

Patients Online: Whither from Here?



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ABSTRACT

There has been a growing interest in patient-centred care, rapid technology development, increasing adoption of digital health by clinicians and consumers and a vibrant dialogue about the associated policy implications and options. In this response, the authors of the lead essay discuss the valuable perspectives raised by the commentators about consumer health solutions, an area that is evolving quickly and has the potential to fundamentally change how several types of healthcare are delivered.

MUCH HAS CHANGED in the year since we wrote the first draft of the lead essay in this issue. There has been a growing interest in patient-centred care, rapid technology development, increasing adoption of digital health by clinicians and consumers and a vibrant dialogue about the associated policy implications and options. We thank all of the authors of commentaries in this issue of *Healthcare Papers* for contributing to this discourse. Each brings valuable perspectives to the important conversations that are needed

in an area that is evolving quickly and has the potential to fundamentally change how several types of healthcare are delivered.

As Adalsteinn Brown (2014) points out in his introduction, the commentators generally agree that Canadians are ready to embrace a range of consumer health solutions. This was perhaps most succinctly summed up by Shirlee Sharkey's title, "All Aboard!" (2014). Commentary authors also share a sense of inevitability of change, in part because, as Fleur-Ange Lefebvre notes, "Today's

communications technology has greatly facilitated patient access to health information in general” (2014: 45).

The papers in this issue cite a variety of reasons for the health system to proactively respond to this demand. For instance, Anne Snowdon, Karin Schnarr and Charles Alessi put forward principled arguments for a patient’s access to his or her own health information. They argue that it is required “to facilitate decision-making based on personal values” (2104: 32). Likewise, outside of this issue, the Office of the Information and Privacy Commissioner for British Columbia recently recommended that “to the maximum extent possible, custodians should implement ‘patient portals’ in their electronic record systems so that individuals can have routine and timely access to their own personal health information” (2014: 43).

In his commentary, David Buckeridge notes other possible advantages, such as increased patient safety and the efficiency of health service delivery. A recent survey completed by Harris Decima (2014) suggests that Canadians share a broad view of the potential benefits ($n = 1,512$ Canadian adults). About three quarters of respondents agreed that consumer health solutions would make accessing healthcare services easier and more convenient (76%), make interacting with multiple healthcare providers better and easier (76%), make the healthcare system more efficient (74%) and help keep them more informed about their health and/or the health of those they care for (74%). Likewise, a recent Statistics Canada survey of Western Canadians with chronic conditions found that most were interested in using email (65%) or videoconferencing (66%) to interact with a specialist (Afshar et al. 2014). Videoconferencing with a primary care provider (50%) and text messaging with specialists (45%) were less popular, but were

still desired options for many. The most common barrier cited was not knowing how to use the technology concerned.

A number of the commentaries reinforce these and other enablers and barriers to the effective use of consumer health solutions. As Joseph Cafazzo notes, “The barriers continue to be more a reflection of the state of our healthcare system itself than of the patients who are demanding more involvement in the management of their care” (2014: 27).

At a practical level, Hartley Stern, Patrick Ceresia and Martin Lapner (2014) note that clinicians may be unsure about compliance with standards of practice and regulatory/legal requirements. They call on regulatory authorities to “update expectations for and encourage permitted uses of such information for the purpose of enhancing healthcare services and programs” (2014: 38). For her part, Fleur-Ange Lefebvre, from the Federation of Medical Regulatory Authorities of Canada, argues that the core issue is “appropriate stewardship of patient records in the electronic world where the ability to share this information is greatly enhanced (but not necessarily appropriately so)” (2014: 45). She notes that professional obligations do not change, whether information is in paper or electronic form. In this regard, she cites the Canadian Medical Association Code of Ethics as indicating that patient access to records should be provided “unless there is a compelling reason to believe that information in the record will result in substantial harm to the patient or others” (2014: 45). As we noted in our lead paper (Zelmer and Hagens 2014), this reflects the 1992 Supreme Court of Canada decision.

More broadly, David Buckeridge (2014) notes that current healthcare and information structures were not designed with consumer health solutions in mind, which can complicate adoption. For instance, benefits may accrue to one group – perhaps they are more

convenient for patients – while costs accrue to others, such as those who pay for health services. That said, there is emerging evidence of opportunities for alignment. Take e-booking, for example. A recent white paper documented benefits for a range of stakeholders (Canada Health Infoway 2014):

- Reduced appointment no-show rates
- Increased staff satisfaction
- Reduced staff time spent booking patient appointments
- Increased patient satisfaction and convenience

Going further, Adalsteinn Brown notes that the shifts needed to reap the full benefits of consumer health solutions are “as much about the culture of our system as they are about policy or practice, although both will be necessary to change our culture” (2014: 4). A number of authors raise similar themes. They argue that the ultimate goal is broader health system transformation, rather than addressing pain points and efficiency gains within the current context. For instance, Shirlee Sharkey (2014: 54) calls for a “shift to empowerment and independence.” Likewise, David Buckeridge (2014) speaks of “reorienting health systems to meet the demand” and Anne Snowdon and her colleagues argue that “health systems can facilitate this shift by supporting the transformation of models of care through providing health consumers with real-time access to their health information, and by employing collaborative and virtual technologies that support individuals to monitor and track their health status in a way that allows them to engage in decisions to manage their health and wellness as a partner in care, rather than recipients of care” (2014: 22).

This relates to the debate among commentators highlighted by Adalsteinn Brown about “how and when to tackle system

problems around the sharing of data and the shifts in initiative and responsibility from provider to patient” (2014: 4). Nobody doubts that the use of consumer health solutions will grow. But the commentaries reflect differing views on which groups to prioritize, which initiatives offer most value and how best to tackle enabling conditions or factors in the broader health system environment that affect the adoption of consumer health solutions.

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Just as in other areas of health policy, there is a related debate among authors about the merits of targeted programs versus whole-population approaches. Some argue for a focus on individuals who have the highest health-care needs. Joseph Cafazzo (2014) and Shirlee Sharkey (2014) are among those advocating for this type of approach. Likewise, David Cruickshank and William Tatham (2014) believe that this is the group for which there is likely to be the highest return on investment. They suggest that a high-user focus could “improve outcomes and patient experience while also generating a reduction of annual health system spending in the range of 5%” (2014: 48). Other authors discuss approaches aimed at broader groups within the population, or indeed all Canadians.

We agree that there can be significant benefits from targeted solutions, such as remote patient monitoring, for individuals with serious chronic diseases. A recent study counted about 5,000 patients enrolled in 19 such programs across seven provinces

and territories, with growth of 15–20% annually (Ernst & Young LLP 2014). Many of the programs focus on individuals with congestive heart failure or chronic obstructive pulmonary disease, two conditions for which the potential value of remote patient monitoring has been established. The study’s summary of the global literature and Canadian experiences found evidence for increased patient satisfaction, compliance and quality of life. In addition, it documented reductions in hospitalizations, emergency department use, caregiver burden and per-client costs.

The study also noted promising results from emerging innovations that target those with additional conditions or use approaches that are suitable for those with lower-acuity conditions. Similarly, both the paper by Joseph Cafazzo (2014) and the one authored by Anne Snowdon and colleagues (2014) identify the explosion in self-management and other applications (apps) as significant for the future of healthcare.

At the same time, there is clearly also potential benefit from consumer health solutions that address the needs of broader groups of citizens. As we note in the lead paper in this issue (Zelmer and Hagens 2014), analysis by the Conference Board of Canada (2012) suggested that it would have been possible to avoid 47 million in-person visits in 2011 if Canadians had had the option to consult with physicians, access test results and request prescription renewals electronically. These findings are reinforced by recent survey results. Harris Decima (2014) reported that about half of those who said that they had consulted with a healthcare provider (58%), accessed medical records (47%) or requested a prescription renewal (63%) electronically in the previous year avoided an in-person visit as a result. While the absolute numbers are currently small, the potential impact is significant as use grows.

Perhaps not surprisingly, what appears to be emerging from recent research in Canada and abroad is a more nuanced understanding of the types of consumer health solutions that best address the needs of different groups, their different value propositions and the associated costs and implementation challenges. Some will always and appropriately be used by a fraction of the population, as Joseph Cafazzo (2014) suggests. Others will have much broader applicability, as demonstrated by the experiences of global leaders and survey results cited.

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We join the authors of many of the commentaries in calling for a continued sharing of lessons learned from early adopters. This is particularly important given the rapid evolution of the technologies, attitudes towards their use and the policy environment. As Shirlee Sharkey says, “This subject is made increasingly challenging when even the most conscientious researchers must struggle with feeling their arguments are outdated even before the proverbial ink is dry on the page” (2014: 54). Nevertheless, it is in all of our interests to collectively accelerate efforts in order to meet Joseph Cafazzo’s challenge to “reflect the system that we want to achieve, not just the one we have” (2014: 27).

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