



for Health I

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Acknowledgements

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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.,

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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 understand whether health care services and procedures make a difference to patients' health status and quality of life. PROMs provide insight on the

- x 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.
- x 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.
- x 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

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-

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

United States

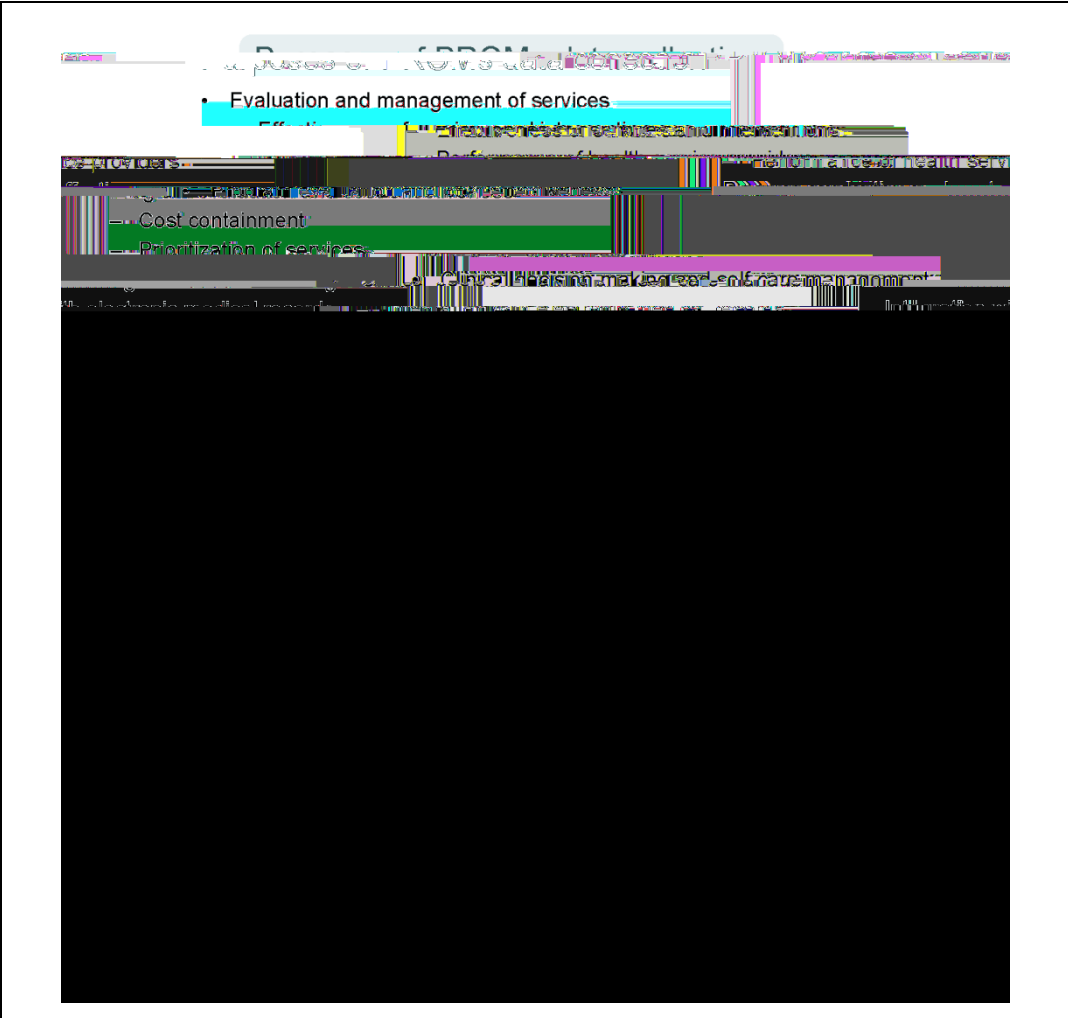
In the U.S., PROMs are integral to the Institute for Healthcare Improvement's [Triple Aim](#) mandate to improve the patient experience of care (including quality and satisfaction), improve the health of populations and reduce the per capita cost of health care.

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-odiMonittTd [(om)ni MOro

Framework for PROMs Initiatives

The selection of PROMs tools, administration of PROMs (sampling, timing, 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).

Generic PROMs

Bryan et al. provide a review of generic PROMs. The review includes a list of generic PROMs and their associated evidence. The review also discusses the challenges of using generic PROMs and provides recommendations for their use.

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				

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 administering 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 conditions 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.

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Appendix A: International PROMs Initiatives

International PROMs Initiatives — Examples

United Kingdom: NHS PROMs Initiative ²⁶

Population	<ul style="list-style-type: none"> x Currently focused on elective surgeries (knee, hip, varicose veins, hernia repair) x 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	<ul style="list-style-type: none"> x Generic: EQ-5D (all) x Condition-specific: SF-36 (hernia), Oxford Knees Score, Oxford Hips Score, Aberdeen Varicose Vein Questionnaire x Linkage with Hospital Episodes Statics and National Joint Registry data
Data Collection	<ul style="list-style-type: none"> x Ongoing since 2009 x Pre- and post-surgery (3 to 6 months after surgery); post-surgery questionnaire is completed by the patient at home x Census-based (no sampling) x Official recruitment rates vary from 44.7% to 81.0% depending on the surgery (note that these rates are overestimated)^{28, 29} x Response rates range from 64.8% to 85.1%



Appendix C: Comparing Generic PROMs Tools

Criteria

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