

# 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.

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