



WHAT IF: PATIENTS' EXPERIENCES GUIDED QUALITY IMPROVEMENT AND ORGANIZATIONAL CHANGE?

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Main concern/ problem

Healthcare organizations in Canada are just starting to focus on using the needs and expectations of patients and their families to guide delivery of high-quality care. This shift to incorporating patient experience recognizes that patients' expertise about themselves, their health and the care they have received are an essential part of improvement efforts. There's a wide range of strategies available for obtaining insight into the needs, expectations, and experiences of patients, including focus groups and interviews, hand-held devices for use at the bedside, and kiosks set up in hospitals. However, patient information is not consistently gathered, analyzed or synthesized, and even where it is, its potential to drive improvement efforts is not maximized.

Proposed options

To make the most of what we can learn from patients, healthcare organizations need to develop:

- improvement processes involving patients and families;
- a variety of ways to gather feedback from patients, at the point and time of care;
- systems to synthesize and analyze that information into meaningful knowledge to guide improvement;
- strong leadership and appropriate resources to respond to patient feedback and knowledge; and
- governance and executive structures that encourage patients and families to be part of decision-making about improvement.

Benefits

Only patients are present for every step of their care journey, giving them a unique perspective on services that address their needs and preferences. Collecting and using feedback from patients, and involving them in improvement processes, creates a more responsive system. It also sends a powerful message to patients, staff and the community about the importance of the patient voice. Long-term transformational change can be achieved by giving patients real power, using their wisdom and experience to help design care processes and systems that are truly patient-focused.

**Experience/
evidence of
success**

Organizations such as the Medical College of Georgia in the United States and Planetree organizations around the world have fully embraced patient-centred care, engaging patients in their own care and in improving systems. By adopting patient-centred care, they have shown numerous improvements, including decreased re-admission rates, fewer hospital-acquired infections, shorter lengths of stay, greater patient satisfaction and increased staff satisfaction and retention. Experience-based co-design is another model that provides evidence for the power of partnerships. It brings patients and staff together to share the role of improving care and re-designing services. Co-design initiatives in cancer care and emergency care in the United Kingdom and Australia have led to improved work practices and processes, clinical pathways and patient flow. These solutions reflect the experience of both patients and staff, have improved patient experience and increased patient and staff satisfaction. Process improvements are important, and better understanding of patient perspectives on outcomes of care is another vital part of quality improvement. Patient-reported outcome measures have been tested with patients getting elective surgery in the U.S., U.K. and Canada, and have proven to be feasible and useful markers of quality and efficiency.

**Challenges
and limitations**

To shape improvement by patient experience, organizations must have a culture and leadership that explicitly value including patients in all decision-making. They also need quality improvement infrastructure to gather, analyze, and systematically respond to the feedback that patients offer. Staff needs the mandate, capacity and resources to do quality improvement projects. Involving patients and families requires preparation to ensure all stakeholders – patients, families, staff and leaders – are able to work as equal partners. In the case of patients, that means processes and criteria for involving them, and ongoing support to prepare them for effective and meaningful engagement suited to their condition and abilities.

**Considerations
for Canada**

Examples of how patients and families work with their healthcare organizations for meaningful, patient-centred change are emerging across Canada, but there is more we can learn from jurisdictions such as the U.K. and Australia, which have demonstrated success in with methods such as experience-based co-design. It is important to seek patient perspectives on both processes of care and on the clinical and functional outcomes of care to guide future improvement efforts. Healthcare policies should make involving patients more directly an expectation for all organizations, both for point-of-care and system improvements. Involving patients in the transformation to a more patient-centred system will improve their experiences and help create healthcare patients can truly call their own.

The Canadian Foundation for Healthcare Improvement supports 17 organizations that engage patients and/or families in the design, delivery and evaluation of their services through the Patient Engagement Project (PEP) initiative. For more information, visit www.cfhi-fcass.ca/WhatWeDo/Collaborations/PatientEngagement.aspx. Carol Fancott is a member of a PEP team funded from 2010 to 2012.

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