Patient-Centred Measurement and Reporting in Canada

Launching the Discussion Toward a Future State
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Introduction

The Institute for Healthcare Improvement’s Triple Aim framework has 3 objectives:

1. To improve the patient experience of care;
2. To improve the health of populations; and
3. To reduce the per capita cost of health care.¹

Health care providers, administrators and policy-makers have increasingly acknowledged that in order to deliver on the Triple Aim objectives they need to move beyond using only clinical and administrative data to evaluate quality of care and outcomes, and include patient perspectives when assessing health system performance. The collection and reporting of comparable patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) using scientifically rigorous tools and methods are integral to this. Over the past decade, patient-centred measurement has become a key priority in many jurisdictions across Canada. However, patient-centred measurement strategies largely lack coordination both within and across jurisdictions; contributing factors include limited health system funding, competing priorities and a lack of alignment across jurisdictions.

In March 2016, the Canadian Institute for Health Information (CIHI) hosted an invitational visioning day event with 33 participants from across Canada. The purpose of the day was

• To explore considerations and opportunities around measuring and reporting patient-reported experiences and outcomes over the next 5 years; and
• To determine a common set of priorities for this measurement and reporting.

Participants included members of the Inter-Jurisdictional Patient Experience Group (IJ), a patient, physicians and CIHI representatives. The IJ includes representatives from ministries of health, regional health authorities, health quality councils, Accreditation Canada, hospital associations, academic health centres and universities from across Canada.

This report summarizes the presentations and discussions that took place during the visioning day. Participants were asked to discuss their jurisdictions’ and/or organizations’ priorities and activities related to patient-centred measurement and reporting. They were also asked to think beyond their regional boundaries, as this was a visioning session to consider what a future state of patient-centred measurement and reporting might look like on a pan-Canadian scale.

This report begins with a brief overview of the structure of the day, followed by a description of the current state of patient-centred measurement and reporting in Canada. It then summarizes the discussion that took place regarding the future state of patient-centred measurement and reporting in Canada, focusing on the common priorities identified for the next 5 years, along with potential opportunities for, drivers of and barriers to achieving the vision.
Overview of visioning day

The specific objectives of the day were to

- Determine a common set of pan-Canadian priorities for measuring and reporting PREMs and PROMs over the next 5 years;
- Identify lessons learned from past and current activities to inform discussions about how to leverage and evolve patient-centred measurement and reporting into the future around a common set of priorities; and
- Identify where CIHI and other partners can be most helpful in advancing a common approach to patient-reported experiences and outcomes data collection, measurement and reporting.

The day was organized into 3 parts:

1. **Setting the stage**: Plenary presentations highlighted the current context of measuring and reporting patient experience and outcomes in Canada based on information obtained from participants prior to the event, as well as from CIHI’s work to date in these areas. Participants joined in a facilitated discussion on whether the presentations accurately reflected the PREMs and PROMs work in their jurisdictions and organizations, and were asked to highlight any innovative initiatives that were taking place.

2. **Identifying common priorities**: Participants used concurrent working group sessions to identify common priorities for measuring and reporting patient-reported experiences and outcomes over the next 5 years. This was followed by a debrief session with the larger group.

3. **Achieving the vision**: Participants used concurrent working group sessions to identify what would be needed to move the priorities forward and to identify key partners and their roles in facilitating a common approach to patient-centred measurement and reporting in Canada. This was followed by a debrief with the larger group. The entire group then engaged in a dialogue to start developing an action plan for achieving the vision.

The agenda and participant list are available in appendices D and E.
Setting the stage

PREMs are self-reported measurement instruments or questionnaires that patients complete to provide information about their satisfaction with and experience of receiving health care. They are focused on the processes of care and how that impacts the patient’s perceptions of his or her experience. PREMs are primarily used to evaluate and monitor service quality.², ³

PROMs are self-reported measurement instruments that patients complete to provide information on aspects of their health (e.g., symptoms; function; physical, mental and social health) that are relevant to their quality of life and that provide insight on the effectiveness of care from the patient’s perspective. 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). PROMs are most often used pre- and post intervention (e.g., in elective surgeries) or longitudinally (e.g., for chronic conditions) to monitor the progress of a health condition or whether a treatment has been effective by comparing results over time.²–⁵

PREMs and PROMs can be used together to more fully assess quality of care from the patient’s viewpoint to inform changes to clinical practice and to improve service delivery.²–⁵

Patient-reported experience measures

International experience

Over the past few decades, many countries have been engaged in PREMs initiatives based on the work of the Picker Institute and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program in the United States.³

- In 1987, the Picker Institute established the Eight Picker Principles of Patient-Centered Care, which over time came to figure prominently as an international framework to support the delivery of high-quality patient-centred care. In 2002, the Picker Institute designed and established the National Health Service (NHS) National Survey Programme for patient experience in the United Kingdom.⁶

- The Agency for Healthcare Research and Quality in the U.S. launched the CAHPS program in 1995 to develop standardized surveys that organizations can use to collect comparable information on patients’ experiences with care, and to generate tools and resources to support the use and reporting of comparable survey results to improve quality of care.⁷ The CAHPS Hospital Survey is part of the Hospital Value-Based Purchasing Program in the U.S.
Although there has been significant investment in patient-centred measurement and reporting in some countries, the opportunity for international benchmarking and learning is limited. The Organisation for Economic Co-operation and Development (OECD) has a small number of comparable indicators on patient experience with doctors in ambulatory care settings. Currently, 19 OECD countries provide this data as part of their routine data submission for reporting in the OECD’s Health at a Glance reports. Indicators include

- Doctor Spending Enough Time With Patient in Consultation;
- Doctor Providing Easy-to-Understand Explanations;
- Doctor Giving Opportunity to Ask Questions or Raise Concerns; and
- Doctor Involving Patient in Decisions About Care and Treatment.

In addition, 11 countries participate in The Commonwealth Fund International Health Policy surveys. These surveys are conducted annually using a 3-year cycle for each target population: the general public (adults age 18 and older), older adults (age 65 and older) and primary care physicians. They cover themes such as access to primary care and specialists, care in emergency departments and hospitals, continuity of care, cost as a barrier to health care, perceptions of the health care system, and health promotion and disease prevention. The 2016 version of The Commonwealth Fund’s survey included 2 additional questions from the CAHPS Hospital Survey that relate to hospitalized patients’ perceptions of being treated with respect and courtesy by doctors and nurses.

**Canadian experience**

In Canada, over the past decade, health care organizations have also placed an increased emphasis on providing patient-centred care to better respond to the needs of patients and to improve quality of care. Provinces and territories have further emphasized this importance by including patient-centred care and measures that demonstrate patient-centredness in their strategic priorities and directions. The imperative for patient-centred measurement and reporting has become stronger as part of the goal to achieve a patient-centred health care system along with accreditation requirements. With this, there has been proliferation of the use of survey instruments across the country to understand patients’ satisfaction and experience of care in various health care sectors.

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i. In January 2013, Accreditation Canada introduced a requirement for acute care organizations to measure and report results of a client experience survey at least once per 4-year accreditation cycle. This requirement has been expanded to other sectors and services and is currently applicable to organizations in acute care, long-term care, home care and home support, primary care and mental health; medical imaging centres; correctional services; and the Canadian Forces Health System. As of 2017, cancer care and residential homes providing care for seniors also have a client experience requirement as part of the accreditation program.

ii. CARF Canada (formerly known as the Commission on Accreditation of Rehabilitation Facilities) requires that accredited organizations obtain input on an ongoing basis from persons served, personnel and other stakeholders using a variety of mechanisms (e.g., written or telephone surveys, forums, councils). In addition, CARF’s standards require that organizations analyze the inputs obtained and use that information for planning, performance improvement and organizational advocacy.
A variety of PREMs survey tools and data collection methods are being used, albeit inconsistently across Canada, to capture patients’ views of their experiences with care. These surveys are being used inconsistently in a variety of health care settings, including inpatient acute care hospitals, emergency departments, rehabilitation care, long-term care, mental health care, community care, cancer care and primary care (see appendices A and B). More recently, some jurisdictions have begun to explore ways to incorporate PREMs survey tools for measurement across the continuum of care.

Some jurisdictions have mandated collecting and reporting patient experience survey data. Several have established province-wide longitudinal survey programs in selected health sectors and centrally coordinate survey administration, which facilitates provincial, regional and peer group comparisons (e.g., Prince Edward Island, New Brunswick, Alberta, British Columbia; see Box 1). In other provinces, this is done at the regional (e.g., Saskatchewan) or individual facility level (e.g., Ontario). However, even here there are attempts to coordinate processes to ease survey administration and mitigate resource constraints (see boxes 2 and 3).

**Box 1: Example of a provincial survey program**

The B.C. Ministry of Health, in collaboration with the province’s regional health authorities, the Provincial Health Services Authority and affiliate organizations, implemented a Provincial Patient-Centred Measurement Initiative in 2002. The program was established to measure the experience of patients in a range of health care sectors (i.e., acute care, emergency departments, cancer care, mental health and substance use, long-term care) in a standardized way across the province. The work is led by the B.C. Patient-Centred Measurement Steering Committee. Recently, B.C. received funding from the Strategy for Patient-Oriented Research (SPOR) in exchange for providing a central, secure data repository for provincial patient experience data.
Box 2: Example of a regional survey program

From 2007 to 2015, the Saskatchewan Health Quality Council (HQC) supported regional health authorities in the province to survey patients in the acute care and primary care sectors. However, due to fiscal constraints, beginning in 2016, there was a shift to local ownership of the entire survey process. Patient experience surveys at the level of the acute care unit are processed at the health region level, and HQC provides a user-friendly tool that regions can use to depict survey results visually. Primary health care patient experience surveys are processed at the health region or clinic level. A Care Experience Measurement Working Group has been established within the Patient- and Family-Centred Care Guiding Coalition to ensure that patient survey work continues in the province despite the change from provincial to regional ownership.12

Box 3: Example of a facility survey program

Beginning in September 2014, the Ontario Hospital Association (OHA) established and convened survey committees to review and identify options for non-proprietary longitudinal patient experience survey instruments, with the goal of identifying and recommending scientifically robust and validated surveys for use by Ontario hospitals in a number of hospital sub-sectors. To date, tools have been recommended for use with adult inpatient (medical/surgical), pediatric inpatient, emergency department, maternity and rehabilitation patients. Recommendations are under way for mental health, ambulatory clinics, ambulatory day surgery and complex continuing care.13 The OHA manages a Patient Reported Performance Measurement vendor services contract on behalf of Ontario hospitals, which facilities can choose to participate in. Approximately two-thirds of acute care hospitals in Ontario (96 corporations) participate in this shared contract.
There is considerable variation in the use of survey instruments across provinces and health sectors. The lack of coordination in the selection of standardized survey instruments and differences in data collection methodologies prohibits pan-Canadian benchmarking and comparisons.

The cancer care sector, followed by acute care, is the most developed in terms of having a national standardized approach to patient-centred measurement and reporting (see appendices A and B).

The Ambulatory Oncology Patient Satisfaction Survey (AOPSS), developed and maintained by National Research Corporation Canada (NRCC), was implemented in 8 provinces between 2003 and 2016. The survey focuses on 2 phases of the cancer care continuum: detection and diagnosis/treatment. It asks patients about their experience with 6 dimensions of patient-centred care:

- Access to care;
- Coordination and continuity of care;
- Emotional support;
- Information, communication and education;
- Physical comfort; and
- Respect for patient preferences.

Questions relate to cancer diagnosis, treatment planning, tests, surgery, chemotherapy, radiotherapy, symptom management, health care providers and overall impressions.\(^{14}\)

The Canadian Partnership Against Cancer (CPAC), as part of its mandate to publicly report on indicators measuring pan-Canadian cancer system performance, reports on comparative patient satisfaction scores from provinces that administer the AOPSS; it has included this information in its annual reports since 2009 and in its Cancer System Performance web application since 2014. The web application currently shows patients’ negative ratings of their experience across all dimensions of care and of overall quality of care by province from 2011 to 2013 for 5 jurisdictions (P.E.I., Nova Scotia, Manitoba, Saskatchewan, Alberta). Dimensions of care with higher negative ratings may be areas that need improvement.\(^{14}\)

Although progress has been made toward standard measurement and reporting in this sector, there is still work to be done to establish comparative reporting across jurisdictions. According to CPAC, this work includes ensuring that inclusion/exclusion criteria for patients to survey, as well as the timing and frequency of surveys, are consistent across organizations and provinces.\(^{14}\)
In 2016, CPAC began conducting the Experiences of Cancer Patients in Transition Study in collaboration with 10 provinces across the country. The purpose of this study is to improve quality of care for patients/survivors as they complete their cancer treatment and transition from the cancer care system to the broader health care and support system.\(^{15}\)

In 2011, several Canadian jurisdictions approached CIHI to lead the development of a pan-Canadian acute care inpatient experience survey to support national comparisons and benchmarking for this sector. CIHI worked with the IJ and other leading experts in the field to develop the Canadian Patient Experiences Survey — Inpatient Care (CPES-IC). The CPES-IC is a non-proprietary standardized questionnaire to gather patient feedback from adults (age 18 and older) about the quality of care they received during their most recent inpatient stay for maternity, surgical or medical services in a Canadian acute care hospital. The CAHPS Hospital Survey, used in the U.S. for more than 12 years, is the base of the CPES-IC survey. Through rigorous cognitive and pilot testing, additional questions that address key areas relevant to the Canadian context were added to make up the CPES-IC.\(^{16}\)

The CPES-IC has been implemented in various jurisdictions across Canada on a voluntary basis, starting with Manitoba and Alberta in 2014, New Brunswick in 2015, and Ontario and B.C. in 2016. CIHI has also developed standards for administering the CPES-IC to support uniform implementation across the country, and it established the Canadian Patient Experiences Reporting System (CPERS) database to collect data and report results using the CPES-IC.\(^{17}\) As of early 2017, CIHI had received data submissions from both Manitoba and Alberta, with more jurisdictions signalling their commitment to submit data later in the year.

Beyond the acute care setting, 2 national household surveys in Canada are designed to measure patient experiences across different health care sectors at the population level:

- **Statistics Canada’s Canadian Community Health Survey (CCHS)** collects information annually on health status, health care use and determinants of health, and is designed to provide estimates at the health region level. Questions focus on health care utilization, contact with various health care professionals (including family physicians, nurses, specialists, allied health providers and mental health professionals) and home care services.\(^{18}\) As of 2015, the survey includes a rotating module on patient experiences with health care services received outside of a hospital.\(^{19}\)

- **The Commonwealth Fund International Health Policy surveys** provide comparative information on patient and provider experiences in 11 developed countries, including Canada. Additional funding is provided by provincial organizations (Quebec, Ontario, Alberta) for increased sample sizes that allow for provincial breakdowns of results (see the “International experience” section above for more information on The Commonwealth Fund). CIHI and the Canadian Institutes of Health Research (CIHR) are the national Canadian co-sponsors of the survey. CIHI reports on the Canadian data and highlights how experiences with health care vary across jurisdictions and how they compare with those in other countries.\(^{20}\)
Patient-reported outcome measures

International experience

The National Health Service (NHS) in the U.K. is the international leader in routine collection of PROMs data at the health system level. Since 2009, the Department of Health, as part of the NHS contract for acute care, has required routine collection of PROMs for all NHS patients before and after surgery who undergo 4 elective procedures: hip replacement, knee replacement, varicose vein surgery and groin hernia repair. Improving outcomes for these planned procedures is one of the objectives in the NHS Outcomes Framework (Domain 3: Helping people to recover from episodes of ill health or following injury). The indicators are publicly reported on the My NHS website, which facilitates region and facility-level comparisons.

A number of other countries are collecting PROMs, with the most common disease groups and interventions being elective surgery (e.g., hip replacement, knee replacement, cataract surgery), mental health, cancer and chronic disease (e.g., chronic obstructive pulmonary disease, arthritis, cardiovascular disease). Some countries have PROMs activities in additional sectors such as long-term care, palliative care and informal care, but not all initiatives are national programs. As development of PROMs programs across countries is not coordinated, opportunities for cross-country comparisons are even more limited than for PREMs.

The International Consortium for Health Outcomes Measurement (ICHOM) is a non-profit organization committed to transforming health care to a value-based system through universal measurement and reporting of patient outcomes. The ICHOM does not currently collect data from provider organizations or countries, nor does it conduct international surveys. However, it is currently working to develop infrastructure to advance comparisons within organizations and across countries and is developing guidelines for collecting PROMs across numerous medical conditions. To date, the ICHOM has published standards for 20 conditions, including coronary artery disease, prostate cancer, cataracts, depression and anxiety, lung cancer, hip and knee osteoarthritis and stroke, and it is in the process of developing guidelines for additional conditions such as end-stage kidney disease and diabetes. As of 2016, the OECD is exploring partnerships with the ICHOM while conducting consultations of its own to shape an international PROMs agenda.

Canadian experience

In Canada, PROMs have been widely used in clinical trials and in other research settings. There are local and regional PROMs programs, but their implementation and use in routine care vary. Alberta and B.C. have made the most progress toward establishing provincial PROMs programs (see Appendix C).
In B.C., an invitational symposium entitled Patient Reported Outcome Measures to Improve Performance, Value and Productivity was held in December 2010 to bring together senior health care leaders from across the province and other jurisdictions in the Western and Northern Health Human Resources Planning Forum and international PROMs experts to confer about the routine collection of PROMs. In 2013, CIHR and the B.C. Ministry of Health conducted a knowledge synthesis project to evaluate PROMs instruments and identify a generic tool for use in primary and community care settings. From 2011 to 2013, CIHR funded Vancouver Coastal Health to conduct the Value and Limitations in Hospital Utilization and Expenditure (VALHUE) Project in several clinical areas to assess the relationship between wait times and trajectory of change in health status, pain and depression. Routine measurement of patient experiences and patient outcomes in health care was identified as a provincial strategic objective in 2016. As such, both PREMs and PROMs are now part of the B.C. Ministry of Health’s Provincial Patient Centred Measurement Initiative. In 2016, B.C. began field testing the EQ-5D and Veterans RAND 12-Item Health Survey (VR-12) with patient experience surveys in acute inpatient (CPES-IC) and emergency department care (Emergency Department Patient Experience of Care Survey). Work is also under way to adapt the VR-12 for use in long-term residential care. B.C. is currently fielding the VR-12 (original) with the adapted VR-12 for long-term care. The adapted survey is currently administered with the interRAI Quality of Life Survey in these sectors across the province.

Alberta has used PROMs in population health surveys for a number of years. The Health Quality Council of Alberta (HQCA) has incorporated the EQ-5D into the Satisfaction and Experiences With Health Care Services Survey (2010 to 2014), the Alberta Community Health Survey (2010 to 2014) and emergency department patient experience surveys (2007 to 2013). In Alberta, the EQ-5D has been used in routine care for quality improvement initiatives in several clinical areas (e.g., cancer care, hip and knee surgery). Alberta plans to expand the routine collection and use of PROMs in cardiovascular disease, chronic obstructive pulmonary disease and primary health care with a focus on chronic diseases. In 2016, primary care networks in Alberta incorporated PROMs into their accountability framework and performance indicators and began integrating PROMs into their workflow.

When the strategic clinical networks (SCNs) were formed in Alberta in 2012, Alberta Health Services (AHS) identified a need for a provincial standardized approach to patient-reported outcomes measurement across all the SCNs for research and program evaluation purposes. As such, the HQCA, in collaboration with AHS, the University of Alberta and the Institute of Health Economics, convened an invitational symposium to discuss the potential for adopting the EQ-5D as a standardized health outcome measure for routine care in the province. In 2015, the Alberta PROMs and EQ-5D Research and Support Unit (APERSU) was established in partnership with the University of Alberta, AHS, HQCA and the EuroQol Group to promote, support and coordinate the use of PROMs across Alberta and to allow the use of the EQ-5D in the province without end-user fees.
While there is active use of PROMs in some jurisdictions, a coordinated pan-Canadian program for routinely administering PROMs is in the early stages of development.

The need for routine PROMs information was identified as a high priority at the October 2014 Consensus Conference co-hosted by CIHI and Statistics Canada. In response, CIHI hosted an invitational pan-Canadian PROMs Forum in February 2015 to convene Canadian health leaders to discuss PROMs and explore opportunities for standardizing PROMs data collection and reporting across Canada. At the PROMs Forum, stakeholders confirmed their interest in a pan-Canadian PROMs program and that CIHI should take a leadership role in advancing common approaches to PROMs in Canada. In September 2015, CIHI established an advisory group to mobilize and guide the development of this common approach; members of the advisory group came from jurisdictions, researchers and clinicians actively using PROMs. Subsequently, a working group tasked with making recommendations for adopting a generic PROMs tool for use across Canada has also been established. The 2 generic tools being considered are the EQ-5D and VR-12. Initial areas of focus include hip and knee replacement and renal care. To guide this work, CIHI has established other working groups and is completing demonstration projects in these areas using data from existing PROMs programs at the Winnipeg Regional Health Authority (hip and knee replacement) and the B.C. Renal Agency (renal care).

Identifying common priorities

Participants at the visioning day were organized into small groups to discuss what patient-centred measurement and reporting would look like in Canada in the next 5 years. A summary of the discussion follows.

Priority areas for measurement

There was general consensus that, where appropriate, standardized, sector-specific PREMs survey instruments should be used for patient-centred measurement and reporting by jurisdictions across Canada to facilitate pan-Canadian benchmarking and comparisons.

Participants felt that guiding principles or selection criteria were needed to identify priority health sectors and populations to survey. Areas of focus would need to be aligned with jurisdictional priorities to ensure provincial/territorial support and to secure funding for the initiative.

Groups discussed what sectors to focus on next to further measure patient experience across the continuum of care at a pan-Canadian level. Sectors that were identified included long-term care, emergency departments, primary care, mental health and pediatrics. Most participants
felt that long-term care should be the next focus area since it is one of the most regulated industries; however, others felt that this might be challenging given that long-term care is a regional rather than provincial responsibility in some jurisdictions. Although mental health and pediatrics are important, it may be a challenge to develop a provincial or national survey program in these sectors due to differences between speciality and non-specialty hospitals. Nevertheless, some participants felt that this was not an issue, as selection of a core tool would consider issues that are relevant to all types of patients and locations, and that hospitals would be compared with those in their respective peer groups. In addition, participants felt that it may be difficult to gain consensus on a common survey instrument for mental health patients since some jurisdictions (P.E.I., Alberta) have been surveying these patients for years and may not want to switch to a new tool if the one they are using is not selected.

Continuity of care was identified as a common priority across jurisdictions. Participants felt that they needed more information to understand patients’ experience of continuity of care before they could improve in this area. High users were identified as a potential patient population for continuity of care surveys. Nevertheless, participants felt that clearer definitions of “continuity” and “transitions” were needed before appropriate target populations and intersecting health sectors could be identified. Some also felt that questions about continuity and transitions of care might be more fitting for population-based rather than sector-specific surveys.

Some participants cautioned that a single standard for PREMs may not always work in all sectors and patient populations, and that the audience and purpose should always be kept in mind. There is the conundrum that what is useful at the system level may not be useful for patients or providers. Nevertheless, there is still value in having unit-, facility- or jurisdiction-specific tools to foster innovation and improvements at the local level. Some standardized, commercially available longitudinal surveys are not specific enough to be relevant to particular clinical program areas.

One participant suggested the following “rights” as guiding principles of patient-centred measurement:

- Are we measuring the right things (right questions)?
- Are we using the right survey modes (technology)?
- Are we surveying at the right time, in terms of both the sector of the system and during the episode of care (length, frequency, point of care versus across the continuum of care)?
- Are we surveying the right patients (diagnosis, complex care)?
- Are we doing it at the right cost (funds available, actionable outcomes)?
- Are we doing it for the right reasons (asking patients about the relevance of the measurement)?
Another important factor to consider is that what is measured needs to be actionable; it must be an area where opportunities for improvement exist and where data can help to meaningfully address the issue.

Participants identified the need for a business case to get engagement and buy-in from key stakeholders to support advancement in patient-centred measurement and reporting in some jurisdictions. In some jurisdictions, a lack of value-based evidence has resulted in reluctance to implement provincial or sector-specific programs because there is little confidence in the return on investment.

Potential barriers to participating in a national patient-centred measurement and reporting program included

- Costs and limited resources for data collection;
- Lack of electronic technology to implement the survey;
- The need for alignment with provincial/territorial strategic priorities and initiatives;
- The extent to which comparable data is needed in particular areas; and
- The ability to reach agreement on common survey instruments to use.

**Real-time versus longitudinal surveys**

Timeliness when reporting on longitudinal survey results was identified as a challenge. Some participants indicated that they were using rapid cycle surveys in selected health sectors to gather additional real-time information at the point of care. They also felt that this data should be linked with the data from longitudinal surveys. There were some concerns about the scientific rigour of the rapid cycle surveys that are currently being used and how this would impact the ability to tie performance to funding incentives. Nevertheless, participants felt there were advantages to using both types of surveys to monitor health system performance and initiate improvement, as well as to identify trends that could be linked to pay-for-performance funding.

**Use of patient-reported experience and outcome measures together**

It was suggested that PREMs and PROMs could be used to enrich existing information on the quality of care and services provided (e.g., clinical-based outcomes) and should be linked to other administrative and clinical data sources. For the most part, participants agreed that PREMs and PROMs can be complementary and could be used together where appropriate. However, groups felt that they needed to have a better understanding of the relationship between patient-reported experience and outcome measures.
Some groups discussed the appropriateness of administering PREMs and PROMs survey instruments together. They questioned whether this should be done, as the instruments were intended to be used for diverse purposes and at different time points in the episode of care. For example, PROMs in elective surgery are to be collected pre- and post-intervention, while longitudinal PREMs can be captured only after patients have received care. However, there was an appreciation that if PROMs were used for clinical management of patients, patients in turn might have a better perception of their experience of care.

Participants suggested further investigation of adding a mini-PREM survey to PROMs (and vice versa) that could link back to the longitudinal survey data.

**Sub-population analysis**

Participants felt that analysis by subgroups was required to assess the variability in PREMs and PROMs results. There was some discussion about focusing on specific priority populations, such as seniors and Aboriginal peoples. For example, analyses could differentiate between different cohorts of seniors, such as those age 65 to 84 and those age 85 and older. Disease-specific analyses for combined jurisdictions would also be useful for rural or small facilities with small sample sizes.

**Targeted reporting to different audiences**

Specific to PREMs, participants identified reporting requirements for different types of target audiences: population-level for patients, the general public, and the media; and granular-level for front-line providers. There is a need for increased availability of patient-centred measurement information in the public realm. Tools that are developed for this audience need to be easily accessible and simple to understand. Transparency and accountability through public reporting was also perceived to be a responsibility to taxpayers.

Participants felt that provider- or unit-level data that allows for comparisons across clinicians, clinical program areas, and facilities is needed to drive practice and health system change. This type of reporting would require administrative and clinical data as well as measures available by subgroup, presented along with benchmarks and performance targets. Aggregate-level reporting is still required for accountability purposes, but granular-level reporting is needed to action data for continuous quality improvement.

System-level aggregate data is needed for accountability. Standardized longitudinal surveys must be scientifically robust to be able to tie funding to performance.
Participants identified several challenges with the use of patient-centred measurement results. Education targeted at the different audiences is needed to help them interpret results and understand how to use information to improve care delivery (clinicians) or inform decision-making (patients). As one participant indicated, guidelines and work tools are needed to educate clinicians on how to effectively use these tools and measures to improve patient care.

Participants felt that accountability for monitoring and improving patient experiences based on patient feedback would require a culture change and funding incentives at the facility level, as well as at the provider level through pay-for-performance programs. In Ontario, implementation of patient experience surveys is the basis for pay-for-performance funding; however, the focus should really be about performance results, not surveying per se.

**Achieving the vision**

The group used Michael Barber’s Map of Delivery to help them draw a road map for achieving the common priorities. A highway analogy was used to identify the short- and long-term priorities that are required to achieve the desired future state of patient-centred measurement and reporting in Canada:

- The high occupancy vehicle (HOV) lane refers to items that should be top of mind when considering the ultimate common priorities for a pan-Canadian agenda.
- The express lane includes priorities that are currently under way and are achievable in the shorter term because they are moving ahead at a faster pace.
- Objectives in the collectors lane are considered to be longer-term priorities because they are moving ahead but at a slower pace.
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<tr>
<td><strong>HOV lane: Keep in mind</strong></td>
<td>• Consider jurisdictional priorities and how these align with what is being proposed at the pan-Canadian level. It is believed that alignment with jurisdictional priorities would help facilitate common approaches to patient-centred measurement and reporting across the country and help secure funding for PREMs and PROMs initiatives in provinces and territories.</td>
</tr>
</tbody>
</table>
| **Express lane: Short-term objectives** | • Continue to identify, develop and promote common patient-reported experience measurement tools for the inpatient care, long-term care and emergency department sectors.  
• Continue to collect CPES-IC data through CPERS and report pan-Canadian results for benchmarking and comparisons for participating jurisdictions.  
• Build capacity for regions and facilities to understand how to use PREMs and PROMs survey data to improve quality.  
• Develop a business case for work on PREMs and PROMs.  
• Continue PROMs demonstration projects in selected clinical areas, including hip and knee replacement and renal care, with an aim to progress to pan-Canadian data collection.  
• Pilot test the use of mini-PREMs and PROMs together (and vice versa). |
| **Collectors lane: Long-term objectives** | • Identify common patient-reported experience measurement tools for the mental health sector.  
• Identify tools to collect information on continuity or transitions of care (helping to establish the differences between these concepts).  
• Explore ways to better obtain information from Aboriginal populations.  
• Develop primary care patient portals.  
• For PREMs, develop a central repository of survey instruments for the various health sectors, as well as a “crosswalk” document that highlights the similarities and differences among sector-specific tools; this would help guide stakeholder discussions when selecting the most appropriate instrument for the sector.  
• Create a centralized bank of validated survey questions that stakeholders could use when considering questions to add to patient experience surveys to meet their own jurisdictional needs. |
Key partnerships

CIHI’s role

Overall, there was general consensus from participants that CIHI is strategically positioned to facilitate a standardized approach to patient-centred measurement and reporting across Canada in health sectors where there is jurisdictional alignment in strategic priorities and directions. CIHI’s Strategic Plan, 2016 to 2021 includes a focus on health system performance (patient experience and outcomes) and places an emphasis on priority populations that have been identified for future work, including seniors and aging, mental health and addictions, and Aboriginal peoples.

CIHI has extensive experience developing standards and methodologies, and in conducting pan-Canadian health system performance measurement and reporting. It also has knowledge of managing national health system databases and registries, as well as coordinating and promoting standards and data quality. This enables CIHI to coordinate centralized data collection and reporting on measures as well as to provide additional value by linking patient-reported experience and outcome data with other administrative and clinical data holdings for enriched information.

In addition, CIHI has established relationships with key organizations that are involved in patient-centred measurement and reporting. Through its stakeholder engagement, it is able to collaborate with jurisdictions and convene discussions to better understand stakeholder needs and their priorities for measuring patient experiences across the continuum of care. At the international level, CIHI provides input into the OECD program of work on PREMs and PROMs through its participation on committees and input via Health Canada.

Other partners

Other key partners that were identified include patients, clinicians and front-line staff, ministries and departments of health, jurisdictions not currently participating in national survey programs and Accreditation Canada. Participants indicated that patients should be engaged throughout the process. It was suggested that Accreditation Canada could help promote recommended survey instruments to help standardize patient-centred measurement across sectors and provinces/territories.
Conclusion and next steps

The visioning day highlighted the vast amount of work being done in both PREMs and PROMs across Canada. Participants agreed that where opportunities exist, work across the country should be leveraged for interjurisdictional alignment, with a focus on quick wins while also addressing the gaps. Key to successfully achieving alignment is engaging patients and listening to their feedback. Hearing what matters most to patients should drive conversations.

The following provides an account of what the visioning day participants considered to be quick wins and focused areas that would benefit from pan-Canadian strategic alignment.

In efforts to get moving on the express lane priorities, the following are under way:

- Building on the work to develop the CPES-IC, CIHI is working to further measure patient experience across the continuum of care by identifying a similar questionnaire for residents in long-term care facilities. CIHI, in partnership with the Inter-Jurisdictional Patient Experience Group for Long-Term Care (IJ-LTC), used validated evaluation criteria to conduct a literature review and environmental scan of survey instruments being used in long-term care facilities across Canada and internationally. There are 3 tools being considered for pan-Canadian use: the interRAI Quality of Life (QoL) Survey, the Long Stay Resident Experience (LSRE) Survey and the Ohio Long-Term Care Resident Satisfaction Survey.

- CIHI recently sponsored a pilot study to test the interRAI QoL Survey in 47 long-term care facilities in 5 provinces (New Brunswick, Ontario, Manitoba, Alberta, B.C.) to compare Canadian sites with international benchmarks and to look at the relationship between RAI 2.0 clinical items/scales and quality of life ratings. Based on the pilot test results and accreditation requirements that came into effect for the long-term care sector in 2016, more than 500 facilities across Canada have implemented or are in the process of implementing the interRAI QoL Survey.

- CPES-IC data received in CPERS will be analyzed to develop and finalize patient experience indicator measures, develop individual and aggregate comparative private facility reports and explore opportunities to enrich existing data sources. CIHI is in the process of developing a public reporting strategy as well as methodological considerations for comparing results.

- CIHI will continue work to develop standards for PROMs collection and reporting in hip and knee replacement and renal care, including completion of demonstration project analyses. Working with interested jurisdictions and site partners, CIHI intends to progress toward pan-Canadian data collection.

- CIHI will also continue work in assessing the generic PROMs tools for pan-Canadian use, through its PROMs Generic Tools Working Group. As part of this work, CIHI is seeking national licences for both the EQ-5D and VR-12 tools.
• CIHI is developing a roadmap for its PROMs program over the next several years, which will involve identifying other potential priority areas and sectors for PROMs standardization. CIHI continues its outreach with other organizations, such as CPAC, to identify collaborative opportunities to progress on PROMs in Canada.

• CIHI hosted the Patient-Centred Measurement Peer Learning Day in December 2016 to bring together stakeholders from across the country who have a broad range of knowledge and experience with patient-centred measurement. Participants learned from each other how to effectively use patient-reported data to improve quality. Participants included patients; provincial-, regional- and facility-level managers, directors and senior executives; and clinical leaders.
# Appendix A: PREM survey activities by province — Acute care inpatient sector

<table>
<thead>
<tr>
<th>Province*</th>
<th>Tool</th>
<th>Survey implementation</th>
<th>Frequency of surveying</th>
<th>Survey coordination</th>
<th>Sampling frame/target population</th>
<th>Survey mode</th>
<th>Results reported publicly</th>
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</thead>
<tbody>
<tr>
<td>Newfoundland and Labrador</td>
<td>CAHPS Hospital Survey (adapted)</td>
<td>2013 Ongoing</td>
<td>Unknown</td>
<td>Centralized; administered by Western Health</td>
<td>Unknown</td>
<td>Mail</td>
<td>Unknown</td>
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<tr>
<td>Prince Edward Island</td>
<td>Acute Care — Client Satisfaction Survey (Accreditation Canada)</td>
<td>2013 Ongoing</td>
<td>Continuous (ongoing)</td>
<td>Centralized; administered by Health PEI</td>
<td>Facility level; anyone discharged from an acute care hospital</td>
<td>Mail, online</td>
<td>No</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>CPES-IC (CIHI)</td>
<td>2016 Ongoing</td>
<td>Unknown</td>
<td>Centralized; administered by New Brunswick Health Council</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Planning under way</td>
</tr>
<tr>
<td></td>
<td>CAHPS Hospital Survey (adapted)</td>
<td>2010 2013</td>
<td>3-month sampling time frame every 3 years</td>
<td>Centralized; administered by New Brunswick Health Council</td>
<td>Facility level; acute maternity, medical or surgical patients, age 18 and older</td>
<td>Mail</td>
<td>Yes, results publicly available on New Brunswick Health Council’s website</td>
</tr>
<tr>
<td>Quebec</td>
<td>Enquête de satisfaction</td>
<td>Unknown</td>
<td>2007</td>
<td>Centralized; administered by Institut de la statistique du Québec</td>
<td>Specific to administrative region</td>
<td>Telephone</td>
<td>Unknown</td>
</tr>
<tr>
<td>Province*</td>
<td>Tool</td>
<td>Survey implementation</td>
<td>Frequency of surveying</td>
<td>Survey coordination</td>
<td>Sampling frame/target population</td>
<td>Survey mode</td>
<td>Results reported publicly</td>
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<tr>
<td>Ontario</td>
<td>CPES-IC (CIHI) plus subsector modules</td>
<td>2016</td>
<td>Ongoing</td>
<td>Continuous (ongoing)</td>
<td>Ontario Hospital Association holds centralized vendor contract for hospitals; not mandatory</td>
<td>Facility level; acute maternity, medical or surgical inpatients</td>
<td>Mail, telephone, email</td>
</tr>
<tr>
<td></td>
<td>Acute Inpatient Survey (NRCC)</td>
<td>Unknown</td>
<td>2016</td>
<td>Specific to individual hospital</td>
<td>Ontario Hospital Association holds centralized vendor contract for hospitals; not mandatory</td>
<td>Specific to individual hospital</td>
<td>Mail</td>
</tr>
<tr>
<td>Manitoba</td>
<td>CPES-IC (CIHI)</td>
<td>2014</td>
<td>Ongoing</td>
<td>Continuous (ongoing)</td>
<td>Manitoba Health, Seniors and Active Living</td>
<td>Facility level; acute maternity, medical or surgical inpatients</td>
<td>Mail, online</td>
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<tr>
<td>Saskatchewan</td>
<td>Acute Care Unit-Level Patient Experience Survey (Saskatchewan Health Quality Council)</td>
<td>2007</td>
<td>Ongoing</td>
<td>Unknown</td>
<td>Effective 2016, administered at the health region level; not mandatory</td>
<td>Unit level</td>
<td>Mail, online</td>
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<tr>
<td>Province*</td>
<td>Tool</td>
<td>First date</td>
<td>Last date</td>
<td>Frequency of surveying</td>
<td>Survey coordination</td>
<td>Sampling frame/target population</td>
<td>Survey mode</td>
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<tr>
<td>Alberta</td>
<td>CPES-IC (CIHI)</td>
<td>2014</td>
<td>Ongoing</td>
<td>Continuous (ongoing)</td>
<td>Centralized; administered by Alberta Health Services</td>
<td>Facility level; acute maternity, medical or surgical inpatients</td>
<td>Telephone</td>
</tr>
<tr>
<td></td>
<td>CAHPS Hospital Survey</td>
<td>Pilot 2004; province-wide 2010</td>
<td>2014</td>
<td>Continuous (ongoing)</td>
<td>Centralized; administered by Alberta Health Services</td>
<td>Facility level; acute maternity, medical or surgical inpatients</td>
<td>Telephone</td>
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<tr>
<td></td>
<td>Satisfaction and Experience With Healthcare Services Survey (Health Quality Council of Alberta)</td>
<td>2003</td>
<td>2014</td>
<td>Annually</td>
<td>Centralized; administered by Health Quality Council of Alberta</td>
<td>Population level; Albertans with landlines</td>
<td>Telephone</td>
</tr>
<tr>
<td>Province*</td>
<td>Tool</td>
<td>Survey implementation</td>
<td>Frequency of surveying</td>
<td>Survey coordination</td>
<td>Sampling frame/target population</td>
<td>Survey mode</td>
<td>Results reported publicly</td>
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<tr>
<td>British Columbia</td>
<td>CPES-IC (CIHI) plus subsector modules†</td>
<td>2016</td>
<td>Ongoing</td>
<td>6-month sampling time frame every 3 years (baseline results); continuous sampling</td>
<td>Centralized; administered by B.C. Patient Centred Measurement Working Group</td>
<td>Unit level</td>
<td>Telephone, online</td>
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</tr>
<tr>
<td>Acute Inpatient Survey (NRCC) plus subsector modules§</td>
<td>2005</td>
<td>2011–2012</td>
<td>3- or 6-month sampling time frame every 3 years</td>
<td>Centralized; administered by B.C. Patient Centred Measurement Working Group</td>
<td>General inpatient population, sub-sector level</td>
<td>Mail</td>
<td>Results publicly available from B.C. Ministry of Health</td>
</tr>
</tbody>
</table>

Notes
* Information for Nova Scotia, Yukon, the Northwest Territories and Nunavut was unavailable at the time of writing.
† Modules: Pediatrics, maternity, rehabilitation, surgery; additional questions on patient safety; continuity across transitions of care; and VR-12.
‡ After baseline has been established, continuous frequency of small samples embedded in blended acute care/emergency department survey.
§ Modules: Pediatrics, maternity, rehabilitation.
CPES-IC: Canadian Patient Experiences Survey — Inpatient Care.
NRCC: National Research Corporation Canada.
## Appendix B: PREM survey activities by province — Other sectors

<table>
<thead>
<tr>
<th>Province*</th>
<th>Emergency department</th>
<th>Ambulatory care</th>
<th>Long-term care/residential care</th>
<th>Cancer care</th>
<th>Mental health care</th>
<th>Home and community care</th>
<th>Primary care</th>
<th>Pediatrics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newfoundland and Labrador</td>
<td>• 2013: CAHPS Hospital Survey (Canadian adaptation)</td>
<td>—</td>
<td>• 2013: Nursing Home Consumer Assessment of Healthcare Providers and Systems (with some modification)</td>
<td>—</td>
<td>• 2013: Community Based and Clinic Care Services Survey • 2013: Acute Care Patient Experience Survey — CAHPS Hospital Survey (Canadian adaptation)</td>
<td>• 2013: Community Based and Clinic Care Services Survey • 2013: Acute Care Patient Experience Survey — CAHPS Hospital Survey (Canadian adaptation)</td>
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</tr>
<tr>
<td>Province*</td>
<td>Emergency department</td>
<td>Ambulatory care</td>
<td>Long-term care/residential care</td>
<td>Cancer care</td>
<td>Mental health care</td>
<td>Home and community care</td>
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<tr>
<td>Prince Edward Island</td>
<td>• Unknown date: Acute Care — Client Satisfaction Survey (Accreditation Canada)</td>
<td>• Unknown date: Ambulatory Care Satisfaction Questionnaire; targeted at individuals receiving ambulatory care services</td>
<td>• Unknown date: Resident/Family Client Satisfaction Survey</td>
<td>• Unknown date: Ambulatory Oncology Patient Satisfaction Survey (NRCC)</td>
<td>• Unknown date: Mental Health and Addictions Survey (Health PEI)</td>
<td>• Unknown date: Diabetes Program Client Satisfaction Survey; targeted at individuals who visit diabetes clinics</td>
<td>• Unknown date: Health Care Client Satisfaction Survey</td>
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<tr>
<td>Province*</td>
<td>Emergency department</td>
<td>Ambulatory care</td>
<td>Long-term care/residential care</td>
<td>Cancer care</td>
<td>Mental health care</td>
<td>Home and community care</td>
<td>Primary care</td>
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<tr>
<td>Nova Scotia</td>
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<td>—</td>
<td>• 2009: Ambulatory Oncology Patient Satisfaction Survey (NRCC)</td>
<td>• Unknown date: Community Based and Clinic Care Services Survey</td>
<td>• Unknown date: Community Based and Clinic Care Services Survey</td>
<td>• Unknown date: Nova Scotia Physician Achievement Review</td>
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<tr>
<td>New Brunswick</td>
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<td>—</td>
<td>• 2013: CSQ-8 Client Satisfaction Questionnaire (New Brunswick Department of Health)</td>
<td>• 2012: Home Care Survey (adapted from 2010 Home Health Care CAHPS Survey)</td>
<td>• 2011, 2014: Primary Health Care Survey</td>
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<td>Province*</td>
<td>Emergency department</td>
<td>Ambulatory care</td>
<td>Long-term care/residential care</td>
<td>Cancer care</td>
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<td>Home and community care</td>
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<tr>
<td>Quebec</td>
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<td>• Unknown date: Sondage sur la satisfaction de la clientèle (CSSS)</td>
<td>• Unknown date: Sondage sur la satisfaction de la clientèle (CSSS)</td>
<td>• Unknown date: Sondage sur la satisfaction de la clientèle (CSSS)</td>
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<td>Ontario</td>
<td>• Unknown date to 2016: Emergency Department Survey (NRCC)</td>
<td>• Unknown date: Day Surgery Survey, Ambulatory Clinic Survey</td>
<td>• Unknown date: Resident and Family Experience Survey (Canadian Consortium)</td>
<td>• 2004: Ambulatory Oncology Patient Satisfaction Survey (NRCC)</td>
<td>• Unknown date: Outpatient Mental Health, Inpatient Long Stay Mental Health, Inpatient Short Stay Mental Health (NRCC)</td>
<td>• Unknown date: Client and Caregiver Evaluation (NRCC/community care access centre)</td>
<td>• Unknown date: Health Care Experience Survey (MOHLTC)</td>
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<td></td>
<td>• 2016: ED Patient Experience of Care Survey (RAND)</td>
<td>• Unknown date: Long Stay Resident Experience (Canadian Consortium)</td>
<td>• Unknown date: interRAI Resident Quality of Life Survey</td>
<td>• Unknown date: Cancer Care Ontario Client Experience Tool</td>
<td>• Unknown date: Client and Caregiver Evaluation (Centre for Addiction and Mental Health)</td>
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<td>Province*</td>
<td>Emergency department</td>
<td>Ambulatory care</td>
<td>Long-term care/residential care</td>
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<td>Mental health care</td>
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<td>Ontario (cont’d)</td>
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<td>—</td>
<td>• Unknown date: Mental Health Inpatient and Outpatient Survey (Accreditation Canada)</td>
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<tr>
<td>Manitoba</td>
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<td>• Unknown date: Resident/Family Satisfaction Survey</td>
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<td>• Unknown date: Resident and Family Experience Survey (NRCC); used by Winnipeg Regional Health Authority</td>
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<td>• 2004: Ambulatory Oncology Patient Satisfaction Survey (NRCC)</td>
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<td>• Unknown date: Inpatient Long Stay Mental Health or Inpatient Short Stay Mental Health Survey (NRCC); used by Winnipeg Regional Health Authority</td>
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<td>• Unknown date: Home Care Client Satisfaction Survey; used in a single regional health authority</td>
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<td>• Unknown date: Physician Integrated Network (PIN) Patient Survey</td>
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<td>• Unknown date: Teen Clinic Satisfaction Survey</td>
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<td>• Unknown date: Home Grown Survey (Manitoba Health, Seniors and Active Living)</td>
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<td>Province*</td>
<td>Emergency department</td>
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<td>Long-term care/residential care</td>
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<td>Mental health care</td>
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<td>Manitoba (cont’d)</td>
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<td>• Unknown date: Mental Health Client Satisfaction Survey (adapted from Mental Health Statistics Improvement Project Consumer Survey V1.1); used in a single rural regional health authority</td>
<td>• Unknown date: Quality and Costs of Primary Care (adapted from Netherlands Institute for Health Services Research); used by Winnipeg Regional Health Authority</td>
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<td>Saskatchewan</td>
<td>• 2011 onward: HCAHPS</td>
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<td>• Unknown date: Ambulatory Oncology Patient Satisfaction Survey (NRCC)</td>
<td>• Unknown date: Primary Health Care Patient Experience Survey (Saskatchewan Health Quality Council)</td>
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<td>Province*</td>
<td>Emergency department</td>
<td>Ambulatory care</td>
<td>Long-term care/residential care</td>
<td>Cancer care</td>
<td>Mental health care</td>
<td>Home and community care</td>
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<tr>
<td>Alberta</td>
<td>• 2003: Satisfaction and Experience With Healthcare Services Survey (HQCA) • 2007 to 2013: British Emergency Department Patient Experience Survey (adapted version)</td>
<td>—</td>
<td>• 2007: Nursing Home CAHPS Family Survey Instrument (AHRQ); targeted at nursing home residents and families • 2007 to 2010: Long Term Care Family Experiences Survey (HQCA); targeted at family members of residents in long-term facilities • 2013: Ohio Residential Care Facility Survey (adapted version); targeted at supportive living residents and family members</td>
<td>• Unknown date: Ambulatory Oncology Patient Satisfaction Survey (NRCC)</td>
<td>• Unknown date: Addiction and Mental Health Client Experience Survey (Alberta Health Services) • Unknown date: SSS10+ Client Satisfaction Survey — Community Version</td>
<td>• Unknown date: Alberta Home Care Survey (HQCA) plus professional services questions based on Home Health Care CAHPS Survey (AHRQ)</td>
<td>• Pilot: Clinician and Group CAHPS Survey (AHRQ) plus visit-specific questions based on Patient Experiences in Primary Health Care Survey (CIHI)</td>
<td>—</td>
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</tbody>
</table>
### Province*


### Notes

* Information for Yukon, the Northwest Territories and Nunavut was not available at the time of writing.

— No provincial-level surveys at this time.

HCAHPS: Hospital Consumer Assessment of Healthcare Providers and Systems.

NRCC: National Research Corporation Canada.

CSSS: Centre de santé et de services sociaux.

MOHLTC: Ministry of Health and Long-Term Care.

HQCA: Health Quality Council of Alberta.

AHRQ: Agency for Healthcare Research and Quality.
## Appendix C: Examples of large-scale PROM initiatives by province/territory/organization

<table>
<thead>
<tr>
<th>Province/territory/organization</th>
<th>PROMs activities</th>
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</thead>
<tbody>
<tr>
<td><strong>Newfoundland and Labrador</strong></td>
<td>• None known</td>
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<tr>
<td><strong>Prince Edward Island</strong></td>
<td>• None known</td>
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| **Nova Scotia**                 | • Nova Scotia Health Authority is interested in using PROMs with its mental health and children and youth populations.  
• The Queen Elizabeth II Health Sciences Centre collects PROMs (EQ-5D, Oxford) from hip and knee replacement patients for research purposes. |
| **New Brunswick**               | • None known; the New Brunswick Health Council is interested in PROMs but the focus remains to be determined. |
| **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. |
| **Ontario**                     | • Ontario has expressed interest in potentially using PROMs but decisions regarding tools have not been made.  
• Cancer Care Ontario collects data from oncology patients using various tools, such as the Edmonton Symptom Assessment System (ESAS) and Patient Reported Functional Status.  
• The Holland Orthopaedic and Arthritic Centre at Sunnybrook Health Sciences Centre collect PROMs (Lower Extremity Functional Scale) on hip and knee replacement patients.  
• One of the goals outlined in the Ontario Renal Network’s *Ontario Renal Plan II, 2015–2019* is to “empower and support patients and family members to be active in their care.” A strategic objective that supports this goal is to “use patient-reported outcomes to drive improvements in kidney care.” The network is developing a pilot project using a version of the ESAS to capture PROMs from renal care patients. |
| **Manitoba**                    | • The Winnipeg Regional Health Authority collects PROMs from joint replacement patients (SF-12, Oxford). |
| **Saskatchewan**               | • In 2015, Regina Qu’Appelle Health Region began collecting PROMs (EQ-5D, Oxford) for hip and knee replacement. Saskatoon Health Region is interested in using PROMs for hip and knee replacement.  
• Several years ago, the province piloted PROMs data collection (EQ-5D and/or condition-specific) for several clinical pathways, including hip and knee replacement, prostate care, lower-leg ischemia and spinal surgeries. |
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<tr>
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| **Alberta**                     | • PROMs have been collected and used in various programs, including annual reporting, performance monitoring, benchmarking and the province’s annual population health survey.  
• In 2012, the Health Quality Council of Alberta (HQCA), Alberta Health Services (AHS), the University of Alberta and the Institute of Health Economics held a symposium titled Patient-Reported Outcome Measurement in Alberta: Potential of the EQ-5D to discuss the potential for adopting the EQ-5D as a standardized health outcome measure in the province.  
• The Alberta PROMs and EQ-5D Research and Support Unit (APERSU) was established in 2015 in partnership with the University of Alberta, AHS, HQCA and the EuroQol Group to promote, support and coordinate the use of PROMs across Alberta and to enable use of the EQ-5D in the province without end-user fees.  
• The EQ-5D has been incorporated into population health surveys, such as the Alberta Community Health Survey, Satisfaction and Experience With Healthcare Services Survey (2010 to 2014) and emergency department patient experience surveys (2007 to 2013).  
• The Alberta Bone and Joint Health Institute has been collecting PROMs data using the EQ-5D, WOMAC and PHQ-9 for several years from hip and knee replacement patients. PROMs measures are used to assess effectiveness of care and are reported on balanced scorecards to support continuous improvement programs.  
• The Northern Alberta Renal Program collects the ESAS, a condition-specific instrument, with the EQ-5D.  
• Alberta plans to expand the routine collection and use of PROMs in cardiovascular disease, chronic obstructive pulmonary disease and primary health care with a focus on chronic diseases.  
• In 2016, primary care networks incorporated PROMs into their accountability framework and performance indicators and began integrating PROMs into their workflow. |
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</table>
| British Columbia (cont’d)       | • The province is adapting the VR-12 for use in long-term and residential care, and administering the adapted survey with the interRAI Quality of Life Survey in these sectors.  
• The B.C. Renal Agency collects the ESAS from patients with chronic kidney disease to support clinical care.  
• The Patient Experiences With Arthroplasty of the Knee (PEAK) Project is a research initiative that involves the collection of the SF-12, EQ-5D and condition-specific PROMs from knee replacement patients to evaluate patient satisfaction and to identify factors that contribute to dissatisfaction.  
• B.C. is interested in doing more provincial PROMs activity over the next year and is planning to conduct consultation with regional health authorities.  
• The Quality of Life Assessment and Practice Support System (QPSS) initiative, which focuses on the use of mobile devices to collect the VR-12, ESAS and other instruments, is under way. The project currently focuses on home care but will be expanded to hospital and palliative care.  
• As part of a Strategy for Patient-Oriented Research (SPOR) initiative, the B.C. Ministry of Health will be including PROMs data in its warehouse to enable linkage of PROMs data with other sources.  
• In 2016, ReBalance, a multidisciplinary team practice for musculoskeletal care, began collecting PROMs from hip and knee replacement patients. |
| Yukon                           | • None known |
| Northwest Territories           | • None known |
| Nunavut                         | • None known |
| Statistics Canada               | • The Canadian Community Health Survey (CCHS) collects the Health Utility Index (HUI). CCHS provides the option to complete an additional module (SF-36), but currently there is little uptake by jurisdictions due to sample limitations and costs.  
• The Health Care Outcome Measurement Project (HCOMP) developed recommendations for approaching PROMs collection (generic and condition-specific), starting with joint replacement. Competing priorities as well as lack of funding and resources impeded further work. |
| Canadian Partnership Against Cancer | • The 2012 to 2017 strategic plan identified embedding a patient-centred perspective through the cancer journey as 1 of 5 strategic priorities. The Patient Experience and Outcomes Initiative was established to advance this priority.  
• CPAC funded projects in patient experience and patient outcomes in 8 jurisdictions (Newfoundland and Labrador, P.E.I., Nova Scotia, Quebec, Ontario, Manitoba, Saskatchewan, Alberta) in 2013–2014.  
  – Improving Patient Experience and Health Outcomes Collaborative — Cancer Care Ontario and Rossy Cancer Network, Montréal, Quebec  
  – Improving Patient Outcomes: A Pan-Canadian Knowledge Translation Strategy to Advance Oncology Professionals’ Distress Management Knowledge and Skills — Canadian Association of Psychosocial Oncology in Nova Scotia, Quebec, Ontario and Manitoba |
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</table>
| **Canadian Partnership Against Cancer (cont’d)** | – Measuring Patient Reported Outcomes to Address Patient Experience in Three Atlantic Provinces — Cancer Care Nova Scotia, Health PEI and Cancer Care Program Eastern Health in Newfoundland and Labrador  
– Patient Experience and Outcomes in the Prairie Provinces — Alberta Health Services, Cancer Care Manitoba and the Saskatchewan Cancer Agency  
- The National Measurement Steering Committee reached consensus on a national set of indicators and tools related to patient-reported outcomes in cancer care.  
- CPAC recognizes the use of PROMs (e.g., ESAS, Canadian Problem Checklist) to screen for distress. In 2015, CPAC began publicly reporting on the extent to which provincial cancer agencies and programs have implemented standardized tools to screen for distress. That year, 7 of 10 reporting provinces had implemented province-wide, provincially coordinated standardized tools to screen for distress in cancer centres, with findings reported centrally.  
- In 2015–2016, 2 videos on patient-reported outcomes were launched in 8 jurisdictions to encourage the use of patient-reported outcomes to help health care teams develop personalized care plans for patients. One video was developed for patients and another for clinicians. |
| **Canadian Institutes of Health Research** | • CIHR funds the Strategy for Patient-Oriented Research (SPOR) Initiative, a coalition of federal, provincial and territorial partners dedicated to integrating research into health care. Patient-oriented research refers to a continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes.  
• CIHR developed SPOR Networks and SPOR Support for People and Patient-Oriented Research and Trials (SUPPORT) Units in provinces or regions.  
• Many SPOR initiatives and projects are focused on PROMs; for example, the Can-SOLVE CKD Network (Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease) was recently funded by CIHR’s SPOR Initiative to pursue optimal ways to deliver patient-centred care to patients with kidney disease. |
Appendix D: Visioning day agenda

Common Priorities for Patient-Centred Measurement and Reporting in Canada: Launching the Discussion

Tuesday, March 1, 2016
CIHI Toronto Office, 4110 Yonge Street, Suite 300, Toronto, Ontario  M2P 2B7

Facilitator: Neil Stuart

Objectives:

1. To determine a common set of priorities for measuring and reporting patient-reported experience measures (PREMs) and outcome measures (PROMs) over the next 5 years.

2. To identify lessons learned from current activities to inform discussions about how to leverage and evolve patient reporting into the future around a common set of priorities.

3. To identify where CIHI and other partners can be most helpful in advancing a common approach to patient experience and outcomes data collection, measurement and reporting.

4. To summarize the discussion in a draft white paper that can be used for further consultation with stakeholders.

<table>
<thead>
<tr>
<th>Time</th>
<th>Subject</th>
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<tbody>
<tr>
<td>8–8:30 a.m.</td>
<td>Participant check-in (muffins/coffee to be provided)</td>
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<tr>
<td>8:30–9 a.m.</td>
<td>Welcome, opening remarks and introduction</td>
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<tr>
<td>9–9:30 a.m.</td>
<td>Facilitated discussion</td>
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<tr>
<td></td>
<td>Progress to date*</td>
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<tr>
<td></td>
<td>PREMs and PROMs in Canada</td>
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<td></td>
<td>What are the driving/motivating forces at play (e.g., accreditation, provincial strategic priority, other)?*</td>
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</table>

* IJ members will be asked to complete a spreadsheet prior to the meeting regarding their jurisdictional activities. The spreadsheet will be summarized and be the basis of the discussion

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<tr>
<th>Time</th>
<th>Subject</th>
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<tbody>
<tr>
<td>9:30–9:45 a.m.</td>
<td>Networking break</td>
</tr>
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</table>
### Identifying common priorities

**9:45–11:30 a.m.**  
**Break-out session 1**  
Topic 1: What will patient-centred measurement look like in Canada in 5 years?  
- What will be measured (e.g., PREMs: sectors, care across the continuum, spotlight on communication or transitions; PROMs: disease-specific, population-based)?  
- What about standardized surveys?  
- Is there anything that should be off the table?  
- Should outcomes and experiences be linked?  
- Recommendations for a common set of priorities for measurement?  

Topic 2: What will patient-centred reporting look like in Canada in 5 years?  
- What should be reported (e.g., common measures across the country, jurisdiction-specific)?  
- Who should be reporting what?  

**11:30 a.m.–12:30 p.m.**  
**Debrief (all)**

**12:30–1 p.m.**  
**Lunch: Brief presentation on international perspective**

### Achieving the vision

**1–2:30 p.m.**  
**Break-out session 2**  
Topic 3: What is needed to move the priorities forward? Are there learnings from others we could employ? What international perspectives should we consider? What is the role of patients?  

Topic 4: Who are the key partners and what are their roles in facilitating a common approach to measurement and reporting? How do we get their buy-in/commitment? What are the timelines?  

**2:30–2:45 p.m.**  
**Networking break**

**2:45–4:30 p.m.**  
**Debrief session 2 and creating an action plan**
Appendix E: Visioning day participant list

### External stakeholders

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michel Arsenault</td>
<td>Research Analyst, Performance Measurement</td>
<td>New Brunswick Health Council</td>
</tr>
<tr>
<td>Della Beattie</td>
<td>Senior Program and Policy Analyst</td>
<td>Manitoba Health, Seniors and Active Living</td>
</tr>
<tr>
<td>Alain Biron</td>
<td>Assistant Professor and Performance Measurement Advisor</td>
<td>McGill University Health Centre</td>
</tr>
<tr>
<td>Brian Clark</td>
<td>Patient Advocate</td>
<td>Patients Canada</td>
</tr>
<tr>
<td>Tim Cooke</td>
<td>Senior Lead, Health System Analytics</td>
<td>Health Quality Council of Alberta</td>
</tr>
<tr>
<td>Lena Cuthbertson</td>
<td>Provincial Director, Patient-Centred Performance Measurement and Improvement</td>
<td>British Columbia Ministry of Health</td>
</tr>
<tr>
<td>Imtiaz Daniel</td>
<td>Director, Financial Analytics and System Performance</td>
<td>Ontario Hospital Association</td>
</tr>
<tr>
<td>Gail Dobell</td>
<td>Director, Performance Measurement</td>
<td>Health Quality Ontario</td>
</tr>
<tr>
<td>Irene Gillis</td>
<td>Health Information Specialist</td>
<td>Health PEI</td>
</tr>
<tr>
<td>Laura Gordon</td>
<td>Health Services Research Specialist</td>
<td>Accreditation Canada</td>
</tr>
<tr>
<td>Anna Greenburg</td>
<td>Vice President, Health System Performance</td>
<td>Health Quality Ontario</td>
</tr>
<tr>
<td>Anthony Jonker</td>
<td>Director, Innovation and Adoption</td>
<td>Ontario Hospital Association</td>
</tr>
<tr>
<td>Scott Klarenbach</td>
<td>Professor, Medicine and Dentistry</td>
<td>University of Alberta</td>
</tr>
<tr>
<td>Brandi McCormack</td>
<td>Director, Outcome Measurement and Strategic Initiatives</td>
<td>Alberta Health Services</td>
</tr>
</tbody>
</table>
### Patient-Centred Measurement and Reporting in Canada: Launching the Discussion Toward a Future State

<table>
<thead>
<tr>
<th>Name</th>
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</thead>
<tbody>
<tr>
<td>Emily Myers</td>
<td>Program Lead, Patient Reported Performance Measurement</td>
<td>Ontario Hospital Association</td>
</tr>
<tr>
<td>Chris Niro</td>
<td>Director, Program Development</td>
<td>Accreditation Canada</td>
</tr>
<tr>
<td>Tracey Sherin</td>
<td>Director, Data Analysis and Research Partnerships</td>
<td>Saskatchewan Health Quality Council</td>
</tr>
<tr>
<td>Neil Stuart (facilitator)</td>
<td>Consultant</td>
<td>Neil Stuart Health Care Consulting</td>
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</tbody>
</table>

### CIHI representatives

<table>
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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Tammy Anderson</td>
<td>Program Lead, CPERS and Special Projects</td>
</tr>
<tr>
<td>Ellis Chow</td>
<td>Program Lead, Patient-Reported Outcome Measures</td>
</tr>
<tr>
<td>Adrian Dallo</td>
<td>Manager, Home and Continuing Care Standards and Support</td>
</tr>
<tr>
<td>Nicole de Guia</td>
<td>Manager, Joint Replacement and Multiple Sclerosis Registries</td>
</tr>
<tr>
<td>Tracy Fernandez</td>
<td>Senior Coordinator, Performance Improvement and Capacity-Building</td>
</tr>
<tr>
<td>Salima Hadibhai</td>
<td>Project Lead, Performance Improvement and Capacity-Building</td>
</tr>
<tr>
<td>Kristen Hart</td>
<td>Senior Analyst, Performance Improvement and Capacity-Building</td>
</tr>
<tr>
<td>Jeanie Lacroix</td>
<td>Manager, Performance Improvement and Capacity-Building</td>
</tr>
<tr>
<td>Kira Leeb</td>
<td>Director, Health System Performance</td>
</tr>
<tr>
<td>Mingyang Li</td>
<td>Methodologist, Performance Improvement and Capacity-Building</td>
</tr>
<tr>
<td>Shannon Masih</td>
<td>Analyst, Performance Improvement and Capacity-Building</td>
</tr>
<tr>
<td>Christine Proietti</td>
<td>Manager, Product Development</td>
</tr>
<tr>
<td>Douglas Yeo</td>
<td>Director, Methodologies and Specialized Care</td>
</tr>
<tr>
<td>Greg Webster</td>
<td>Director, Acute and Ambulatory Care Information Services</td>
</tr>
<tr>
<td>Juliana Wu</td>
<td>Manager, Decision Support, CORR and Trauma Registries</td>
</tr>
</tbody>
</table>
References


5. Canadian Institute for Health Information. PROMs: Background Document. 2015.


