparent communication about the objectives of the PRM program and opportunities for clinicians and patients to become involved in the planning phase enhance clinician acceptance and use of the data[21,22].

Accuracy of Tools and Data

Stakeholders using PRMs report concerns about the validity, accuracy, and sensitivity of measures and accuracy of data (e.g., biases, confounding factors, chance)[9,20,21]. Education that conveys the validity of PRM data, explains statistical methods to recognize and account for confounding factors, provides justification to support the use of specific PRM tools, and gives instruction on how to interpret the results, has been shown to enhance acceptance and use of PRM data.[9,20-22,40]. The acceptance and effective use of PRM data improved in programs where statistical and analytic support was available, improved[22]. Overall, health care professionals tend to place a lower value on PRM data when they are not involved in the process or where there is insufficient communication or education in place at the start of a project[21,22].

Presentation of Data

Much work has gone into developing strategies to present PRM data in a form that can be readily used and understood[41,42]. Clinicians prefer to have results provided to them in ways that support clinical-decision makings[40]. This preference is especially true when data are aggregated and used for quality improvement or when used at the system level to understand variation in practice[9,41]. While clinicians are comfortable with quantitative data presentation, patients prefer to have data presented to them using familiar scales such as percentages and language that makes the results personally meaningful to them[9].

Knowledge translation strategies play an essential role allowing knowledge emerging from PRM data to be effectively communicated and appropriately used[9,23].

The International Society for Quality of Life Research (ISOQOL) created a User’s Guide for Implementing Patient-Reported Outcomes Assessment in Clinical Practice that highlights best practices for reporting and using PROMs data in a clinical setting. This guide includes identifying who will receive the reports, when and how the results will be addressed, and the importance of carefully formatting PROMs reports[40]. The user guide also highlights the need for tools or guidelines to help clinicians interpret PROMs scores and strategies for responding to issues identified through the results[40].

A recognized facilitator of effective PRM-data analysis and presentation is support from a central data analysis unit - support that includes interactive tools for analysis and presentation[9,20]. MHSC, Provincial Information Management & Analytics (PIMA), and Shared Health are working together to develop innovative analytic and reporting tools to support individual patient-level care, health services delivery, and health system performance.

Next Steps

Patient-reported outcome and experience measures not only serve as a mechanism for engaging patients and families by giving them a voice in improving the quality of care and services that they receive, they also provide us with important data to help measure the impact of our changes effectively, and in a patient-centred manner. However compelling our vision is, actioning such a vision will require a considerable collective effort. Each stage of a PRM initiative brings a range of operational, methodological, and practical challenges that will need to be addressed. Thankfully, Manitoba has the leadership, clinical and patient engagement, and methodological expertise in place to guide this work. The collaborative nature of this provincial PRM strategy reflects our willingness and demonstrates our ability to work together to strongly launch this priority initiative on behalf of Manitobans.

Presently, we are testing digital data collection tools as part of ongoing demonstration projects and will further expand the PRM collection currently in place to evaluate and improve their implementation and reporting. Over time, we will leverage our successes to enhance the use of PRMs to inform the efficient, transparent, and value-based function of a learning health system in Manitoba.

We look forward to continued engagement with our partners across the healthcare system as we build the tools, resources, and infrastructure to support the routine collection, analysis reporting and use of PRMs in Manitoba.

Immediate Next Steps (2021 – 2024):

1. Create a provincial implementation team to share PRM implementation experience and help set priorities for implementation across the healthcare system.
2. Build system wide PREM capacity through partnerships with teams currently exploring PREM collection and use.
3. Establish a province-wide, digital data collection platform that is interoperable within and between provincial health data systems.
4. Demonstrate the value of PRMs to support clinical care decisions, continuous quality improvement, and the evaluation of health care services by pilot testing PRM collection and reporting through project currently underway within the health system.
5. Build on and support established PRM processes to improve methodological and province-wide implementation challenges and to demonstrate utility and feasibility.
6. Develop resources and training opportunities to address implementation challenges and support the interpretation of PRM data.

Abbreviations

CHI	Centre for Healthcare Innovation
CIHI	Canadian Institute for Health Information
CPES-IC	Canadian Patient Experiences Survey – Inpatient Care
CPERS	Canadian Patient Experiences Reporting System
EMR	Electronic Medical Record
EQ-5D-5L	EuroQol 5 Dimension 5 Level Questionnaire
ISOQOL	International Society for Quality of Life
KT	Knowledge Translation
MHSC	Manitoba Health and Seniors Care
MCHP	Manitoba Centre for Health Policy
MindSet	**M**anitoba **IN**tegrated **D**ata **Set**
MQLF	Manitoba Quality and Learning Framework
NHS	National Health Service
PIMA	Provincial Information Management and Analytics
PREMs	Patient-Reported Experience Measures
PROMs	Patient-Reported Outcome Measures
PROMIS	Patient-Reported Outcomes Measurement Information System
PROQOLID	Patient-Reported Outcome Quality of Life Instrument
PRMs	Patient-Reported Measures
RHAs	Regional Health Authorities
UK	United Kingdom

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Appendix A: Summary of Manitoba PROMs and PREMs Initiatives

The following is a summary of programs in Manitoba collecting PROMs and PREMs as part of routine care (as of September 2020)

Summary of Manitoba PROMs Initiatives	
Hip and Knee Replacement Surgery - Provincial	
Population	Patients undergoing hip and knee joint replacement surgery in Manitoba
Purpose	Quality improvement, clinical decision making, and research
PROMs Tools	Generic: EQ-5D-5L Condition-specific: Oxford Hip Score and Oxford Knee Score
Other Data Collected	Intraoperative information related to; diagnosis, surgical technique, and implant details; and self-reported data about complications and satisfaction
Data Linkages	Discharge Admission Abstract Database (DAAD)
Data Collection	Preoperatively in clinic and 1-year post-operatively by mail
Mode of Data Collection	Paper-based survey
Regulatory Considerations	Consent obtained from patients
Data Storage	The Manitoba Joint Replacement Registry
Data Reporting	Annual report by region, site, and surgeon – reviewed by regional quality and standards committees
Benefit to Patients	PROMs provide a more complete picture of the patients' outcomes after surgery and are used to help improve the way care is delivered
Spine Surgery – Provincial	
Population	Patients undergoing spine surgery in Manitoba (excluding traumatic spinal cord injuries [which are already collected with RHSCIR, another data collection group] and pediatrics)
Purpose	Clinical support and quality improvement, research, and national partnerships
PROMs Tools	SF-12 Quality of Life questionnaire, EuroQol (EQ-5D), PHQ-9, Neck Disability Index, or Oswestry Disability Index
Other Data Collected	Surgeon initial assessment information, surgical procedure information, discharge information, and adverse event information
Data Linkages	None
Data Collection	Pre-operatively, 3 months post-operatively, and 1, 2, 5, 10 years post-operatively
Mode of Data Collection	Paper-based survey and direct entry into internet database
Regulatory Considerations	UofM Ethics Board approval and patients' consent for participation
Data Storage	A national internet-based registry with the Canadian Spine Society
Data Reporting	Yearly reporting of performance through CSS and ability to pull reports from the database anytime needed
Benefit to Patients	The CSS registry promotes efficient and effective national data comparative reporting and tracks practice patterns and small area

	variations, helping surgeons ensure best practices, resource utilization and acquisition for best patient care, collaborations and development of best treatment practices and quality improvement initiatives
Outpatient Shoulder and Knee Surgery– Regional – Pan Am Clinic	
Population	Patients undergoing shoulder- or knee-related outpatient surgeries in an orthopaedic clinic in Winnipeg, Manitoba
Purpose	Quality improvement, clinical decision-making, and research
PROMs Tools	**Generic:** EQ-5D-5L **Condition-specific (knee):** International Knee Documentation Committee (IKDC) subjective evaluation, MARX activity rating scale, Tegner activity scale, and SANE score **Condition-specific (shoulder):** American Shoulder and Elbow Surgeons Standardized Shoulder Assessment Form (ASES), SANE score, Western Ontario Rotator Cuff index (WORC) or Western Ontario Shoulder Instability Index (WOSI)
Other Data Collected	Demographic data and self-reported data about work status and post-op surgical complications
Data Linkages	Surgical OR form registry
Data Collection	Pre-operatively in clinic and, 3, 6, 9 months and 1 year post-operatively
Mode of Data Collection	Paper-based survey
Regulatory Considerations	“Permission to contact for future research” consent form obtained from patients
Data Storage	On-site database
Data Reporting	Not reported
Benefit to Patients	PROMs provide a more complete picture of the patients’ outcomes after surgery and are used to help improve the way care is delivered
Cataract Surgery - Provincial	
Population	Patients undergoing cataract surgery in Manitoba
Purpose	Quality improvement, clinical decision-making, and research
PROMs Tools	Visual Function Index Questionnaire (VF-14)
Other Data Collected	Length of wait times for surgery, work impairments due to cataract, work driving impairments, and potential loss of driver’s license due to cataract
Data Linkages	None
Data Collection	Pre-operatively by telephone, and 1 year post-operatively
Mode of Data Collection	Questionnaire administered by telephone
Regulatory Considerations	Consent obtained from patients
Data Storage	Stored in The Manitoba Cataract Waiting List Program
Data Reporting	None
Benefit to Patients	PROMs help improve cataract surgery wait times
Cancer - Provincial	
Population	Cancer patients across Manitoba
Purpose	Help inform treatment and care plans

PROMs Tools	Comprehensive Problem and Symptom Screening (COMPASS) Questionnaire with the Canadian Problem Checklist and Edmonton Symptom Assessment System-revised (ESAS-r)
Other Data Collected	Medication and medical history changes
Data linkages	Directly linked to patient record at CCMB
Data Collection	At each clinic visit
Mode of Data Collection	Paper-based survey with data entered into the CCMB EMR
Regulatory Considerations	Consent implied as part of care delivery
Data Storage	CCMB EMR as discrete data elements (as of 2011/2012)
Data Reporting	Secondary use for Disease Site Groups administration and research
Benefits to Patients	PROMs are used as part of clinical practice to inform day-to-day care and direct targeted interventions (psychosocial, smoking cessation, symptom management, etc.)

Summary of Manitoba PREMs Initiatives	
Inpatient Hospital Survey - Provincial	
Population	Patients discharged from a Manitoba hospital who had an overnight stay
Purpose	To better understand the inpatient experience in hospital and inform quality improvement initiatives
PREM Tool	Canadian Patient Experience Survey – Inpatient Care
Other Data Collected	Data related to patient safety and other spoken languages including the use of French-language services
Data Linkages	None
Data Collection	Monthly random sample of all patients discharged in the previous month
Mode of Data Collection	Mailed paper-based survey with option to complete online
Regulatory Considerations	Passive consent from patients; privacy statement is provided
Data Storage	By MHSC and CIHI
Data Reporting	Monthly reporting of selected measures in the provincial performance management dashboard; semi-annual and annual reports provided to RHAs; reporting by CIHI with restricted access for participating jurisdictions.
Benefit to Patients	Survey results are used to inform quality improvement initiatives
Emergency Department Survey – Regional	
Population	Patients who visited an Urgent Care/ Emergency Department
Purpose	To better understand the patient's experience of urgent/ emergency care to inform quality improvement
PREM Tool	Urgent Care and ED Survey
Other Data Collected	Data related to patient's general health background and level of education
Data Linkages	None
Data Collection	Monthly random sample of all patients who use urgent care or emergency department in the WRHA
Mode of Data Collection	Mailed paper-based survey with option to complete online
Regulatory Considerations	Implied consent
Data Storage	WRHA?
Data Reporting	Data is reported quarterly. Data is available to view in a WRHA Regional Patient Engagement SharePoint page.
Benefits to Patients	Quality improvement

Appendix B: Engaging People with Lived Experience

Patients and people with lived experience, including caregivers and family members, are key partners in successful PROMs and PREMs initiatives world-wide[9,20]. Involving people who have lived with a particular health condition informs our understanding of its day-to-day impact and effects on quality of life. These individuals bring a unique perspective and knowledge to the planning table.

Patient-reported data can be effectively utilized only if patients are first 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.

Instances where people with lived experience can provide valuable input include.

1. Developing a shared understanding of the purpose for collecting PRM data

2. Selecting PROMs and PREMs tools
   - ✓ Ensuring patient 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 or experiences that are relevant to patients and captures these in a comprehensive and understandable manner

3. Creating 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. 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

Selecting People with Lived Experience

When selecting people with lived experience to be part of your team it is *essential* to recruit people who are representative of the condition you are collecting PRMs on. For example, if you want to learn more about changes to a dialysis program, then it is *necessary* to include people with chronic kidney disease on your team. If you would like to use PROMs to improve the treatment of depression in adults, then you must include people with experience of depression on your advisory team.

- Include informal caregivers, family, and community,
- Include people who have recent lived experience (within the past three to five years) to ensure their recommendations and experience reflect current practice* (surgical vs. chronic conditions).
- Consider who is affected differently by this health condition and who has different access to care. This will help capture a range of Manitobans who have different lived experiences with the health issue.
- Consider geographical barriers faced by Manitobans (rural, remote, urban), as well as systemic barriers (racism, sexism, colonialism, ageism, transphobia, homophobia, sizeism, xenophobia, and ableism).

Methods of recruitment may include

- Contacting current or previous patients
- Using on-location advertisements (such as posters, digital ads, pamphlets, or cards) in health care service settings (e.g., hospitals, waiting rooms, or primary care health clinics)
- Reaching out to existing patient and public engagement networks in Manitoba, such as CHI's Patient and Public Engagement Collaborative Partnership
- Connecting with leaders of local community organizations outside of health care, such as Indigenous organizations; newcomer, refugee, or immigrant organizations; women's resource centres; seniors organizations, etc.
- Going on local radio shows or advertising in local newspapers in rural and remote areas
- Advertising on social media (e.g., through established patient bloggers, Twitter, or Instagram to share information).
- Promoting through organizational e-newsletters or event kiosks – attending events, in general, helps to get to know the community and build relationships
- Presenting to patient support groups, at information sessions, and to health care consumer groups in the area you are looking at

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 groups are a participatory method of engagement that involve regular meetings to help provide direction and advice into different aspects of the program. This might involve people with lived experience meeting regularly to provide specific input as a group or it might involve people with lived experience participating 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.).

Perspectives to Use When Facilitating Advisory Committees

Depending on the sector of care you are working in, 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[43].

The following strategies are recommended:

- Use anti-oppressive and trauma-informed approaches. It is highly recommended for the research team to participate in critical reflexive practice exercises 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 expectations 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 experiences, but also allows enough time for each member to contribute in a meaningful way. Facilitating of a large 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 effectively.
- 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 addictions, 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 an Advisory Group 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)
- Patient Engagement in Quality Improvement Initiatives: 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 Meetings 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 Partners

- 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

Appendix C: EQ-5D-5L Selection Criteria

The following features of the EQ-5D-5L tool were taken into consideration when making this recommendation:

☐ *Level of Psychometric Evidence*: The EQ-5D-5L has been proven to be valid, reliable, and responsive in numerous conditions and populations[44].

☐ *Track Record*: One of the most widely used health utility PROMs in the world, the EQ-5D-5L includes benchmarks to guide interpretation and will allow us to make national and international comparisons. It is the generic tool that is part of CIHI's national standards for hip and knee arthroplasty PROMs,[45] and is the generic PROM of choice in Alberta[29].

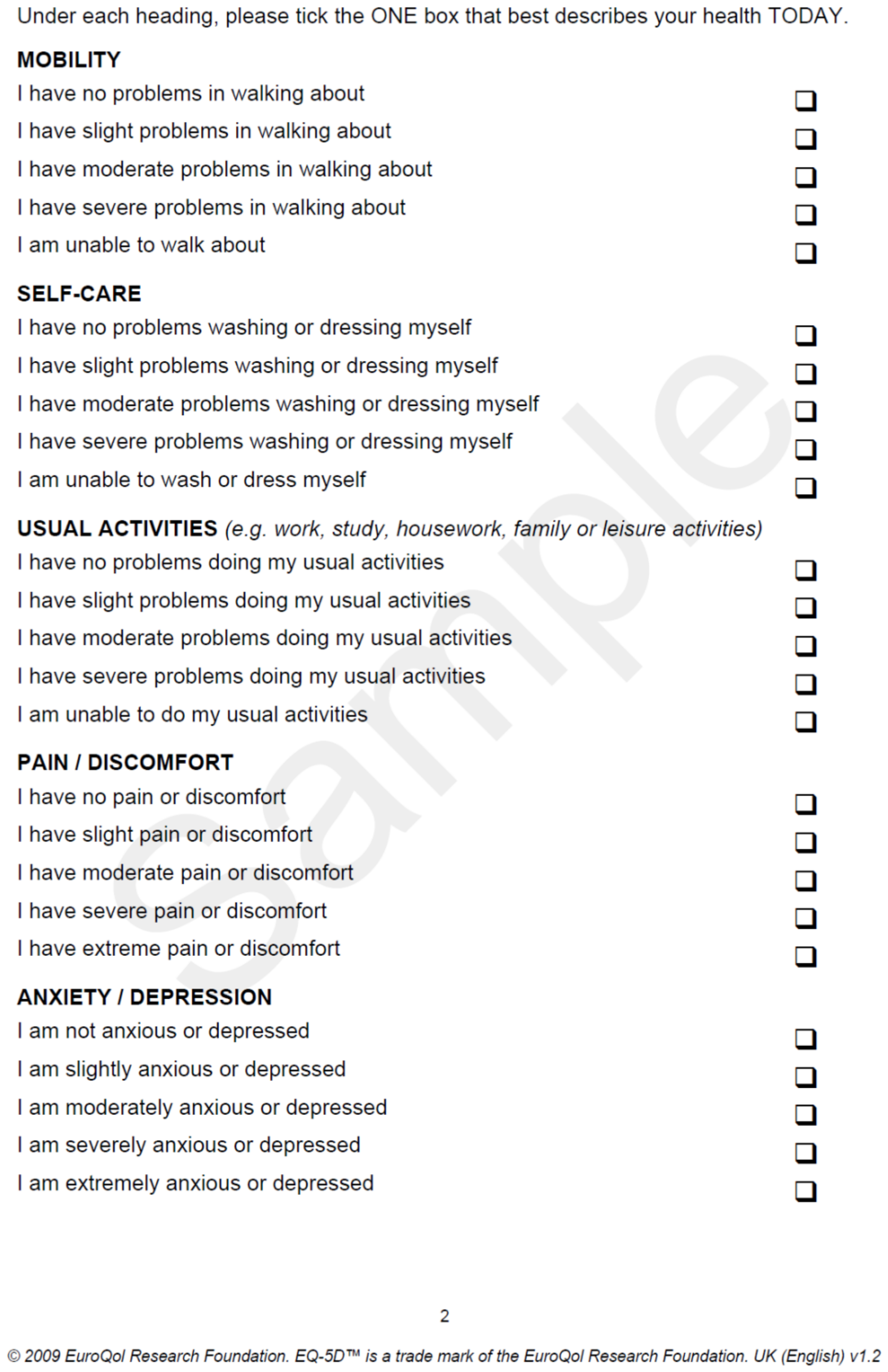
☐ *Instrument Content*: It includes questions about mental, physical, social, and general health and produces an overall health utility score to support economic evaluations. It is one of the only generic PROMs that have utility scores derived from a Canadian sample and supplies Canadian population norms[28].

☐ *Patient Acceptance*: The response burden is low (only 5 questions), it has been translated extensively (including Canadian English and French), it has high cross-cultural validity, and multiple modes of administration are available, including proxy versions for patients who are unable to complete surveys themselves[28].

☐ *Licensing:* There is no cost to use the paper version of the EQ-5D-5L for collection in routine care. CIHI holds a national license for this tool, and it may be able to sub-license it to Shared Health for users in Manitoba.

☐ *Ease of Administration:* It offers an overall low administration burden compared to other generic PROMs due to the low number of questions (5) and validity across multiple modes of administration.

Appendix D: EQ-5D-5L Sample Survey



Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ☐
I have slight problems in walking about ☐
I have moderate problems in walking about ☐
I have severe problems in walking about ☐
I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐
I have slight problems washing or dressing myself ☐
I have moderate problems washing or dressing myself ☐
I have severe problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

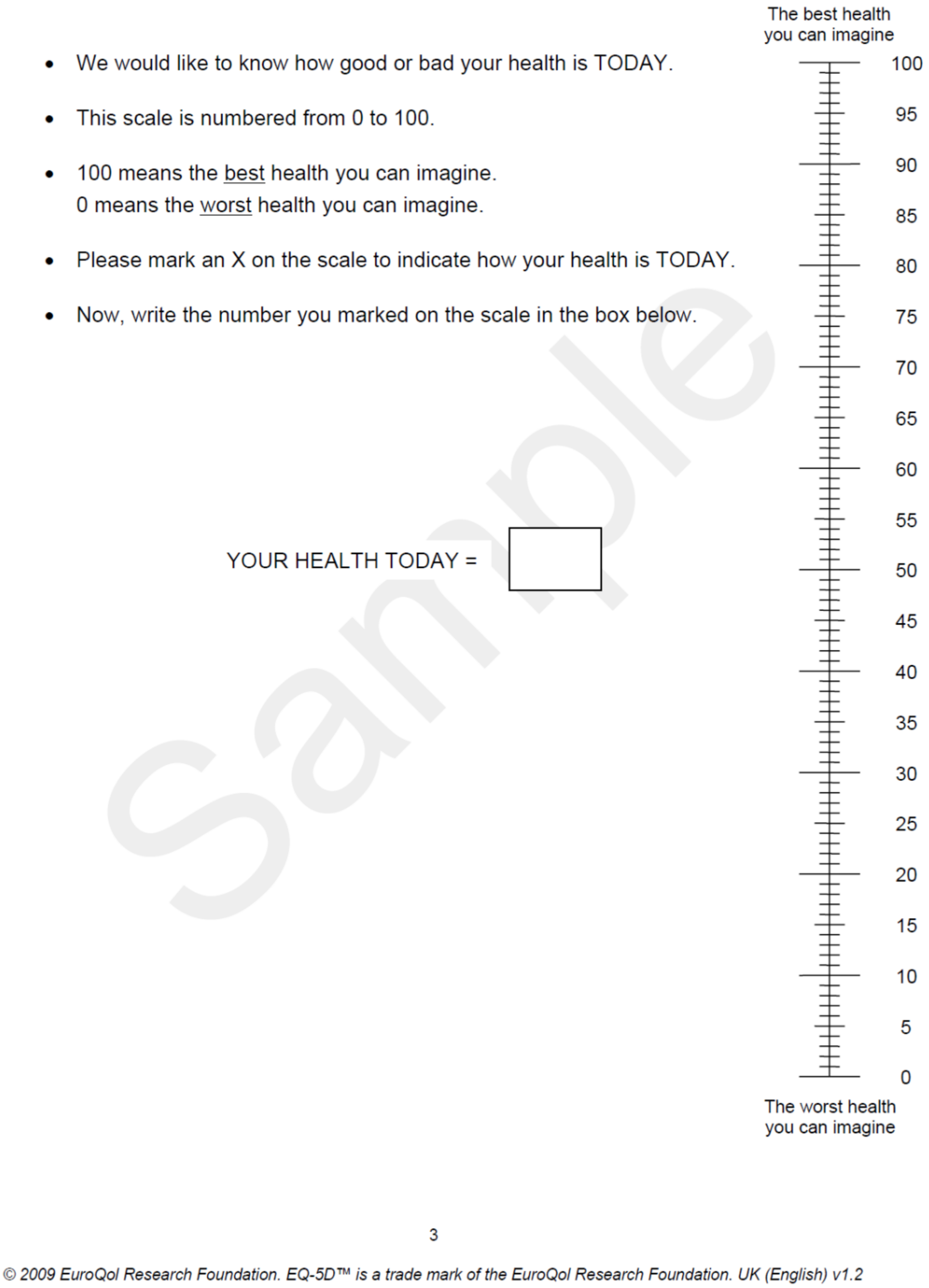
I have no problems doing my usual activities ☐
I have slight problems doing my usual activities ☐
I have moderate problems doing my usual activities ☐
I have severe problems doing my usual activities ☐
I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐
I have slight pain or discomfort ☐
I have moderate pain or discomfort ☐
I have severe pain or discomfort ☐
I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐
I am slightly anxious or depressed ☐
I am moderately anxious or depressed ☐
I am severely anxious or depressed ☐
I am extremely anxious or depressed ☐



- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Please mark an X on the scale to indicate how your health is TODAY.
- Now, write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐

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Appendix E: Proposed Privacy Statement in English and French

Proposed Privacy Statement

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities, and it will be used to enhance your care.

Your survey responses may also be shared with [*service providers, hospital decision-makers, and researchers*] to inform and improve patient-centred care and patient outcomes *[in Manitoba*]. Your information will never be used in a way that could identify you, and reporting will only be done at the group level. Your access to appropriate medical care will not be affected in any way by your responses.

Proposition d’énoncé de confidentialité

Le présent sondage est destiné à connaître votre point de vue sur votre santé. Ces renseignements aideront à savoir comment vous vous sentez et comment vous êtes capable d’effectuer vos activités habituelles, et seront utilisés pour améliorer vos soins.

Vos réponses au sondage peuvent aussi être communiquées aux [*prestataires de services, décideurs hospitaliers et chercheurs*] afin d’informer et d’améliorer les soins axés sur le patient et les résultats pour les patients *[au Manitoba*]. Vos renseignements ne seront jamais utilisés de manière à pouvoir vous identifier, et les rapports ne seront faits qu’au niveau du groupe. Vos réponses n’auront aucune incidence sur votre accès aux soins médicaux appropriés.

Appendix F: Suggested Minimum Data Set for PRM Collection in Manitoba

Category	Data Element	Information Sources
Patient-reported Measurement Surveys Used Validated self-report instrument that must be completed by the patient	EQ-5D-5L (6 questions) (recommended)	Must be completed by patient
	Responses to PROM and/or PREM surveys used	
Patient Information Enables linkage of PRM surveys to other data sources	Personal health identification number (PHIN)	Administrative sources (e.g., patient chart). Electronic sources (e.g., auto-populated through registration system) Provided directly by patient
	Postal code	
	Date of birth	
	First and last name	
	Sex assigned at birth[b]	
Questionnaire (Survey Instrument) Administration	Full name and version of each of the PROM and or PREM questionnaire used	Completed by questionnaire (survey) administrator Can be auto populated if using a digital platform to collect PRM data
	Questionnaire completion date	
	Questionnaire score	
	Questionnaire time points (e.g., pre-intervention, post-intervention)	
	Questionnaire language	
	Questionnaire mode (paper, electronic, interview)	
Clinical/Administrative Should include information on the patient's episode of care that can be used for reporting and enables linkage of PROMs and PREMs questionnaires to other data sources	Clinician identifier	Completed by questionnaire (survey) administrator Can be auto populated if using a digital platform to collect PRM data (e.g., facility identifier) or obtained via electronic interfaces with other source systems Can be obtained from administrative sources (e.g., patient chart)
	Date of treatment/procedure	
	Type of treatment/procedure	
	Facility identifier	

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[b] May not be the most suitable in all cases.

Appendix G: Suggested Elements for a Data Dictionary[c]

Data Element Identifier	Data Element Name	Field Size	Data Type	Expected Values	Data Format	Description*
Patient Information						
PA_1	PHIN	9	Num		NNNNNNNNN	Personal health identification number
PA_2	PostalCode	6	Num/Text		LNLNLN	Postal code
PA_3	PatientDOB	10	Date/Time		DD/MM/YYYY	Date of birth
PA_4	PatientFirstName	20	Text		-	First name
PA_5	PatientLastName	30	Text		-	Last name
PA_6	PatientSex	10	Boolean	M/F/X	L	Sex assigned at birth
Questionnaire Administration						
QA_1	QuestionnaireName	15	Num/Text			Complete questionnaire name and version for each questionnaire (survey) administered (e.g., EORTC QLQ-EN24, SF-36, etc.)
QA_2	QuestionnaireLanguage	3	Text	ENG FRE OTH	LLL	A 3-letter code representing the language of the questionnaire
QA_3	QuestionniareMode	10	Text	Telephone Paper Electronic In-person (verbal)	-	Mode of questionnaire administration
QA_4	QuestionnaireCompDate	10	Date/Time		YYYY/MM/DD	Date the patient completed the survey
QA_5	QuestionnaireTimePnts		Num/Text		-	Time points when questionnaire was administered (e.g., 4 weeks pre-intervention, at time of intervention, one-

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[c] Selection of data element types should involve consultation with data system experts from Digital Health as well as data linkage experts from PIMA, MCHP and/or CHI

Data Element Identifier	Data Element Name	Field Size	Data Type	Expected Values	Data Format	Description*
						year post-intervention
QA_6	QuestionnaireScore		Num		N	Provide a composite score based on the specific scoring methods for each PROM or PREM tool used
Clinical Administration						
CA_1	ClinBillingNum		Num		N	An organization - assigned number that uniquely identifies a clinician
CA_2	FacilityNum		Num		NNN	A unique identifier associated with the site where the treatment or procedure was administered
CA_3	ClinDate	10	Date/Time		YYYY/MM/DD	Date that the treatment or procedure was completed
CA_4	ClinProcedure		Text			Specific type of treatment or procedure undertaken
Generic PROM – EQ-5D-5L						
EQ5D_1	Mobility	1	Num	1=no problems 2=slight problems 3= moderate problems 4=severe problems 5 = unable to 9 = missing value	N	Current mobility; ambiguous values should be treated as missing values
EQ5D_2	Self-Care	1		1=no problems 2=slight problems 3= moderate problems		

Data Element Identifier	Data Element Name	Field Size	Data Type	Expected Values	Data Format	Description*
				4=severe problems 5 = unable to 9 = missing value		
EQ5D_3	Usual Activities	1		1=no problems 2=slight problems 3= moderate problems 4=severe problems 5 = unable to 9 = missing value		
EQ5D_4	Pain_Discomfort	1		1=no problems 2=slight problems 3= moderate problems 4=severe problems 5 = unable to 9 = missing value		
EQ5D_5	Anxiety_Depression			1=no problems 2=slight problems 3= moderate problems 4=severe problems 5 = unable to 9 = missing value		
EQ5D_6	PatientHealthState	5	Num		NNNNN	Unique health state defined by combining one level from each of the five dimensions*
EQ5D_7	EQVAS	2	Num	0::100 (value range	N NN NNN	Your health today

Data Element Identifier	Data Element Name	Field Size	Data Type	Expected Values	Data Format	Description*
				between 1-100)		Self-reported measure between 0 and 100* Missing values should be coded as 999
*See the EQ-5D-5L User Manual for data collection instructions						

Appendix H: Sample of Barriers & Facilitators for the Reporting and Use of PRM Data

Analysis and Presentation of Data[20-22,40]

Facilitators[20]

- Accessible data infrastructure, providing interactive tools for analysis and presentation
- Support from a central data analysis unit
- Statistical support available
- KT strategies employed
- Easy-to-read reports linked to concrete actions needed for change

Barriers

- Outdated results due to inefficient data collection and analysis
- Lack of standardized data collection makes comparisons between services difficult
- Concerns about the accuracy of data
- Statistical and technical data issues (e.g., risk and case-mix adjustments, skewed data, ceiling-effect, small samples)
- Absence of baseline (benchmark) data

Usefulness of Data (Decision-Makers Perspective)[9,20-22,40]

Facilitators

- Transparency: availability of user-friendly, comparable, reliable, and understandable public information in a central place
- Staff engagement, training and support, and ownership of knowledge obtained from measurements
- Timely feedback to healthcare professionals
- Use of performance data for auditing and accreditation
- Non-blaming tone in feedback reports; objective presentation of results of analysis
- Rigorous performance monitoring and evaluation system

Barriers

- Difficulties in demonstrating the impact of PROMs and PREMs on quality of care
- Delay in publication of results or feedback reports
- Lack of clear actionable feedback to ensure changes are made
- Lack of time between feedback reports to allow the implementation of improvement work

Usefulness of Data (Patient Perspective)[9]

Facilitators

- Data presented in terms of an experience rather than a number
- Data reports focus-tested with patients and people with lived experience

- Report using language that makes the metrics personally meaningful and linked to familiar scaling (e.g., percentages) and to experience

Barriers

- Results presented as quantitative data are difficult to interpret