



Engaging Patients in Designing Healthcare Services Summary of a Panel Discussion at the 2010 Annual CAHSPR Conference

"What is interesting about having patients at the table is that ...they are not aware of the elephant in the room and so they ask the questions that have to be asked."

– Kathleen Peterson

To help launch its new theme of Patient Engagement, the Canadian Health Services Research Foundation (CHSRF) sponsored a panel discussion on May 11, 2010 at the Canadian Association for Health Services and Policy Research conference, held in Toronto on May 11, 2010. The panellists were:

- ▶ **Dr. Marie-Pascale Pomey**, Associate Professor, Department of Health Administration, Université de Montréal
- ▶ **Sholom Glouberman**, President, Patients' Association of Canada and Director of the International Master's Program for Health Leadership at McGill University
- ▶ **Kathleen Peterson**, Director, Health System Planning and Policy, and First Nations and Métis Health Policy, Policy and Planning Branch, Saskatchewan Health
- ▶ **Nancy Lefebvre**, Chief Clinical Executive and Senior Vice President of Knowledge and Practice, Saint Elizabeth Health Care

Diane Gagnon, Director, Patient and Citizen Engagement at CHSRF, acted as panel moderator.

Patient-centeredness — a concern for, and responsiveness to patient preferences — is believed to be a key component of quality health care, Gagnon said in her introduction. However, very few organizations in Canada systematically engage patients in various levels of decision making. Canada lags behind both the United States and the United Kingdom when it comes to exploring patient engagement concepts and principles. Thus, the purpose of the session was to "help get the discussion going."

Gagnon posed three questions to the panellists:

1. What is patient engagement?
2. What are the barriers?
3. How can it be facilitated?

HIGHLIGHTS

There was a general consensus about the importance of increasing patient engagement in healthcare and about the challenges involved. Participants identified some key issues:

- ▶ the healthcare system is not structured to include patients from participation at the organizational level, and so it is challenging to make the necessary changes to include them
- ▶ when patients do serve on health care committees, they typically are given little or no training and support

- ▶ patients typically spend only a short time in acute care and therefore don't have a long-term relationship with the care providers or institution
- ▶ healthcare providers need to be given tools and resources so they understand the importance of patient engagement and ways to engage patients
- ▶ expectations for patient engagement must be set so providers can be held to account
- ▶ patient satisfaction surveys may not be measuring the right things
- ▶ fee-for-service payment for physicians can create disincentives to patient engagement and
- ▶ patients usually feel vulnerable if they challenge healthcare professionals

Several speakers noted that “patient” engagement really means family involvement. “Patients are always in an envelope with family,” said Sholom Glouberman. There was some discussion of whether a culture shift was needed among healthcare providers — for example, from a culture of gatekeeping to a culture of sharing — or simply new ground rules (“you can't be rude to patients”). Other issues that were explored included the usefulness of patient charters and a perception that, within the healthcare system, quantitative research is valued far more than qualitative research, though the latter captures more of patients' lived experiences.

Marie-Pascale Pomey

The term “patient engagement” is intriguing because it combines a word that suggests passivity (patient) with one that denotes action (engagement), Dr. Pomey observed. She argued that patients offer important knowledge about the healthcare system, but that knowledge could also be described using two seemingly contradictory words — “naïve expertise”.

Pomey identified three levels at which patients should be part of decision making in healthcare:

- ▶ with the healthcare professional who is taking care of them (shared decision making about the health problem)
- ▶ at the organizational level (patient involvement in designing and improving the quality and safety of care and sharing what they learned through their own experiences) and
- ▶ at the policy level.

But to make this a reality, “we have to find tools to enable patient participation and engagement.”

It is easy “to look at the disease name and the room number and forget that someone behind that door is suffering,” said Dr. Pomey. Too often, health professionals are more interested in the technical aspects of care and neglect the emotional aspects of care, she added.

Patient engagement can be challenging in the acute care sector, because many patients are only in hospital for a day or two and have no long-term association with the healthcare provider or institution. Quebec has created healthcare user committees to involve patients in the way healthcare is structured, but hospital boards and CEOs are not obliged to act on committee recommendations. Furthermore, there is no requirement to train these representatives and they have no back-up support. As a result, she said, “They feel almost mute.” Although committee members are supposed to be elected, there is little to no publicity about the vote. Thus, they are often acclaimed.

Dr. Pomey commented that healthcare providers and staff also need resources and tools to deal with patients, and a clear set of expectations in order to facilitate a culture shift from gatekeeper to sharing.

Sholom Glouberman

When decisions are taken about the direction of health care, everyone at the table is altruistic. Doctors, nurses, managers, and policy-makers—all are doing everything they can for the benefit of patients. However, they often have different perspectives on what is in the patient's interest. Oddly, there are often no patients in the room. Glouberman told the session that it might be a good idea to bring patients to the table. His experience as a patient, and then hearing other people's stories about their experiences as patients, made it clear to him that patients' perspectives on their experience are different from those of providers.

The healthcare system is not structured to include patients, and most patients are not properly prepared to present a general patient perspective. Patients need a broader view of the patient experience if they are to represent others on governing bodies. He argued that patients have to get together, think about their experiences and articulate what they want. When patients are asked what they want, the answers can be surprising. "We need to develop expert patients."

And patients who have concerns need to have some recourse to more independent ombudsmen, he said, noting that he heard a patient ombudsman at an Ontario hospital remark: "What has he got to complain about? We saved his life."

Glouberman offered the example of the late singer/songwriter Kate McGarrigle, the patron of the Patients' Association, who received excellent care, including daily phone calls from her doctors and house calls. But McGarrigle attributed the high level of attention to the fact that she was a celebrity, which prompted Glouberman to observe that this standard of care might be a goal to set: every patient deserves to be treated as a celebrity.

Kathleen Peterson

"What is interesting about having patients at the table is that ...they are not aware of the elephant in the room and so they ask the questions that have to be asked," Peterson said.

After Saskatchewan's Patient First Review recommended adopting a patient- and family-centred approach to care and reducing surgical wait times, patient advisors were recruited to be members of an Executive Sponsorship Group and of a Guiding Coalition providing advice on strategies to improve the patient experience, address the surgical backlog and reduce wait times. Patients are providing good advice, but it's clear that more work needs to be done to support them and there should be more structured ways to find and include patients in decision making, she said.

Peterson, who has been to conferences and training sessions with the U.S.-based Institute for Family-Centered Care, stressed the importance of shared decision making about what care is provided to patients. For example, when a surgeon recommends a knee replacement because a patient has arthritis, the limitations after that surgery might not suit the patient and other options should be discussed. As well, family members need to be included when care is delivered. Peterson recounted that although her husband had asked her to stay at his bedside in hospital following an accident, a nurse ordered her to leave the room. Her husband "backed up the nurse because he didn't want his care to be affected."

Healthcare professionals “have to recognize that family members add value.” Patients who receive challenging health news often can’t concentrate well and family members can ask important questions. As well, family members are often the ones who will be helping patients get well.

Patient satisfaction surveys may not be capturing the right things, she noted. For example, First Nations and Métis patients routinely experience racism in their lives and so may not comment on this in hospital surveys.

She closed by saying: “It isn’t about satisfaction, but about engagement. For example, did the attending doctor introduce him or herself and explain what was happening, did nurses acknowledge the patient’s own knowledge and understanding and did staff listen? We have to think how we get that information from patients.”

Nancy Lefebre

How you become acculturated in the health care system — what fundamental values you learn — depends on where you begin, Lefebre told the session. “Where you start your journey has a significant impact on where you end up.” Because they are invited guests, health professionals who go into a patient’s home have a good opportunity “to begin to understand the client experience” and to see things from their perspective. “Perhaps we should all begin in healthcare where we are all guests — in the person’s home.”

Lefebre questioned the usefulness of patient charters and patient bills of rights. “It is rare that a patient will walk in with a document or say ‘I am quite clear about my rights’.” She suggested that some staff engagement principles could be applied to patient engagement, and that instead of provider or system-driven care, there needs to be an emphasis on the outcomes a patient wants.

In order to create a patient-centred culture, there is a need for support and training, but also a need to be clear about what kind of behaviour, on the part of health professionals, will no longer be acceptable. This requires involvement at the top level of organizations (CEOs), as well as other champions and cheerleaders. “It is an investment for the long haul.” Lefebre recently established a social network, caretoknow.org, to exchange information related to patient engagement and patient-centred care among patients, families, healthcare professionals and administrators.

NEXT STEPS

As part of its 2009–2014 strategic plan, CHSRF aims to build evidence on effective ways to involve patients in the design, delivery and evaluation of health services and to help organizations use that evidence to develop healthcare services that are truly patient-centred. In addition to sponsoring this panel session, CHSRF plans to fund up to six Patient Engagement Projects (up to \$100,000 each for a maximum of \$600,000). The call for proposals was issued in April 2010 and the successful projects will be announced in summer 2010. CHSRF also issued a call for a research project to identify the lessons learned from the six projects and to document promising practices.

For more information regarding CHSRF’s patient engagement initiatives, please contact ruzica.subotic-howell@chrsf.ca.

