

# The Patient Experience in Ontario 2020: What Is Possible?



INVITED ESSAY

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## ABSTRACT

*Words are important. They signal an intention behind a thought. So when Ontario's Ministry of Health and Long-Term Care publishes an action plan (Ontario Ministry of Health and Long-Term Care, 2012) that declares itself to be "obsessively patient-centred," curiosity ensues and terms abound. Patient-centred care, patient engagement and patient experience – all seem to be in the mix in Ontario. This paper will propose a set of definitions for these commonly used terms, examine the progress being made in Ontario towards a more patient-centred healthcare system and suggest where we might aim to be by 2020.*

WE RECOGNIZE THERE is a lot of activity across the country focused on patient experience and patient engagement. For example, the Canadian Foundation for Healthcare Improvement (CFHI) has funded two rounds of patient engagement projects (2010 and 2011) and is currently supporting 22 quality improvement collaborative teams of patients and families across Canada. The Canadian Institutes for Health Research has created a strategy for patient-oriented research that involves patients and caregivers in the decision-making structures. Most provinces have created regular province-wide patient experience surveys and some have invested in partnership structures that support the inclusion of the patient voice in healthcare improvement, such as the BC Patients as Partners program. Therefore, while the focus on this commentary is Ontario, there is a lot to learn from other jurisdictions.

The Institute of Medicine (IOM) defines patient-centred care as “providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (IOM 2000). There is a lot packed into that one sentence, but there is a growing body of evidence that patient-centred care leads to more engaged patients and more engaged patients have better perceived health outcomes (Doyle 2013; Gill 2013) and improved quality of care (Barello 2012).

Don Berwick, the godfather of all things quality, defines patient-centred care as “the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care” (Berwick 2009). And, The Beryl Institute, known for its pioneering patient advocacy, defines patient experience as “the sum of all interactions,

shaped by an organization’s culture, that influence patient perceptions across the continuum of care” (The Beryl Institute 2010).

The Change Foundation has struggled somewhat with the language and initially argued that the terms were interchangeable. However, as we listened to our citizens panel PANORAMA, we realized that while the concepts were connected, there were differences. Our patients and caregivers argued that the concepts exist at different levels and that the language was actually very important. Eventually we landed on the following distinctions, which we found useful when taking a formal, organized approach to the topic.

*Patient-centred care* is about an overall philosophy and approach that ensures that everything individual providers or healthcare organizations do clinically or administratively is based on patient needs and preferences. This covers a range of activities – planning, care, evaluation and research, training, and even staff recruitment.

*Patient engagement* is the way in which individual providers or healthcare organizations solicit patient needs and preferences to ensure they are delivering patient-centred care. This covers a range of tools and processes – motivational interviewing, surveys, focus groups, story-telling, advisory councils, board participation, patients as improvement advisors and a commitment to co-designing solutions with patients.

*Patient experience* is how patients perceive and experience their care (hopefully patient-centred). This involves the ability to hear what is being said, measure the experience and develop the capacity to use the information to change practice, policies and rules. It requires a feedback loop that enables improvement conversations about the breadth and depth of an individual’s or organization’s patient-centredness.

All three concepts represent the principles of good relationships – i.e., partnership, equality, communication, trust and respect – and are crucial levers for change.

In the fall of 2011, The Change Foundation travelled to six different regions in Ontario to hear directly from seniors and their family caregivers about their patient and caregiver experiences. Common themes emerged (The Change Foundation 2012). Patients and family caregivers wanted:

- Greater predictability with timing of appointments;
- Advance notice when home care staff or shift times change;
- Higher level of confidence that providers in different locations have all the records relevant to one's condition – and have read them;
- Reassurance that the right medications have come home with them from hospital;
- To be informed and asked about the next step in their care;
- To have families involved in treatment and care plan discussions;
- To know who to call if there are questions or issues and feeling confident someone can and will answer.

The seniors and caregivers we spoke with did not want the moon. They wanted straightforward and timely communication, shared decision-making with a collaborative health-care team, the knowledge that the system would support them at home or in a long-term care or retirement home and respect for their time and convenience.

So if those providing healthcare communicate directly with patients and caregivers, listen to what they say about their health and about receiving care clinically and administratively and change rules if need be, they will be delivering patient-centred care. In turn, true patient-centred care requires thoughtful

patient engagement and will contribute to a better patient experience as well as improving quality, safety and cost.

Is there evidence to back this up? In a word, yes. A systematic review by Doyle and colleagues focused on inpatient hospital care and primary care found 55 studies that met the inclusion criteria (Doyle 2013). Using a variety of measures ranging from mortality to treatment adherence to patient self-rated health, they concluded that “Patient experience is positively associated with clinical effectiveness and patient safety, and supports the case of the inclusion of patient experience as one of the central pillars of quality in healthcare. It supports the argument that dimensions of quality should be looked at as a group and not in isolation” and recommends that “Clinicians should resist sidelining patient experience as too subjective or mood-oriented, divorced from the ‘real’ clinical work of measuring safety and effectiveness.” A good overview of the research literature as well as key informant interviews can be found in a recent CFHI “evidence boost” looking at how patient engagement contributes to improved care (Baker 2014).

Comparative five-year evaluations of healthcare organizations that use a standardized patient-centred model of care with those that don't demonstrated shorter lengths of stay, lower cost per case and shift in use from higher-cost staff to lower-cost staff, and a higher average overall patient satisfaction score (Stone 2008).

Health Quality Ontario (HQQ) has highlighted the connection in its recent review of quality improvements plans, stating that “when healthcare is perceived through the eyes of the patient and their family and/or caregivers, research shows that the quality of care rises, costs decrease, provider satisfaction increases, and the patient care experience improves” (HQQ 2014).

### **Winning Conditions for Patient-Centred Care by 2020**

In 2011, The Change Foundation released our Winning Conditions report, in which we argued that unless certain conditions were met in Ontario, truly integrated patient care would not be achieved (The Change Foundation 2011). An overall approach and philosophy was required at the system level to knit together the various reforms underway in Ontario. We make the same argument now for patient-centred care.

Demographics alone dictate that Ontario needs to push forward system redesign with the patient at the centre. Ontario's population is aging and the percentage of people aged 65+ accounts for 15% of the population. This number is projected to double by 2036, reaching 24% of the population (Ontario Ministry of Finance 2013; Statistics Canada 2013a). This change will prompt an increase in the need for family caregiving as well as more home care and long-term care services. Furthermore, the average size of Ontario families will be smaller, as people are having fewer children. So we know we will have a greater percentage of older individuals living in their homes without family members to support them (Carriere 2008; Change-Ability 2009). And even in those cases where family members are able to contribute, there is a growing concern that our current system does not do a good job of supporting families as they take on caregiving roles (Turcotte 2013).

To address these expected demographic changes, certain reforms must be made and need to be undertaken within a patient-centred approach and philosophy. If supports are not designed around the patient to support them staying in the community, individuals will have no choice but to use services elsewhere in locations where they would rather not be. In particular, Ontario needs to evolve the design and organization of local

community care linked to a strong primary care system. There is a mountain of evidence in Ontario that the connections between hospital, home and primary care aren't the most developed. As more care moves into the community, there is an urgent need to approach the joining up of these sectors with the input of patients and their families.

The recently established Health Links are an initial attempt to address capacity building in this area, and they need ongoing support as they mature and reach full geographic coverage across the province. By 2020, based on solid evaluation, they could be the standard delivery model for people of any age living with chronic conditions. Primary care, whether attached to a Health Link or not, should be interprofessional whenever appropriate and integrated with the rest of the system. A recent position paper on home care from the Ontario Medical Association proposes ways in which the sectors could work more closely together (Ontario Medical Association 2014). The Local Health Integration Networks (LHINs) could have formal agreements with practices or networks of practices, so that planning for common health needs can be undertaken systematically and collaboratively.

To support the kind of ongoing interaction and care coordination required, we must rapidly sort out our inability to electronically share patient health information – across providers but also between providers and patients. Ontario is behind others on this front and it is impeding innovation. There are existing platforms and applications that could be easily adopted by 2020, and when patients are involved in the design discussion, privacy concerns are less insurmountable. (see [www.changefoundation.ca/projects/path.](http://www.changefoundation.ca/projects/path.))

We will also need to continue to strengthen regional planning, and the Ministry of Health and Long-Term Care

has recently made it clear that LHINs are “here to stay.” They should be given further responsibilities for planning all parts of their local health system – true patient-centred care cannot be managed and planned if the LHINs cannot wrap their arms around all the providers in their community. Not doing so runs against a patient-centred approach, as gaps in care and bumpy transitions will continue as long as some providers are in and some are outside of the LHINs mandate.

Finally, the way in which providers are funded needs to be re-examined and coordinated. Separate funding envelopes can create perverse incentives, and funding currently does not support a bundled package of activities for a patient. It supports single-service pathways. This needs to be changed. Interesting innovations are already underway, such as the integrated comprehensive care program in Hamilton and the five recently launched bundled care projects, the health village model in Carleton Place and the proposals for local health hubs (Ontario Hospital Association 2012).

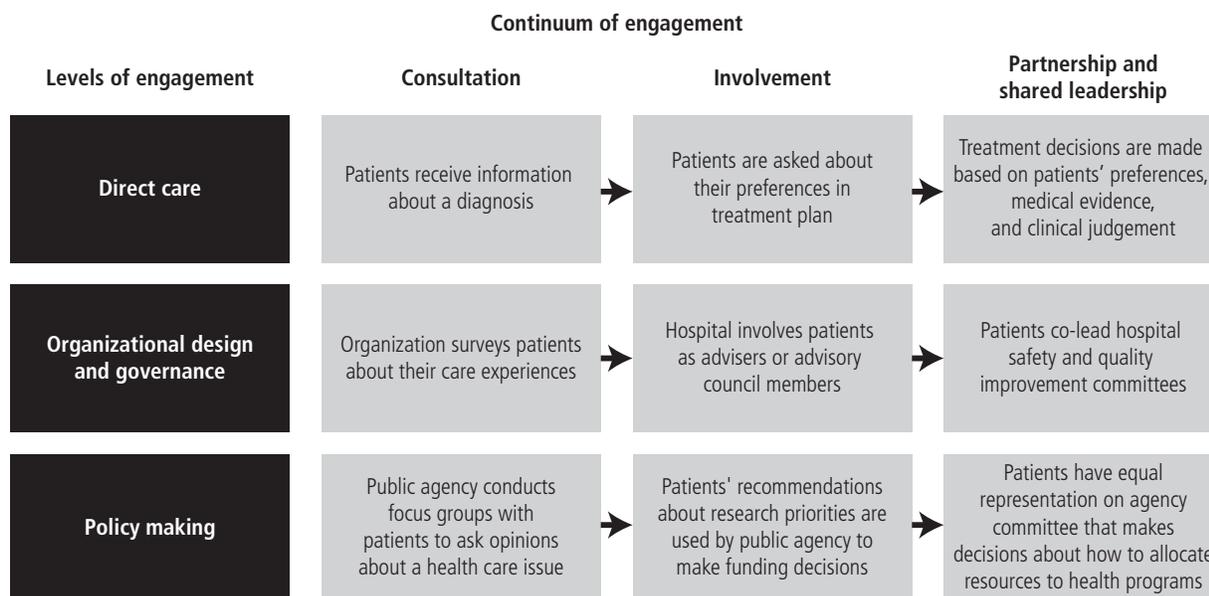
### Winning Conditions for Patient Engagement by 2020

A useful framework to help assess patient engagement activity has been developed by Carman and colleagues at the American Institutes for Research (Carman 2013). They describe a continuum of patient engagement moving from consultation to involvement to partnership and shared leadership and look at three different levels of interaction with healthcare delivery: direct care, organizational design and governance and policy making. Figure 1 outlines their framework.

Let’s assume that the right-hand side of the framework is ideal in terms of deep patient engagement and ask “where is Ontario at present?”

We can point to a number of activities and programs that would indicate that Ontario is beginning to focus on patient engagement as a priority. As referenced earlier, the advent of Health Links has been a notable contribution to the policy scene. Designed to provide coordinated care for patients with complex health conditions, Health Links are meant

**Figure 1. Framework for patient and family engagement in health and healthcare**



to engage with patients and families directly about their care and to base treatment plans on patient preferences. A number of the Health Links have already gone beyond the clinical discussions and have begun involving patients in discussions about the organization of administrative practices, office hours, access to records, online scheduling of appointments and the ability to email their practitioners.

Another engagement mechanism – patient and family advisory councils – have been in place for many years in paediatric and mental health organizations but have recently appeared elsewhere. In the spring of 2014, The Change Foundation partnered with the Ontario Hospital Association to survey their members on the existence and functioning of patient and family advisory councils (The Change Foundation 2014). Ninety hospitals participated and one-third indicated they had a council. Table 1 highlights the most important role played by the patient and family advisory councils as identified by them.

Provincial-level groups have also created their own patient advisory panels such as eHealth Ontario, Cancer Care Ontario, Health Quality Ontario, and the Drug Reform Secretariat within the Ministry of Health and Long-Term Care.

Not all healthcare organizations have councils, but they do use other engagement mechanisms such as surveys and focus groups. A small number have invested in training patients to be improvement advisors involved in program and unit-level quality rounds, and some are involving patients in staff recruitment interviews. Table 2 highlights some examples of patient and family engagement efforts in some Ontario healthcare organizations using the Carman framework.

It is probably an oversimplification, but it would appear that we have some pockets of activity at the direct care and organizational design level that sit somewhere on the continuum between consultation and involvement. But widespread, it is not. Yet.

Over the past two years, The Change Foundation facilitated regional patient engagement workshops across Ontario. Organized through and with the LHINs and with representatives of Health Links, they were designed to outline the rationale for deep patient engagement by healthcare provider organizations and to introduce the basic principles and techniques of patient engagement to support groups of providers and patients in thinking about what might be possible for them. There was lots of enthusiasm about

**Table 1. Role of the patient and family advisory council in selected Ontario hospitals as identified by patients, 2014**

Role of the patient and family advisory council	Percentage
Advisory: A consultative and advisory role to the hospital to improve the patient experience through the patient and family voice.	39%
Fostering a culture of patient and family voice: Fostering a culture of patient-centred care within the hospital through the patient/family voice. The PFAC is the mechanism that expresses the need for a shift in institutional culture.	29%
Partnership and collaboration: Engaging patients and their families, not merely soliciting their advice, but collaborating as partners in the healthcare improvement process. Giving them a role in their own care; identifying needs and solving problems together.	21%
Information sharing/educational: Sharing information with stakeholders throughout the hospital and community. Supporting the hospital in areas that require more information from patients and families.	11%
Total	100%

**Table 2. Examples of patient engagement efforts in selected health organizations in Ontario, 2014**

Organization	Types of activity or mechanisms	Level of engagement
Some Ontario hospitals	Spot phone polls, surveys, focus groups	Consultation
	Patient and family advisory councils	Involvement
	Members of board of trustees/board committees	Partnership/shared leadership
	Improvement advisors	Partnership/shared leadership
Some Health Links	Surveys, focus groups	Consultation
	Patient and family advisory councils	Involvement
All health links	Individual care plans based on stated patient preferences/needs	Partnership/shared leadership
Long-term care homes (all types)	Residents councils (mandatory)	Involvement
	Family councils (only mandatory if requested)	Involvement
eHealth Ontario	Patient advisory panel	Consultation
Cancer Care Ontario	Patient and family advisory councils (centrally and at regional cancer centres)	Involvement
	Experience-based co-design projects in regions	Partnership/shared leadership
Health Quality Ontario	Developing a patient and family engagement strategy	To be determined
Drug Reform Secretariat	Ontario citizen's council	Involvement
Some LHINS	Regional patient advisory council	Involvement
Some CCACs	Client/Caregiver councils	Involvement
Some family health teams	Patient advisory councils	Involvement

the why but some skepticism about the how. Barriers were often noted as potential reasons for not moving forward. It is important to understand these barriers, as they were remarkably consistent and can prohibit deeper engagement with patients.

### What gets in the way?

Some of the concerns we heard at these regional workshops were:

1. *We will have to hire more staff and we can't afford it.* There is no doubt that our legacy systems were not designed for patient comfort or convenience and that these sorts of engagement activities do create the need for action. A truly committed organization will likely at some point start thinking about technology supports, enhanced physical space or

rapid fire communication opportunities. However, it does not necessarily mean more staff – it means maximizing the interactions between patients and current staff. Studies show that efficiencies in process can actually free up staff time to be devoted back to direct care. There are indeed resources required up front to provide training for staff and participating patients but they are short term and can be built in to staff developmental budgets (Charmel and Frampton 2008). Experience shows that once an organization changes the way it approaches issues and decision-making through true partnership with patients, it is almost impossible to return to the old way of doing things.

2. *You are really just talking about being nice to people. We are already nice to our patients.*

It's true that there is an aspect of this that is related to being empathetic, respectful and polite. But, there is something much more fundamental underlying the rationale for deep patient engagement than just being nice.

Don Berwick encapsulates it best when he asks (Berwick 2009):

Is it nice to ensure patients access to their own health records or does it increase the ability to ensure there are no errors of fact in the record?

Is it nice to respond to a call button promptly or is it a way to avoid a patient getting out of bed on their own and falling?

Is it nice to communicate with families about care planning or is it smart practice to get the full picture of the patient's family circumstances before putting together a plan?

3. *This doesn't relate to me because patient engagement is someone else's job.*  
Organizations rated as highly patient-centred report that patient engagement is everyone's job. In our regional sessions with patients and caregivers, they often commented after sessions that the most consistent person in a patient's hospital room over time was the cleaning staff and that they often knew family members by sight. Every person on staff needs to understand that they contribute to the experience of patients and their families. Every person.
4. *We are already patient-centred because our patient satisfaction scores are pretty high and our quality indicators are good.*

There is a developing literature on the difference between questions measuring patient satisfaction and questions measuring patient experience (Whelan et al. 2011). Overall ratings of average, good or excellent do not necessarily provide granular-level feedback on what mattered to patients. Secondly, satisfaction surveys are often done once an episode of care has concluded and the details of what contributed to a good or bad experience can fade. Patient experience surveys tend to be in real time and on site, thus capturing issues with care as they occur. And in circumstances where questions are being asked in the middle of ongoing services, patients report they are afraid to be too critical in case there are repercussions afterwards.

What is reasonable to expect by 2020?

No one mandated method is going to work for all the healthcare organizations in Ontario, but it is worth noting that Accreditation Canada has already included client- and family-centred care in their governance and leadership standards. They use the language of meaningful partnerships with clients and families, representation on advisory committees and a commitment to co-designing services ([www.accreditation.ca](http://www.accreditation.ca)).

In April of 2014, the Ontario government proposed a new regulation under the *Excellent Care for All Act* that would require patient engagement as part of the development of quality improvement plans for hospitals. Specifically the regulation would:

- i. Require that each healthcare organization (currently only hospitals) to engage with patients and their caregivers in the development of its annual quality improvement plan; and

2. Require that every healthcare organization's annual quality improvement plan contains a description of the organization's patient engagement activities and an explanation of how these activities inform the development of the quality improvement plan.

While not all healthcare organizations are currently required to have quality improvement plans (maybe that will come in the future), establishing the expectation that publicly funded healthcare organizations in Ontario have a locally determined patient engagement strategy by 2020 seems reasonable. This could easily be done collaboratively so that not every organization has to have its own development structure but rather a network of groups could create something together, particularly when it's the same set of patients being engaged.

Finally, HQO has signalled a refocus of its energy and resources on patient engagement both for itself as an organization and for the health system as a whole. This should be supported and developed so that by 2020, HQO is the provincial resource for capacity development and training for patients and providers wanting to understand how to undertake this kind of work. And, it will have developed evidence-based standards and practices, and a robust set of patient experience metrics, with patients to be used across the system.

### **Winning Conditions for Patient Experience by 2020**

If some of the system issues discussed here are addressed and some of the engagement techniques are implemented, the provision of healthcare would truly put patients and their families at the centre. So what could the experience look like by 2020?

Every patient would have a care team that includes their family if they choose. Managing care would be a shared partnership combining clinical expertise, patient preferences, patient self-management where appropriate and family contributions. Patients would have full access to their personal health records – electronically or otherwise – and they would have the ability to interact with their healthcare team via secure email. And when the patient gives consent, family members broadly defined would be able to access information as well. There are already a number of networking platforms available that can facilitate a meaningful and active role for family and friends connected to a professional support network. All electronically.

The time and convenience for the patient and family will be valued equally with the time and convenience of the provider.

Booking appointments would be done online and primary care schedules would be open and flexible for at least part of the day. Thus, same-day appointments for urgent matters would be the norm and would be booked with the most appropriate member of the team. Longer appointments would be available for people with multiple conditions.

Patient travel time – especially for specialist appointments outside of town – would be viewed as a burden to be avoided, rather than a necessity. The use of technology would alleviate the need for all interactions to be in-person, as patients would have access to virtual consults where appropriate. Technology will also facilitate the patient being in the room during provider-to-provider consultations.

Hospitals and long-term care homes would ensure that family presence policies have replaced policies on visiting hours. Organizations will do everything they can to reduce noise levels to allow patients to

sleep. Any care planning conversations will occur directly with the patient, including any family the patient wishes involved. Attention will be paid to what is said in front of the patient. For example, patients won't have to hear a staff member saying "I suck at IVs" right before a line is put in or "I don't know why the doctor would tell you to do that" after consulting a chart (Lewis 2012). Signage will be understandable. Food will taste good.

When patients leave the organization to go home or to a community facility, they will be crystal clear about next steps in their care, any follow up that is required and who they can call if they have any further questions.

Patient and family charters will be in evidence and adhered to in all healthcare organizations. As Lewis points out in his discussion paper for the Saskatchewan Ministry of Health on patient-centred care, the charter could include statements about timeliness of care, convenience of care, the right to be heard, courtesy and respect, shared decision-making and the right to have family members and others as advocates and partners (Lewis 2009).

Personal support networks – family members, friends and neighbours – will be valued and viewed by healthcare providers as a knowledgeable source of information and comfort. Their personal circumstances will be taken into account as care plans are designed and they will be viewed as an equal member of the team.

What happens to people as they use the healthcare system matters deeply. We have enough evidence that the historic approach to health system reform – a little of this and a little of that focused on parts of the healthcare system rather than the system as a whole – has created a disjointed patient journey. Taking a step back and embracing a patient-centred philosophy as a way to approach

health system reform will produce a different set of conversations than the ones focused on money and structure. It will lead to meaningful patient engagement about care, processes and environments. It will also improve the patient experience. We leave the final words to Sir Robert Francis, Chair of a health service public inquiry in England who said it best (Francis 2013):

Individual patients and their treatment are what really matters. Statistics, benchmarks and action plans are tools, not ends in themselves. They should not come before patients and their experiences.

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