Let’s go to the PROM*

I’m so glad you asked.

*The case for routine patient-reported outcome measurement

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Notes from the Editor-in-Chief

Less than a year ago, many of us (at least, those without doctorates in macroeconomics) held out hope that the worst of the global recession that began in 2008 was behind us. Yet, open nearly any newspaper over the past few months, and it is abundantly clear that Canada, the United States and the rest of the post-industrial world are mired in a prolonged period of deep economic malaise.

One of the major challenges besetting governments in all these places is what to do about healthcare. Taking one fairly representative example, in its recent Speech from the Throne, the Government of Ontario (November 22, 2011) indicated that, despite the wobbly times in which we live, that province’s citizens could count on a “quality” healthcare system. Here are a few pertinent excerpts:

With health care consuming an ever-increasing portion of the Budget and with the growing pressure created by our aging population, many Ontarians fear for the future of health care.

Your government commits itself wholeheartedly to the exciting task of renewing and reforming health care for the benefit of our generation and future generations of Ontarians.

Reforms will not compromise quality.

Any reforms adopted must lead to better value for money through improved efficiencies and greater productivity.

Granted, throne speeches are, by genre, filled with more rhetoric – “exciting task” (!) – than substance. However, governments, policy-makers and care providers near and far are making many of the same noises: we need to renew and reform our healthcare systems by improving efficiency and being more productive.

Better Living through Data

This short meditation on reform, renewal, efficiency and productivity in challenging economic times ushers me into the lead article in this issue of HealthcarePapers. In “Let’s All Go the PROM,” Kimberlyn McGrail, Stirling Bryan and Jennifer Davis (2011) argue that, given the fact that 6% growth in healthcare expenditure cannot be sustained, one of the best ways to drive system-level improvement is through “the routine collection of outcome data.”

In particular, the authors introduce and advocate the concept of patient-reported outcome measures (PROMs). “Measurement of ‘success’ in terms of improvements in patient health status or health-related quality of life is virtually non-existent in Canada,” McGrail, Bryan and Davis contend. We are too often stuck, they say, with mere mortality statistics and “limited” (e.g., small sample) indicator data. PROMs, meanwhile, would be an ideal means of overcoming this information gap and improving patient health (the first element of the Institute of Healthcare Improvement’s “Triple Aim”).

McGrail, Bryan and Davis make three main recommendations in their article:

- All health authorities across Canada should collect PROMs data for all elective surger-
ies (the area in which the most robust proof of PROMs’ efficacy exists).

- Begin work – starting with pilot studies at the health-authority level – to incorporate PROMs into chronic care management.
- Establish a pan-Canadian PROMs working group to plan the pilot testing, implementation and analysis of PROMs data.

At the heart of the recommendations set out in this article is the belief that PROMs information would enable us to understand how differences in care are linked to differences in outcomes, thereby supporting our efforts to improve care quality. I agree wholeheartedly with the basic premise of this argument which, the authors acknowledge, is deeply indebted to Avedis Donabedian’s now entrenched view that outcomes are the “ultimate validators of the effectiveness and quality of medical care.” I am also impressed by McGrail, Bryan and Davis’s contention that “individual patients are the best judges of their own welfare. If you want to know whether an individual’s health status has improved, you have to ask that individual!” As a firm supporter of patient-centred care, I believe that directly involving patients – for example, through PROMs – is foundational to the optimal delivery of their medical care. If well-designed and integrated into the health system, the information derived PROMs would also, it seems to me, help to inform and strengthen the elements patients have a right to expect when receiving care (e.g., transparency, safety, timeliness, continuity).

One important aspect of McGrail, Bryan and Davis’s work to which I encourage the authors to give further thought is what might be called the theoretical underpinnings of their claims. Throughout their paper, the authors make implicit and explicit connections between PROMs and quality (especially notable in their backing of PROMs for chronic conditions). At this stage, however, their assertion of a strong link is still more at the intuitive than evidence-based level. I am not saying there is not a causal connection; however, before investing all sorts of time and money setting up a new outcomes-reporting system, let’s understand the relationship more precisely and via multiple domestic and international examples.

I also strongly encourage the authors, as they pursue this valuable work, to consider more thoroughly the distinction between data/information and knowledge. The former is intrinsically interesting, but the latter is the stuff out of which good clinical decisions are made. How we transform data/information into knowledge is central to the potential success of PROMs (for more on this point, see the commentary by Doris Howell and Geoffrey Liu).

The Responses
Near the outset of their paper, McGrail, Bryan and Davis cite Steven Lewis’s contention that “We spend so much and achieve so little” in Canadian healthcare. PROMs, they hold, is a way to improve that sorry situation. So, what does Lewis himself have to say in response? In his reply to the lead authors’ article, Lewis is unstintingly enthusiastic. Characterizing PROMs as a vital form of “healthcare intelligence,” he asserts that they invert our healthcare system’s standard inputs-to-outputs orientation. “Applied judiciously,” Lewis also says, PROMs could help in “weaning patients from dependency on the system (Lewis 2011).” Certainly, the system-level cost-savings that would arise from such a result are not insignificant, let alone, if the evidence Lewis cites from Seattle’s Group Health Cooperative is widely reproducible, the potential quality improvements for the patients themselves. Where the light in Lewis’s commentary shone brightest for me was, however, in his argument for building PROMs “into the core of health records
and health information systems.” Truly, if we are to go the PROMs route, the advent of digitization makes this a perfect moment in history to move forward.

Largely agreeing with the lead authors’ arguments relating to PROMs’ potential benefits in elective surgery and chronic-disease care, our second commentator, Greta Cummings, diverges from them in her assessment of the worthiness of a pan-Canadian working group (Cummings 2011). The main problem, she argues, is that the PROMs such a group would establish “would retrieve outcomes from patients about their experiences with the current healthcare system.” Instead, what we first require is reform of the system so that it is integrated and person-centred. In addition, Cummings calls for a theoretical framework that would guide the development and use of PROMs, briefly citing the Institute of Medicine’s quality framework as a possible example.

Next to weigh in is Sholom Glouberman, the president of the Patients’ Association of Canada. Glouberman (2011) locates the origins of patients’ non-involvement in medical treatment and research in the healthcare system’s inception in the 1880s, which focused largely on acute infectious diseases. Now, in an era characterized more by chronic non-communicable diseases (at least in the post-industrial world), that orientation no longer fits: “chronic non-communicable diseases require patient involvement in their treatment to avert acute episodes and to control morbidity.” PROMs, he concludes, “are a critical step in this direction.” Nevertheless, Glouberman introduces important caveats, noting, in particular, that “highly standardized instruments such as PROMs” do not accord neatly with the quest to increase patient participation in non-surgical chronic disease management. A PROMs working group, he concludes, is worth striking, yet it must include patients in its deliberations.

David Gray and Ian Rongve (2011) provide additional insights into this complex topic through a brief report on the symposium Measures of Health Outcomes to Improve Performance, Value and Productivity. Held in December 2010 in Victoria, BC, this gathering of senior health-system leaders and administrators from western and northern Canada explored many of the issues raised by McGrail, Bryan and Davis. Participants were in large agreement that PROMs “offers a good opportunity to improve the ability of the system to make decisions,” are aligned with patient-centred care and help to manage system costs.

Where the lead paper’s authors were short on next-step specifics, Gray and Rongve – drawing on the Victoria symposium – offer a much clearer set of four intersecting activities to pursue: stakeholder consultation, priority definition, non-acute care innovation and small-scale implementation (and quite unlike McGrail, Bryan and Davis, they sharply affirm, “We do not need more pilot projects.”). I will be intrigued to see whether the “leadership,” which symposium delegates identified as “key” to the success of PROMs emerges to guide these worthy initiatives.

Drawing on their experience with PROMs in connection with cancer care, Doris Howell and Geoffrey Liu (2011) shed light on the considerable challenges confronting routine patient-reported data collection in the context of chronic diseases. The experience of Cancer Care Ontario in this regard suggests that leadership (see also Gray and Rongve), technology (see also Lewis) and local coordination are essential to success. I was especially struck by the commentators’ point that actually improving patients’ health through PROMs “is still questionable.” If there is a link there, Howell and Liu contend, it is sure to be in how we implement such information in “routine practice.” I am in full accord with the authors that “knowledge translation
strategies” are required in order to integrate PROMs into clinicians’ decision-making (perhaps the lack of this element was, in part, responsible for the lacklustre response of BC surgeons cited by McGrail, Bryan and Davis).

And, even more forcefully than Glouberman, Howell and Liu emphasize the need to include patients’ perspectives when designing and selecting PROMs.

Our final commentators, Albert Wu and Claire Snyder, bring a perspective on the issue from south of the border. In their piece, Wu and Snyder (2011) creatively offer recommendations that respond to four questions germane to PROMs – metaphorically, the high-school dance variety and, literally, the clinical practice kind. Urging a broader definition of health-related PROMs than the one put forth by McGrail, Bryan and Davis, they argue for the importance of assembling a broad coalition of collaborators. They also briefly note several of the existing PROMs questionnaires and data-collection systems (including PatientViewpoint, which Wu and Snyder helped to develop). And, like several of their fellow commentators, Wu and Snyder underscore the importance of developing recommendations for how to use PROMs information.

“Rewarding and memorable” – that, Wu and Snyder conclude, should be the result of going to the PROMs, not just for teenagers, but also for patients and clinicians. While we are still a long way in Canada from choosing outfits, dates and corsages, I am confident that the discussion initiated in this issue of HealthcarePapers will be immensely useful as jurisdictions throughout the post-industrial world strive to find a healthy fit amongst system reform, cost-effectiveness and patient-centred care.

Peggy Leatt, PhD
Editor-in-Chief

Reference


Let’s All Go to the PROM: The Case for Routine Patient-Reported Outcome Measurement in Canadian Healthcare

INVITED ESSAY

Kimberlyn McGrail, PhD
Associate Director and Assistant Professor, Centre for Health Services and Policy Research and the School of Population and Public Health, The University of British Columbia

Stirling Bryan, PhD
Director and Professor, Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health Research Institute and School of Population and Public Health, The University of British Columbia

Jennifer Davis, PhD
Post-Doctoral Fellow, Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health Research Institute

ABSTRACT
Overall life expectancy in Canada is among the highest in the world and research evidence suggests that the healthcare system is part of the reason for this. However, patient waits, low international rankings and continued expenditure growth all provide a buttress against complacency. There can be little doubt that improvement can and must happen. Improvement depends on information, and more specifically information about outcomes of care. Without sound analysis of what works in the real world when applied to real patients, we have not done our jobs as stewards of the healthcare
Let's All Go to the PROM

system. Current outcomes information in Canada is limited and tends to focus on measures of failure (e.g., hospital readmissions) rather than measures of success (e.g., improvement in functioning). Patient reported outcome measures (PROMs) must become part of regular data collection in the healthcare system. The importance of this is even more pronounced given that healthcare is now dominated by chronic conditions that need to be managed over long periods of time. We offer three recommendations for action: that we begin immediately to collect PROMs in elective surgery; that we start small-scale and coordinated experiments on the implementation of PROMs in care for chronic conditions; and that we convene a pan-Canadian working group to help coordinate and organize these activities. We recognize the challenges these issues raise, but our contention is that there are even greater challenges in continuing on as we are.

Canadian Healthcare: A Work in Progress

The Canadian healthcare system with its foundations of equity and universality forms part of our national identity and is rightly a source of pride for Canadians. Overall life expectancy in Canada is among the highest in the world and continues to increase, and what evidence there is suggests that an increasing proportion of those longer lives are spent without disabilities (Chen and Millar 2000). Studies comparing the United States and Canada suggest that our social safety net, including the healthcare system, likely contributes to the life expectancy gap between these two countries that has developed and increased since the 1970s (Siddiqi and Hertzman 2007). People who work in healthcare should be proud of their achievements.

However, there is no room for complacency. If the comparative lens is broadened, the picture begins to change. Canadian patients report longer waits for appointments in primary care, appointments with specialists and elective surgery (Schoen et al. 2010), and Canada is far behind on the adoption of an electronic health record (Schoen et al. 2009). Further, in recent international health and healthcare comparisons, Canada has not performed well:

- Canada ranked 11 of 24 Organisation for Economic Co-operation and Development (OECD) countries in terms of overall health performance (including life expectancy, disease rates and self-reported health) (Canadian Institute for Health Information [CIHI] 2008).
- According to a Euro-Canada Health Consumer Index (based on factors such as patient rights and information, waiting times, clinical outcomes and access to treatment), Canada ranked 23 out of 30 countries (CIHI 2008).

These ongoing challenges for Canadian healthcare cannot be blamed on fiscal constraints: currently we spend more than $190 billion annually on healthcare (CIHI 2010). As a percent of gross domestic product, our healthcare spending ranks fifth among OECD countries and continues to increase faster than might be predicted based on population growth, aging and inflation; an average 75-year-old in 2010 receives more (and more expensive) services (after adjusting for inflation) than his or her counterpart received in 2000. In British Columbia, in 2005–2006, more than $170 million in physician spending (about 8% of the total physician budget) would have been avoided if age-specific use rates from 1996–1997 had remained stable (McGrail et al. 2011).

It seems a safe assumption that these upward pressures for spending growth will...
continue – more is possible and more will be promoted – while downward pressures will continue from outside the system. The financial crisis has made this point a bit sharper than it might have been otherwise, but there is no escaping that 6% growth in healthcare expenditures, as promised in federal transfers in the 2004 Accord, cannot be sustained.

Steven Lewis sums up the Canadian healthcare situation in a stark but honest way: “We spend so much and achieve so little” (Baker et al. 2008: 291). There can be little doubt that improvement can and must happen, and this paper provides a discussion on improvement driven through the routine collection of outcome data.

**Improvement Science: Learning from Berwick, Donabedian and Wennberg**

The Institute for Healthcare Improvement (IHI), and its founder Don Berwick, promotes improvement through healthcare system redesign that simultaneously accomplishes three key objectives (the “Triple Aim”; Berwick et al. 2008):

- Improving population health
- Enhancing patient care experience (including quality, appropriateness and satisfaction)
- Reducing, or at least controlling, the cost of care

The big-picture goal is, of course, to improve all three, but this framework recognizes that some decision-making may be focused on one area. In that situation, the objective is to make improvements in the chosen area without causing backsliding in the others: for example, to curtail the growth in healthcare expenditures without harming care quality. This may sound simple, but the perspective is fundamentally important when we are seeking improvements in the performance of the healthcare system.

Improvement of the Triple Aim operational in the system requires routine gathering of information on all three components. This is an agenda of “measurement to support improvement” in a dynamic healthcare system, where all actors in the system search for improvements in care delivery and opportunities for redesign to promote enhanced quality and better outcomes. Routine measurement is then to support formative and summative analyses of progress toward the Triple Aim: do the redesign initiatives indicate improvement or not? Our focus in this paper is on the population health outcomes piece of the Triple Aim approach.

“Without sound analysis of what works in the real world when applied to real patients, we have not done our jobs as stewards of the healthcare system.”

The importance of outcomes is not a new concept. Avedis Donabedian, the father of the quality movement in healthcare, introduced us to the notion of “structure – process – outcome” for categorizing and understanding healthcare services. In his first article on the subject, in 1966, he argued strongly for outcome measurement: “Outcomes, by and large, remain the ultimate validators of the effectiveness and quality of medical care” (Donabedian 1966: 169). In other words, without information on outcomes and an investigation of what systems or structures are related to outcomes, we have not done our job as health service analysts. And without sound analysis of what works in the real world when applied to real patients, we have not done our jobs as stewards of the healthcare system.

More recently, the seminal work of Wennberg and his colleagues highlights the
importance of outcome assessment. They have analyzed and mapped variations in Medicare spending per person across 306 health regions in the United States. One of their key findings is that more care does not produce better (and may even deliver worse) health outcomes (Fisher et al. 2003a, 2003b). Without collecting and analyzing information on outcomes, variations analyses can only show differences in quantity of service delivery and not variation in quality.

What Do We Mean by Health Outcomes?
Routine outcome data collection in healthcare systems has a long but far from glorious history. In the 1850s, during the Crimean War, Florence Nightingale used information she collected to assess the causes of increased mortality among soldiers. Subsequently, she focused less on mortality as an outcome but, rather, on whether, following a hospital episode, the sick were restored to full health. In the early 20th century, E.A. Codman, a Boston physician, collected before and after information from patients undergoing surgery. What unites these efforts are two important features: (1) they did not depend on sophisticated technology (five by eight inch pieces of paper in Codman’s case) and (2) while they were driven to collect outcomes information to understand better the impact of healthcare practices on health, their efforts were not met with widespread support, and, in Codman’s case, were met with derision (Neuhauser 2002).

Bringing the story up to date, in a Canadian context, we do in fact have some information on outcomes. Mortality statistics, the most hard-edged outcome, is well collected and routinely available. CIHI and Statistics Canada have developed a suite of indicators that characterize the Canadian population and the performance of the healthcare system. This is good information, but it is limited. These measures are either generally available only for small samples or at an ecological level (e.g., health status measures based on Canadian Community Health Survey data), or represent important but rare failures in the delivery of care (e.g., hospital readmissions, admissions for ambulatory care sensitive conditions).

Measurement of “success” in terms of improvements in patient health status or health-related quality of life is virtually non-existent in Canadian healthcare. The latter can be referred to as patient-reported outcome measures (PROMs), and our interest in particular is on such measures. The rationale for outcomes has been indicated earlier; our interest in outcomes reported by patients is driven by a belief that individual patients are the best judges of their own welfare. If you want to know whether an individual’s health status has improved, you have to ask that individual!

Despite their absence in routine clinical practice in Canada, PROMs have been used widely in clinical trials and other research settings (Cella et al. 2007; Fayers and Machin 2007). Extensive work on the development of PROM-type survey tools has been undertaken in recent years, such that there now exist a large number of PROM instruments, many of which have been well validated, some using Canadian populations (Devlin et al. 2010). PROMs are designed to measure either “general” health status (i.e., generic PROMs [Brazier et al. 1998; Dolan 1997; Feeny et al. 2002]) or health status relating to a specific condition (i.e., condition-specific PROMs [Massof and Rubin 2001; Morey et al. 1998]). Examples of generic PROMs are given in Table 1, with an indication of the health domains and number of possible health states captured.

Examples of PROM Data Collection to Promote Improvement
Let us now consider implementation issues: how might PROM data be collected and used to promote improvement? This is not virgin
British Columbia

One of the earliest attempts to explore the benefits and costs of routine collection of PROMs comes from British Columbia: the Regional Evaluation of Surgical Indications and Outcomes (RESIO) Project (Wright et al. 2002). This work was undertaken in the late 1990s and involved 138 surgeons and 5,313 patients who underwent one of the following elective procedures: cataract replacement, cholecystectomy, hysterectomy, lumbar discectomy, prostatectomy or hip replacement. Data on health-related quality of life (using the Short Form [36] Health Survey [SF-36] and condition-specific measures) were gathered through patient self-report before surgery and then at either three months or 12 months post-surgery. The data were fed back to surgeons in real time to allow use of the data in clinical management. The project’s main aim was “to determine the feasibility of routine evaluation of indications for and outcomes of elective surgery” (Wright et al. 2002: 461).

The most controversial finding of RESIO was that some patients who received surgery had had relatively minor symptoms and levels of disability. For example, 31% of patients who underwent cataract surgery had experienced a visual function score of 91 or higher (on a scale where 100 indicates no visual impairment at all). The authors interpreted their data as evidence for the need to reconsider indications for elective surgery. Further, they found a wide variation in practice patterns and rates of surgical intervention.

The cost of the program, administered using postal distribution and manual data entry and analysis, was estimated to be $12 per patient. The conclusion by the investigators was very positive: “Evaluation of indications for and outcomes of elective surgery could be implemented systematically at reasonable cost and could be included in an accountability framework for health services” (Wright et al. 2002: 461).

The most concerning finding was that almost half of the surgeons indicated that the exercise was of “little value” and stated that they did not wish to continue receiving such information. The need to engage physicians and surgeons fully in such an initiative is clearly critical. RESIO teaches us that collaboration between clinicians and managers is required for success, with management taking

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Domains/Attributes</th>
<th>Number of Possible Health States</th>
<th>Boundaries</th>
</tr>
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<tbody>
<tr>
<td>Health Utilities Index 2 (HUI2) (Feeny et al. 1995)</td>
<td>Sensation (vision, hearing, speech), mobility, emotion, cognition, self-care, pain</td>
<td>24,000</td>
<td>−0.03 to 1.00</td>
</tr>
<tr>
<td>Health Utilities Index 3 (HUI3) (Feeny et al. 2002; Horsman et al. 2003)</td>
<td>Vision, hearing, speech, ambulation, dexterity, emotion, cognition, pain</td>
<td>972,000</td>
<td>−0.36 to 1.00</td>
</tr>
<tr>
<td>Short Form 6D (SF-6D) (Brazier et al. 2002)</td>
<td>Physical functioning, role limitation, social functioning, pain, mental health, vitality</td>
<td>1,800</td>
<td>−0.30 to 1.00</td>
</tr>
<tr>
<td>EuroQol-5D (EQ-5D) (Dolan 1997)</td>
<td>Mobility, usual activities, self-care, pain, anxiety/depression</td>
<td>243</td>
<td>−0.59 to 1.00</td>
</tr>
</tbody>
</table>
shared accountability with clinicians for ensuring that the PROMs data are collected and used appropriately.

The United Kingdom
Other examples of routine PROMs data collection include the private hospital sector in the United Kingdom (Bupa) and the UK National Health Service (NHS) (Devlin and Appleby 2010). Bupa is an association of private UK hospitals. Much of their work is elective surgery undertaken in their facilities by surgeons, most of whom work in parallel in the public sector. The routine collection of PROMs data before and after surgery has been standard practice of care since the late 1990s, under the leadership of their senior medical team. The data are used to support clinical governance, audit and quality improvement, with data reported as control charts (Vallance-Owen et al. 2004).

The success of the Bupa model in part inspired a similar development in the NHS with the rollout of a routine PROM data collection process following pilot work by Browne et al. (2007). The pilot work collected data on five prospective cohorts of elective surgery patients: hip replacement, knee replacement, hernia repair, varicose vein surgery and cataract surgery. Patients were assessed before surgery and at three or six months post-surgery using the EuroQol (EQ-5D) and a condition-specific instrument relevant to their surgery. The feasibility results were very positive, with high response rates and a cost of approximately £6.50 per patient for the postal-based follow-up data collection – a very similar cost estimate from that reported in the RESIO study in Canada. The conclusion from the pilot was that “any future programme of routine PROMs administration is feasible,” and this is borne out by the NHS uptake of the approach (Browne et al. 2007: 86). Routine collection of PROMs data commenced in 2010 and is now standard practice for selected elective surgery procedures in all English hospitals (Devlin and Appleby 2010).

Recommendation One: PROMs for Elective Surgery
It should be noted that all the examples cited here involve PROMs in the context of elective surgery. There is a clear case for PROMs in this area. PROMs data, gathered through routine collection in the context of elective surgery, offer opportunities to deliver benefits at a number of different levels in the healthcare system:

• Supporting patient choice and empowerment – The patient who has undergone surgery asks, “Is my recovery post-surgery similar to that of others or should I be worried?” More fundamentally, routine reporting on patient experience after surgery can help patients decide whether surgery at a particular point in time is right for them in the first place.
• Improving clinical management – The surgeon asks, “Which of my patients are experiencing ongoing health problems and might benefit from early clinical review?”
• Assessing performance and supporting quality improvement – The health sector manager asks, “Which are the high performing surgical teams and what lessons can they offer to other groups?”

The PROMs case in elective surgery is, in fact, so clear that it is difficult to understand why there has not been widespread adoption in Canada already.

Our first recommendation is that we rectify this immediately: all health authorities should plan now for the collection of PROMs data, with the aim being that by 2013 they are collected routinely for all elective surgeries nationally. Yes, there are implementation
issues – Who collects the data? Using what tools, what collection methodology? Where do the data reside? and so on – but there is also readily available guidance from jurisdictions with experience, most notably the United Kingdom. A central coordinating body or information clearinghouse is clearly required to ensure a level of consistency of approach. This may be a relevant role for CIHI.

**But What about PROMs for Chronic Conditions?**

Elective surgeries, however, represent only a small part of healthcare services delivery – the real challenge is the management of chronic disease. It is here where there is little (or no) experience in the use of PROMs, and here where there is potentially a great deal to be gained.

More than nine million Canadians have chronic conditions. One third of these, or three million people, have more than one chronic condition (Health Council of Canada 2007). About 20% of people who are 65 years and older have two or more chronic conditions that are considered major, as defined by the associated expected use of healthcare services (McGrail et al. 2008). No matter how we slice it, it is clear that chronic conditions are a major feature of life for a significant proportion of Canadians and their families.

Chronic conditions are significant for the healthcare system as well. The top 5% of users of healthcare services are responsible for 30–40% of all expenditures (Deber 2009; Reid et al. 2003), and those users tend to be quite sick. At least at the high end, healthcare services provision appears to be in response to identified needs.

That healthcare services are provided in response to a need, however, is not the same as saying that they are always thoroughly and appropriately provided. There is an extensive literature on variations in healthcare services use, and the research evidence shows that the largest of those variations are found in areas where there is the least medical certainty. Where there is a lack of research evidence or clinical consensus about the right amount or course of care, there tends to be the greatest variation in care provided (Wennberg 2010).

Variations are a potential means to understand a great deal more about the effectiveness of healthcare delivery systems. It is possible with currently available data to identify variations in care delivery. The addition of information on outcomes would, in principle, allow differences in care – how many times and what specialists are consulted, what drugs or drug combinations are used, the organization and delivery of primary care and so on – to be linked to differences in outcomes, giving the opportunity to improve the quality of care for complex patients. This is crucial because complex patients tend not to be part of randomized trials, nor are pathways or patterns of care for people with multiple chronic conditions generally subject to rigorous testing or evaluation.

Patient-reported outcomes are particularly suited to helping improve care for patients with chronic conditions precisely because the conditions are chronic. Once diagnosed, people can expect to live many years with their conditions, and the efforts of the healthcare system are directed more to alleviating symptoms and forestalling progression in the disease than in effecting a cure. Mortality, in contrast, is an extremely poor outcome to
guide us in identifying high-quality care since mortality is unexpected (at least in the short term) and is (thankfully) rare.

Given the potential utility of PROMs in chronic care, it is perhaps surprising that there is little evidence of their use in Canada or internationally in routine practice. This surprise may diminish somewhat once we start to contemplate how, exactly, they might be introduced for chronic conditions. Unlike surgical interventions, there is no obvious before and after because there is no obvious or discrete “intervention.” Chronic conditions require longitudinal care, which is often multi-faceted and sometimes from multiple providers. Also unlike surgical interventions, the “condition” itself is difficult to define. A knee replacement is easy to understand. The care of someone who is over 75 years old and has four chronic conditions, two of which are considered major and one of which is unstable, is somewhat more difficult.

It is, nevertheless, precisely these more complex populations that consume a large share of healthcare services. Even marginal improvements in quality while controlling cost could have a large impact on the population’s overall health. And so, while somewhat more conceptually challenging, there is a strong argument for movement toward the collection and use of PROMs in chronic care.

**Recommendation Two: PROMs for Chronic Conditions**

Our second recommendation is to begin work to incorporate PROMs into the provision of healthcare for chronic care management in Canada. Since we are talking about ongoing conditions, it can be inferred that we will need ongoing data collection. The lack of a specific intervention or point in time at which PROMs ought to be collected suggests that collection should occur at regular intervals, perhaps annually.

As a starting point, we suggest that coordinated pilot work be taken forward at across the country, at the health authority level, with pilots focusing on different patient groups (such as the frail elderly, or people with three or more chronic conditions) as well as perhaps different timings and modes of data collection.

**What Will It Take to Get Canada to the PROM?**

So, what will it take to get Canada to the PROM? First, we must acknowledge that Canada is not an outlier in this regard. Most countries are not collecting patient-reported outcomes in any broad-based and systematic way, and none that we know of are collecting these data for people with chronic conditions. In looking forward, perhaps the most productive first step is to understand the roadblocks to this point.

The discussion above indicates several possible reasons why PROMs are not currently collected in Canada. Clinical leadership is critical to the success of any PROMs initiative, as demonstrated in the RESIO study. While care providers are clearly not the only group that needs to be engaged, success is impossible to imagine without leaders from the provider community understanding the potential of PROMs, being willing to experiment with their collection and using the results to change their practice.

Another clear impediment is structural: at present, there are no incentives for institutions or providers to gather and use such information to improve quality of care. Payment incentives tied to patient outcomes might be an option to consider and would likely grab attention and deliver some momentum but, in truth, pay-for-performance initiatives in healthcare have mixed success (Gavagan et al. 2010; Van Herck et al. 2010; Werner et al. 2011).

Two other structural challenges may in the end be more significant. The first concerns
the current fiscal climate, which makes this a particularly difficult time to promote new investments in healthcare that are not tied to direct patient care. The collection of PROMs would, we argue, improve care and help to control costs, but the payoffs will not be immediate; the impact will not be felt in next year’s budget. On top of this, pursuing PROMs now would require international leadership from Canada to build evidence for the most efficient and effective ways, at a system level, to collect, analyze and use such data. This is a critically important development in healthcare, but not having a blueprint to follow makes it daunting.

Data collection is of course only the first step to promoting “improvement” in Canadian healthcare; if we stop there, our efforts are wasted. We should not underestimate what is involved in using PROMs to their best advantage. Any PROMs data we collect must be linkable (and linked) to administrative records of healthcare services use. This linkage is absolutely essential because it is only with a connection to services received that the outcomes data can truly take on their full meaning.

Recommendation Three: A Pan-Canadian Working Group on PROMs

At this point, our recommendation is to form a working group, ideally a cross-national group, that would create the needed plans for the pilot testing, implementation and analysis of PROMs data. A cross-national working group might be particularly useful because there are many implementation issues that would be common to each jurisdiction, and working together would lessen the implementation burden on each individual jurisdiction. Some of those most critical implementation issues include choosing instruments and timing for data collection; choosing the route of data collection (e.g., direct to patients, through general practitioners); how best to engage and encourage clinical leadership for the collection and use of these data; and identifying data stewardship issues such as housing, linking and providing access to data. Leadership from and a coordinating role for CIHI would seem appropriate.

We should be clear that this is not a call for a stringently controlled cross-national effort driven from the top down. Our call for a pan-Canadian group simply recognizes the scale of the common challenge facing all jurisdictions in collecting and using PROMs. It would be inefficient in the extreme for each health authority, or even each province, to develop independently everything outlined above. We have provided a sketch of the research and development that needs to be done around PROMs. Rapid progress requires lessons to be shared, pilot work to be coordinated and some decisions (such as regarding the generic instrument to be used) to be made jointly across jurisdictions. For example, some health authorities could proceed with working through implementation issues for PROMs in elective surgery, others could focus on collecting PROMs for chronic conditions and still others could deal with the privacy, information sharing and analytical issues. This approach would accelerate progress and could leapfrog Canada to become an international leader in the use of outcomes information to improve patient care and population health.

We recognize the challenges these issues raise, but our contention is that there are even greater challenges in continuing on as we are. There is general acceptance of patient-reported outcomes in the clinical trials that determine the safety, efficacy and cost-effectiveness of new drugs and devices that enter the healthcare system. The overall effectiveness of the system, and our ability to monitor our progress toward the Triple Aim of a
healthy population, great quality of healthcare and controlled expenditures, depends on similar data in routine practice.

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Healthcare Papers

COMMENTARY
Realizing the PROMise of PROMs

COMMENTARY

Steven Lewis, MA
President, Access Consulting
Saskatoon, SK

ABSTRACT

McGrail and colleagues have made a strong case for embedding PROMs into the everyday healthcare system. This commentary focuses on translating their argument into policy and practice. PROMs can no longer be considered a “nice to have”; they are core elements of a patient-centred, quality-oriented healthcare system. Putting PROMs at the centre of the health information agenda signals a major shift in the orientation of the system. Their development should be mandatory, and they should be used to support quality improvement, accountability, and clinical practice redesign, particularly in primary care.

McGrail and colleagues (2011) have begun an important discussion to fill a major gap in our understanding of how healthcare – and other factors – affects individuals’ health status over time. The measurement of health outcomes in Canada has concentrated (unfortunately, in retrospect) on the “sharp end” of the system. As a result, it focuses on important but crude outcome measures such as hospital readmissions, 30-day and sometimes one-year mortality rates and hospital-acquired pathologies. But the vast majority of everyone’s health and healthcare experience takes place outside hospitals and, as the authors note, acute care measures are quite meaningless in other settings.
The authors of the lead essay have likewise performed a service by reporting the considerable range of approaches to patient-reported outcome measures (PROMs). Those committed to incorporating PROMs into their practices can choose from a fairly eclectic range of approaches, from relatively simple and straightforward (the Short Form 12 [SF-12] and SF-36 scales) to almost infinitely complex (the Health Utilities Index 3, with no fewer than 972,000 possible health states). Recognizing this plurality of approaches, McGrail et al. have recommended a co-operative national effort to design a common approach to PROMs in the hope of generating consensus on what to measure and how to measure it.

The proposals for moving the PROMs agenda forward are sensible and realistic. In this commentary, I want to create a greater sense of urgency and make a stronger statement of the implications of delay. It would be a mistake to view PROMs as “nice to have.” They are fundamental to quality improvement, efficiency, resolving debates about appropriateness of care and system redesign. The rhetoric of the healthcare system, as the authors point out, is scarcity when the reality is plenty. A great deal of healthcare makes no contribution to health outcomes. There is routine overuse, underuse and misuse of healthcare. If we are truly to move toward a patient-centred healthcare system, the patient perspective must be central and the patient experience must be measured and accounted for.

**The Transformative Power of PROMs**

Applied judiciously, PROMs have the potential to accelerate major change in how healthcare is organized and delivered. The purpose of PROMs is not simply to chart patients’ health status over time. It is to deepen understanding of the relationship between healthcare inputs (human resources, capital etc.) and outputs (units of service) to health outcomes that patients consider important. This is a major shift from the current focus on the relationship of inputs to outputs, which defines productivity in terms of volumes and activity rather than impact on health, with little or no regard for appropriateness or need. An outcomes orientation stands this equation on its head: success is achieving the best health outcomes with the resources available. And the ultimate success is weaning patients from dependency on the system. Doing less is more productive than doing more. Southcentral Foundation in Alaska and Group Health Cooperative in Seattle are examples of health systems that have created a culture of doing less wherever possible. Southcentral has reduced hospitalization rates, referrals to specialists and – notably – primary care visits. Group Health Cooperative produces excellent health outcomes and patient satisfaction by delivering evidence-based, comprehensive primary care and minimizing referrals to specialists and hospitals.

A PROMs orientation shifts accountability from technical quality and efficiency (Did the procedure go well? Was the patient discharged within the target time? Were unit costs low?) to impact on health status. The purpose of healthcare is instrumental: it is useful if, and only if, the patient’s health status is better after receiving healthcare than it would have been in the absence of healthcare. The general indifference or even hostility to the findings of Wright et al. (2002) reveals a culture that strongly resists this orientation. PROMs data raise the issues of appropriateness and waste, and there is powerful antipathy to any suggestion of an overabundance of healthcare. PROMs introduce hard evidence into the cost-benefit equation and create a foundation for improved decision-making at all levels.

A further transformative element of PROMs lies in the choices about which baseline data should be collected and compared with future health states. For example, the
Adverse Childhood Experiences (ACE) study revealed how profoundly early exposure to various forms of family and behavioural dysfunction affects future behaviours and health outcomes, irrespective of socio-economic status (Felitti et al. 1998). The research originated in the insight that conventional healthcare was variably successful in maintaining or improving health outcomes in a fully insured, middle-class American patient population. It turns out that there is a remarkable correlation between the number childhood traumas of various types and elevated risk for health and behavioural problems as adults. Without screening for ACE, patients who do not respond well to conventional arrays of inputs and outputs will likely be dismissed as “difficult” or “impossible to treat.” PROMs analysis can and should prompt continuous analysis of the causes of good and poor outcomes, some of which may be inattention to critically important patient-specific information.

**PROMs and Patient-Centred Primary Care**

The term personalized medicine usually refers to the genomic revolution and the prospect of tailoring drugs and other therapies to the genetic signature of the patient. Whether this is realistic in the foreseeable future is unresolved. But there is a domain where personalized care is not only warranted but feasible: primary care. McGrail et al. have rightly raised the issue of PROMs and chronic disease management, by far the largest and trickiest aspect of primary care. First-class primary care is person-centred. PROMs are not only useful in improving system accountability and value for money, but are also instrumental to quality improvement. Patient-centred care requires patient-centred care regimens. Protocols that may produce health gains for some patients may yield fewer for others. If clinicians lack systematic knowledge of how their patients are doing over time, they will not know where they are failing and will only be able to adjust care plans on an ad hoc and reactive basis. Healthcare interventions are typically heterogeneous in result, and this variability is often chalked up to unavoidable uncertainty. PROMs have the potential to reduce the uncertainty by relating outcomes to an increasingly sophisticated array of antecedent conditions.

Even more fundamentally, PROMs data are almost certain to reinforce the need to move toward team-based primary care. Measuring outcomes across several dimensions implies a duty to address them all. Primary care clinics will have to assume responsibility for improving outcomes (or reducing the rate of decline) across the board and configuring their services to succeed. High-needs, complex patients will require the skills of a multidisciplinary team. Form should follow function in mapping the care plan for each patient. Up to now, the debate about whether physician-centred, traditional primary care requires fine-tuning or a complete overhaul has not produced consensus. PROMs data could bring clarity to the debate and help create pressure to abandon obsolete practice patterns and experiment with new approaches.

**PROMs and Surgery**

McGrail et al. have made a compelling case for implementing PROMs for elective surgery. It is not clear why one should stop there. If PROMs data are important to evaluate appropriateness and effectiveness in circumstances where life or death is not on the table, they are even more important when the stakes are higher. While it may be hard to imagine someone refusing potentially lifesaving surgery, such a decision may be entirely rational and consistent with a patient’s value system that takes into account evidence that
Realizing the PROMise of PROMs

the extended life span would be of poor quality, overburden one's family or diminish one's sense of self-worth.

How long should PROMs data be gathered? The time period will vary by condition and the nature of the intervention. In some cases outcomes stabilize in a relatively short period of time; in others it may take years. If collecting and analyzing PROMs data incurs additional costs and makes non-trivial claims on people's time, practical solutions will have to be found. But, as explained below, if PROMs are built into the core of health records and health information systems, the burden of data collection can be minimal and there need not be any arbitrary limits on follow-up periods.

Moving Boldly on the PROMs Front

PROMs are fundamental to a deeper and more individualized understanding of patients' health conditions and their responses to care, and to greater accountability for the quality and efficiency of the system. It is time to upgrade their status. They must be embedded into the core of healthcare. To that end, in addition to endorsing the recommendations of McGrail et al., I propose stronger – if perhaps less realistic – measures on how to move forward:

- PROMs should become core features of the electronic health record and the health information system, with data gathered routinely from patients in all sectors.
- PROMs should be central features of both the practice and evaluation of primary care, and particularly chronic disease management.
- PROMs data should be essential evidence in assessing the appropriateness of various diagnostic and therapeutic modalities.
- PROMs data should be disaggregated to the level at which they are actionable. In some cases, this will be the level of the individual provider.

- Part of the e-health agenda should be the development of standards and templates so that healthcare organizations and practitioners can easily produce the PROMs analyses they need to support quality improvement.
- PROMs should be widely and publicly reported to inform both a broader public discussion of healthcare effectiveness and patient choices about treatment options.
- PROMs’ goals and performance should be explicit components of quality improvement agendas and accountability agreements.

Much of the PROMs revolution can and should be automated, and costs should be modest in the scheme of things. A public healthcare system that spends about $4,000 per capita on health and knows shockingly little about the relationship between spending and results cannot afford to work in the dark indefinitely. Canada is going to have to learn the lesson that under-investing in healthcare intelligence not only perpetuates wasteful practices and makes healthcare less effective, it also borders on negligence. PROMs are valid measures whose power has been sufficiently demonstrated to warrant universal implementation. For once, Canada should lead the way.

References


The Road to Improving Patient-Reported Outcomes: Measures or Healthcare Reform?

COMMENTARY

Greta Cummings, RN, PhD
Professor, Faculty of Nursing
University of Alberta

ABSTRACT

Some argue that the way to improve the current health system is to ask patients about their experiences and perceptions of whether specific interventions (e.g., surgery) achieve expected health outcomes. Others argue that the way to improve health outcomes is to reform the system, particularly for those patients who suffer from complex chronic diseases and symptoms that do not fall neatly into a clinical pathway. I argue that patient reported outcome measures based on our current healthcare delivery system are necessary but not sufficient to improve patient outcomes. Ongoing dialogue, leadership and action are urgently needed to achieve a preferred future where our silo/sector/disciplinary based health system is reformed into an integrated person-centred system.

Influencing health outcomes for patients is, needless to say, the hallmark of healthcare practitioners’ work and the aim of the healthcare delivery system. Patient-reported outcomes (PROs) are a means by which the patients’ voices can be heard related to their perceptions of the efficacy and effectiveness of health services on their individual health status and function. Increased public expectations about access to healthcare and quality of care, and increased concerns about healthcare system sustainability (being able to pay for it), have supported much of the focus on PROs. This focus has also fuelled
several recent initiatives by healthcare research funding agencies to raise the profile of achieving improved patient outcomes, for example, the UK National Health Services (NHS) Outcomes Framework (Department of Health n.d.), the US National Institutes of Health (NIH; http://www.nih.gov/) Patient Reported Outcomes Measurement Information System (PROMIS) (http://www.nihpromis.org/) and, most recently, the Canadian Institutes of Health Research (2011) SPOR (Strategies for Patient Oriented Research) program. However, it is still too early to see the greater impact of these programs on population health.

The emphasis on PROs has led to an increased effort in many countries to develop tools to measure outcomes for patients from the patients' own perspectives. These measures are globally referred to as PROMs or patient-reported outcome measures. A very few of these include the NIH-funded PROMIS program (PROMIS n.d.), efforts by the Patient Reported Outcomes Measurement Group (n.d.) at the University of Oxford, the NHS PROMs for four clinical areas (NHS 2011) and a comprehensive structured review in 2006 by the UK Department of Health of patient-reported measures in relation to selected chronic conditions, perceptions of quality of care and carer impact (Fitzpatrick et al. 2006).

In this issue of Healthcare Papers, McGrail and colleagues (2011) present an overview and case for measuring outcomes for patients in Canada by asking the patients themselves whether their health status has changed. They present the most common use of PROMS as being in the case of elective surgeries because the interventions are identifiable, suggesting that the case for implementing PROMs is so clear that all health authorities in Canada should plan to routinely collect PROMs data for elective surgeries across the country by 2013. However, this recommendation requires considerable discussion and debate before it can be implemented, as not everyone involved with implementing processes to measure patient outcomes is engaged in what it can achieve. McGrail and colleagues outline some issues encountered during the implementation of PROMs for elective surgery in the United Kingdom and British Columbia. For the British Columbia example, where almost half of the surgeons reported that the exercise was of little value, McGrail et al. suggest that engagement of the surgeons is critical, as is collaboration between surgeons and management. This is clearly important as the implementation of a new policy, procedure or processual change in an organization or system requires that attention be paid to the values – that is, ideologies, beliefs and interests – of the key stakeholders involved (Lomas 2000), something apparently not addressed in this setting. Ideologies are described as the views of what ought to be (Lomas 2000), or the opportunity to envision and build a preferred future, in this case, a health system that reflects the voices of empowered patients. Beliefs are causal statements that underlie current reality (Lomas 2000). For example, beliefs can include perceived barriers to change reflected in statements such as, “It will never work because we don’t have enough time now,” or “Getting patients’ perspectives is simply not a priority.” Interests are responses to incentives or rewards (Lomas 2000), which include performance based on fee schedules that reflect time per procedure, or an understanding that better-informed patients actually can be empowered to improve their health status. Attending to stakeholder values allows for vital, comprehensive discussions centred on expectations about anticipated barriers, enhancements and outcomes of change.

McGrail and colleagues’ second recommendation calls for the development and use of PROMs in chronic diseases, but the authors
leave off providing detailed processes for doing so. They highlight the challenges of using PROMs in chronic diseases given the frequent lack of a specific intervention and, rather, the ongoing provision of complex care. These require longitudinal monitoring of patient symptoms, management and outcomes and, more importantly, asking patients about their expectations of care, whether cure, mitigation or symptom management. McGrail et al. also appropriately call for clinical leadership, a willingness to take risks and the need for incentives to change practice and procedures.

The authors’ third recommendation is to develop a pan-Canadian working group on PROMs to lessen the implementation burden on each jurisdiction in Canada. Unfortunately, this group would establish PROMs that would retrieve outcomes from patients about their experiences with the current healthcare system; some argue that the way to improve health outcomes is to reform the system. Indeed, the structure of the current health system – with its focus on disease rather than health, and the ever-increasing specialization of providers rather than integrated patient-focused teams that provide continuity of service from the prevention of disease through rehabilitation – is an inherent part of the problem. In a recent editorial, Starfield (2011) argued that the benefits of primary care are underappreciated in the current system because primary care is person/population centred rather than disease centred, structuring a degree of inequity into the system. The process for measuring outcomes in a disease-focused system is challenging for people with chronic conditions, in which disabling conditions such as chronic pain cannot necessarily be attributed to a specific disease (Starfield et al. 2011). Hence, in such a system where clinical pathways and best practice guidelines are built on a disease-, provider- and specialist-focused model, many patients could be placed on several potentially conflicting clinical pathways for a variety of disorders and symptoms, adding layers of ambiguity to the measurement of achieved outcomes.

How to transform the system into one that is patient centred rather than provider centred is still an elusive endeavour, largely because the system is complex. In 2004, Glouberman and Zimmerman presented an eloquent argument for the distinctions between simple, complicated and complex systems and the approach required to manage and change each. Simple systems require a recipe with step-by-step instructions to follow. Complicated systems require protocols and guidelines with some assurance that if they work in one situation, they will probably work in future opportunities in the same setting. Complex systems are likened to raising a child; raising one child provides experience but no assurance of success with the next. Experience can contribute but is neither necessary nor sufficient to ensure success (Glouberman and Zimmerman 2004). Our healthcare system is such a complex system, if we perceive that Canadians should receive person-centred rather than disease-focused care. Person-centred care would indeed require that the data for PROMs be based not solely on disease-focused systems but on health, wellness, functionality, symptom management etc. or, in other words, on a holistic view of the person. Starfield (2011) also called for

"PROMs would retrieve outcomes about experiences with the current healthcare system; some argue that the way to improve health outcomes is to reform the system."
the use of electronic capabilities to collect data that enable the calculation of a morbidity burden. Some researchers and healthcare stakeholders have also advocated for the use of comprehensive electronic health records and administrative datasets as sources of data to assess increases in patient benefits and positive outcomes (Rozenblum et al. 2011).

What is needed in the arena of measuring patient outcomes is (1) a theoretical framework to guide the development and use of PROMs to assess changes in outcomes for patients and (2) a renewed focus on health systems that are based appropriately on person-centred care and the values underlying it. One framework that could guide the development and use of PROMs is the Institute of Medicine (IOM) quality framework. The IOM model stresses that healthcare and its systems and processes should be as follows (Committee on Quality of Health Care in America, IOM 2001):

- **Safe** – avoiding injuries to patients from the care that is intended to help them
- **Effective** – providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit
- **Patient centered** – providing respectful and responsive care to individual patient preferences, needs and values and ensuring that patients’ values guide all clinical decisions
- **Timely** – reducing waits and sometimes harmful delays for both those who receive and those who give care
- **Efficient** – avoiding waste, including that of equipment, supplies, ideas and energy
- **Equitable** – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographical location and socioeconomic status

Lastly, the development of PROMs based on our current healthcare delivery system is necessary but not sufficient to improve patient outcomes. What is needed additionally is ongoing dialogue, leadership and action to achieve a preferred future where our silo/sector/disciplinary system into an integrated person-centred system where patients’ voices are heard regarding expectations, quality, and values that guide clinical decision-making.

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ABSTRACT

Bringing the patient perspective into healthcare is now widely recognized as a somewhat-urgent need, and patient-reported outcome measures (PROMs) are an excellent example of attempts to do more of this. In this commentary, the author puts PROMs into a broader perspective and then speaks more specifically about this particular initiative. The question addressed is, how well can PROMs increase patients’ participation in their care?

Bringing the patient perspective into healthcare is now widely recognized as a somewhat-urgent need, and patient-reported outcome measures (PROMs) are an excellent example of attempts to do more of this. In this commentary, I first put PROMs into a broader perspective and then speak more specifically about this particular initiative.

Patient reporting on outcomes is one of many attempts to increase patients’ participation in their treatment – a relatively recent phenomenon in healthcare. Our healthcare systems were born in the 1880s in response to acute infectious diseases such as influenza, typhoid fever and tuberculosis, which, at the time, caused the vast majority of deaths. Robert Koch and Louis Pasteur led the scientific work that showed that these diseases could be easily identified by the microorganisms that caused them, their course could be well described and they could be averted with appropriate vaccines. The healthcare system
that grew out of these discoveries had the acute hospital as its hub, professional scientist physicians as its key personnel and research laboratories as the sources of its knowledge.

Two aspects of the healthcare system that began in 1880 are worth noting: the lack of patient participation in treatment and its research orientation:

- **Patient role in the post-1880 healthcare system.** In a system focused on acute infectious diseases, there was almost no need for patients to participate in their care or to report on the outcomes. For such diseases, this made good sense because they were acute and life threatening and required expert knowledge of the body, not the person. Patients did not have to report the outcomes since they were clearly measurable independent of the patients’ perspective.

- **Research orientation of the post-1880 healthcare system.** The research and treatment program focused on finding the cause and cure of all diseases whether infectious or not. This included determining definitive tests that would indicate the presence of a particular disease, clear protocols for the treatment of that disease and public health initiatives such as vaccinations that might prevent the disease from occurring.

The great success of the healthcare system was a dramatic reduction of deaths due to acute infectious diseases in the developed world. By 1970, the majority of deaths were no longer caused by such diseases but, rather, by chronic non-communicable diseases. The success of the system reinforced the prevailing approaches to research programs. For example, in 1970 Richard Nixon declared his “War on Cancer,” which proceeded to fund cancer research for the next 40 years at an average rate of US$1 billion per year in order to find the cure for cancer. Patients continued to have little role in their treatment.

Between 1970 and today there has been a growing recognition that non-communicable diseases such as heart disease and diabetes cannot be “conquered” by the kinds of research programs that deal with acute infectious diseases. And it is also becoming widely accepted that chronic non-communicable diseases require patient involvement in their treatment to avert acute episodes and to control morbidity. Chronic conditions cannot be treated with surgical or pharmacological interventions alone – they usually are linked to emotional, behavioural, social and environmental factors. The lead essay states that of the nine million Canadians who suffer from chronic diseases, 30% have more than one (McGrail et al. 2011). As a consequence, the complexity of treatment is geometrically increased and patient participation is even more important.

PROMs are a critical step in this direction. Almost everyone is aware that the entire healthcare system must be adjusted to engage patients in the care of non-acute, non-communicable chronic diseases if it is to deal appropriately with the morbidity of the population. Perhaps it is worth stressing the slowness of this change. Early on, the system focused primarily on acute episodes of chronic diseases. In the 1950 and 1960s, there was less talk of heart disease than of heart attacks. In Canada, acute hospital care was covered by publicly funded health insurance before primary care was added.
The introduction of the patient perspective on outcomes is obviously a valuable addition to the evaluation of all outcomes in healthcare: it adds a critical dimension to the assessment of healthcare. The question that remains is, how well can PROMs increase patients’ participation in their care? The lead paper makes three recommendations, which I review below in sequence.

**Recommendation One: PROMs for Elective Surgery**

Most elective surgeries are acute interventions for chronic conditions. In the UK National Health Service (NHS), hip and knee replacements seem to be the most prominent surgical procedures reviewed by means of PROMs. When the focus was almost entirely on acute care, clinicians alone were the ones to decide if such surgeries were successful. Patients’ limbs were tested for the effects of the surgery without considering impacts on lifestyle, social activity and so on. At times, a successful surgery on these measures would leave a patient without the gains in capacity needed to revive social, work and recreational functions. (This perhaps is the source of the old joke, “The operation was successful, but unfortunately the patient died.”)

Bringing the patient’s perspective into the outcomes of elective surgery is clearly an important step forward. The lead paper does not give an example of the data that are collected by the NHS. It is important to note that typical PROM questionnaires used by the NHS, like the Oxford Orthopaedic Scores, were developed with significant patient input and revised and finalized only after patient consultation and review. The knee questionnaire has been simplified and streamlined to ask only 12 questions pre- and post-operatively; and patients answer the following question on a scale of one to five:

**During the past four weeks:**

1. How would you describe the pain you usually have from your knee?
2. Have you had any trouble with washing and drying yourself (all over) because of your knee?
3. Have you had any trouble getting in and out of a car or using public transport because of your knee? (whichever you tend to use)
4. For how long have you been able to walk before the pain from your knee becomes severe? (with or without a stick)
5. After a meal (sat at a table), how painful has it been for you to stand up from a chair because of your knee?
6. Have you been limping when walking because of your knee?
7. Could you kneel down and get up again afterwards?
8. Have you been troubled by pain from your knee in bed at night?
9. How much has pain from your knee interfered with your usual work (including housework)?
10. Have you felt that your knee might suddenly “give way” or let you down?
11. Could you do the household shopping on your own?
12. Could you walk down a flight of stairs?

The questionnaire appears to consider the surgical intervention as the single pivotal causal event that has any bearing on the outcomes. Surgical method and skill, though unmentioned, appear to be the factors that differentiate more effective knee replacements from less effective ones. This hardly allows for patient contributions to the success of knee replacements. Patient-initiated strategies to prepare for knee replacements can go well beyond the hospital measures and include
careful attention to exercise regimes that increase post-operative mobility, and preparation for and acceptance of strong pain control to speed up post-operative mobilization of the joint to allow earlier and more intensive physiotherapy. In fact, engaged members of the Patients’ Association of Canada who have experienced knee replacement surgery tell us that patients can do a lot to prepare for and follow up from the actual knee surgery that can make a large difference to the outcome. Although this is widely acknowledged, it is not reflected in the PROMs structure as described.

The results that have come in from use of PROMs in the NHS indicate that knee replacements are successful in reducing pain and increasing general health and activities of daily living. The NHS reports that “91.5 per cent of knee replacement respondents recorded joint related improvements following their operation as measured by their response to a series of questions about their condition (Oxford Knee Scores)” (NHS 2011). Using the scale, patients overwhelmingly confirm the value of these surgical interventions. In policy terms, if the measures we are to identify and concentrate on are the ones listed and the success rate is as high as indicated here, then the clear policy solution is to lower the threshold for surgical interventions and provide even more joint replacements. This consequence is not atypical in a system that focuses on acute interventions, and much of the evidence-based research provides measures to support this.

**Recommendation Two: PROMs for Chronic Conditions**

Knee and hip deteriorations are chronic conditions, and we must ask what can be done to avert or delay the need for surgery. This does not easily lend itself to the PROMs approach, which uses structured questionnaires that focus on degrees of disability and pain states. The possible variation in factors that can contain and work around joint deterioration is much wider than individual patient strategies for coping with surgery, and many alternatives must be explored, including everything from weight loss to weightlifting regimens. Moreover, in most chronic conditions, interventions must often be customized to individuals. It is not unusual in the case of chronic conditions, such as joint deterioration, that what works for one person is not effective for another, and may not even work for the same person at a different time. To some extent, this may be due to the fact that 30% of people with chronic conditions have more than one.

The limited application of PROMs to elective surgeries suggests that it would be relatively difficult to apply them in their present form to more pervasive and even more complex areas of healthcare such as the vast array of chronic diseases that do not lend themselves to surgical interventions. While it is clear and glaringly obvious that patient participation in the care of chronic diseases is essential, it is less clear how PROMs can contribute to this kind of participation.

While it is clear and glaringly obvious that patient participation in the care of chronic diseases is essential, it is less clear how PROMs can contribute to this kind of participation.
will include patient initiatives to contain the condition and avert acute episodes, such as the use of alternative therapies, customized regimens of diet and exercise, relaxation therapies and psychological counselling. Many of these strategies for dealing with chronic conditions lend themselves to narrative accounts of both the condition and the therapeutic consequences of particular interventions. Coming to understand how a patient learns to respond well to a chronic condition requires time and listening. These are rarely part of the current standard medical approach for dealing with chronic conditions, and it is hard to see how PROMs would make this change easier.

**Recommendation Three: A Pan-Canadian Working Group on PROMs**

Any working group to consider the use of PROMs for elective surgery must include patients as active contributors. Care must be taken to gain a better understanding of the patient experience of undergoing and recovering from elective surgeries in order to learn more about their outcomes. If there is to be an expansion of efforts to study effective ways of dealing with chronic diseases, then the patient perspective is doubly necessary. Certainly, there needs to be a pan-Canadian task force to think about and develop more robust strategies to deal with chronic disease in our country. That, after all, is thinking about the present dilemma of a healthcare system that is less and less appropriate to our needs. And patients must be part of those discussions.

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Role for PROMs Data to Support Quality Improvement across the Healthcare System: An Informed Exchange with Senior Health System Leaders

ABSTRACT

The Institute for Healthcare Improvement’s Triple Aim (initiated in 2007) and several high-level Canadian studies have made general calls to improve health system performance. Managers and administrators have been urged to tackle the challenges of quality improvement and cost control. In the lead essay, McGrail et al. point to patient-reported outcome measures (PROMs) as something worth doing, and this has been welcomed as an appropriate response to long-standing calls for action. A recent gathering of senior health system leaders explored the prospect of routinely collecting PROMs data to drive quality improvement. The symposium, Measures of Health Outcomes to Improve Performance, Value and Productivity, was held in Victoria, British Columbia, on December 9, 2010. The symposium delegates considered the challenges and issues involved in moving forward with PROMs,
Quality improvement has been a top priority for health system leaders for years. In the US a linked set of goals, the Triple Aim, has been promoted to guide healthcare improvement initiatives (Berwick et al. 2008). The past decade has seen several high-profile Canadian efforts directed at system renewal that contemplated new investments in data resources as a cost-effective means of improving system performance.

According to the Senate Committee report, the committee was persuaded “that, in addition to other necessary reforms, it is essential to invest additional money into Canada’s health-care system in order to renew and sustain it” (Kirby 2002: 258). Its “detailed plan of action” called for the creation of a data resource to capture information on system performance and outcomes, and urged that “measuring treatment outcomes and system performance must become an essential part of the health information system” (Kirby 2002: A20).

In their report (Law et al. 2008), the Listening for Direction III partners asked, simply, “What works?” They highlighted the need for health improvements while canvassing for recommendations from informed observers, leaders and experts in the health field about general areas where investments could reasonably be made. One research question identified was this: “Where are the gaps in the existing databases and other information sources (for example, patient-reported outcomes)?”

Recently, it appears, in the judgement of Dodge and Dion, that it is possible to bend the cost curve through “better price incentives and bottom-up accountability measures leading to more cost-effective treatments and practices [which could contribute to] … a major reduction in the rate of growth of costs, provided that very significant efforts are deployed” (2011: 7, 8). The authors urge, “It is now up to Canadians to have an adult discussion about how to manage [health spending]” (2011: 11).

**Do We Have a Well-Defined Problem?**

External pressures have been mounting for efficient, effective care. Romanow reported, “Overwhelmingly, Canadians told the Commission that they are prepared to pay more for healthcare to ensure the system’s sustainability, provided the system is prepared to change to meet their needs and expectations” (2002: 43). There is clearly widespread concern that the healthcare system is ceaselessly absorbing ever-more resources while generating little improvement in measured health outcomes. The suspicion appears to be that a significant fraction of overall spending is unproductive in areas that matter most to people; however, lacking good-quality information, there is a reasonable reluctance to cut expenditures for fear that health outcomes would deteriorate.

In light of the general direction affirmed in the above reports, it is timely to have McGrail et al. (2011) inquire into the steps required to solve the problem of how to improve health outcomes.

**Taking Stock of Where We Stand Today**

The public debate surrounding sustainability ranges from those who view the budget as being subject to an absolute per capita limit, to those who envision “bending the cost curve” and holding healthcare spending at an acceptable share of the gross domestic product looking closely at the potential for enhancing the quality of data resources available for managing our healthcare system. Senior leaders and administrators from the publicly funded healthcare systems of British Columbia and western and northern Canada participated in a frank discussion of challenges and requirements for moving forward with a PROMs initiative.
(GDP). Recently, total healthcare spending (public and private spending combined in 2008, according to the Organisation for Economic Co-operation and Development [OECD 2011]), as a share of GDP, stood at 10.3% in Canada, compared with 16.4% in the United States. Alternatively, we can compare our system with those of other countries that have a health system more similar to Canada's in that more than two thirds of the system's funding comes from general taxation (which some describe as a “Beveridge” model, as represented by the National Health Service [NHS] in the United Kingdom). Compared with the 10.3% ratio for Canada, others in this group exhibit a lower ratio: health spending as a share of GDP is 8.7% in Australia, 8.8% in the United Kingdom, 9.2% in Sweden and 9.6% in New Zealand.

The levels of total healthcare spending per capita in 2008 (comparison in US funds, adjusted for national differences in cost of living) range from a high of $7,720 in the United States, to $4,024 in Canada, to a low of $2,784 in New Zealand; Canadian spending per capita is 10% above that of Sweden, which has the next highest level of spending among this Beveridge group.

Admittedly, there is qualitative evidence that some improvement in health outcomes can be attributed to increased expenditures (Figure 1), but the magnitude of improvement varies greatly and bears little resemblance to spending patterns. For example, we observe the reduction in deaths from causes amenable to healthcare achieved in the United Kingdom and the United States, and we know how spending differed in each country from 2000 to 2003. While the chart shows that improvement was greater in the United Kingdom, the United States spent much more per capita to lesser effect; total spending grew at a 5.6% compound annual rate in both countries, and the level of spending in 2003 was US$2,317 per capita in the United Kingdom versus $5,986 in the United States.

The question of how we can move forward with renewal is inadequately addressed in the above high-level studies. We must come down to earth, develop the means for making efficient resource allocation decisions and identify specific actions and innovations that will deliver quality improvement.

External pressures do exist, and they do reflect the desire for health improvement, including effective treatments with timely delivery in response to adverse events. It is important to recognize that people (both as prospective patients and taxpayer members of a Beveridge-style insurance plan) are fundamentally interested in comparing the added cost of a treatment with the expected gain in health that it may afford. Knowledge of “what

![Figure 1. Age-standardized death rate (per 100,000) from causes amenable to healthcare among males 0–74 years old](image-url)
works” in healthcare is at the heart of the sustainability discussion; given that technological change is an inherent feature of the health sector (Cutler and McClellan 2001), cost-benefit assessments will be continually relevant for driving quality improvement, updating “best practices” and supporting system renewal.

As McGrail et al. state, “without information on outcomes and an investigation of what systems or structures are related to outcomes, we have not done our job as health service analysts” which is to support changes that will improve the performance of the healthcare system. The views of those present at a recent PROMs symposium provide a solid basis for moving in the direction recommended by McGrail et al.

The Senate Committee does not clarify what “measuring treatment outcomes and system performance” means, but it presumably means going beyond the existing clinical and mortality indicators. At the very least, for example, PROMs could quantify health improvement as measured by quality-adjusted life years gained in the real world by patients actually treated.

**Findings of a PROMs Symposium**

Recently, a symposium on PROMs was hosted in Victoria, British Columbia. It was sponsored by the Western and Northern Health Human Resources Planning Forum and its member jurisdictions and was made possible through a financial contribution from Health Canada. Briefly, the objectives of the event were threefold: to create awareness of the potential of PROMs to improve performance; to engage senior leaders in discussion about possible priorities for PROMs initiatives; and to canvass the interest of senior leaders to explore next steps. Thirteen presenters and some 50 delegates attended the day-long event.

A more complete account of the symposium is available in a proceedings volume (Gray and Noyes 2011), posted on the web. Materials pertaining to the symposium are posted at http://www.effectiveproductivity.info/index.php; to access these materials click on Resources and then click on the link/folder “Patient Reported Outcomes Measures - Indicator for Healthcare Productivity.” Materials available include the symposium program; “Introduction to PROMs” by Stirling Bryan, PhD, director, Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health Research Institute; 11 slideshows by other presenters; and the proceedings (Gray and Noyes 2011).

This commentary is an opportunity to share with a wider audience some of the experiences and views of symposium delegates about the proposition of routinely collecting PROMs data in a real healthcare system.

**Issues and Questions about PROMs Addressed by Experts**

**Would PROMs Improve the Quality of Our Data Resources?**

PROMs complement other data on a patient’s health; generic PROMs results are meaningful regardless of whether the survey respondent is receiving care. Andrew Vallance-Owen, MBA, FRCSEd, group medical director for Bupa, observed that “there’s a great difference between the output of PROMs compared with all the other clinical indicators. Practically, all the other clinical indicators that are collected routinely are indicators of failure – it’s all about where things went wrong …

If you collect PROMs, what you see is health gain.”
If you collect PROMs, what you see is health gain, invariably.”

**How Reliable Are PROMs?**
Sceptical clinicians may say, “Well, PROMs are subjective data, so we don’t give them much credit. Do PROMs results matter?” Arlene S. Bierman, MD, senior scientist in the Keenan Research Centre, Li Ka Shing Knowledge Institute, St. Michael’s Hospital, pointed out that there is evidence that US Medicare Advantage plans that manage diabetes better actually achieve greater improvement in functional health outcomes in two years, as measured by generic PROMs. And David Feeny, PhD, senior investigator, Center for Health Research, Kaiser Permanente Northwest, pointed to evidence on the test/retest reliability of various PROMS that shows, in general, that PROMS are as or more reliable than standard, recognized clinical measures (e.g., taking blood pressure, tumor response, measuring blood gases).

**Is Collecting PROMs Cost-Effective?**
In Vallance-Owen's opinion, there is huge value and cost-effectiveness in the PROMs project that has been launched by the NHS in England. According to D. Douglas Cochrane, MD, chair of the BC Patient Safety and Quality Council, an important reason to collect PROMs data routinely is their potential to influence the decisions patients will make in the future: “I think that’s where the true value is, because PROMs will help us change individual and collective decisions around the uptake and the acceptability of an intervention.”

**Can PROMs Add Value for Both Patients and Clinicians?**
Can PROMs add value for both patients and clinicians? Yes, in a number of ways. PROMs can affect appropriateness of care by giving patients information about others’ experiences that can help them make decisions about their care. Vallance-Owen acknowledged that the availability of PROMs data matters when it comes to facilitating patient choice at the NHS: “We tell people, if you have this operation, here’s the amount of health gain you are likely to get.”

**Why Hasn’t This Already Been Done in Canada if It’s Such a Winning Idea?**
The question arises, so why hasn’t routine PROMs data collection been set up in Canada? Claudia Sanmartin, PhD, chief and senior researcher, Health Services Research, Statistics Canada, described a proposed national initiative, a pilot project, which aimed to collect PROMs for select surgeries in Canada (c. 2005/2006) that did not proceed due to a lack of funding. Similarly, no program of routine PROMs collection was generated by the Regional Evaluation of Surgical Indications and Outcomes (RESIO) project conducted in British Columbia. A reasonable conjecture as to why this did not occur is that the senior health system leadership of the day was preoccupied with other priorities.
Consensus Views of Delegates

Plenary and small-group discussions considered how PROMs might be used to prompt priorities and generate forward momentum. A synopsis of their ideas follows.

Consensus Favours PROMs

The overwhelming consensus was that routine collection of patient-reported outcomes data offers a good opportunity to improve the ability of the system to make decisions. This mirrors the consensus of the Canadian Institute for Health Information/Statistics Canada Data Users Conference, September 2010, in Toronto, where, among some 320 data users, virtually all were in favour of the routine collection of PROMs data. At our symposium, people enthused that PROMs align with patient-centred care. Some were hopeful that access to PROMs data would herald a sea change, whereupon their routine use would become a tenet of best practice system wide, enabling continual quality improvement in patient care. There is clear recognition that PROMs data could help us to successfully manage cost pressures over the long run. Yoel Robens-Paradise, MPA, executive director of Health Information Management for the BC Lower Mainland, described a PROMs system architecture that would best meet users’ needs and that would relate to “each trajectory of clinical illness.” This suggests that “event history data” would possess the appropriate structure to support comprehensive, dynamic modelling. It also implies that non-users of the system comprise a reservoir of potential future patients, a group that must be duly recognized if we are to gain a complete understanding of the dynamics that underlie the demand for care services and system utilization.

A Consistent Framework and Coordinated Actions

Themes that emerged emphasized leadership, centralized actions to facilitate efficient collaboration and comprehensive planning processes (design, implementation and evaluation). Most felt that leadership is key. Delegates want a consistent and disciplined approach across the system. To this end, centralized leadership could deliver a common framework that enables local activity and avoids counterproductive divergent approaches. Other deliverables would coordinate important issues: how an electronic health record (EHR) and existing data management infrastructure would fit with PROMs implementation; due diligence about risk adjustment (case mix) for a proper interpretation of PROMs results; and the cost-effectiveness of routine collection of PROMs data.

Elements Needed to Move PROMs Forward

To move PROMs forward, we first need to map the use of PROMs data and clarify our purposes in collecting them. Most important, if clinicians do not use PROMs data to improve care every day, these data are not worth collecting. The patient-provider relationship could drive this change; if patients and providers find real value in PROMs results, then other stakeholders will buy in. Second, we need to educate prospective PROMs users. A necessary cultural transformation of clinical practice will occur only if PROMs and similar data are infused into health science education curricula.

Pitfalls to Avoid

We do not need more pilot projects. Although issues of optimality regarding data collection and management may remain, the feasibility of collection is confirmed by experience in other care systems. The absence of desirable conditions (e.g., EHR and data collection systems) should not thwart progress. Delay is costly in terms of forgone benefits of quality and safety improvement. We should not develop PROMs in isolation from other data.
collection processes, and we should avoid tying PROMs to incentives. Experts find that risk-adjustment issues are difficult to resolve; they advise using PROMs results to initiate discussions with care providers and to better understand performance variations.

Opportunities for Collective Action
Specifically, people saw merit in standardization and in collaboration with stakeholders within the local system and across jurisdictions. Partnerships with national agencies (e.g., CIHI and Statistics Canada) were viewed as advantageous.

Immediate Next Steps
Delegates suggested priority actions to move PROMs forward:

- Consult with stakeholders. Support collaboration on PROMs between clinicians and managers, which McGrail et al. argue is required to improve system performance. Consultations would clarify the multiple purposes of implementing PROMs collection, which would then drive the selection of the best suite of PROMs and data system architecture.
- Define priorities. Develop criteria for deciding where to start PROMs collection and use. Identify areas where suitable infrastructure already exists, and organizations that have mechanisms for responding to PROMs results.
- Innovate in non-acute care. Initially focus on some vulnerable populations (e.g., people with chronic conditions, frail elderly) for which PROMs results would likely make the largest difference to health outcomes and spending.
- Implement. Start small, assess how it works and then expand from there. Seize the opportunities afforded by local initiatives.

Conclusion
The ministry is actively engaged in PROMs research and pilot projects and is open to working with health authority partners and other stakeholders in examining how PROMs data could be collected and used within the system. It is clear that the consensus view of the participants of the Victoria symposium supports the perspective presented in the lead essay by McGrail et al. The routine collection of PROMs data would be an important step in ensuring that the decisions made in our health system are based on the best, and most appropriate, evidence.

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References
Can Routine Collection of Patient Reported Outcome Data Actually Improve Person-Centered Health?

**COMMENTARY**

*Doris Howell, RN, PhD*
RBC Chair, Oncology Nursing Research and
Co-Director, ON-PROST Applied Cancer Research Unit
Princess Margaret Hospital, University Health Network
Scientist, Ontario Cancer Institute and Adjunct Scientist, Cancer Care Ontario
Associate Professor, Lawrence Bloomberg Faculty of Nursing and
Dalla Lana School of Public Health, University of Toronto

*Geoffrey Liu, MD, MSc*
Alan B. Brown Chair in Molecular Genomics
Co-Director, ON-PROST Applied Cancer Research Unit
Princess Margaret Hospital, University Health Network
Cancer Care Ontario Research Chair in
Experimental Therapeutics and Population Studies
Scientist, Ontario Cancer Institute
Associate Professor, Dalla Lana School of Public Health and
University of Toronto

**ABSTRACT**

McGrail et al. have provided an important overview of an argument for the routine collection of patient-reported outcome measures (PROM) data as a critical step toward the improvement of population health in the Canadian healthcare system. In this commentary, the authors argue that equal attention must be paid to knowledge
The lead paper by McGrail, Bryan and Davis (2011) highlights the lack of progress in the routine collection of patient-reported outcome measures (PROM) data and the urgency to address this shortcoming, given its potential to improve population health in the Canadian healthcare system. Indeed, routine PROMs data collection offers promise for improving health outcomes and for population surveillance for estimating illness burden beyond survival and mortality, evaluating system and population-based interventions and stimulating improvement in the quality of clinical care and the nature of the encounter between patient and provider (Lipscomb et al. 2004). Routine collection of PROMs data can also facilitate research that provides insight into healthcare system quality (Barbera et al. 2010) and the underlying mechanisms contributing to disease development and treatment effectiveness (Liu et al. 2008), which could lead to better future healthcare.

In spite of these benefits, based on our early experience of implementing routine PROMs data in cancer, we suggest that the challenges to be faced, particularly in chronic diseases such as cancer, cannot be underestimated. We also argue that to reach a goal of improved population health, equal attention in the routine collection of PROMs data must be paid to (1) ensuring a high-quality clinical response to PROMs data as part of a systematic and planned knowledge translation endeavour; (2) the use of formalized methods to reach consensus on a core framework for PROMs data to be collected across healthcare jurisdictions that capture the person-centredness of current healthcare reform efforts (World Health Organization [WHO] 2007; Department of Health 2001); and (3) building on the National Institutes of Health (NIH) Patient Reported Outcomes Measurement Information System (PROMIS; Cella et al. 2007) taxonomy since it reflects the broad physical, emotional and social domains and dimensions of health particularly relevant to those with chronic disease.

**Complexity of PROMs Implementation in Chronic Diseases**

First, we update the story and share progress to date in the systematic implementation of PROMs data for routine collection in cancer, now labelled a chronic illness (Wagner 2011). Following initiatives in one region of the province, Cancer Care Ontario (CCO) implemented and evaluated the routine collection of symptom and psychological distress data in 13 regional cancer programs with an initial target of palliative populations (Dudgeon et al. 2011). This routine collection of core PROMs symptom and distress data in all cancer populations is a performance expectation in Ontario (CCO 2011). While it took a number of years to implement this limited core set of PROMs data, over 85,000 patients have now completed these data in 2010 (CCO 2011) and there is evidence to support the value of these data in the clinical encounter between patients and clinicians (Gilbert et al. in press).
Parallel efforts are also under way nationally to facilitate the routine collection of a similar core PROMs data set as part of the worldwide endorsement of distress as the sixth vital sign in cancer (Bultz and Carlson 2005; Howell and Olsen 2011).

Some of the key factors for success in the implementation of PROMs data we learned in this work were as follows (Gilbert et al. in press):

• Top-down leadership and decision-making with clear designated accountability are essential but must be combined with bottom-up engagement of clinicians across care sectors and disciplinary boundaries to identify local solutions to implementation challenges.

• Access to technological infrastructure to ensure direct data entry and interpretability of data to both clinicians and patients along with data upload for provincial performance reporting stimulates further uptake.

• Local coordination to push change forward and ensure the engagement of patients in the completion of PROMs data and the input of all team members to facilitate the data's use to inform clinical practice is essential.

Others have noted that data must be acceptable to patients and clinicians and the PROMs must be seen as offering legitimate and relevant data that are useful to clinicians to inform the clinical encounter (Valderas et al. 2008).

Even after five years’ experience, a number of implementation issues still need to be addressed, for example: What is the ideal frequency of routine PROMs data collection since patients have episodic and daily treatment visits? How do we incorporate core (generic) PROMs data for population comparison with disease and condition specific PROMs necessary at the point of care? And, finally, how do we routinize PROMs data collection across multiple phases of illness and treatment extending to post-treatment survivorship care? More importantly, since the input of different providers is essential to the achievement of health outcomes, we still need to consider the integration of routine PROMs data collection across healthcare sectors such as primary, home and long-term care so that we do not miss important inputs to health or changes in health outcomes. The implementation of Health Outcomes for Better Information and Care (HOBIC) in institutions, home care and long-term care agencies may provide some insights regarding the implementation of PROMs data in diverse healthcare sectors (Doran et al. 2006, 2007).

Ensuring a High-Quality Response to PROMs Data

While we agree with the urgency for health jurisdictions to plan now for the implementation of PROMs for routine data collection, whether this can actually improve health is still questionable. To date, there is little high-quality evidence to support a claim that the routine collection of PROMs data will result in improved health (Devlin et al. 2010; Greenlaugh and Meadows 1999; Howell et al. 2009; Marshall et al. 2006; Vallderas et al. 2008). Even though clinicians value PROMs data in the overall assessment of patients and the data's ability to increase the detection of psychological and functional problems, the way in which PROMs data are implemented in routine practice may impact on their effectiveness on health outcomes (Greenlaugh and Meadows 1999; Dawson et al, 2010). Trials of the effectiveness of routine collection of PROMs data were fundamentally flawed since investigators assumed that data fed back to clinicians and, primarily, the physician
would automatically lead to the adoption of appropriate patient-management interventions or actions. As noted by Greenlaugh and Meadows (1999), the causal relationships between organizational structure/processes of care and changes in health outcomes must be clearly specified. This notion is consistent with the interconnectedness of structure, process and outcomes as articulated in the quality healthcare model (Donabedian 1966).

Linking patient-reported experience measures (PREMs) to PROMs data might provide insight into the shortcomings in care processes that require modification to achieve improvement in health outcomes (Devlin et al. 2010). Consequently, we recommend that as regions plan for the implementation of PROMs data, equal attention be paid to the use of knowledge translation strategies as part of the overall plan to ensure an effective high-quality clinical response to PROMs data for health improvement to be possible. It is argued that there must be clear links between PROMs data and guidelines for clinical practice and care pathways (Snyder and Aaronson 2009). However, even when PROMs data are linked to clinical guideline recommendations and care pathways (Howell and Olsen 2011), a systematic approach using the knowledge-to-action cycle planning framework (Graham et al. 2006) is critical to ensure the uptake of best clinical practices for effective patient management. Knowledge translation approaches may also be key to ensuring the uptake of routine PROMs data collection, and experts in knowledge translation should be engaged early in the implementation process. We must also take account of the fact that patients are co-producers of health; the clinical interaction between patients and providers in response to PROMs data will need to emphasize best practices that also support patient behaviour change if improved health outcomes are to be achieved (Bodenheimer et al. 2002).

**Attending to the Person-Centredness of PROMs Data Collection**

As noted by McGrail and colleagues, PROMs emphasize outcomes that are important from the patients’ points of view. However, for PROMs to be useful, particularly in chronic disease, they must be able to capture a broad range of health domains consistent with a person-centred approach that is part of the global effort to improve the quality of healthcare (WHO 2007). Collection of PROMs data that are person focused can enhance our understanding of the burden of illness and the impact of clinical and health service interventions on daily living and quality of life (Gondek et al. 2007). Reaching consensus on core PROMs domains and dimensions that capture the person-centredness of healthcare and the broad domains of physical, psychological and social health adopted by the NIH PROMIS initiative may facilitate the standardization of PROMs data collection for common problems. We have made some initial progress to reach national consensus on a similar taxonomy of domains and dimensions for PROMs in cancer populations (PROMs – Cancer Core; Howell et al. 2010). Unique to our initial research was the inclusion of both key policy and administrative decision-makers along with cancer survivors in reaching consensus on core PROMs dimensions for routine collection. Rarely are patients involved in the selection of relevant PROMs for implementation in routine clinical practice (Rowan et al. 2010). Additionally, in our scoping review, we found that many “patient-based” measures are not conceptually or content valid from the patients’ perspective. We suggest that the processes used by PROMIS (Cella et al. 2007) that also include the perspective of patients in determining the relevance of PROMs data should be considered for guiding work in the Canadian health system. Finally, the routine collec-
tion of PROMs data must consider issues of low literacy and multicultural diversity in the healthcare population and whether all age groups will be comfortable with entering sensitive health information on technology-based platforms.

**Conclusion**

McGrail and colleagues’ call for a national forum to discuss the implementation challenges that must be addressed in the routine collection of PROMs data is timely and warranted. Globally, the collection of patient-reported outcomes (PROs) data is emerging as a health system policy imperative (Darzi 2008; De Walt and Revicki, 2008; Hewitt and Simcoe 1999; US Food and Drug Administration [FDA] 2006), and payment for quality performance (Checkland and Harrison 2010; Darzi 2008) is closer than we think. The suggested forum should target thought leaders in the field, clinicians, policy and administrative leaders, knowledge translation experts, and also patient advocacy groups to reach consensus on a core PROMs framework to guide future efforts, learn from each other about keys to successful implementation and scale the priorities for action. More importantly, ensuring that PROMs data collection is accompanied by effective knowledge translation to best practices and care processes, resulting in a high-quality response in patient management, will be fundamental to improving physical, psychological and social health in chronic disease populations including cancer.

**References**


Can Routine Collection of Patient Reported Outcome Data Actually Improve Person-Centered Health?


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ABSTRACT

Patient-reported outcome measures (PROMs) include reports and ratings provided by patients or their proxies about their health, functioning, health behaviours and quality of care. PROMs reflect the patient perspective and increase the comprehensiveness of outcome measurement in clinical research. There is growing interest in using PROMs in clinical practice: for screening, monitoring and improving communication at the individual level; and to aid in decision-making, monitor populations and assess quality in the aggregate. For use in clinical practice, the authors draw an analogy to getting to the prom (a North American graduation dance). Whom to go with? They recommend seeking a group of partners and developing methods and standards with national and international groups. The authors advocate for incentives to encourage broad participation. What to wear? They suggest selecting
Patient-reported outcome measures (PROMs) involve outcomes data provided by patients or patient proxies, as opposed to data provided by other sources (Acquadro 2001). PROMs refer to patient ratings and reports about any of several outcomes, including health status, health related quality of life, quality of life defined more broadly, symptoms, functioning, satisfaction with care and satisfaction with treatment. Patients can also report about their health behaviours, including treatment adherence and health habits. PROMs convey some unique benefits to observational research studies. Advantages include increasing the comprehensiveness of outcome measurement beyond the consideration of clinical outcomes and, in some cases, increasing the reliability and validity of measurement of specific concepts.

Recently, there has been an increased interest in using PROMs in clinical practice. At the individual patient level, they may be used for screening, monitoring, promoting patient-centred care and facilitating communication within teams. At the aggregate level, they may be used to aid decision-making, monitor populations and assess the quality of care (Greenhalgh 2009; Wu 1997).

In this issue of Healthcare Papers, McGrail and colleagues (2011) begin with accolades for the Canadian healthcare system, of which they are understandably proud. However, they are frank about the challenges faced by Canadian healthcare and the need for improvement. Mindful that all improvements require change but that not all changes represent improvement, they point to the importance of evaluating outcomes. They observe that what outcomes data there are, are not assessed from the patients’ points of view. They describe PROMs and provide a few examples from Commonwealth countries of PROMs data collection to promote improvement. It is relatively easy to see that PROMs data could be helpful to evaluate the comparative benefits of elective surgery, and the authors recommend that this be done systematically. They go on to argue for incorporating PROMs into the care management of chronic conditions and argue that a key goal of managing chronic conditions is to optimize PROMs. They conclude by acknowledging the importance of structural challenges: clinicians do not in general appreciate the value of PROMs, and there is a lack of incentives for data collection and mechanisms to do so. They end by recommending a cross-national working group to help plan the pilot-testing, implementation and analysis of PROMs data.

It is possible to quibble with some of the details of McGrail et al.’s treatment of the subject. Their definition of PROMs is relatively narrow, including general health status and health status relating to a specific condition. We would advocate for applying a broad definition of PROMs, as described above. This creates a greater number of advocates interested in having the different kinds of data. In addition, most reports or ratings from patients and family members can be collected, described and analyzed using the same methodologies.

In addition to the examples of PROMs in clinical practice highlighted by the authors,
there have been a range of studies demonstrating the feasibility of and interest in the intervention. For example, Wasson (1992) has more than two decades of experience using the COOP Charts in general practices in several countries. Velikova et al. (2004) have conducted randomized trials of usefulness in cancer. For hemodialysis patients in the United States, PROMs are now collected routinely and used both clinically and for research (Meyer 1994; Gabbay 2010). And there are notable Canadian examples (Carlson 2001; Bainbridge 2011; Santana 2010).

Building off the paper of McGrail and colleagues – and carrying through the PROMs metaphor – in the next section, we discuss how PROMs data can be used for individual patient care, for quality assessment, quality improvement and comparative effectiveness and other clinical research. We restrict our discussion largely to the implementation of PROMs in clinical practice, although there are obvious benefits to be gleaned in the other spheres (Wu 2010).

**Recommendations for Getting to the PROM in Clinical Practice**

For those who have never been a teenager in North America, a brief description of a prom is in order. The prom is a formal dance for high-school students, generally held near the end of the senior year of high school. As any teenager in the United States can tell you, there are several important considerations related to the prom: whom to go with, what to wear, how to get there and how to get the most out of the experience. An analogy may be drawn to implementing PROMs in healthcare.

**Whom to Go With**

There are options for how one may attend the prom. Although traditionally, one goes with a partner (i.e., a date), it is also possible to go by oneself (“go stag”) or to go with a group of friends. Regarding PROMs in clinical practice, a relevant parallel is the selection of collaborators. While it is tempting to try to develop an intervention on one’s own, it is advisable to seek a partner or, perhaps even better, a group of partners. There are different kinds of partners, including expert advisors, colleagues in health information technology, instrument developers, software vendors and purveyors of electronic medical records.

> Because the prom is most enjoyable if there is wide participation, it is important to get your friends to join you.

Because the prom is most enjoyable if there is wide participation, it is important to get your friends to join you. This type of persuasion is also important for applying PROMs in clinical practice. PROMs data collection is only valuable if a large number of clinicians use and become familiar with these data and enter data into the system. There are several means to encourage the use of PROMs systems by clinicians, including creating incentives to participate or disincentives not to participate, and mandating data collection. Both individual organizations and higher-level organizations, such as payers, could create incentives. Another option is to establish systematic, routine data collection to be the default option, in the same way that hemoglobin A1c tests are ordered for patients with diabetes. A choice to opt out would be included. A specific type of incentive would be to allow clinicians or institutions to bill payers for the collection of PROMs data in the same way that they bill for a laboratory test.

There are efficiencies in developing conventions, methods and standards at multi-
ple levels, including institutional, provincial or territorial, national and international. Acting at the higher level, the International Society for Quality of Life Research (ISOQOL) has taken the initiative to develop guidance for implementing PROMs in clinical practice (ISOQOL 2011; Snyder et al. 2011).

What to Wear
Everyone wants to look their best for the prom, but cost is also a consideration. Regarding PROMs in clinical practice, this section can refer to which questionnaires to use. The most reliable and foolproof solution, particularly for novice users, is to take advantage of existing questionnaires, formats and scoring, using individual PROMs such as Short Form (36) (SF-36; Ware 1992), modular measurement systems such as the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core plus specific modules approach (Aaronson 1993) or static questionnaires developed for the US National Institutes of Health Patient-Reported Outcomes Measurement Information System (PROMIS; Cella 2007), after obtaining necessary permission. PROMIS also provides dynamic tests tailored to the performance level of each individual patient (Reeve 2007), which may be the most elegant solution.

How to Get There
There are several ways to get to the prom. Some teenagers may drive themselves in their own or a borrowed car; others may be conveyed by their parents. Some attendees may rent a limousine that will take a couple or a group to the prom venue. Regarding PROMs in clinical practice, this can be taken to refer to data collection systems. There are “clunky” or cumbersome data collection approaches, such as traditional paper-based collection; but newer technologies have enabled electronic, web-based solutions. For example, we have worked with a multidisciplinary team to develop PatientViewpoint, a web-based system that provides three functions: (1) clinicians order the PROMs they want their patients to complete and how often they want them completed; (2) patients receive e-mail reminders to complete the PROMs and log on to respond to their assigned surveys; and (3) patients and clinicians can review results (Snyder 2009). Score reports highlight “out-of-range” values that merit further attention and make suggestions for potential actions to take to remedy specific problems. Importantly, PatientViewpoint also links with the Johns Hopkins electronic medical records so that the reports are readily available to clinicians, alongside other more clinically derived data. Other ways to collect data include telephone or in-person interviews, which may be required for certain populations (e.g., those with low literacy or poor vision).

Getting the Most out of the Prom
Of course, the most important thing about the prom is getting as much as possible out of the experience. Similarly, PROMs data are not helpful unless they are used. As noted above, the data can be used at the individual level to screen for conditions and monitor progress over time. Evidence suggests that for PROMs data to be most useful, recommendations for how clinicians should interpret and respond to the information are needed (Rubenstein 1989). In our own application of PatientViewpoint,
we have developed suggestions for actions that clinicians can take to address commonly measured PROMs domains. In addition to using the PROMs data for individual patient management, these individual observations can be aggregated for quality of care evaluations and comparative effectiveness research. Thus, there are multiple ways to benefit from the PROMs intervention.

Conclusion
In summary, we agree whole-heartedly with the assertion that PROMs can be usefully applied in clinical practice. While stress inducing for the early adopters, with adequate preparation, planning and coordination, it is possible to get to PROM in clinical practice, and for the experience to be rewarding and memorable.

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References


THE AUTHORS RESPOND

Healthcare Papers
“In God We Trust; All Others Must Bring Data”

THE AUTHORS RESPOND

Stirling Bryan, Kimberlyn McGrail and Jennifer Davis

We would like to express our gratitude to the commentators for their thoughtful and insightful responses to our paper (McGrail et al. 2011). Our purpose in preparing the article was essentially to issue a call to arms for the use of patient-reported outcome measures (PROMs) in Canadian healthcare. It is our interpretation that all of the commentaries, in broad terms, support the call: the focus was less on the whether and far more on the how. We were particularly struck by the elegant characterization of the issues in Wu and Snyder’s (2011) extension of our analogy to the high-school senior prom: what to wear, whom to go with and how to get there.

However, some commentators did express concerns, for example, about the potential for unintended consequences and the need to plan for their avoidance; and some asked for greater clarity with regard to the conceptual or theoretical framework we use to link the routine collection of PROMs data to positive impacts in the healthcare system. In this response, we therefore seek to clarify the conceptual frame underlying our call to arms and discuss the practical challenges ahead.

Conceptual Issues

The harsh and irrefutable current reality for healthcare systems everywhere is that both public and private finances are stretched thin. The reverberations of the financial meltdown will be felt for years to come. Compounding this are a predicted slowing in the growth of gross domestic product and steadily increasing pressure on healthcare budgets, both partly the result of an aging population (Ragan 2010). The days of high levels of health sector
growth are surely coming to an end. The bleak fiscal outlook emphasizes the importance of an “improvement” focus for those working in the healthcare sector: we have always had an obligation to make our healthcare dollars work hard, but now the need is even greater. This means that, over the coming years, healthcare systems will be forced to do more with the same, or perhaps even more with less.

In the context of tight finances, the best route to increasing value, or the return on our healthcare investments, is quality improvement – the constant attention to maximizing quality and the population’s health while controlling cost growth. This is the essence of the Institute for Healthcare Improvement’s Triple Aim and also draws on the work of W. Edwards Deming (to whom the quotation in our title is popularly attributed) and his advocacy of continual evidence-based, data-informed improvement (Deming 1986).

For us, it is self-evident that quality improvement requires data and evidence to understand the impact of any new initiatives or process changes instituted to bring about improvement. In a world dominated by chronic disease, mortality statistics and other indicators of failure in the system (e.g., readmissions to hospital) are only a small part of the “evidence” required. As the old adage says, you can’t manage what you don’t measure. We want to see clinical leaders of quality improvement initiatives seeking to “manage” population health. If this is our objective, then we need to measure the effect that healthcare services are having on population health. If we want to measure impact effectively and in a patient-centred manner, we need PROMs.

To be clear, we are not suggesting that PROMs represent a silver bullet – that making this one change will address all of our current quality and policy challenges – but we are saying that without such data we have little hope of quantifying the success of all of our other changes and innovations. This point was made forcefully by Lewis (2011) when, in his commentary, he pleads for more emphasis in Canada on outcomes and much less focus on the traditional output metrics.

Our starting point is the use of PROMs data in quality improvement work and, so, the collection and use of PROMs data are, for us, system-level initiatives. While data on outcomes reported by patients could have some utility in individual clinical interactions and the direct provision of care to individual patients, our primary arguments for their use are more easily understood at the system level. From our perspective, this implies the use of such data by clinical leaders charged with understanding variation in outcomes and performance of the various actors in the healthcare system.

Some of the commentaries rightly point out the challenges of balancing top-down and bottom-up approaches to implementing PROMs. The quality improvement perspective is again helpful here. We challenge healthcare leaders to embrace fully the quality improvement agenda and, through that, to welcome PROMs. The vision is healthcare as a learning system, one that uses information on practice and outcomes to identify opportunities to improve and to make such changes. With this vision in place, it is then critically important that front-line providers as well as patients and their families be involved in the design, implementation and use of PROMs data.

The point was also made in the commentaries that PROMs provide an opportunity to begin to move the healthcare system in the direction of being more patient-centred, giving a routine voice to patients. There is little doubt that such a move would widely be seen as a positive step, but interestingly one commentator suggested that there may be negatives in simply bolting a PROMs initiative onto a disease-oriented healthcare system (Glouberman 2011). The questions raised are these:
• Will the collection of PROMs lead to more treatment and even more medicalization?
• Would building a PROMs initiative divert health policy attention from the hard (and necessary) work of re-forming/re-structuring the system?

These are challenging questions, and we fully understand the concerns. In response to the first question, we share the view that further medicalization, the encroaching desire to diagnose and label everything that ails us, is to be guarded against. This speaks, in part, to the importance of using PROMs data to highlight low-value (or zero-value) interventions, allowing disinvestment in some service provisions. Further, it reiterates the need for PROMs work to be directed also at health maintenance and prevention activities rather than simply targeting acute surgical interventions. In terms of the second question, again we are sympathetic to this notion, particularly the idea that there is a finite supply of “policy attention” and that devotion to one potential lever may distract from other equally valuable reform initiatives. On the other hand, if outcomes information is routinely collected, it is our contention that these data will not serve as a distraction but, rather, as a tool to strengthen the case for fundamental reform. Such data have the potential to demonstrate the high level of variability in medical practice and to identify areas of low-value service provision. Surely such data would serve to galvanize those seeking reform.

Practical Issues
Several of the commentaries make reference to implementation issues, and certainly we do not wish to underestimate the scale of the implementation challenge. Not being the “first off the blocks” has its advantages – we must ensure that Canada learns the implementation lessons from those who have already paved the PROMs route. It would appear that we have examples of existing good practice both internationally (e.g., the system described by Wu and Snyder [2011] in use at Johns Hopkins) and within Canada (e.g., the experience of Cancer Care Ontario described by Howell and Liu [2011]). One of the important messages from the Ontario experience concerns the use of web-based technology for data collection that ensures a high response rate at a reasonable cost.

As indicated earlier, we see data on PROMs as one piece in the quality improvement information set – it is necessary but not sufficient. Therefore, we would not want to downplay the importance of other information components, most notably patient experience or satisfaction. We would argue that while our focus has been on PROMs, if it is accepted that we ask patients for information, it makes sense to ask about patient experience as well. On a theme of more being better than less, an analysis perspective speaks to the importance of data on other factors that might help to explain variation in the outcomes we see (Glouberman 2011). And so, ideally, we would also gather information on socio-demographic factors, attitudes, values, beliefs and health practices, all of which might influence the need for services in the first place as well as the effectiveness of services provided. But once we open this box, are we doomed to continued inaction? Is it better to start small and move out? Or start big and perfect as we go? These are ultimately questions for our proposed pan-

Healthcare services are a means to an end of good health status and quality of life, not an end in and of themselves.
Canadian PROMs task force as they consider implementation and analysis issues.

Healthcare is instrumental to health and well-being. In saying this, we acknowledge that healthcare services are a means to an end of good health status and quality of life rather than an end in and of themselves. Therefore, we agree wholeheartedly that outcomes data need to be incorporated into the core management information set of healthcare systems (Lewis 2011). If the collection of this sort of information is built in rather than painted on, it may be easier for everyone to begin to address implementation issues. A purchase from Apple Inc. is accompanied by a follow-up survey asking about satisfaction. Surely healthcare is more important than iPads.

Conclusions
We agree with those commentators who sense a need to change to a patient-centred business model of healthcare. The healthcare system and its management have traditionally focused more on outputs than outcomes and more on the convenience of providers than patients. We believe the time has come for this to change.

In moving forward, many of the concerns raised centre on the issues of what comes first and what follows. Do we implement other necessary reforms and then move to PROMs? Do we ensure the “sustainability” of the healthcare system (whatever that means) and then think about talking to patients regarding their health status? Do we work with clinical leaders and get providers to buy in and, only then, start collecting data? Wu and Snyder (2011) refer to a combined top-down and bottom-up approach. We see a certain attractiveness to this model:

• Top-down: stake a commitment to PROMs and to forming the healthcare sector into a patient-centred, learning system
• Bottom-up: ensure that providers, patients and the general public work together to define the information set to be collected, the process by which it will be collected and some initial priority areas for analysis

We invite you all, once again, to join us in taking Canada to the PROM.

References
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