PROMs

Background Document

Canadian Institute for Health Information
Institut canadien d'information sur la santé

Our Vision

Better data. Better decisions.
Healthier Canadians.

Our Mandate

To lead the development and maintenance of comprehensive and integrated health information that enables sound policy and effective health system management that improve health and health care.

Our Values

Respect, Integrity, Collaboration, Excellence, Innovation

Table of Contents

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Executive Summary

Patient-reported outcome measures (PROMs) are measurement instruments that patients complete to provide information on aspects of their health status that are relevant to their quality of life. Some countries, such as the United Kingdom, have implemented comprehensive PROMs programs to evaluate health services and outcomes. In Canada, while some regional-level PROMs initiatives exist, a coordinated pan-Canadian program for the routine administration of PROMs for use in health services management, quality improvement and performance measurement currently does not exist. Given the range of possible uses of PROMs information, there are significant potential benefits for Canada that could be achieved through a coordinated approach to PROMs data collection, which would make this information available to clinicians, health system administrators, policy-makers, researchers and the public.

Several jurisdictions across Canada are assessing how best to implement PROMs. This report provides information about several factors to consider when implementing a PROMs program. When planning a PROMs initiative, an essential first step is to confirm the purpose of collecting PROMs information and how the data will be used. Once the purpose of the PROMs program has been confirmed, stakeholders need to agree on which PROMs instruments would best serve the PROMs initiative and determine the target populations (e.g., patient groups, health care sectors) where initial routine PROMs data collection should focus. Elective surgery (e.g., orthopedic surgery, cataract surgery) and chronic illness care (e.g., kidney disease, congestive heart failure, chronic obstructive pulmonary disease, cancer, mental health care) are 2 general clinical themes to consider for initial PROMs data collection and reporting.

Selecting PROMs instruments includes making decisions about what is to be measured (domains) and which tools (generic and/or condition-specific) will be used. PROMs tools are categorized as generic (can be applied across different populations) or condition-specific (used to assess outcomes that are characteristic of or unique to particular diseases or sectors of care). Since generic and condition-specific instruments provide complementary information, the typical recommendation is that both be used to provide the full set of information. Criteria to consider when assessing the various PROMs tool are effectiveness, evidence of widespread and successful implementation, appropriateness, feasibility and Canadian and international comparability. 4 generic PROMs tools were considered for common use in PROMs initiatives across Canada: the SF family of instruments (such as the VR-12), the EQ-5D, the Health Utilities Index (HUI) and the Patient Reported Outcomes Measurement Information System (PROMIS) Global Health Instrument. At the CIHI PROMs Forum, participants identified the VR-12 and EQ-5D as the most suitable generic tools for routine PROMs data collection and reporting.

In designing a PROMs program, consideration must be given to administration of surveys, including sampling design, timing of data collection and method of administration (electronic, paper, telephone). The ability to link PROMs information to other clinical and administrative data sources should also be investigated to support analytical purposes.

It is important for jurisdictions to consider taking a common and coordinated approach to PROMs data collection and reporting; this would allow for the benefits of more cost-effective data collection and the availability of comparable PROMs data with which to drive health system enhancements.

Background

In 2013–2014, CIHI conducted an environmental scan of the Canadian and international PROMs landscape. This scan confirmed that while there are some regional-level PROMs initiatives in Canada, a standardized program for routine PROMs collection and reporting does not exist here. The need for enhanced PROMs information to support a range of health care goals has been identified as a high priority, including at the October 2014 Consensus Conference co-hosted by CIHI and Statistics Canada.

During stakeholder consultations, jurisdictions indicated a desire to better understand the strengths and weaknesses of the options for implementing PROMs data collection and reporting. In response, CIHI coordinated a national PROMs Forum in February 2015 in Toronto, Ontario, to provide Canadian health leaders an opportunity to discuss PROMs and explore considerations and opportunities for standardizing PROMs data collection and reporting across Canada. The 60 participants who attended this invitational event included senior policy-makers from federal/provincial/territorial governments, senior health system decision-makers and selected clinicians and senior researchers actively involved in PROMs. A summary of discussions that took place during the PROMs Forum is available in the *PROMs Forum Proceedings*.

This background document was developed to contribute to achieving a common understanding of PROMs.

PROMs Overview

Patient-reported outcome measures (PROMs) are measurement instruments that patients complete to provide information on aspects of their health status that are relevant to their quality of life, including symptoms, functionality and physical, mental and social health.

Why collect PROMs? Patient-reported outcomes are essential to understanding whether health care services and procedures make a difference to patients' health status and quality of life. PROMs provide insight on the effectiveness of care from the patients' perspective and complement existing information on the quality of care and services provided.

Who uses PROMs? PROMs can be used to inform clinical practices; health services programming, planning and policies; performance measurement; comparative effectiveness analysis; and quality improvement initiatives.

Why is a standardized approach to PROMs important? A common approach to collecting and reporting PROMs data is more cost-effective and provides much more comparable data with which to drive health system enhancements (e.g., in the areas of quality, funding and patient-centred care).

What Are PROMs?

Health outcomes are defined as changes in health status that occur as a result of a health care intervention. PROMs are instruments completed by patients for use in reporting on aspects of their health status that are relevant to their quality of life. These can include evaluating symptoms, functionality, and physical, mental and social health.[1, 2] PROMs have also been referred to as measures of health-related quality of life.[1, 3–7] Similar to patient-reported experience measures (PREMs), which measure satisfaction and experience with care, PROMs are self-report instruments, and information is gathered directly from the patient without interpretation by a clinician or any other person.[8]

Why Collect PROMs?

A broad range of key stakeholders working in Canadian jurisdictions indicated the need for more patient-reported information about health care experiences and outcomes. At the Consensus Conference hosted by CIHI and Statistics Canada in October 2014, the need for PROMs information to support health system goals was identified as a top priority.

PROMs provide insight on the effectiveness of care from patients' perspectives and complement existing information on the quality of care and services provided. Patient-reported outcomes are essential to understanding whether health care services and procedures make a difference to patients' health status and quality of life. Decision-makers are increasingly turning to PROMs to evaluate the impact of health care interventions on life expectancy and health-related quality of life.

- PROMs complement traditional, clinical-based outcomes, enabling a more comprehensive understanding of outcomes and effectiveness.

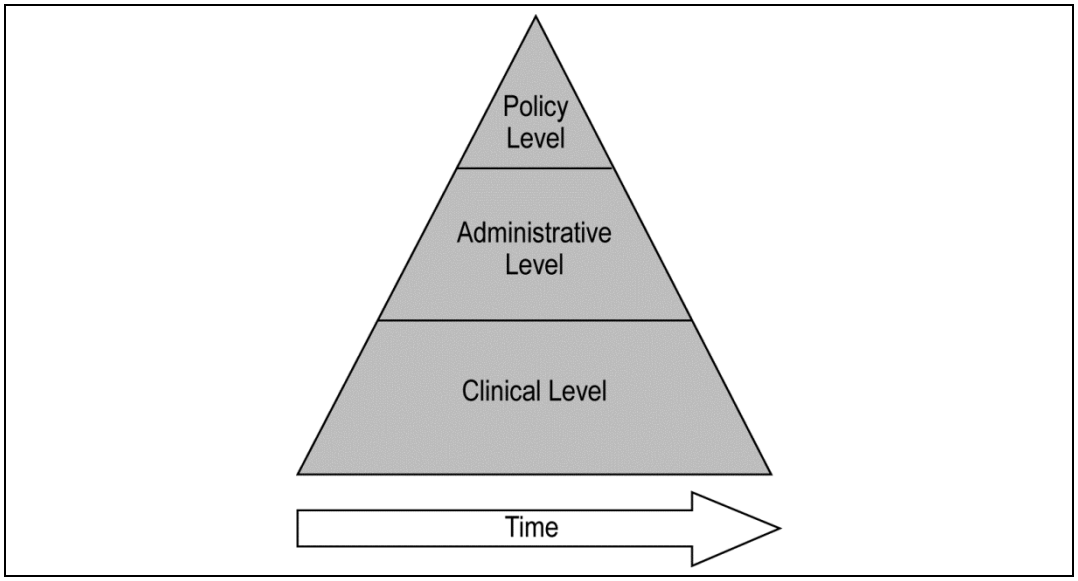
- PROMs support service delivery improvements by allowing the effectiveness of services to be evaluated, identifying patients who would benefit from interventions and encouraging the sharing of best practices.
- PROMS can be incorporated into the evaluation of performance and effectiveness of care to enable a potential shift in health system resource management from a volume-based to a value-based model.
- PROMs can also inform decisions regarding resource allocation to ensure investments support improvements in population health.

How Can PROMs Be Used in Health Care?

Integrated Health Outcomes Information

Health outcomes information can be collected at various levels for a range of different purposes, from clinical to policy-making. The information pyramid (Figure 1) illustrates the hierarchical nature of an integrated information system. This approach is based on the notion that proper health information systems can function to improve patient care, support effective management of service delivery and provide the foundation for effective performance monitoring.[9] The model applies to the collection of various types of information needed to inform and improve a range of dimensions of care delivery, including effectiveness of care.

Figure 1: Information Pyramid — Integrated Health Outcomes Information



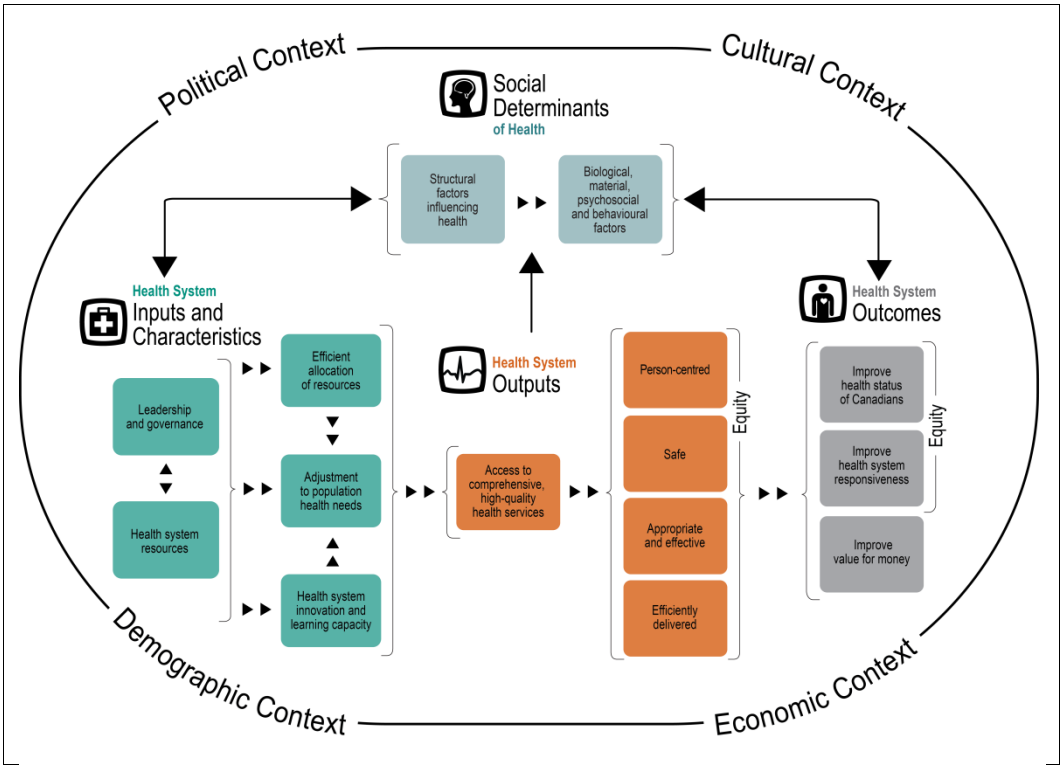
Source
Canadian Institute for Health Information. *Health Outcomes of Care: An Idea Whose Time Has Come*. 2012.

The information pyramid underscores the need for health outcomes information at several levels, including the clinical, administrative and policy levels. In an ideal information system, health outcomes data would be routinely collected at the clinical level and used by health care providers to manage individual patient care. This data could then be aggregated to create key performance indicators to support decision-making at the administrative level and to create composite performance indicators at the policy level.[9]

This model applies to the full spectrum of health care services and incorporates health outcomes measures at all points during patients' care. The information is grounded in the use of clinically validated measures of health status. The points of measurement should reflect anticipated changes in health status. In the case of elective surgical procedures, for example, pre- and post-operative measures of health status may suffice to determine the health outcomes of care. However, ongoing monitoring may be required to detect changes in health outcomes among those with chronic conditions, such as diabetes.

In addition, health outcomes information must be linked to details regarding the care path as well as to the broader determinants of health, such as lifestyle and socio-economic status. This comprehensive approach is reflected in the Health Outcomes Conceptual Framework developed by Statistics Canada and CIHI.[9]

Figure 2: CIHI's Health System Performance Measurement Framework



Source
Canadian Institute for Health Information. *A Performance Measurement Framework for the Canadian Health System*. 2012.

The Value of PROMs Information

Despite the long-standing promotion of a patient-centred approach to health and health care, there is currently a data and reporting gap in the dimension of the patient's perspective within CIHI's Health System Performance Measurement Framework (see Figure 2).[10] Providing the patient's perspective is essential to measuring outcomes more broadly. PROMs are especially important in elective surgeries and chronic illness management, where the predominant goal is to enhance patients' quality of life.

PROMs data collection has multiple levels of potential value to health systems. The uses of PROMs at different levels are summarized in Table 1 below:

Table 1: Value of PROMs to Stakeholders

Stakeholder	Uses
Health System Policy-Makers/ System Managers	• Compare outcomes locally, regionally and provincially, over time, as well as with similar regions and jurisdictions. • Compare different care models and clinical pathways for outcome analysis and for the potential realignment of referral patterns to target best outcome organizations. • Support health service allocation decisions informed by information about the relative cost of achieving desired outcome states ("value-based care"). • Identify clinical organizations and/or regions that would benefit from further education and support to improve outcomes.
Health Care Organizations	• Monitor organization and provider performance; compare with peer organizations; identify organizations with high outcomes scores for engagement and improvement. • Identify areas and providers that would benefit from further education and support.
Health Care Providers	• Direct feedback that can be used to modify the care path for that patient and provide evidence toward improving or maintaining a high level of care and expected outcomes. • Support improved clinician–patient communication and raise awareness of problems that would otherwise be unidentified. • Facilitate performance comparisons with expected standards.
Patients	• Provide opportunity for patients to provide input from their perspective and to be more aware of expected outcomes and how they compare. • Provide opportunity for patients to provide feedback independent of their provider's view and also potentially identify themselves as not having a satisfactory outcome. • Enhance communication with care providers and patient involvement in care planning and decision-making.

PROMs and PREMs

As described above, PROMs measure aspects of a patient's health status at a particular point in time during an illness or with a health condition. In some cases, using pre- and post-event PROMs, the impact of an intervention can be measured. A complementary source of information is PREMs, which provide the patient's view on the delivery of services (e.g., communication with staff, cleanliness, timeliness). Both PROMs and PREMs are measured from patients' perspectives, and they can be used together to more fully assess quality of care.

Coordination of PROMs and PREMs reporting in Canada can provide additional value. There has been increasing interest in using both PROMs and PREMs for health services evaluation. For example, the Medicare Health Outcomes Survey Program in the United States uses PROMs, PREMs and other data in the Healthcare Effectiveness Data and Information Set (HEDIS) to produce star ratings for comparison of service providers.

Why Is a Standardized Approach to PROMs Important?

PROMs data could be collected and used for a range of purposes, all of which could, in principle, rely on the same data. It is anticipated that future developments in the large-scale and routine administration of PROMs will focus on finding ways to meet the needs of all stakeholders (policy-makers, administrators, clinicians and researchers). This will require a coordinated approach through which data is collected from patients, timely feedback is provided to clinicians and PROMs data is made readily available to support ongoing program evaluations, health services delivery and management, and health policy decision-making.

Consistent with other health information initiatives, taking a common approach to collecting and reporting PROMs data is seen as an efficient and effective way to support local, regional, national and international comparisons as well as to inform health system performance activities in areas such as quality, funding and patient-centred care. Without a coordinated approach, meaningful comparisons and assessments cannot be conducted to inform a broad range of health system decision-making needs.

PROMs Landscape

International PROMs Environment

There is widespread interest in the use of PROMs for population health monitoring, health policy and health care administration in many countries. For example, PROMs are collected for joint replacement procedures in several countries, including the U.K., Sweden, the Netherlands and New Zealand.

United Kingdom: Since 2009, it has been mandatory to collect PROMs data for hip and knee replacement surgeries, hernia repairs and varicose vein surgeries for procedures funded by the National Health Services (NHS).

United States: Several national PROMs initiatives exist. Examples include the Medical Outcomes Study (MOS, which led to the development of the SF-36 health survey), PROMIS (a freely accessible suite of PROMs instruments, computerized adaptive testing and an online PROMs administration and data collection system supported by the National Institutes of Health), the Veterans Health Administration (the largest integrated health care delivery system in the U.S., which used PROMs for service evaluation and monitoring and also developed the VR-36 and VR-12 surveys) and the Centers for Medicare and Medicaid Services Medicare Health Outcomes Survey (which uses VR-12 to help produce star ratings for the comparison of Medicare Advantage organizations).

World Health Organization: The objective of the World Health Organization Quality of Life (WHOQOL) project was to develop a quality of life assessment instrument that would facilitate cross-cultural comparisons.

There is widespread international interest in the use of PROMs for population health monitoring, health policy and health care administration. While some countries have yet to adopt national PROMs programs, the importance of health outcomes information is broadly acknowledged. This section provides examples of PROMs programs in other countries. A more detailed summary of selected programs is available in Appendix A.

United Kingdom

The U.K. has been a leader in PROMs instrument development, research and utilization for several decades. The NHS PROMs Initiative is one of the largest PROMs initiatives worldwide that explicitly focuses on the comparison of PROMs scores before and after treatment to support continuous quality improvement at the system level. Since 2009, data has been collected on NHS-funded hip and knee replacement surgeries, hernia repairs and varicose vein surgeries for use in health services evaluation and to inform patient treatment choices. The data is predominantly being used to evaluate, monitor and compare health care providers and organizations and to provide feedback to clinicians.

United States

In the U.S., PROMs are integral to the Institute for Healthcare Improvement's Triple Aim mandate to improve the patient experience of care (including quality and satisfaction), improve the health of populations and reduce the per capita cost of health care.

The MOS conducted in 1989 by the RAND Corporation is one of the first examples of a large national PROMs initiative. This 2-year study included patients with chronic conditions and was specifically designed to compare patient outcomes across different systems of care and health care sectors, as well as to develop instruments for the routine collection and monitoring of patient-reported outcomes.[11] The MOS led to the development of the 116-item MOS Measures of Quality of Life Core Survey, which provides the basis for the Short Form 36-Item Health Survey (SF-36) and subsequent short forms and adaptations of the survey.[12]

In 2004, the National Institutes of Health established a large multicentre network of clinicians, researchers and measurement experts to develop what is now known as PROMIS. This network is currently made up of members from 13 universities, who have developed various PROMs, and a freely accessible measurement information system. PROMIS predominantly focuses on using PROMs for clinical and comparative effectiveness research and provides access to a suite of PROMs instruments, computerized adaptive testing and an online PROMs administration and data collection system. Although there is limited use of PROMIS in national-level population health services evaluation and monitoring, national norms are available for the PROMIS Global Health Instrument (10 questions) and the PROMIS Adult Profile Instrument (29 questions).

Population-based data on health status and clinical information is also being linked in innovative ways to assess the health outcomes of patients enrolled in various health care plans. The Veterans Health Administration is the largest integrated health care delivery system in the U.S. and has played a significant role in developing and using PROMs for health services evaluation, quality monitoring and research.[13] The Veterans Health Administration developed the Veterans RAND 36- and 12-item short forms (VR-36 and VR-12) using the RAND SF-36.

Since 2006, the VR-12 has been used in the Centers for Medicare and Medicaid Services Medicare Health Outcomes Survey.[14] This survey is a large initiative that involves administering the VR-12 to approximately 200,000 people in the Medicare Advantage program annually. Data from the VR-12 is combined with survey information collected from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) and administrative data in the HEDIS to produce star ratings for the comparison of Medicare Advantage organizations.[15]

The Behavioral Risk Factor Surveillance System (BRFSS) of the Centers for Disease Control and Prevention (CDC) is another national initiative that uses PROMs for population health surveillance. The BRFSS is a national cross-sectional survey that involves the use of the 4-item "healthy days" measure for assessing health-related quality of life.[16]

Other Countries

The WHOQOL project, which began in 1991, is an example of an international PROMs initiative.[17, 18] The aim of this project was to specifically develop a quality of life assessment instrument that would facilitate cross-cultural comparisons.[17] The resulting instruments, the WHOQOL-100[18] and the WHOQOL-BREF,[19] have been used in many studies. These instruments continue to be widely used in research.

There is growing interest in using PROMs for health services evaluation and quality improvement initiatives in different countries. For example, there has been much interest in collecting PROMs for joint replacement procedures, since pain relief and improved function, among other aspects of health-related quality of life, are primary objectives of joint replacement surgery. A number of countries in addition to the U.K. have implemented national PROMs programs for joint replacements:

- The Swedish Hip Arthroplasty Register began collecting PROMs data for total hip replacement patients in 2002.[20, 21]
- The Dutch Arthroplasty Registry, the national joint replacement registry in the Netherlands, has collected PROMs since 2013. PROMs for total hip replacements have been collected pre-operatively as well as post-operatively (at 3 months and 1 year after surgery).[22]
- The New Zealand Joint Registry has collected PROMs since its inception in 1998. Data is collected from a random sample of 20% of joint replacement surgery patients.[23]
- There is also interest in collecting PROMs data among collaborators at the Danish, Norwegian and Finnish arthroplasty registers.[24]

Canadian PROMs Environment

Current uses of PROMs across Canadian jurisdictions vary. Agreement on a common approach to PROMs will help ensure that the Canadian PROMs environment will not continue to evolve in a disjointed manner. It is recognized that while there is significant benefit to having a single set of standard PROMs tools that is consistently used across Canada, jurisdictions may also want flexibility in choosing additional, optional PROMs tools for their purposes.

The ongoing and routine use of PROMs for health services quality improvement and monitoring is at the very early stages of development and consideration in Canada. PROMs initiatives in Canada predominantly involve their use for independent research projects and patient registries, and only a few examples of national PROMs initiatives were found. Although not an exhaustive list, Appendix B provides some examples of larger-scale research initiatives, projects and registries in Canada that involve PROMs.

In 2013–2014, CIHI conducted a series of stakeholder interviews to assess the PROMs environment in Canada. These discussions confirmed that there are several independent regional programs but limited leadership and coordination among initiatives at the provincial or national level. Table 2 provides a high-level summary of PROMs activities in Canadian jurisdictions. This table is intended to provide examples of PROMs activities within the provinces/territories and does not include all local PROMs initiatives.

Table 2: Examples of PROMs Initiatives in Canada

Jurisdiction	PROMs Activities
British Columbia	• Workshop held in 2013 to investigate use of PROMs in community care • Interest in more provincial PROMs activity over next year; planning to conduct consultation with health authorities • Administration of a generic PROMs tool (VR-12) with B.C.'s patient experiences surveys for a sample of inpatient and emergency department patients (April 2015) • Examples of local initiatives: Rick Hansen Spinal Cord Registry, Patient Experience with Arthroplasty of the Knee (PEAK)
Alberta	• Initial selection of generic PROMs tool (EQ-5D) by Alberta Health Services for health service user surveys; consideration of condition-specific tools for future expansion • Population norms developed for the EQ-5D in the province by the Health Quality Council of Alberta
Saskatchewan	• Initial pilot collection of PROMs data (EQ-5D and/or condition-specific) for several clinical pathways: hip and knee replacement, prostate care, lower-leg ischemia • Interested in understanding how to use PROMs provincially
Manitoba	• No province-wide initiatives at this time • Examples of local initiatives: Winnipeg Joint Replacement Group (SF-12, Oxford) Manitoba Inflammatory Bowel Disease Cohort Study (SF-36 and condition-specific tool)
Ontario	• Needs evidence of the value of large-scale PROMs collection and reporting • Potential interest in using PROMs information to support Quality-Based Procedures • Use of PROMs (ESAS and PRFS) implemented by Cancer Care Ontario to report symptoms in cancer patients
Quebec	• Quality of life measures have been used to measure program effectiveness as well as for pain and symptom management in areas such as cancer and palliative care
New Brunswick	• Quality council may have some interest but focus is still to be determined
Nova Scotia	• None known • Interest in Capital Health region
Newfoundland and Labrador	• None known
Yukon	• None known
Northwest Territories	• None known
Nunavut	• None known
Statistics Canada	• Canadian Community Health Survey (CCHS) includes the HUI; SF-36 is an optional module in the CCHS but currently no uptake by jurisdictions due to sample limitations and costs • The Health Care Outcome Measurement Project developed recommendations for approaching PROMs collection (generic and condition-specific), starting with joint replacement; competing priorities and lack of funding and resources impeded further work

Notes

EQ-5D: EuroQol 5-dimension questionnaire.

ESAS: Edmonton Symptom Assessment System.

PRFS: Patient-Reported Functional Status.

VR-12: Veterans RAND 12-Item Health Survey.

Refer to the section on PROMs tools for details on specific PROMs tools listed in the above table.

Potential Future State for PROMs in Canada

PROMs information has been identified as a high-priority area that is essential to support the achievement of health system goals. Over the next few years, PROMs have the potential to evolve into a major aspect of the measurement of health system performance. Leading provinces are already in the early stage of selecting PROMs tools and developing implementation strategies. Several other jurisdictions are considering how best to use PROMs. Taking a common approach to PROMs across Canada will provide the greatest value to jurisdictions while still allowing for flexibility to address regional priorities.

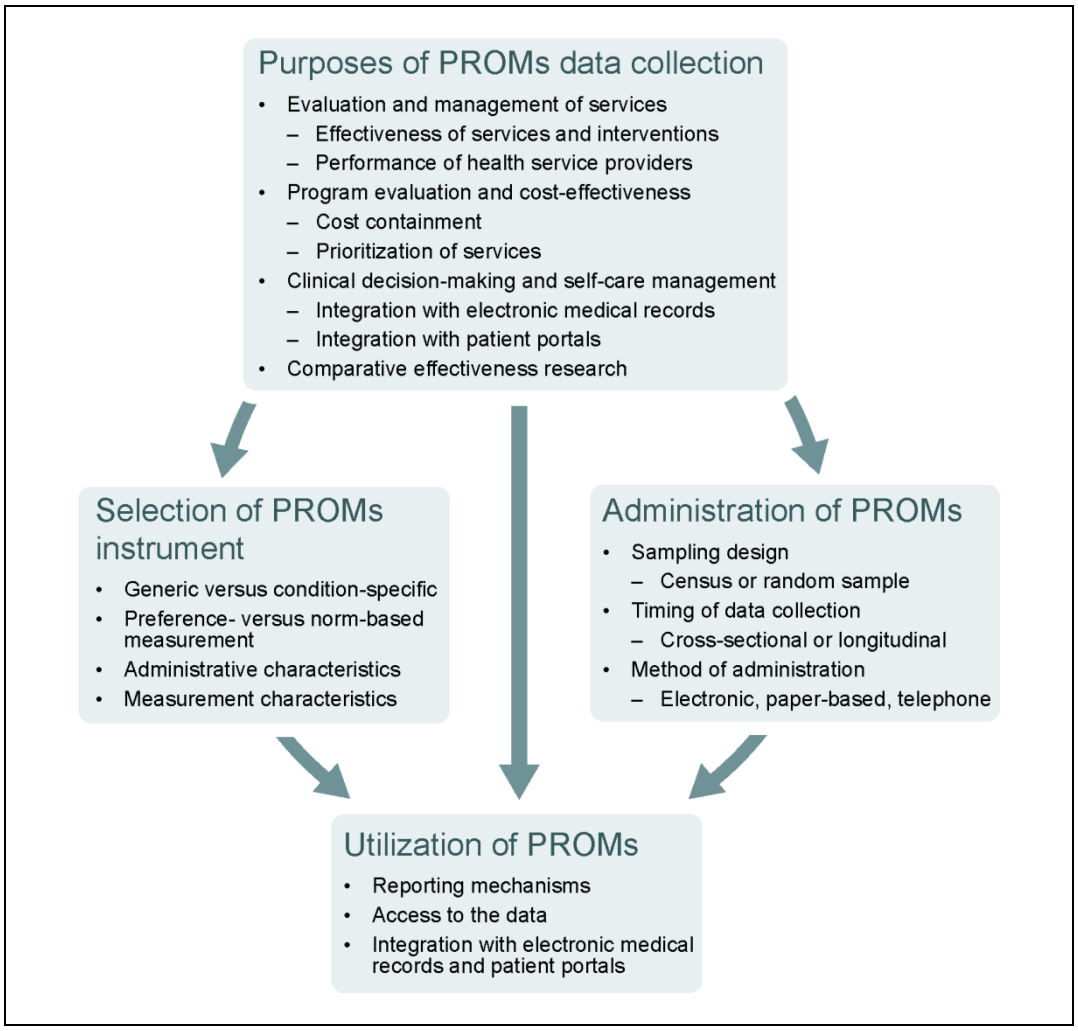
Characteristics of a PROMs future state in Canada could include the following:

- Collection of PROMs data across a broad spectrum of conditions and interventions and across a representative population of Canadian patients and providers;
- Availability of PROMs data from the acute care sector and other clinical areas (ambulatory care, primary care, long-term care, mental health) for selected conditions;
- Opportunities for jurisdictions to align PROMs choices with a national direction and the option to collect supplementary PROMs tools for their individual priorities; and
- Availability of timely PROMs data that is reported in accessible formats for those who need it.

Framework for PROMs Initiatives

The selection of PROMs tools, administration of PROMs (sampling, timing, method of administration) and utilization of PROMs data (reporting mechanism, access to data, integration with administrative and clinical data) must be aligned with the purposes of PROMs data collection and reporting.

Figure 3: Framework to Guide Decisions About PROMs Initiatives



PROMs initiatives require decisions about the selection of PROMs instruments, methods by which the instrument is administered and data is collected, and ways in which the data is reported and used. It is of fundamental importance that the characteristics of the PROMs instrument, the sampling and data collection strategies, and the reporting mechanisms align with the purposes for which PROMs data is collected (see Figure 3).

Purposes of PROMs Data Collection

The purpose of collecting PROMs information and how the data will be used will influence decisions about the selection of PROMs instruments and administration of the PROMs program. The availability of complementary clinical and administrative data should also be considered.

When developing a PROMs initiative, the purpose of collecting PROMs information and how the data will be used should be established. The development of programs for the routine collection of PROMs information has garnered the most attention. The general rationale is that information about patients' perceived health outcomes is critical for monitoring and evaluating quality of care.

When designing a PROMs program, how the data will be used must be taken into consideration. Selecting PROMs instruments includes making decisions about what is to be measured (domains) and which tools (generic and/or condition-specific) will be used. For example, utility measures are used for cost-effectiveness analysis, whereas profile scores and normative scores may be more informative for program evaluation and health services monitoring.

Uses of PROMs data will also affect decisions about the administration of the PROMs program. For example, measuring the effectiveness of surgery will require collection of PROMs information pre- and post-intervention, while monitoring chronic illness will require PROMs data to be continuously collected at multiple points over time.

Data Linkage

Most PROMs initiatives should include plans for data linkage with administrative databases or registries. The availability of relevant clinical and administrative data should also be considered when planning a PROMs program. Data linkage serves 2 important purposes:

- It prevents having to collect additional data for descriptive analytical purposes (e.g., to describe particular groups within the larger population and evaluate the representativeness of the data); and
- It allows for case mix adjustments based on available administrative data, which are recommended for obtaining meaningful comparisons across jurisdictions and care providers.[25] These adjustments require individual-level data linkage (otherwise, additional data must be collected as part of the PROMs survey itself).

PROMs Instruments

Many PROMs instruments are available. PROMs tools are categorized as generic (can be applied across different populations) or condition-specific (used to assess outcomes that are characteristic of or unique to particular diseases or sectors of care). The general recommendation is that both generic and condition-specific instruments be used, as they provide complementary information. When selecting PROMs instruments, criteria to consider include effectiveness, record of widespread use, meaningfulness, appropriateness, feasibility and availability of population norms. 4 widely used generic PROMs tools that should be considered for a national PROMs initiative are the SF-36 family (which includes the VR-12), the EQ-5D, the HUI and PROMIS.

Many PROMs instruments have been developed to evaluate the impact of health challenges and outcomes following the receipt of treatments and services. More than 700 instruments are listed in the Patient-Reported Outcome and Quality of Life Instruments Database. Most of the instruments are multidimensional in that they measure various domains of health, including symptoms, functional status and psychological and social well-being.

Generic Versus Condition-Specific PROMs

PROMs tools can be generic or condition-specific. Condition-specific PROMs are also known as disease- or population-specific PROMs. Table 3 compares the characteristics of the 2 types of PROMs tools.

Table 3: Generic and Condition-Specific PROMs

Generic PROMs	Condition-Specific PROMs
• Facilitate comparisons across different diseases and sectors of care • Can be applied in populations of people with different diseases and across health sectors • Can be used for comparisons with population norms • Generally produce utility scores that can be used to calculate quality of life–adjusted years (QALYs) for cost-effectiveness analysis • Examples: SF instruments, EQ-5D, HUI	• Designed to assess outcomes that are characteristic of or unique to particular diseases or sectors of care • Tend to be more sensitive in detecting change over time and differences between groups of people who have the same condition • Provide more detailed information that is relevant to the practice of clinicians • Typically do not produce utility scores • Do not readily facilitate the comparison of health outcomes with those of the general population or across different clinical areas

Generic PROMs developed for a general population are typically less sensitive to health outcomes that are relevant to particular diseases or conditions (e.g., they may be less sensitive to detecting changes in functional challenges, symptoms or other concerns that are relatively unique to a particular health care sector or disease). Conversely, condition-specific PROMs do not readily facilitate comparisons across different patient populations. Since generic and condition-specific instruments provide complementary information, the general recommendation is that both be used to provide the full set of information required to support a broad range of health system decision-making.[26]

General Criteria for Selecting PROMs Instruments

Agreement to use a particular PROMs instrument is a key component of a common approach to PROMs in Canada. Taking into account the purposes for which PROMs information would be used for clinical health policy and health services management, the following criteria should be considered when assessing the various PROMs tools:

- Effectiveness (reliability, validity, responsiveness)
- Track record of widespread and successful implementation
- Meaningfulness (ability to produce information that is meaningful for stakeholders)
- Appropriateness (match with target population and survey design requirements)
- Feasibility (cost, data reporting requirements, administrative characteristics)
- Potential for Canadian norm comparisons and international comparability

The selection of a PROMs instrument influences what is being measured, and the relative importance of each category depends on the intended purposes of the PROMs program. For example, some instruments, such as the EQ-5D, are relatively short but may be less sensitive to the detection of change than some longer PROMs instruments.

PROMs instruments are typically made up of questions that cover several health domains; however, there are significant differences in the extent to which different domains are presented. For example, the SF family of instruments includes relatively more items that measure mental health compared with the HUI-3 instrument, which consists predominantly of items that measure physical symptoms.

In addition, some instruments are designed to measure health profiles (they consist of subscales that represent different domains), whereas other instruments provide only an overall score (in addition to the scores of individual items). For example, the SF family of instruments measures up to 8 health domains that can be combined to produce physical and mental health scores.

Generic PROMs

Bryan et al. provide a review of widely used instruments.[27] Relatively few instruments have been adopted for widespread use at national levels. Internationally, the SF-36 family and the EQ-5D are the most commonly used PROMs instruments for health policy and health services management purposes.

The SF family of instruments (e.g., VR-12) and EQ-5D were identified as the generic tools most suitable for use in Canada. The decision about the most appropriate tool for national implementation will depend on the purposes of collecting PROMs data (i.e., the questions to be answered).

At the PROMs Forum, consideration was also given to the HUI, since this tool has been used in Canada for national initiatives, such as the CCHS. There was also interest in the potential use of PROMIS instruments; however, PROMIS has been predominantly used for research purposes rather than health system management.

Appendix B provides a comparative review of the 4 generic PROMs instruments that were considered for a national PROMs initiative in Canada. A summary of these tools follows in Table 4.

Table 4: Widely Used Generic PROMs Tools

	SF-36/SF-12/ VR-36/VR-12	EQ-5D	HUI	PROMIS GH
Description	36 questions Short forms available (12 questions) Provides a profile of 8 domains	5 questions 5 dimensions: mobility, self-care, usual activities, pain/ discomfort, anxiety/ depression	15 items Predominantly physical symptoms Also measures function and mental health	A system that includes many PROMs Measures physical, mental and social health domains
Languages	Many translations, including English and French	Many translations, including English and French	Many translations, including English and French	Translation efforts are in progress Many instruments available in English, Spanish and Dutch Currently not available in French
Administration	Pen and paper Telephone Online/electronic	Pen and paper Telephone Online/electronic	Pen and paper Telephone	Pen and paper Telephone Online/ electronic

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Table 4: Widely Used Generic PROMs Tools (cont'd)

	SF-36/SF-12/ VR-36/VR-12	EQ-5D	HUI	PROMIS GH
Psychometric Reliability/ Validity	Strong evidence base for reliability and validity, including cross-cultural studies	Weaker evidence of validity and reliability than other instruments	Weaker evidence of validity and reliability than other instruments	Rigorous reliability and validity testing using modern methods (item response theory)
Scoring	Scores can be mapped onto utilities Population norms available	Provides an overall health utility score Overall health utility score produced using a visual analogue scale/ "thermometer"	Provides an overall health utility score Individual item scores can also be used	Provides scaled scores Profile scores are also available U.S. population norms are available for several of the instruments
Opportunities and Challenges	Most widely published instrument Several different versions	One of the most widely used health utility PROMs (used in the NHS PROMs Initiative) Has been critiqued for lack of sensitivity and reliability of domain scores (this concern applies to all short PROMs instruments)	Used in Statistics Canada's CCHS	Rigorous psychometric testing already completed Computer adaptive tests available to reduce response burden Developing a large network of U.S. and international researchers
Cost	Some versions are proprietary and come at a cost The VR instruments are free	Licensing fees are determined by the EuroQol Executive Office on the basis of the user information provided on registration Costs depend on the type of study/ trial/project, funding source, sample size and number of requested languages	In general, the minimum licensing fee is US$3,000 for use of 1 version of HUI questionnaire and appropriate coding procedures manual in 1 study If the study requires more than 1 questionnaire, the fee schedule becomes more complicated	Free to use

Administration of PROMs

The choice of design depends on the purposes of collecting PROMs data. The 3 dominant models of large-scale PROMs administration are pre- and post-intervention, longitudinal and cross-sectional.

The 3 dominant models of large-scale PROMs administration are pre- and post-intervention, longitudinal and cross-sectional. The choice of design depends on the purposes of collecting PROMs data. The following table provides a comparison of these approaches.

Table 5: Models of PROMs Administration

	Pre- and Post-Intervention	Longitudinal (Multiple Points Over Time)	Cross-Sectional
Purposes	Evaluate relative impact of intervention(s) or service(s) Approach used for elective surgeries	Evaluate whether health outcomes improve or decline over time Compare relative differences in improvements across service providers	Establish norms or benchmarks for different population groups (e.g., different regions, service providers)
Benefits	Readily interpretable change scores Directly answers the question of how much improvement people experienced (e.g., before and after surgery)	Applicable to populations or health care sectors where there is no single intervention but rather a series of complex and ongoing interventions	Facilitates relative comparisons
Limitations	Does not apply as readily to contexts of complex or multiple interventions, or contexts where change may be inconsistent over a prolonged period of time (i.e., the optimal time for administering the PROMs instrument is unknown)	More difficult to isolate the impact of a particular intervention Presumably a more complex design, depending on the context in which it is applied	Cannot evaluate impact based on change scores
Examples	NHS PROMs Initiative with application to elective surgery Joint replacement surgeries	MOS (administration of PROMs in annual cohorts of health care recipients with 1- or 2-year follow-ups) Chronic conditions in primary care or residential care	Population health surveillance

Sampling Considerations

Sampling considerations include whether the PROMs instrument should be administered to the entire target population (e.g., an entire registry or service sector) or whether it should be administered to a random sample of people from the target population. The amount of data required depends largely on the purposes for which the data is collected. If PROMs are to be used for comparisons of individual service providers, all recipients may need to be surveyed to enable the detection of statistically significant differences. If the goal is to compare larger jurisdictions, a random sample of recipients may suffice.

In national initiatives focused on health services evaluation, PROMs have typically been administered to all recipients of a particular service (e.g., elective surgeries in the U.K., Medicare recipients in the U.S.). Given the complexities and potential costs of developing and administrating a random sampling design within each jurisdiction across Canada, a census-based approach that includes all service recipients may be the more cost-effective solution.

Method of Administration

Since PROMs are self-report instruments, surveys are typically self-administered or conducted via an interviewer who records the patient's perspective. Information can be collected on paper surveys or electronically. For example, patients can complete a PROMs survey (e.g., via a computer in the waiting room or an online tool at home) prior to their clinician assessment and evaluation.

Compared with paper surveys, collecting PROMs electronically may be more cost-effective and provide timelier information (e.g., provide immediate feedback to clinicians). Electronic PROMs also have the opportunity to reduce respondent burden (e.g., via computer adaptive testing).

Clinical Areas of Interest

Elective surgery and chronic illness care are 2 general clinical areas to consider for initial PROMs data collection. Many condition-specific PROMs tools may exist for a particular clinical area.

When planning a large-scale PROMs initiative, it may be useful to initially focus PROMs data collection and reporting on a small number of specific clinical areas. This will allow the value of PROMs information in those areas to be demonstrated before expanding PROMs data collection and reporting to other clinical areas.

Elective surgery and chronic illness care are 2 general clinical areas to consider for initial PROMs data collection. Characteristics of PROMs data collection and use in these 2 areas are summarized in Table 6.

Table 6: Clinical Areas to Consider for a National PROMs Initiative

Elective Surgeries	Chronic Illness Care
Surveys are typically offered pre- and post-surgery and administered at specific times	Surveys are administered longitudinally (e.g., baseline with annual follow-ups)
Data is used to evaluate patient outcomes following surgeries	Data is used to evaluate patient outcomes over time
Combined generic and condition-specific PROMs instruments	Combined generic and condition-specific PROMs instruments
Examples • Orthopedic surgeries (hip and knee arthroplasty) • Cataract surgeries • Cardiac procedures (coronary artery bypass graft, angioplasty) • Inpatient and major outpatient surgeries	Examples • Renal dialysis • Congestive heart failure • Community mental health • Chronic obstructive pulmonary disease • Cancer treatments (systemic and radiation therapies, surgeries)

At the CIHI PROMs Forum, preferred clinical areas for initial PROMs collection and reporting were hip and knee replacements, mental health and renal care. PROMs in hip and knee replacements and renal care are supported by existing relationships with and confirmed readiness from the clinical community, and are 2 areas where initial demonstration projects will be implemented to illustrate the value of PROMs in Canada.

Appendix A: International PROMs Initiatives

International PROMs Initiatives — Examples	
United Kingdom: NHS PROMs Initiative[26]	
Population	• Currently focused on elective surgeries (knee, hip, varicose veins, hernia repair) • Future plans to focus on other conditions, including mental health, cancer and long-term conditions (diabetes, asthma, chronic obstructive pulmonary disease, heart failure, stroke, epilepsy)
PROMs and Other Data	• Generic: EQ-5D (all) • Condition-specific: SF-36 (hernia), Oxford Knees Score, Oxford Hips Score, Aberdeen Varicose Vein Questionnaire • Linkage with Hospital Episodes Statics and National Joint Registry data
Data Collection	• Ongoing since 2009 • Pre- and post-surgery (3 to 6 months after surgery); post-surgery questionnaire is completed by the patient at home • Census-based (no sampling) • Official recruitment rates vary from 44.7% to 81.0% depending on the surgery (note that these rates are overestimated)[28, 29] • Response rates range from 64.8% to 85.1%; rates are greatest for joint replacement surgeries
Considerations (Opportunities and Challenges)	• Health services evaluation; inform patient treatment choices • Health services evaluation includes an explicit focus on reduction of health inequalities; this may be of particular interest to Canadian health care • One of the goals is for patients to be able to use this information to choose between providers; this is perhaps not so realistic in a Canadian context • The initiative is sector-based in that only a few selected health services are currently included, but there are plans to include more sectors • There is some concern about missing data and whether the results are therefore truly representative
United States: Medicare Health Outcomes Survey Program	
Population	• General population of Medicare recipients (predominantly older adults with chronic conditions)
PROMs and Other Data	• Generic: VR-12 • Condition-specific: None • Other variables: Health services and demographic questions (self-reported)
Data Collection	• Ongoing since 1998 • Annual cohorts with 2-year follow-up • ~200,000 per cohort (297,974 in 2012; 51.5% response rate)[15]
Considerations (Opportunities and Challenges)	• Monitoring the quality of care provided by Medicare Advantage organizations • Predominant focus on older adults with chronic conditions. Data collection is not focused on any sector in particular, nor is there a pre- and post-services design; a 2-year follow-up design is used instead. • This type of design is a good option if the intent is to focus on primary care, including different sectors • Used in combination with CAHPS survey data and other data in the HEDIS to help produce star ratings for comparison of service providers

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International PROMs Initiatives — Examples (cont'd)

United States: Patient-Reported Outcomes Measurement Information System	
Population	• Current predominant focus on general populations with a range of chronic disorders and diseases
PROMs and Other Data	• Uses item banks and short forms of PROMs instruments that measure many aspects of physical, mental and social health • National norms are available for the PROMIS Global Health Instrument (10 questions) and the PROMIS Adult Profile Instrument (29 questions)
Data Collection	• PROMIS Assessment Center is a comprehensive online research management tool that facilitates administration of PROMIS instruments, data collection and data sharing • Currently limited use of PROMIS measures in national-level population health services evaluation and monitoring. However, there is interest in using particular PROMIS tools, including the Global Health Instrument (10 questions) and the Adult Profile Instrument (29 questions) that are based on modern state-of-the-art science.
Considerations (Opportunities and Challenges)	• The vision is "to provide clinicians and researchers access to efficient, precise, valid, and responsive adult- and child-reported measures of health and well-being"[30] • Started in 2004 and funded by the National Institutes of Health, PROMIS is both an initiative and a system (tool) for patient-reported outcomes measurement for clinical research • The PROMIS Global Health (10 items) and Adult Profile (29 items) instruments may be the way of the future, but they do not yet have a strong track record of widespread use
United States: Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System	
Population	• General population
PROMs and Other Data	• Generic: Healthy days (CDC HRQOL–4 and CDC HRQOL–14) • Condition-specific: None • Other variables: Demographics, health behaviours, chronic conditions
Data Collection	• Ongoing large-scale national data collection starting in 1993 (first data collection in 1983; currently ~400,000 per year) • Cross-sectional design (no follow-up) • Stratified random sampling • Data collected by phone
Considerations (Opportunities and Challenges)	• Purpose is "to collect uniform, state-specific data on preventive health practices and risk behaviors that are linked to chronic diseases, injuries, and preventable infectious diseases that affect the adult population"[31] • Somewhat similar to the CCHS in focus and design, but the BRFSS uses different instruments

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International PROMs Initiatives — Examples (cont'd)

Sweden: Hip Arthroplasty Register[20, 21]	
Population	• Hip replacement surgery population (registry)
PROMs and Other Data	• Generic: EQ-5D • Condition-specific: Charnley functional assessment • Other variables: Visual analogue scale for pain and satisfaction with outcome of care
Data Collection	• All hip replacement surgery patients • Part of the Hip Arthroplasty Register • Data collection pre-surgery and 1, 6 and 10 years post-surgery • Administered at the clinics via questionnaire or touch-screen computers • Post-surgery data collected via mail survey (response rate = 92%) and internet (response rate = 49%)
Considerations (Opportunities and Challenges)	• The overall aim is "to monitor and improve outcome of THR [total hip replacement] for each patient in Sweden"[20] • An example of including PROMs in a national registry; the initiative appears to be very successful with relatively low rates of missing data • There is some evidence of the utility of the PROMs data in informing health services

Appendix B: Canadian PROMs Initiatives

Canadian PROMs Initiatives — Examples	
National: Canadian Community Health Survey (Statistics Canada)	
Population	• Canadian population, excluding people living in institutions, members of the Canadian Armed Forces and people living on Aboriginal reserves
PROMs and Other Data	• Generic: HUI, RAND SF-36 (optional module) • Other variables: Many other measures of health status, health care utilization and health determinants
Data Collection	• Annual cross-sectional survey • Stratified clustered random sampling to ensure representation of health regions and particular population groups (oversampling of youth and older adults) • Data collected using computer-assisted interviewing • 65,000 respondents per year (response rate for 2012 = 67.0%)
Considerations (Opportunities and Challenges)	• Purpose is to support health surveillance programs and population health research • Largest ongoing health survey in Canada that includes PROMs • The CCHS could be an important resource for normative comparisons, provided the same PROMs instruments are used. Alternatively, the possibility of adding another PROMs instrument to the CCHS could be explored. • Probabilistic linkage may be desirable for purposes of case mix adjustments
National: Spinal Cord Injury Registry (Rick Hansen Research Institute)	
Population	• Patients with traumatic spinal cord injury in 31 facilities across Canada in 9 of 10 provinces (plans to include non-traumatic spinal cord injury patients in 2015)
PROMs and Other Data	• Generic: SF-36 • Other clinical variables, including the Functional Impairment Measure (FIM®) • Data is linked to the Discharge Abstract Database and National Trauma Registry
Data Collection	• Longitudinal since 2004 (baseline, 1, 2, 5 years, and every 5 years thereafter) • Response rates vary by site (between 90% and 40%)
Considerations (Opportunities and Challenges)	• Example of an ongoing longitudinal registry that includes a generic PROM
National: Canadian Multicentre Osteoporosis Study	
Population	• People with osteoporosis in Canada
PROMs and Other Data	• Generic: SF-36 (version 2), HUI
Data Collection	• Longitudinal since 1995 baseline with annual follow-up; 9,423 at baseline
Considerations (Opportunities and Challenges)	• Data collected predominantly for research purposes • Used to establish Canadian population norms for the SF-36[32]

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Canadian PROMs Initiatives — Examples (cont'd)

British Columbia: Patient Experience With Arthroplasty of the Knee (PEAK Project)	
Population	• Knee replacement surgery patients in B.C. (~500)
PROMs and Other Data	• Generic: EQ-5D, SF-12 • Condition-specific PROM: Western Ontario and McMaster Universities Arthritis Index (WOMAC) • Other variables: Satisfaction with outcomes
Data Collection	• Longitudinal: baseline, pre-surgery and 6 and 12 months post-surgery • Baseline sample size = 515; response rate = 87% • Data collected via mailed questionnaire, starting in 2011
Considerations (Opportunities and Challenges)	• A research project to examine factors predictive of satisfaction with surgical outcomes
Alberta: Edmonton Heart and Lung Transplant Clinic Pilot Project[9]	
Population	• Pre- and post-operative transplant patients
PROMs and Other Data	• Generic: HUI (Mark 2 and Mark 3)
Data Collection	• Pre-operative health information collected when a patient was placed on the transplant list • Post-operative information collected each time the patient attended the clinic • Patients used touch screens to complete survey while waiting to see the clinical team
Considerations (Opportunities and Challenges)	• Goal was to collect and use health-related quality-of-life (HRQL) information for the care of patients before and after surgery to assess the feasibility of including HRQL measures in routine patient care and training clinicians to use this information • HUI score was graphically presented, printed, added to the patient's medical file; the clinical team then reviewed the information before examining the patient • The patient's medical file contained all previous HUI data, so clinicians could readily assess the patient's health outcomes over time
Alberta: Alberta Health Services	
Population	• Several current initiatives, including the Alberta Health Services Bone and Joint Strategic Clinical Network, South Alberta Renal Program, Integrated Symptom Relief Service (cancer) and Health Quality Council of Alberta
PROMs and Other Data	• Predominant interest in the EQ-5D, with possibility of including condition-specific measures
Data Collection	• Most initiatives use longitudinal data collection. Since 2009, the Health Quality Council of Alberta has implemented the EQ-5D in population surveys (presumably cross-sectional).
Considerations (Opportunities and Challenges)	• Intended to target a range of audiences, from high-level decision-makers to clinicians at point of care • The EQ-5D was predominantly selected because of practical advantages: short length, different formats, simplicity and availability of health utilities to calculate QALYs

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Canadian PROMs Initiatives — Examples (cont'd)

Saskatchewan: Surgical Care[9]	
Population	• All elective surgery patients
PROMs and Other Data	• Generic: EQ-5D
Data Collection	• Survey is completed at 4 key points in the care path (initial admission to clinic, pre-operative assessment in the clinic, 3 months after surgery, 1 year after surgery)
Considerations (Opportunities and Challenges)	• Initiative by the Ministry of Health in Saskatchewan to provide data to understand and standardize patients' care paths and changes in patients' health status along the path
Manitoba: Inflammatory Bowel Disease Cohort Study	
Population	• Manitoba residents recently diagnosed with Crohn's disease or ulcerative colitis
PROMs and Other Data	• Generic: SF-36 • Condition-specific: Inflammatory Bowel Disease Questionnaire
Data Collection	• A longitudinal cohort with baseline in 2003 and 6-month follow-ups • Sample size: 388 individuals at baseline; 86% response rate
Considerations (Opportunities and Challenges)	• Used for research purposes
Manitoba: Hip and Knee Replacements[9]	
Population	• Joint replacement patients in Manitoba
PROMs and Other Data	• Generic: SF-12 • Condition-specific: WOMAC, Oxford Score • Other variables: Complications, dislocations, pulmonary embolisms and infections
Data Collection	• Surveys completed before surgery at the pre-admission clinic and 1 year after surgery as part of the post-op consultation
Considerations (Opportunities and Challenges)	• Used to assess effectiveness of surgery
Ontario: Electronic Rheumatology (eRheum) Initiatives Research Program[9]	
Population	• Rheumatology patients in Toronto
PROMs and Other Data	• Generic: SF-36 • Condition-specific: Health Assessment Questionnaire (rheumatology-specific)
Data Collection	• Survey completed during in-office wait time on computers located in waiting room or via a secure online system prior to the visit
Considerations (Opportunities and Challenges)	• Integrates electronic capture and reporting of patient self-reported data into service delivery • Survey information is provided to clinician to guide the clinical encounter • Goal is to improve quality of patient care

Appendix C: Comparing Generic PROMs Tools

Criteria	SF-36/SF-12/ VR-36/VR-12	EQ-5D	HUI	PROMIS Global Health Instrument
Effectiveness				
Scientifically valid and reliable	+++	+/-	+/-	++
Responsive for detection of change and meaningful differences	+++	--	+/-	++
Track record of widespread and successful implementation	+++	+++	++	+
Meaningfulness: Ability to produce meaningful information for stakeholders				
Population norms: To allow for normative comparisons	✓(CDN)	✓(CDN)	✓(CDN)	✓(CDN)
Utility scores: Allows for the computation of QALYs and cost-effectiveness analysis	✓	✓(CDN)	✓(CDN)	✓
Clinically important differences: Required to interpret what amount of change in scores denotes a relevant change	✓	✓	✓	✓
Measures the relevant domains of interest	Multiple physical and mental health domains	Overall score and single items Predominantly physical health	Overall score and single items Predominantly physical symptoms and function	Overall score and single items Equal distribution of important domains
Appropriateness: Match with target population and survey design requirements				
Requirement for multiple translations: minimally English and French, but should include other common languages	+++	+++	++	+
Multiple modes of administration	Paper-based Telephone Online	Paper-based Telephone Online	Paper-based Telephone	Paper-based Telephone Online
Feasibility				
Cost and licensing fees	VR-36 and VR-12 versions are free QualityMetric versions are proprietary and require licensing fees	Licensing fees; costs depend on the type of project, funding source, sample size and number of requested languages	Licensing fees	Free
Data reporting requirements	None	None	None	None

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Criteria	SF-36/SF-12/ VR-36/VR-12	EQ-5D	HUI	PROMIS Global Health Instrument
Length of the instrument	SF-12: 12 items 453 words	6 items 239 words	15 items 1,173 words	10 items 217 words
Time for completion	SF-12: “few minutes”	2 minutes	1–10 minutes	2 minutes
Readability: Flesch-Kincaid Grade Level	SF-12: 7.1	10.6	7.4	7.6

Legend

+++ or ---: Strong evidence.

++ or --: Moderate evidence.

+ or -: Limited evidence.

+/-: Conflicting evidence.

Source

Adapted from The Centre for Clinical Epidemiology and Evaluation. *What Are the Most Effective Ways to Measure Patient Health Outcomes of Primary Health Care Integration Through PROM (Patient Reported Outcome Measurement) Instruments?* 2013.

References

1. Fayers P, Machin D. *Quality of Life: The Assessment, Analysis and Interpretation of Patient-Reported Outcomes.* 2007.
2. U.K. Department of Health. *Guidance on the Routine Collection of Patient Reported Outcomes Measures (PROMs)*. 2009.
3. Bowling A. *Measuring Health: A Review of Quality of Life Measurement Scales*. 3rd ed. 2005.
4. Ferrans CE. Definitions and conceptual models of quality of life. In: Lipscomb J, Gotay CC, Snyder C, eds. *Outcomes Assessment in Cancer: Measures, Methods, and Applications*. 2005.
5. Grant MM, Dean GE. Evolution of quality of life in oncology and oncology nursing. In: King CR, Hinds PS, eds. *Quality of Life From Nursing and Patient Perspectives: Theory, Research, Practice*. 2003.
6. Padilla GV, Grant MM. Quality of life as a cancer nursing outcome variable. *Advances in Nursing Science*. October 1985.
7. Spilker B. *Quality of Life and Pharmacoeconomics in Clinical Trials*. 2nd ed. 1996.
8. U.S. Department of Health and Human Services, Food and Drug Administration. *Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims*. 2009
9. Canadian Institute for Health Information, Statistics Canada. *Health Outcomes of Care: An Idea Whose Time Has Come: A Framework for Health Outcomes*. 2012.
10. Canadian Institute for Health Information. *A Performance Measurement Framework for the Canadian Health System*. 2012.
11. Tarlov AR, Ware JE Jr, Greenfield S, Nelson EC, Perrin E, Zubkoff M. The medical outcomes study: an application of methods for monitoring the results of medical care. *Journal of the American Medical Association*. August 1989.
12. Hays R, Sherbourne CD, Mazel RM. *User's Manual for the Medical Outcomes Study (MOS) Core Measures of Health-Related Quality of Life*. 1995.
13. Selim AJ, Berlowitz, D, Kazis LE, et al. Comparison of health outcomes for male seniors in the Veterans Health Administration and Medicare Advantage plans. *Health Services Research*. April 2010.
14. Kazis LE, Selim AJ, Rogers W, Qian SX, Brazier J. Monitoring outcomes for the Medicare Advantage program: methods and application of the VR-12 for evaluation of plans. *The Journal of Ambulatory Care Management.* October/December 2012.
15. Centers for Medicare and Medicaid Services, Health Services Advisory Group. *Medicare Health Outcomes Survey: Sample 2012 Cohort 15 Medicare Advantage Organization Baseline Report*. 2013.

16. Mokdad AH. The behavioral risk factors surveillance system: past, present, and future. *Annual Review of Public Health*. April 2009.

17. The WHOQOL Group. The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social Science and Medicine*. November 1995.

18. The WHOQOL Group. The World Health Organization quality of life assessment (WHOQOL): development and general psychometric properties. *Social Science and Medicine*. June 1998.

19. The WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*. May 1998.

20. Rolfson O, Karrholm J, Dahlberg LE, Garellick G. Patient-reported outcomes in the Swedish Hip Arthroplasty Register: results of a nationwide prospective observational study. *The Journal of Bone and Joint Surgery*. July 2011.

21. Rolfson O, Salomonsson R, Dahlberg LE, Garellick G. Internet-based follow-up questionnaire for measuring patient-reported outcome after total hip replacement surgery — reliability and response rate. *Value in Health.* March–April 2011.

22. Dutch Arthroplasty Register. What PROMs. Accessed January 2015.

23. Rolfson O, Rothwell A, Sedrakyan A, et al. Use of patient-reported outcomes in the context of different levels of data. *The Journal of Bone and Joint Surgery*. December 2011.

24. Healio. European orthopaedic community steps up its adoption of patient-based outcomes. Accessed January 2015.

25. Nuttall D, Parkin D, Devlin N. Inter-provider comparison of patient-reported outcomes: developing an adjustment to account for differences in patient case mix. *Health Economics*. September 2013.

26. Devlin NJ, Appleby J. *Getting the Most Out of PROMs: Putting Health Outcomes at the Heart of NHS Decision-Making*. 2010.

27. The Centre for Clinical Epidemiology and Evaluation. *What Are the Most Effective Ways to Measure Patient Health Outcomes of Primary Health Care Integration Through PROM (Patient Reported Outcome Measurement) Instruments?* 2013.

28. Hutchings A, Neuburger J, van der Meulen J, Black N. Estimating recruitment rates for routine use of patient reported outcome measures and the impact on provider comparisons. *BMC Health Services Research*. February 2014.

29. Hutchings A, Neuburger J, Grosse Frie K, Black N, van der Meulen J. Factors associated with non-response in routine use of patient reported outcome measures after elective surgery in England. *Health and Quality of Life Outcomes.* March 2012.

30. PROMIS. PROMIS mission, vision & goals. Accessed May 26, 2015.

31. Centers for Disease Control and Prevention. *Behavioral Risk Factor Surveillance System — Overview: BRFSS 2013*. 2014.

32. Hopman WM, Towheed T, Anastassiades T, et al. Canadian normative data for the SF-36 health survey. Canadian Multicentre Osteoporosis Study Research Group. *Canadian Medical Association Journal*. August 2000.

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