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PROMs

Forum Proceedings



Canadian Institute
for Health Information

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CIHI PROMs Forum Proceedings

Acknowledgements

The Canadian Institute for Health Information (CIHI) would like to thank everyone who attended the Patient-Reported Outcome Measures (PROMs) Forum for their valuable contributions and enthusiastic participation. We would also like to express appreciation to the external speakers (Drs. Eric Bohm, Stirling Bryan, Scott Klarenbach, Bob Kaplan, Lewis E. Kazis, Rick Sawatzky and Andrew Vallance-Owen) and CIHI speakers (Brent Diverty, David O’Toole and Dr. Jeremy Veillard) who presented at this event.

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Executive Summary

In February 2015, CIHI hosted the Patient-Reported Outcome Measures (PROMs) Forum to provide an opportunity for Canadian health leaders to discuss PROMs and to explore considerations and opportunities for advancing a common approach to PROMs in Canada. Participants included senior policy-makers from federal/provincial/territorial governments, senior health system decision-makers, international guests and selected clinicians and senior researchers actively involved in using PROMs. PROMs experts from the United Kingdom, the United States and Canada shared their experiences with the implementation of PROMs programs and the use of PROMs data. A round-table discussion summarized the status of PROMs use in Canada. The following provides highlights of the discussions at the forum.

The importance of PROMs to support health system performance was presented. PROMs provide information from patients' perspectives regarding their health status and are essential to support a patient-centred approach to care. Clinical, administrative and patient-reported experience measures data can be enriched with PROMs information. Standardized PROMs information is important to allow for comparative reporting regionally, nationally and internationally. Data collected from PROMs has the potential for widespread use across the health care system, including for health system management, policy-making and decision-making. Health system goals identified by participants that would most benefit from PROMs information were improving quality and evaluating the impact of health care interventions.

Hip and knee replacements, renal care and mental health were identified as the current clinical areas of significant interest on which to focus initial PROMs data collection and reporting. Clinical experts in hip and knee replacements and in renal care highlighted the opportunities to use PROMs to enhance patient care and outcomes. PROMs in hip and knee replacements and renal care are supported by the clinical community and would be areas where a demonstration project could illustrate the value of PROMs.

PROMs tools are categorized as generic (can be applied across different populations) or condition-specific (are used to assess outcomes that are characteristic of or unique to particular diseases or sectors of care). The applicability of tools and indicators will vary between the general population and specific clinical areas. Typically, generic and condition-specific instruments are administered concurrently, as they provide complementary information. The VR-12 and EQ-5D were the 2 generic PROMs tools identified as most suitable for routine PROMs data collection and use in Canada. The differences between these instruments were discussed. Participants indicated a preference for selecting a common tool for use across Canada. Additional discussions will be required to select a preferred generic tool.

Considerations for PROMs initiatives, including the selection and utilization of PROMs, were also discussed. Clarity around the purpose of collecting PROMs information is mandatory to ensure an appropriate PROMs program is planned. Factors that may influence response bias and the use of statistical analyses or case mix methodologies to adjust PROMs results to improve accuracy of analysis were highlighted. Patient engagement and education were also identified as vital. In addition to a well-defined purpose for collecting PROMs, jurisdictional support and buy-in from clinical champions were noted as important success factors. Limited resources for data collection and engagement of stakeholders were identified as the most challenging factors to overcome. Leveraging existing infrastructure and systems to minimize resource requirements and data collection burdens would help mitigate these challenges.

CIHI will continue to support the advancement of PROMs in Canada. Initiatives include forming an advisory group to further discuss PROMs and collaborating with stakeholders to implement PROMs demonstration projects. CIHI will also assess existing infrastructure and initiatives to move PROMs forward, such as evaluating the feasibility of submitting PROMs data to CIHI's existing data holdings, including clinical registries as well as acute and ambulatory databases like the Discharge Abstract Database (DAD) and the National Ambulatory Care Reporting System (NACRS).

Introduction and Background

Patient-reported outcome measures (PROMs) are measurement instruments that patients complete, typically pre- and post-treatment, to provide information on aspects of their health status that are relevant to their quality of life. PROMs provide insight on the effectiveness of care from patients' perspectives and complement existing clinical and administrative information to support the evaluation of health system performance. Despite the long-standing promotion of a patient-centred approach to health and health care, a data and reporting gap remains in the patient perspective dimension of CIHI's Health System Performance Measurement Framework. CIHI has made progress in filling this gap with the development of the Canadian Patient Experiences Reporting System (CPERS) to support the collection of patient-reported experience measures (PREMs). CIHI is actively exploring options to further enhance the availability of patient-reported measures by assessing the potential for standardized administration, collection and use of PROMs.

In 2013–2014, CIHI conducted an environmental scan of the Canadian and international PROMs landscape. It confirmed that while there are some regional-level PROMs initiatives, a standardized program for routine PROMs collection and reporting does not exist in Canada. 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 options for implementing PROMs data collection and reporting. In response, CIHI coordinated the pan-Canadian PROMs Forum to advance the development of PROMs information across Canada.

CIHI's PROMs Forum was held on February 3 and 4, 2015, in Toronto, Ontario. The 60 participants who attended this invitational event included senior policy-makers from federal/provincial/territorial governments, senior health system decision-makers, international guests and selected clinicians and senior researchers actively involved in using PROMs. The goal of this event was to provide Canadian health leaders an opportunity to discuss PROMs and explore considerations and opportunities for standardizing PROMs data collection and reporting across Canada. Specific objectives of the forum were to

- Achieve a shared understanding of PROMs and how PROMs can be used to support jurisdictions on a range of health system goals;
- Discuss considerations for a common approach to PROMs data collection and use, such as PROMs tools suitable for routine administration across Canada, potential clinical areas to focus initial data collection efforts on, and success factors and barriers regarding the implementation of PROMs data collection and reporting; and
- Assess interest in and capacity to participate in standardized PROMs collection and reporting, as well as to agree on next steps for collaborative project work, including a demonstration project.

The forum included formal presentations and opportunities for discussion. It was organized in 3 sessions: PROMs Use in Health Care, Considerations for Implementing a PROMs Program and Advancing the Use of PROMs Across Canada. The PROMs Forum agenda and speaker biographies are available in appendices A and B.

This document summarizes the discussions that took place during the PROMs Forum. For general information on PROMs, including findings from the environmental scan conducted by CIHI and additional resources, refer to the PROMs Background Document.

Session 1: PROMs Use in Health Care

The Case for PROMs in Canada's Health Systems

The PROMs Forum began with 2 presentations that provided participants with an appreciation of why PROMs are needed to support health system performance.

The Importance of PROMs in Health Care

Dr. Stirling Bryan reviewed the use of PROMs in health system management and policy-making. He indicated that PROMs could be used to improve the quality of health care services as they would inform demand and preferences by supporting shared decision-making between the patient and provider and help identify how services can be improved (e.g., by understanding the appropriateness of services).

To keep clinicians engaged, Dr. Bryan suggested focusing on the use of PROMs for quality improvement. Prematurely linking improvements in PROMs to reimbursement programs may result in a loss of support from service providers.

Since there are costs involved in planning and implementing PROMs initiatives, there needs to be an understanding of the value proposition (improvement versus investment) of this work. PROMs data collected from routine care and delivery has the potential for widespread use across the health care system. PROMs have been used in health research and are increasingly used for program management (evaluation and quality improvement), policy decision-making and delivery of individual patient care.

The Potential Role for PROMs in Canada — A CIHI Perspective

Information from patients' perspectives is required to support a patient-centred approach to care. Dr. Jeremy Veillard presented on the need for standardized PROMs information, such as for comparative reporting, and the ability to link PROMs with other data sources to better inform decisions. PROMs complement existing clinical and administrative data as well as PREMs. Within CIHI's Health System Performance Measurement Framework, there are 3 areas — health outcomes, quality of care and spending (value for money) — where PROMs data would be informative.

The Organisation for Economic Co-operation and Development (OECD) has initiated a working group to review the status of PROMs internationally and to advocate for comparable PROMs measurements across countries. It is important that Canada develop an approach that will enable comparison of Canadian results internationally.

International PROMs Initiatives

PROMs experts from the United Kingdom and the United States were invited to share their experiences with the development and implementation of successful national PROMs programs.

PROMs in the United Kingdom

Dr. Andrew Vallance-Owen shared his experiences with PROMs in the U.K. Implementing PROMs across the U.K. took several years. In 1997, Bupa hospitals, which are funded by private health insurance, began collecting routine PROMs. Following a successful pilot for routine PROMs data collection that was initiated in 2005, the National Health Service (NHS) began routinely collecting PROMs data in 2009 for NHS-funded hip and knee replacements, varicose vein surgeries and high-groin hernia repairs. Each questionnaire, with the exception of that for hernia repairs, includes 2 measures — a generic measure (EQ-5D) and a condition-specific measure. These procedures were selected for the NHS PROMs program because they were high-volume procedures that required significant resources and had potential variation in quality. Aggregate results from PROMs surveys are publicly accessible on the [Health & Social Care Information Centre](#)'s website and published quarterly.

When reporting PROMs, it is important to ensure that measures and results can be easily understood by patients and providers. It is also important to be aware of how low recruitment and response rates may bias results and whether case mix adjustments can be applied to take these into account. It is crucial to have direct patient involvement and to ensure correct choice of measures (e.g., pre- and post-intervention) to demonstrate health gains.

The NHS will continue to routinely measure patient outcomes and experiences to evaluate performance, drive quality improvement and support decision-making. PROMs support data transparency and availability of information to patients. Clinical performance indicators typically measure failure (e.g., mortality rates). PROMs enabled a program that also illustrates health benefits gained.

PROMs in the United States

Dr. Lewis E. Kazis presented on the use of PROMs in the U.S. In the U.S., PROMs are used at different levels across the health system, from the general population to specific clinical outcomes and individual patients.

The *Patient Protection and Affordable Care Act* has placed considerable importance on using patient measures for purposes of accountability of health care with consumer input. The *Affordable Care Act* (ACA) mandated the use of quality of care measures, public reporting and performance payments. PROMs are repeatedly referred to in the law within the context of patient-centredness, patient satisfaction, patient experience of care, patient engagement and shared decision-making. The ACA will likely drive a shift in the U.S. health system from a fee-for-service paradigm to one that is based on quality of care.

In the U.S., a generic survey (VR-12) is included in the Medicare Health Outcomes Survey (HOS). HOS results are a principal component of the Star Rating System for consumer evaluation of Medicare Advantage plans and are also used to support resource allocations (e.g., allocation of more resources to states where outcome scores are lower to support service improvements). In addition to case mix variables, PROMs information may also be used in the future to explain differences in outcomes, including access to health care and decisions on clinical pathways.

Use and Implementation of PROMs

This panel–participant session provided an opportunity for participants to direct questions to PROMs experts regarding the use of PROMs and the implementation of large-scale or national PROMs programs. Panel members were Drs. Stirling Bryan, Lewis E. Kazis, Andrew Vallance-Owen and Jeremy Veillard.

The following is a highlight of the discussions:

- “Value” in health care can be defined as the outcome as a function of costs or as the comparative cost as a function of gains in units of life or functional quality of life. These units might be health status achieved or retained, degree of recovery or sustainability of health. The value of a procedure may not always be determined by comparing pre- and post-intervention status. For example, there may be some procedures that may not result in immediate differences in health gains, but this does not mean that the procedure was not beneficial.
- The granularity of measurement required as well as the applicability of tools and indicators will vary between the general population and population sub-segments (such as specific patient populations). Foundational work and survey attributes for many of the well-respected instruments started from a total population–based perspective. Generic tools cover a broad range of factors. There will always be clinical populations for which a condition-specific tool may be needed to supplement information collected from a generic tool.
- The knowledge translation process includes the patient’s involvement and engagement in framing questions. Patients have been increasingly involved in the development of surveys and measures. It is important to ensure that information collected is presented back to patients in an understandable format.
- For policy-making, careful consideration has to be made in terms of what is being compared on a macro level and how that information relates to the system, plans and administration versus patients and clinicians. The desired culture within the Canadian health care system and how this relates to improvements in quality of care will need to be considered.
- Case mix adjustments are important, especially to clinicians. It is important to determine and agree on case mix methodologies to ensure the right balance of complexity and relevancy for comparability of results and appropriateness of inferences.
- It is important to address potential reporting biases. For example, there is the ability to risk-adjust for bias due to parental reporting in the pediatric population. Similarly, in the elderly population, when there is a need for others to complete questionnaires, it is important to avoid clinician bias and evaluate the process for collecting this information.

PROMs in Canada

The purpose of the round-table update was for participants to share experiences with PROMs within their jurisdiction or organization and to gain an awareness of the PROMs environment in Canada.

Most participants indicated that their organization or agency was not directly involved in collecting PROMs information at this time but acknowledged the importance and usefulness of including the patient voice in the design and delivery of care in areas such as patient engagement strategy and health technology. Participants expressed an interest in PROMs and acknowledged the importance of a common approach to data collection and comparability of information.

Statistics Canada has been collecting PROMs through the Canadian Community Health Survey (CCHS) using the Health Utilities Index (HUI), a Canadian-developed PROMs instrument. The CCHS provides the option to complete additional questions, such as those from the SF-36 survey. CCHS data has also been used to develop international comparisons, such as the Washington Group/Budapest Initiative and the World Health Organization Disability Assessment Scale. In addition, CCHS data has been used to assess PROMs following hip and knee replacement surgeries as well as improvement in health status post-intervention.

British Columbia and Alberta have made the most advancement toward a provincial PROMs program; however, at this time, each has selected a different instrument for its initial PROMs activities. In April 2015, B.C. will begin administering the VR-12 as a generic PROMs measure with its patient experiences surveys for inpatient and emergency department care. Alberta Health Services is considering the use of the EQ-5D as a provincial PROMs measure, and the Health Quality Council of Alberta has developed risk-adjusted norms for this instrument.

Some jurisdictions have implemented PROMs initiatives focused on specific clinical areas. Quality of life measures and symptom assessments have been used to measure program effectiveness and to support pain and symptom management in areas such as cancer and palliative care. For example, PROMs have been used in Saskatchewan to evaluate clinical pathways and support decision-making in areas such as prostate care, hip and knee replacements and lower-leg ischemia. Some provinces, such as New Brunswick, indicated that they may be collecting PROMs information but not with a standard PROMs tool.

There is an increased focus on quality improvement as well as patient-centred care across the country, and these are areas that would be supported by PROMs information. For example, Ontario's Health Action Plan (Patients First), which launched in February 2015, places patients at the centre of care. Ontario is implementing Quality-Based Procedures and investigating reimbursement based on quality of care in areas such as congestive heart failure, chemotherapy and jaundice. Cancer Care Ontario collects symptom reports from cancer care patients.

When developing a pan-Canadian program for PROMs, consideration should be given to the unique challenges of smaller jurisdictions, such as the territories, where health care delivery models are different (e.g., remote locations, decentralized services) and cultural context (e.g., large Aboriginal populations) is important.

The Strategy for Patient-Oriented Research (SPOR) initiative led by the Canadian Institutes of Health Research (CIHR) was also highlighted. There are support units as well as pan-Canadian networks being established for patient-oriented research in areas such as youth and adolescent mental health, primary and integrated health care innovations, and chronic diseases. These networks are funded by CIHR with additional resources provided through the provinces/territories and may be potential partner organizations for future PROMs initiatives.

Clinical Perspectives on PROMs

Joint Replacement Surgery

CIHI's Canadian Joint Replacement Registry (CJRR) collects information on hip and knee replacements in Canada. Dr. Eric Bohm, co-chair of the CJRR Advisory Committee, shared his experiences with PROMs in hip and knee replacements and highlighted the usefulness of PROMs in supporting treatment decisions. As a collaborative effort between the Winnipeg Regional Health Authority (WRHA) and the Manitoba Orthopaedic Society, PROMs and other measures of satisfaction and pain relief are collected in Manitoba regions.

PROMs information also provides a quality assurance process for patients. Since intake for total hip and knee replacements is centralized, PROMs provide patients with an indication of their provider's performance based on surgical outcomes.

Annual reports on PROMs are generated by region, site and surgeon and are reviewed by the WRHA Orthopedic Standards Committee. The ability to show the value of PROMs information to clinicians and administrators, as well as to ensure data review and accountability, was instrumental in the success of the WRHA PROMs initiative. For example, providing information on the cost of revision risks, complications with PROMs and patient satisfaction results supported improvements in patient care. Challenges included determining data capture resources, reporting results in a timely and straightforward manner, and establishing appropriate case mix adjustments, outcome thresholds and performance targets.

The Canadian Arthroplasty Society (CAS), a subgroup of the Canadian Orthopaedic Association, supports CJRR. The CAS is interested in collaborating with CIHI on a demonstration project to collect PROMs for hip and knee replacements. This initiative will help inform future pan-Canadian data collection efforts and comparisons of outcomes and other variables (e.g., timeliness of interventions) to assess quality of life improvements.

The International Society of Arthroplasty Registries is also investigating tools and recommendations and has established a PROMs working group.

Renal Care

The Canadian Organ Replacement Register (CORR) at CIHI contains information on organ transplants, organ donation and end-stage renal disease (ESRD) in Canada. The CORR community, which includes renal care specialists, was represented by Drs. Joseph Kim and Scott Klarenbach — the CORR Board's president and vice president, respectively. Dr. Klarenbach provided an overview of chronic kidney disease (CKD) and ESRD and why this area is well-positioned for the routine capture of PROMs. CKD and ESRD are chronic conditions characterized by high mortality, poor quality of life and significant symptom burden with a great deal of variability in disease trajectories and treatment options. ESRD occurs in less than 1% of the population but accounts for disproportionately high health care costs.

There has been a change in the demographics of ESRD patients. With the largest growing population being 75 and older, there is an increased emphasis on conservative management to improve quality of life rather than aggressive disease management and extending life. PROMs can be used to determine whether an intervention or knowledge translation has an impact on care and may be able to support guidelines on when to begin dialysis.

There are a number of PROMs tools available for renal disease. In Alberta, routine PROMs for CKD and ESRD include quality of life measures, symptom burden and functional status using generic tools and condition-specific tools. The B.C. Renal Agency and the Ontario Renal Network are also considering the routine collection of PROMs in renal care patients.

The renal care community supports the routine capture of PROMs and the integration of PROMs into its CKD research network. PROMs from ESRD patients can be used with data collected in CORR for comparative reporting on patient-reported measures. Further discussions on the selection of appropriate PROMs tools, implementation, workflow and use of PROMs information are required.

Session 2: Considerations for Implementing a PROMs Program

The Selection and Utilization of PROMs

Dr. Rick Sawatzky presented a framework of considerations for selecting and using PROMs. The first step in planning for PROMs data collection is to obtain clarity about the purposes of and inferences (decisions, judgments and actions) desired from PROMs information.

The underlying value of PROMs is to measure patient perspectives and monitor these over time. From a measurement perspective, 3 foundational considerations need to be taken into account when selecting PROMs instruments and analyzing PROMs scores:

- **Comparisons of different people (groups and individuals):** Many factors influence how individuals interpret and respond to questions about their health, including cultural, developmental or personality differences; contextual factors or life circumstances; and different health experiences or events. Especially when comparing groups, it is important to recognize that individuals in the groups (e.g., within jurisdictions or clinical populations) may not be homogenous in the manner in which they respond to PROMs surveys.
- **Comparisons over time:** Response shift may cause a change in patients' frame of reference from which questions are interpreted and responded to, leading to measurement bias in changes over time. This is especially important in longitudinal comparisons (including pre- and post-intervention), disease trajectories (such as cohort studies) and individual trajectories to monitor and inform individual care plans.
- **Consequences:** The value implications, including personal and societal consequences, of using PROMs need to be evaluated. There may be intended and unintended consequences of decisions and actions resulting from the use of PROMs. It would be important to determine whether data users (researchers, administrators, clinicians and patients) share the same values with respect to the use of PROMs and that the instruments selected reflect these.

Scoring algorithms (e.g., using statistical analyses or case mix adjustments) can adjust for responses between different people but also for the same person over time to improve the accuracy of PROMs data analysis. Selecting appropriate tools that have been validated for the population of interest will be important.

In designing a PROMs initiative, the following should be considered:

- **Survey design:** This includes factors such as sampling design (census or random sampling), timing of data collection (cross-sectional, pre-/post-procedure, longitudinal), languages (availability of surveys in “validated” translated versions) and length and burden (not just the number of questions but the time it takes to complete the survey).
- **Utilization of PROMs information:** PROMs can be used by different users for a broad range of objectives and decisions. It is important to consider the integration of PROMs into a more comprehensive framework by combining PROMs data with other data sources (e.g., PREMs, clinical and administrative data) to enrich information and better inform decision-making. The impact of PROMs on patient and clinician burden as well as opportunities to integrate PROMs into clinical practice and electronic systems should be evaluated.
- **Selection of PROMs instruments:** Different PROMs instruments have varying characteristics and measure different items. Representation of different domains, psychometric and cross-cultural characteristics, and validity and utility scores need to be considered and aligned with the purposes of collecting PROMs information. It is also important to determine whether the tools selected are suitable for the population of interest. Generic PROMs enable comparisons across different patient populations, whereas condition-specific PROMs are designed to assess health outcomes relevant to particular health care sectors or diseases.

Sharing Experiences With PROMs

This panel–participant session provided an opportunity for participants to direct questions to PROMs experts regarding PROMs tools, use of PROMs in clinical practice and considerations when designing a PROMs program. Participants also asked questions regarding challenges and success factors for implementing PROMs. Panel members were Drs. Eric Bohm, Lewis E. Kazis, Scott Klarenbach, Rick Sawatzky and Andrew Vallance-Owen.

The following is a highlight of the discussions:

- It is important to clarify the purpose of collecting PROMs — provincial/territorial and national objectives. Determining what information is desired as well as the decisions and actions that will be supported by PROMs at different levels (individual/clinical, regional, jurisdictional and national) will inform the purpose of PROMs.
- The advantages of PROMs in routine clinical care should be showcased to generate grassroots support for PROMs. Different communities and interest groups can be brought together to discuss why it is important to move PROMs forward. Support from clinical champions will help generate buy-in from the clinical community. It is also important to keep PROMs reporting simple so that information is understood and can be used. Initial PROMs efforts could focus on areas that have high-volume treatments or a need for cost-effectiveness evaluations.

- It is more important to emphasize the use of PROMs in improving patient care than to link PROMs to incentive models. It may be difficult to determine what appropriate performance targets should be or provide evidence on how outcomes can be changed. PROMs can support discussions on cost-effectiveness, but it was suggested that they not be used as a basis for institutional payments or pay for performance at this stage.
- PROMs can support shared decision-making between clinicians and patients to ensure appropriate expectations are set, such as establishing realistic expectations of intervention outcomes. From a quality assurance/quality improvement perspective, including PROMs as part of clinical intake allows for a better understanding of patients. Even when there are not significant changes in PROMs scores, the availability of PROMs acts as quality assurance and allows for comparison of patient status over time.
- Patients need to understand the value of PROMs in order for them to advocate moving PROMs forward. There will likely be a need to invest in patient education and to ensure patient engagement at appropriate points.
- It may be difficult to get consensus in all areas; however, consider getting started in an area where there is greater alignment and support for PROMs. It will be important to ensure there is a framework for evaluation and to include defined timelines (e.g., project evaluation after 1 year of implementation). Contingency plans should be developed so that appropriate changes can be made if the project is not working.
- It will be difficult to make interjurisdictional comparisons if there are too many tools being used across jurisdictions. Different tools have varying attributes. The types of decisions that will be supported by PROMs data will determine the most suitable instruments for use across Canada. The opportunity for each province/territory to include additional items within a common core set of PROMs that is administered nationally should be investigated.

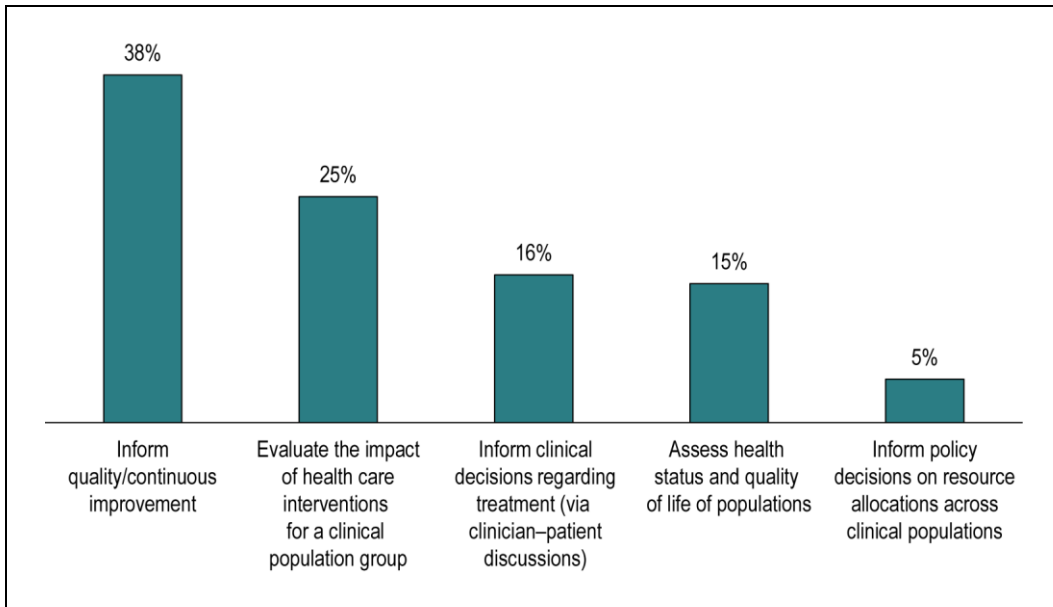
Options and Considerations for PROMs Initiatives

Small groups were assigned to provide participants an opportunity to discuss and share their opinions about potential tools, clinical areas and implementation considerations for a pan-Canadian PROMs program. Participants were polled in real time on a number of questions (refer to Appendix D for detailed results). A summary of the discussions and polling results follows.

Health System Goals

Health system goals that would be supported by PROMs information include quality/continuous improvement initiatives, evaluation of the impact of health care interventions, selection of treatment options, assessment of health status and quality of life as outcomes, and policy decisions on resource allocations among provider organizations and across clinical populations.

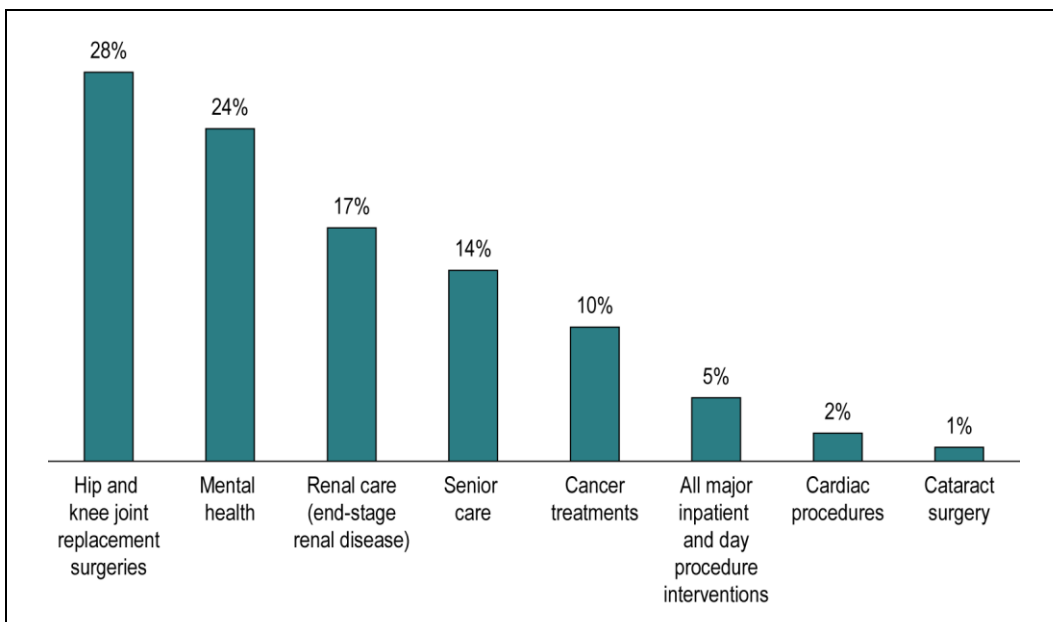
Figure 1: Health System Goals That Would Most Benefit From Additional PROMs Information



Clinical Areas

Initially focusing on areas where PROMs are well-established and in use would allow for illustration of their value. Condition-specific tools would depend on the clinical area selected. Participants indicated interest in PROMs collection and reporting for hip and knee replacements, mental health and renal care. PROMs in hip and knee replacements and renal care are supported by the clinical community and would be areas where a demonstration project could showcase the value of PROMs.

Figure 2: Clinical Areas for Initial PROMs Data Collection and Reporting

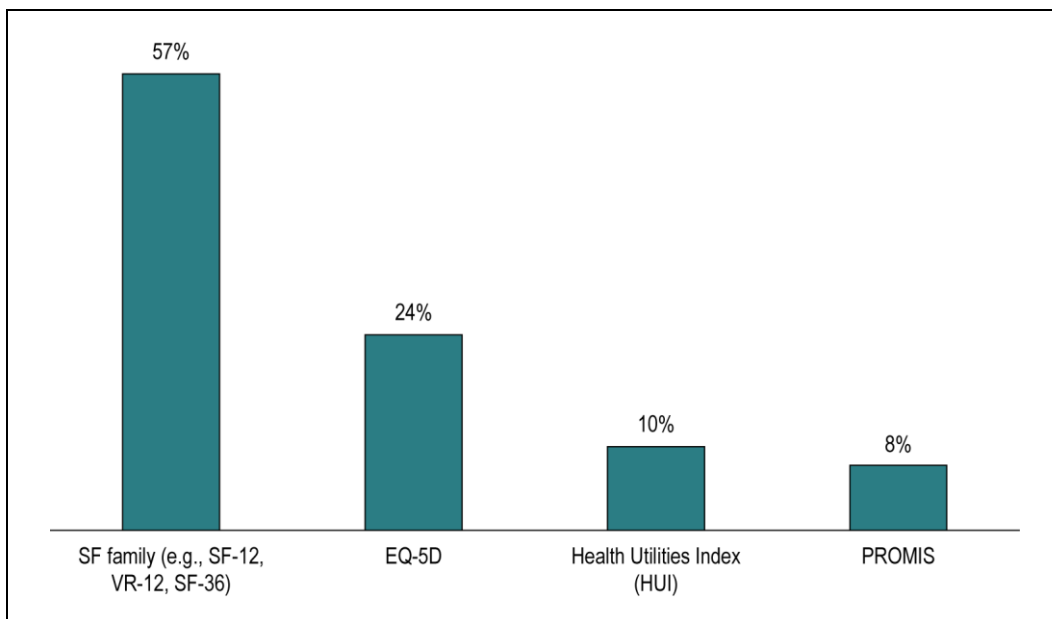


Generic PROMs Instruments

The SF family of instruments (such as the VR-12) and EQ-5D were identified as the generic tools most suitable for use in Canada. Participants indicated that a common tool should be selected for use across the country, rather than different tools. 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). Although B.C. and Alberta have chosen different generic tools to pilot in their jurisdictions, there is still opportunity for alignment.

There are a number of differences between the VR-12 and EQ-5D. With respect to the time frame for which people are asked to evaluate their health, the EQ-5D measures current state, whereas the VR-12 measures health state from the previous 4 weeks. While the EQ-5D does produce an overall health utility score, it does not provide a separate physical and mental health score; the VR-12 is based on 8 dimensional profiles (e.g., pain, physical function, social function, mental function). The EQ-5D also has a tendency to produce a ceiling effect (most people get a close-to-perfect score). The EQ-5D-5L (5-level version) has been developed to address this issue; however, reference values are not as readily available for this newer instrument.

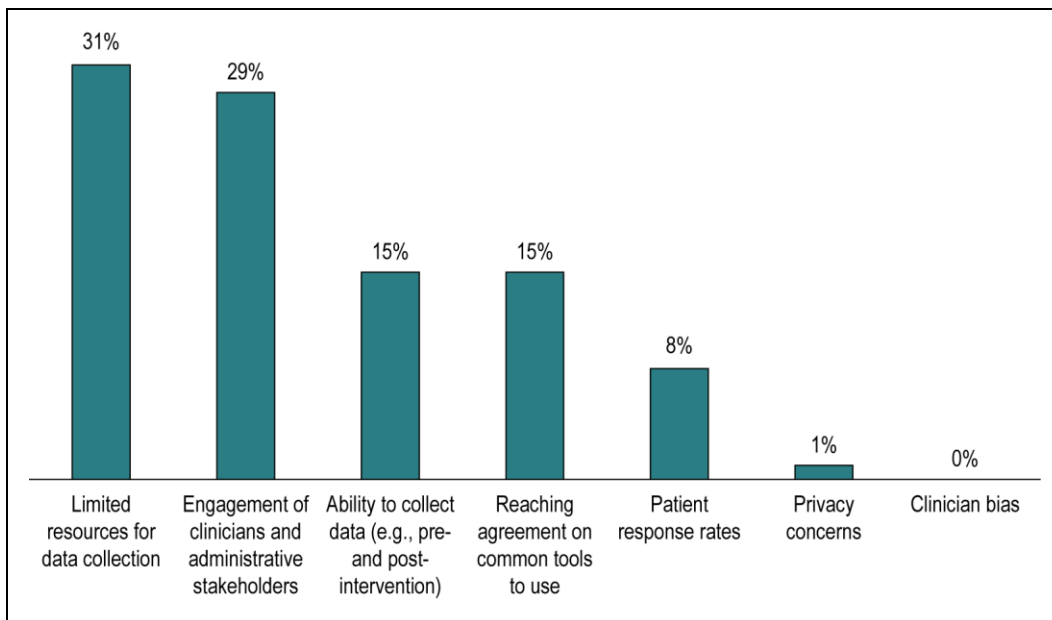
Figure 3: Most Suitable Genetic PROMs Tools for Common Use Across Canada



Challenges/Barriers With Implementing PROMs

The challenges that were identified as the most difficult to overcome were limited resources for data collection and engagement of clinicians and administrative stakeholders. The ability to collect data (e.g., pre- and post-intervention) and reaching an agreement on common tools were also identified as barriers.

Figure 4: Barriers/Challenges That Would Be Most Difficult to Overcome

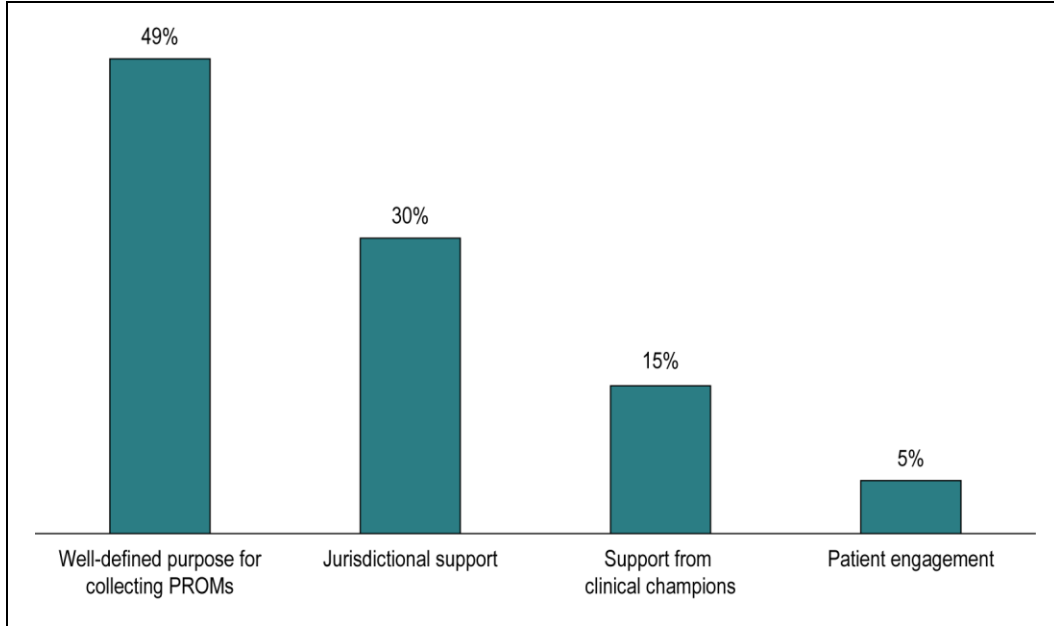


PROMs initiatives do not need to be cost-prohibitive. There are options to innovatively leverage existing infrastructure and systems to implement PROMs, while being sensitive to the fact that the system is already running at capacity. A realistic assessment of required resources should be conducted to confirm the feasibility of plans and the value of investments.

From a survey administration perspective, it would be important to ensure patients were aware of how data (individual versus aggregate results) would be used. It was also suggested that clinicians be removed from the survey process to reduce the risk of bias in patient responses resulting from clinician influence.

The most important factor in advancing PROMs in Canada is a well-defined purpose for collecting PROMs. Support from jurisdictions and clinical champions is essential. The ability to leverage existing resources, such as clinical registries, should also be explored.

Figure 5: Most Important Factors in Advancing PROMs in Canada



Session 3: Advancing the Use of PROMs Across Canada

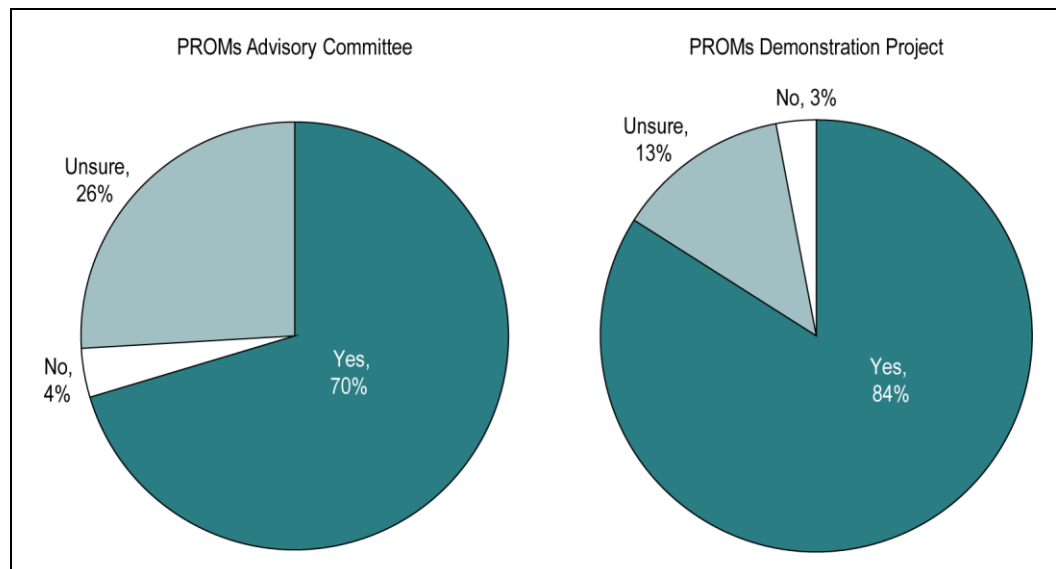
Common Goals and Next Steps

The purpose of this session was to gain an understanding of what participants envision for a PROMs program in Canada and CIHI’s role in supporting a pan-Canadian PROMs initiative. Comments included the following:

- CIHI should set up guiding principles and considerations for PROMs, including the selection of PROMs tools and case mix methodology, rather than having these established by individual jurisdictions.
- CIHI can provide advice on how to report information back to administrators, providers and individual patients.
- CIHI can play a key role in comparing Canadian PROMs results with those of international peers, such as the U.S. and Europe. The OECD is committed to clarifying an international approach to PROMs, which may also influence the direction of PROMs in Canada.
- CIHI can produce material (e.g., briefing notes) to support the case for PROMs in Canada.

The majority of forum participants indicated an interest in a PROMs Advisory Committee and in a PROMs demonstration project. CIHI could potentially lead these initiatives.

Figure 6: Interest in Participating in a PROMs Advisory Committee or Demonstration Project



Closing Remarks

Mr. Brent Diverty provided a summary of discussions from the PROMs Forum. Potential next steps and considerations to advance PROMs in Canada include the following:

- **Advisory Group:** CIHI can take the lead to support and manage work with an advisory committee, with participation from the various stakeholder groups, to define and direct a way forward. The role of this group could include clarifying objectives and benefits of PROMs for key stakeholder groups and supporting the development of an evaluation framework and work plans for PROMs.
- **Convergence on generic PROMs tool:** Continue working toward increasing support for the use of a common generic PROMs tool across the country, with consideration given to international developments and domestic needs.
- **PREMs and PROMs as complementary:** Ensure that PREMs and PROMs come together in an appropriate manner, and that PROMs plans and data are complementary to other health system measures and data sources.
- **Potential for demonstration projects in joint replacement and renal care:** Evaluate existing initiatives and how these programs can be adapted and expanded in a timely and cost-effective manner. For example, investigate the model used at the WRHA for PROMs in joint replacements.
- **Existing infrastructure and initiatives:** Leverage opportunities to use existing infrastructure and initiatives to move PROMs forward. Examples include using existing national surveys (such as Statistics Canada's CCHS) to implement PROMs, collaborating with organizations where patient-centred care and measurements are important (such as CIHR and Accreditation Canada), discussing the need for PROMs with the Conference of Deputy Ministers and promoting the submission of PROMs data through CIHI's existing clinical registries and acute care and ambulatory care data holdings.
- **Impact of strategic consultations:** CIHI is currently conducting consultations across the country for its 2016 to 2020 strategic plan. PROMs will likely be identified as a priority area.

Appendix A: CIHI PROMs Forum Agenda

Tuesday, February 3

9 a.m.	Forum Registration Opens (Geneva Room)
9 a.m.	Breakfast
10 a.m.	Day 1 Welcome and Opening Remarks <i>David O'Toole</i> President and CEO, CIHI
10:05 a.m.	Introduction and Overview <i>Brent Diverty</i> Vice President, Programs, CIHI <i>Terry Sullivan</i> President, Terry Sullivan and Associates
Section 1: PROMs Use in Health Care	
10:15 a.m.	The Case for PROMs in Canada's Health Systems <i>The Importance of PROMs in Health Care</i> <i>Stirling Bryan</i> Director, Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health Research Institute; and Professor, School of Population and Public Health, University of British Columbia <i>Potential Role for PROMs in Canada — A CIHI Perspective</i> <i>Jeremy Veillard</i> Vice President, Research and Analysis, CIHI
10:50 a.m.	International PROMs Initiatives <i>PROMs in the United Kingdom</i> <i>Andrew Vallance-Owen</i> Chair, South West Peninsula Academic Health Sciences Network, U.K. <i>PROMs in the United States</i> <i>Lewis E. Kazis</i> Professor, Health Policy and Management, and Director, Center for the Assessment of Pharmaceutical Practices (CAPP), Boston University School of Public Health; and Director, Pharmaceutical Research Program, Center for Health Quality, Outcomes and Economic Research, Bedford VA Medical Center, U.S.
11:30 a.m.	Panel–Participant Discussion* — Use and Implementation of PROMs <i>Panel: Stirling Bryan, Lewis E. Kazis, Andrew Vallance-Owen, Jeremy Veillard</i>

12:15 p.m.	Lunch
1:15 p.m.	<p>PROMs in Canada* — Round-Table Updates Highlights of current PROMs uses and future plans from jurisdictions and organizations</p>
2:45 p.m.	Break
3:15 p.m.	<p>Clinical Perspectives on PROMs</p> <p><i>PROMs in Joint Replacement Surgery</i> <i>Eric Bohm</i> Co-Chair, Canadian Joint Replacement Registry Advisory Committee; Orthopedic surgeon and Director, Research, Concordia Hip & Knee Institute, Concordia Hospital</p> <p><i>PROMs in Renal Care</i> <i>S. Joseph Kim</i> President, Board of Directors, Canadian Organ Replacement Register; Co-Director, Kidney Transplant Program, University Health Network; and Nephrologist, Division of Nephrology and Kidney Transplant Program, University Health Network</p> <p><i>Scott Klarenbach</i> Vice President, Board of Directors, Canadian Organ Replacement Register; and Associate Professor, Division of Nephrology and Transplantation Immunology, Department of Medicine, University of Alberta</p>
Section 2: Considerations for Implementing a PROMs Program	
3:50 p.m.	<p>Selecting PROMs Uses and Tools — Considerations and Options <i>Rick Sawatzky</i> Canada Research Chair in Patient-Reported Outcomes; and Associate Professor, Nursing, Trinity Western University</p>
4:15 p.m.	<p>Panel–Participant Discussion* — Sharing Experiences With PROMs <i>Panel: Eric Bohm, Lewis E. Kazis, Scott Klarenbach, Rick Sawatzky, Andrew Vallance-Owen</i></p>
4:50 p.m.	<p>Day 1 Summary <i>Terry Sullivan</i></p>
5 p.m.	Break
5:15 p.m.	Networking Reception (Alpine Foyer)
6 p.m.	Dinner (Alpine Room 1)
6:30 p.m.	<p>Dinner Presentation: Shifting Perspectives — Influence of PROMs in Medical Care and Research <i>Robert Kaplan</i> Chief Science Officer, Agency for Healthcare Research and Quality, U.S.</p>

Wednesday, February 4

7:45 a.m.	Breakfast (Geneva Room)
8:30 a.m.	Day 2 Welcome and Opening Remarks <i>Brent Diverty</i>
8:35 a.m.	Overview of Day 2 <i>Terry Sullivan</i>
8:45 a.m.	Small Group Discussions: Options and Considerations for PROMs Initiatives <ol style="list-style-type: none"> 1. Which health system goals and clinical areas would benefit most from more PROMs information? 2. Which generic and condition-specific PROMs tools would be most suitable for common use across Canada? 3. What are potential challenges/barriers with implementing PROMs at different levels (patient, clinical, administrative, facility/regional/jurisdictional)? 4. What can be done to support collection and use of PROMs, as well as to overcome identified challenges/barriers?
9:45 a.m.	Sharing Results From Group Discussions* — Tools and Clinical Areas
10:15 a.m.	Break
10:45 a.m.	Sharing Results From Group Discussions* — Barriers and Success Factors
Section 3: Advancing the Use of PROMs Across Canada	
11:15 a.m.	Group Discussion* — Common Goals and Next Steps <ol style="list-style-type: none"> 1. Are there common goals for advancing PROMs information across Canada? 2. How can organizations like CIHI best support your goals for more PROMs information? 3. Which jurisdictions and organizations are interested in participating in a working group to further explore PROMs opportunities, including possible pilot/demonstration projects for PROMs?
12:15 p.m.	Summary, Next Steps and Closing Remarks <i>Brent Diverty</i>
12:30 p.m.	Adjournment
12:30 p.m.	Lunch to Go

* Discussions moderated by Terry Sullivan.

Appendix B: Speaker Biographies

David O'Toole

David O'Toole is the president and CEO of CIHI. Prior to joining CIHI, Mr. O'Toole spent more than 20 years in the Ontario public sector, most recently as deputy minister, Ministry of Natural Resources. He began his career in health care, working in both the public and private sectors. For 6 years, he was senior project director for the Ontario Drug Benefit Program and executive assistant/policy advisor to the Office of the Assistant Deputy Minister of Health. He has also held positions as the deputy minister, Northern Development, Mines and Forestry, and assistant deputy minister, Cabinet Office (economic and environment portfolios).

Mr. O'Toole has served as commissioner for the Ontario Public Service Commission and on the Executive Development Committee of the Ontario Public Service. He is a graduate of both Queen's University and the Executive Program of the Ivey School of Business, University of Western Ontario.

Brent Diverty

Brent Diverty is the vice president of Programs at CIHI. He has executive responsibility for CIHI's range of health services, expenditure and workforce data holdings and many of the standard information products that flow from them.

Prior to rejoining CIHI in February 2013, Mr. Diverty spent 2 years at the Australian Institute of Health and Welfare in Canberra, where he provided strategic leadership to the organization as a member of the executive team and programmatic leadership to a diverse portfolio of health and welfare information programs.

Previously, Mr. Diverty worked as a director at CIHI, in management consulting roles and at Statistics Canada. Over his 20-year career, he has worked on both the supply and demand sides of data and information, in most cases with a focus on health services and population health. He holds an MA in economics from McMaster University, with a specialization in health.

Stirling Bryan

Dr. Stirling Bryan, PhD, is an economist with a career-long specialization in health care. His early career was spent in the United Kingdom, initially in London and subsequently in Birmingham.

His research seeks directly to inform policy and practice. This is demonstrated, in part, through an extensive involvement with both the U.K.'s National Institute for Health and Care Excellence (NICE) and the Canadian Agency for Drugs and Technologies in Health (CADTH). In 2005, he was a Harkness Fellow, and spent a year at Stanford University researching U.S. technology coverage decision-making.

In 2008, Dr. Bryan moved to Canada (on appointment as a full professor in The University of British Columbia's School of Population and Public Health and as director of the Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health Research Institute) where he continues a focus on policy-relevant research. His current position is sponsored by Vancouver Coastal Health, one of B.C.'s largest regional health authorities.

Jeremy Veillard

Jeremy Veillard, PhD, is CIHI's vice president of Research and Analysis and an assistant professor (status only) at the University of Toronto's Institute of Health Policy, Management and Evaluation. He is also president of the Canadian Association for Health Services and Policy Research (CAHSPR) for 2013–2015.

Dr. Veillard has expertise in health policy development and health system reform, as well as in evaluation and health system performance measurement, and he has extensive professional experience in the health sector in both Europe and Canada. Dr. Veillard was the regional advisor for health policy and equity at the World Health Organization (WHO) Regional Office for Europe from 2007 to 2010.

Dr. Veillard's previous experience includes leading work on the Health Results Team at the Ontario Ministry of Health and Long-Term Care, serving as a policy advisor at the WHO/EURO in charge of hospital reforms and working as a hospital administrator in France. Dr. Veillard has a PhD in health systems research from the faculty of medicine of the University of Amsterdam (Netherlands) and 2 master's degrees.

Andrew Vallance-Owen

Dr. Andrew Vallance-Owen, MBE, MBA, FRCS Ed, qualified at the Birmingham University Medical School, later undertaking surgical training in Newcastle upon Tyne and Melbourne, Australia.

His career within the British Medical Association (BMA) started as provincial medical secretary for the North of England, followed by promotion to the post of BMA Scottish Secretary. Latterly, he moved to London to become the head of Central Services and International Affairs, a role which also developed into the head of Policy Development.

In 1995, he became group medical director (chief medical officer) of the international health care company Bupa, where he furthered his interests in the quality of health care and outcomes, particularly patient-reported outcomes, and established the first routine reporting of patient-reported outcomes in Bupa's hospitals in 1998. At age 60, he retired from Bupa in 2012 and relinquished the chair of the Department of Health's Patient-Reported Outcomes Stakeholder Group in 2013 but remains a member of NHS England's PROMs Advisory Group.

Since leaving Bupa, Dr. Vallance-Owen has established a portfolio of non-executive roles. He chairs the U.K.'s Private Healthcare Information Network and also the South West Academic Health Science Network. He is the senior independent director at the Royal Brompton and Harefield NHS Foundation Trust.

He was appointed a member of the Order of the British Empire (MBE) in the 2014 Queen's Birthday Honours and awarded an honorary doctorate by the University of Birmingham in July 2012.

Lewis E. Kazis

Dr. Kazis is professor of Health Policy and Management and director of the Center for the Assessment of Pharmaceutical Practices (CAPP) at the Boston University School of Public Health. He is also director of the Pharmaceutical Research Program at the Center for Health Quality, Outcomes and Economic Research at the Bedford Veterans Affairs Medical Center. He received his doctoral degree from Harvard University School of Public Health in 1980.

Dr. Kazis joined the Veterans Health Administration (VHA) in 1992, where he was recipient of the prestigious Research Career Scientist Award from the U.S. Department of Veterans Affairs (VA) for almost a decade. He has also been a special consultant to the Office of Quality and Performance in the VA, where he was previously director of Functional Status for the VHA and principal investigator of the well-known Veterans Health Study. He is the developer of the Veterans RAND 36- and 12-item health surveys (VR-36 and VR-12), formerly called the Veterans SF-36 and SF-12 (SF-36V and SF-12V) and developed from the Medical Outcomes Study (MOS) SF-36 survey.

From 1996 to 2007, close to 4 million administrations of these surveys occurred both inside and outside the VA for purposes of monitoring patient outcomes of care. The VR-12 has now been adopted by the VHA for quality improvement purposes and by the Centers for Medicare & Medicaid Services (CMS) as part of its national Health Outcomes Survey (HOS) for evaluating the Medicare Advantage Program. The VR-12 was included in 2006 as one of the Healthcare Effectiveness Data and Information Set (HEDIS) measures by the National Committee for Quality Assurance (NCQA). Dr. Kazis' research team was the recipient of the esteemed Peter Reizenstein Prize for the best paper published in the *International Journal for Quality in Health Care* in 2006.

Eric Bohm

Dr. Eric Bohm, BEng, MD, MSc, FRCSC, works at the Concordia Hip & Knee Institute in Winnipeg, Manitoba, where he specializes in primary and revision hip and knee replacement surgery. He has undergraduate degrees in both mechanical engineering and medicine from McMaster University, and a graduate degree in community health and epidemiology from Dalhousie University. He completed his orthopedic residency at the University of Saskatchewan and undertook an arthroplasty fellowship at Dalhousie University in Halifax. In 2009, he completed the prestigious American–British–Canadian (ABC) orthopedic fellowship, visiting the United Kingdom, Ireland and South Africa.

Dr. Bohm's areas of research interest include access, appropriateness, effectiveness and safety of health care, clinical registries, clinical trials, implant retrieval analysis and radiographic stereometric analysis. He currently chairs the Winnipeg Regional Health Authority Orthopedic Standards Committee, the Canadian Orthopaedic Association National Standards Committee, and the advisory committee of the Canadian Joint Replacement Registry. He serves as medical advisor to the Winnipeg Regional Health Authority's orthopedic waitlist, joint replacement registry and central intake program. He is also a member of the George and Fay Yee Centre for Healthcare Innovation, where he serves as director of its Health System Performance platform.

S. Joseph Kim

Dr. S. Joseph Kim, MD, PhD, MHS, FRCPC, is a staff nephrologist in the Division of Nephrology and co-director of the Kidney Transplant Program at the Toronto General Hospital, University Health Network in Toronto, Ontario. He is also an assistant professor in the Department of Medicine and the Institute of Health Policy, Management and Evaluation at the University of Toronto. He is the president of the Canadian Organ Replacement Register board of directors, vice chair of the U.S. Organ Procurement and Transplantation Network Data Advisory Committee, and associate head of the Kidney, Dialysis and Transplantation program at the Institute for Clinical Evaluative Sciences.

Dr. Kim completed medical school, internal medicine residency, chief medicine residency and fellowships in nephrology and kidney transplantation at the University of Toronto. In 2008, he completed a PhD in epidemiology and a master's degree in biostatistics at the John Hopkins Bloomberg School of Public Health. His research interests lie in the areas of access to and outcomes of kidney transplantation using data from both centre- and population-based cohorts. His methodological interests include survival analysis and statistical models for causal inference.

Scott Klarenbach

Dr. Scott Klarenbach, MD, MSc, FRCPC, is an associate professor in the Department of Medicine at the University of Alberta. He received his medical training at the University of Alberta and completed his MSc in health economics at the University of York, United Kingdom.

His research interests include health outcomes and health economics research. He has conducted numerous economic evaluations and health technology assessments for both chronic and acute conditions. Dr. Klarenbach is currently chair of the Canadian Society of Nephrology's Clinical Practice Guidelines Committee, and vice president of the Canadian Organ Replacement Register board.

Richard (Rick) Sawatzky

Dr. Richard Sawatzky, PhD, RN, holds a Canada Research Chair in Patient-Reported Outcomes at Trinity Western University, is research scientist with the Centre for Health Evaluation and Outcome Sciences (CHEOS) with Providence Health Care, and is a member of the board of directors of the International Society for Quality of Life Research. He leads an active program of research that focuses on the validation and utilization of patient-reported outcome (PRO) instruments and quality of life assessments in various health care contexts, including those for people with chronic life-limiting illnesses.

Current research activities include evaluating the validity of PRO instruments and computerized adaptive assessment systems; the use of tablet devices for quality of life assessments; the selection and utilization of PRO instruments in health care practice and health services decision-making; nursing care delivery and practice supports for a palliative approach; educational approaches for patients with colorectal cancer; and patient-reported experiences with knee surgery.

Robert (Bob) Kaplan

Robert M. Kaplan, PhD, was named chief science officer at the Agency for Healthcare Research and Quality (AHRQ), effective May 5, 2014. He provides scientific oversight for research activities at the AHRQ, especially related to investments in safety, quality and patient-centred outcomes. He also works on coordinating AHRQ's research efforts with those of other federal partners.

Previously, Dr. Kaplan was associate director for Behavioral and Social Sciences, Office of the Director, and director of the Office for Behavioral and Social Sciences Research at the National Institutes of Health. Prior to his federal service, Dr. Kaplan was distinguished professor of health services at the University of California, Los Angeles (UCLA), and distinguished professor of medicine at UCLA's David Geffen School of Medicine. He was principal investigator of the California Comparative Effectiveness and Outcomes Improvement Center and also led the AHRQ-funded UCLA/RAND health services training program and the UCLA/RAND Prevention Research Center.

Dr. Kaplan is active in a variety of cross-governmental activities. He co-chairs the Social, Behavioral and Economic Sciences subcommittee of the Committee on Science for the U.S. National Science and Technology Council, within the U.S. Executive Office of the President. He is also a member of the National Committee on Vital and Health Statistics and the Intergovernmental Working Group on Quality of Healthcare.

Dr. Kaplan is a past president of several organizations, including the American Psychological Association Division of Health Psychology. In 2005, he was elected to the Institute of Medicine of the National Academies of Sciences.

Terrence (Terry) Sullivan

Terry Sullivan has held leadership positions at Cancer Care Ontario (2001 to 2011), including 7 years as president and CEO. He was the founding president of the Institute for Work and Health (1993 to 2001). He held senior policy roles at the Ontario Ministry of Health and Long-Term Care, Cabinet Office and Ministry of Intergovernmental Affairs between 1986 and 1992. He was the assistant deputy minister, Constitutional Affairs and Federal–Provincial Relations, during the Charlottetown negotiations, and he also served 2 premiers as executive director of the Premier’s Council on Health Strategy, including a period as deputy minister (1991).

A behavioural scientist, Dr. Sullivan has published widely on cancer control, performance improvement and occupational injury. He is a professor at the Institute of Health Policy, Management and Evaluation and the Dalla Lana School of Public Health at the University of Toronto, and an adjunct professor of oncology at McGill University. He also chairs the board of the Canadian Agency for Drugs and Technologies in Health and the board quality committee of the Toronto Hospital for Sick Children.

Advisory engagements include the Conference of Deputy Ministers of Health, the World Bank (Brazil), the Canadian Institutes of Health Research — Institute of Health Services and Policy Research, Hamilton Health Sciences, Saskatchewan Ministry of Health, the Canadian Nurses Association, Cancer Care Manitoba, Princess Margaret Hospital, the Larry and Cookie Rossy Family Foundation and McGill University.

Appendix C: Participant List

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Appendix D: Polling Questions and Results

When participants were asked to select responses in order of preference, responses were weighted. For example, when asked to select 2 choices in order of preference, weights were assigned as first choice = 2, second choice = 1; when 3 choices were provided, first choice = 3, second choice = 2, third choice = 1.

- 1) Which health system goals would benefit from more PROMs information? Select top 2 in order of preference (priority ranking).

	Responses	
	Percentage	Weighted Count
Quality/continuous improvement	38%	40
Evaluate the impact of health care interventions for a clinical population group	25%	26
Inform clinical decisions regarding treatment (via clinician–patient discussions)	16%	17
Assess health status and quality of life of populations	15%	16
Inform policy decisions on resource allocations across clinical populations	5%	5
Totals	100%	104

- 2) Which clinical areas would benefit most from more PROMs information? Select top 2 in order of preference (priority ranking).

	Responses	
	Percentage	Weighted Count
Hip and knee joint replacement surgeries	28%	55
Mental health	24%	47
Renal care (end-stage renal disease)	17%	33
Senior care	14%	27
Cancer treatments	10%	19
All major inpatient and day procedure interventions	5%	9
Cardiac procedures	2%	4
Cataract surgery	1%	2
Totals	100%	196

- 3) Which generic and condition-specific PROMs tools would be most suitable for common use across Canada? Select top 3 in order of preference (priority ranking).

	Responses	
	Percentage	Weighted Count
SF family (e.g., SF-12, VR-12, SF-36)	57%	49
EQ-5D	24%	21
Health Utilities Index (HUI)	10%	9
PROMIS	8%	7
Totals	100%	86

- 4) Which of the following barriers/challenges would be most difficult to overcome? Select top 2 in order of difficulty (priority ranking).

	Responses	
	Percentage	Weighted Count
Limited resources for data collection	31%	30
Engagement of clinicians and administrative stakeholders	29%	28
Ability to collect data (e.g., pre- and post-intervention)	15%	15
Reaching agreement on common tools to use	15%	15
Patient response rates	8%	8
Privacy concerns	1%	1
Clinician bias	0%	0
Totals	100%	97

- 5) Which of the following would be most important in advancing PROMs in Canada? Select top 2 in order of difficulty (priority ranking).

	Responses	
	Percentage	Weighted Count
Well-defined purpose for collecting PROMs	49%	45
Jurisdictional support	30%	28
Support from clinical champions	15%	14
Patient engagement	5%	5
Totals	100%	92

6) Would you be interested in participating in a PROMs advisory committee or working group (multiple choice)?

	Responses	
	Percentage	Count
Yes	70%	19
Unsure	26%	7
No	4%	1
Totals	100%	27

7) Would you be interested in further discussing or participating in a PROMs demonstration/pilot project (multiple choice)?

	Responses	
	Percentage	Count
Yes	84%	26
Unsure	13%	4
No	3%	1
Totals	100%	31

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