

# Turning what we know into action:

A commentary on the  
National Symposium on  
Patient Engagement



Health Council of Canada  
Conseil canadien de la santé

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Our intention was three-fold: to raise awareness of the potential of patient engagement as an instrument of change; to spark a national dialogue that would build support for patient engagement; and to help those who are entering this burgeoning field of system-level change to gain insight into tools and experiences that are available to either start or advance their patient engagement work.



## Foreword

In October 2011, the Health Council of Canada hosted a national symposium on patient engagement. The plan was simple enough: we wanted to explore how good ideas have been, and could be, turned into action. As we began to develop the agenda for the day, we learned there is no shortage of Canadians—both within and outside the health system—with much to say on the matter.

The over 160 people who attended collectively represented the Canadian health care system: patients; representatives from patient organizations; federal and provincial governments, regional health authorities, and local health integration networks; health system administrators; health care providers; and researchers.

We heard many perspectives. Patients told us what it is like to navigate the often intimidating and confusing Canadian health care system. Health care providers gave us an insider's view of how they would improve this same system for their patients, and planners and administrators told us how they're working to make patient-centred care a reality.

Our intention was three-fold: to raise awareness of the potential of patient engagement as an instrument of change; to spark a national dialogue that would build support for patient engagement; and to help those who are entering this burgeoning field of system-level change to gain insight into tools and experiences that are available to either start or advance their patient engagement work.

To keep the momentum from that day going, we developed this commentary and proceedings report to inspire governments, health care workers, and patients to take up patient engagement in their own ways. For the Health Council of Canada, our work didn't end with the symposium. We will keep what we learned in October fresh in our minds, and embed it into all that we do. Patient engagement at all levels happens when we ask ourselves, "Is this the right thing to do so that patients and their caregivers have a voice?" We hope all symposium participants are doing the same.

We can learn from one another, share what others are doing well, and, more importantly, not be afraid to ask them how they did it. The ideas for change are out there. By sharing what we learn from those actively involved in health care, and putting that knowledge into practice, we can start to turn ideas and experience into a better reality for all Canadian patients.

Dr. Jack Kitts  
Chair, Health Council of Canada



## A commentary on patient engagement

On the surface, engaging patients in their own health seems really quite obvious: health care providers, patients, and their families *should* work together as a team. After all, they know more about the patient's needs than anyone else.

In reality, it's not so simple. The Canadian health care system just isn't set up that way. Too often, all actors in the system, from doctors with a full day's list of patients to see, to patients wanting expensive tests, get stuck in their own processes and forget that the best quality care and the best outcomes for the patient are everyone's goals.

The *whys* are irrefutable. It's *how* to change the system that's the challenge—in fact, this was the basis for the day-long symposium we held in October 2011.

Engaged patients better understand, and know more about, their care, which leads to better use of health services and resources.<sup>1</sup> More broadly, for over a decade, researchers and others have advocated that engaging patients in planning and designing health care services is an important means to improving the quality of care and strengthening accountability in the system.<sup>2</sup> As we heard from our keynote speaker, Dr. Susan Frampton, it's also a matter of patient safety.

In September 2011, the Health Council of Canada published *How Engaged are Canadians in their Primary Health Care: Results from the 2010 Commonwealth Fund International Health Policy Survey*. This survey looked at how engaged patients are, and what helps them to be more engaged.

We found that patients who are engaged in their primary care are happier with their care and feel better about their health. Engaging patients is better not only for the patients themselves, but also for providers and the system as a whole. Patients who are involved and who feel respected in their interactions with health care providers do better and feel better than those who aren't. They take a more confident and active role in maintaining their health, are more satisfied with their care, and feel more positively about their overall health.<sup>3</sup> For physicians, shared decision-making is increasingly recognized as an ideal model of care.<sup>4</sup>



*“We didn’t want another symposium to talk about it [patient engagement]. We wanted to start taking action.”*

## Patients as partners

We truly believe it is not overstating the case when we say that patient engagement is crucial to the future of our health care system. We have a rare opportunity today, as we approach the end of the current health accords in 2014, to make many voices heard. It's time to start thinking about the new direction the Canadian health care system could take. And this time, patients with informed voices should be at the table. Canadians need to be involved in the design, planning, and delivery of their own health care.

As we heard in the Patients as Partners session based on patient engagement work in British Columbia, patient engagement is a continuum of involvement. On one end, the provider merely informs patients of what will happen and how they will be cared for. That's all too often where we are today, and where we have been historically. But the role of the patient should not be to passively receive care. Far from it.

The provider–patient relationship belongs on the other end of the spectrum, where there is a two-way exchange of information: patients are empowered, providers are willing to listen to them, and decisions are made as a team. That's where we need to be. While we have evidence that shows that engaged patients tend to have better health outcomes, we suspect that the health care system could have better results if patients were actively involved in its design and continuous improvement.

The time has come for organizations at all levels of the health care system—including hospitals, family doctor's offices, and long-term care facilities—to recognize patients as partners. So what's the problem? Canadian patients are not yet empowered or do not feel they are empowered. The current model of care is designed for a single intervention or a series of interventions; health care professionals traditionally 'treat' people. The health care system is structured to allow this to happen, through payment methods, for example, and processes that are easy to 'count,' such as admission rates, doctors' visits, and flu shot administrations. Engagement is really the opposite of these concepts—it is ongoing, it takes time, and, more importantly, it is not easily measured.



The Spectrum of Engagement is reproduced with permission from Patients as Partners, Primary Health Care and Specialist Service Branch, British Columbia Ministry of Health. It is adapted from the International Association for Public Participation – IAP2 Spectrum of Public Participation. Source: <http://iap2.affiniscape.com/index.cfm>



# A shift to patient-centred care: the role for patient engagement

Engaging patients is key to patient-centred care, a concept that has been gaining in popularity in recent years. Essentially four things need to change to move from provider-focused to patient-centred care:

1. The system must be flexible to allow for the input of many, at multiple points along the continuum of care.
2. A culture of caring must be reinforced.
3. Patient experiences must be valued and measured.
4. Patients need tools and encouragement to engage in a positive, meaningful way.

## Patient experience must be valued

As we heard in the Ideas Café, the Canadian health care system is designed to enable and support health care professionals, not patients. We need a system that is focused on the patient. It needs to be flexible enough to accommodate the changing demands of a population that is aging and fraught with chronic health conditions, and that needs management instead of fixing. We need a coordinated system that will keep track of us when we leave the hospital and provide support when we are not an 'active' patient. To put patients at the centre of the health care system, governments, hospital administrators, and providers must listen for cues from patients and their families. This is putting the human perspective into planning and design.

Shifting an entire health care system to patient-centred care may seem like a tall order. But the system can be changed if health planners and administrators individually take steps in the right direction, with a common purpose. Right now, said one presenter, "everyone's isolated."

**"[Patients are hospitals'] true assets.  
They see things that you never will.  
They have the 360 degree view."**



# “Patients are the experts of their own care.”

## A culture of caring must be reinforced

We heard from Mary Ferguson-Paré, in her session *Achieving Culture Change in Health Care*, that to be successful, patient-centred care and, in turn, patient engagement, must be embedded in health care organizations from the CEO on down. It must be part of all organizational communications. She told us, “Top down isn’t good enough. It has to be top down, bottom up, and side-to-side. Staff at all levels must be trained and, most importantly, must be treated in the same way they are expected to treat patients.” Patient-centred care must also be embedded in employee screening and performance management. Staff will only put the patient at the centre of care if the organization and management do as well. This is the culture change needed for success.

As we heard from Amber Alecxe in her session on Saskatchewan’s Patients and Families First Initiative, another important point is to provide a forum for administrators and front-line workers to hear from, and learn from, the experiences of patients and their families. One symposium participant said that patient satisfaction surveys are limited as a barometer. Instead, some felt that hearing patient stories and having an ombudsman, for example, can create a more responsive system for patients.

Patients today, we heard, are struggling with different health care providers and locations of care. Our system can be confusing, overwhelming, and complicated to navigate for the patient, who is often in an unfamiliar environment. Doctors can be intimidating for patients who are afraid of being labelled as “bad patients” if they voice their opinions or complain too loudly. But when patients feel supported, respected, listened to, and included in their own care, they told us it can make a world of difference. This not only applies to patients, but also to their support teams, such as their family and friends. As our keynote speaker, Dr. Susan Frampton, told us, “We’re still pushing family away when they’re needed the most. It’s a simple thing, and I can’t believe we haven’t gotten it yet.”

As we heard in the session, *Improving Patient–Provider Communication: A Focus on Health Literacy and Cultural Competency*, we also need to take a patient’s level of health literacy into account—the ability to find, understand, and use health information, services, and supports that help a patient make informed health care choices—since it may affect the patient’s ability to take an active role in his or her own care. Also, by providing culturally competent care, particularly with regards to Canada’s Aboriginal Peoples, we can reduce long-standing health inequities; improve access, quality of service, and health outcomes; decrease provider liability; and improve health system efficiency.



## Patients need to be allowed to engage in positive, meaningful ways

Patients can play a role and have a voice in health system and hospital governance at all levels. As we heard in both Dr. Bruce Brown's session on his patient engagement initiative at Montreal's St. Mary's Hospital Centre and Tanya Spencer Cameron's session on Ontario's Patient Journey Project, that role must be meaningful, the patients must feel empowered and respected, and they must be properly oriented and prepared for their roles. What is important is to open the doors to patients and allow them to be involved at whatever level they feel most comfortable. In our Ideas Café, we heard that being a patient advocate can require a large time commitment. In some countries, patient groups receive government funding and patient advocates are paid for their time. Perhaps it is time for Canada to follow suit.

That said, patients need to be prepared to walk through that door and make the necessary time commitment. They must also be prepared, as Daniel Stolfi said in his presentation on his own experiences with cancer, to build a relationship with their care team whenever possible. For example, a physician can't possibly know about all community and peer supports available to their patients. One idea suggested by an audience member was that patients should inform their doctors of, or "reverse prescribe," these supports, so they can better help other patients in the future.

**"No matter how much noise you make outside the door, unless you can get inside the door and at the table, you don't make a difference."**

Another useful idea expressed at the symposium was that patients should write a short "patient impact statement" before seeing the doctor. This statement would briefly explain the reason for their visit and any preferences or questions they might have about their care. This approach helps physicians spend less time trying to figure out why the patient is there, and more time diagnosing or treating.

For patients to make a meaningful contribution to their care and to the health care system, they need to be educated and informed about the system. When receiving care, they need to realize that more is not always better. And they need to get engaged in patient groups. The more engaged the patient, the more effective the care team, since all members can be on the same page.



## Bringing physicians on board

Physicians often do not work in the health care system, but rather work next to it. The challenge then becomes how to communicate the culture change towards patient engagement to them.

According to Dr. Danielle Martin, in her session Achieving a Culture Change in Health Care, two things must be done to get them on board: “Tie the money to the outcomes, and provide feedback.” On the first point, doctors currently aren’t paid in a way that prioritizes patient-centred care. That needs to change. It can be something as simple as being able to email your doctor to save you a needless trip to their office.

Physicians share some of the responsibility here, too. As Dr. Martin said, “We need a culture change [for physicians] from doing to, to doing for, to doing with. We are still at doing for.”

Traditionally, physicians have held the control in the patient-provider partnership. This shift to “doing with” will be a challenge since, as one physician told us, “we’re used to being in control of the system.”

Physicians are used to dealing with one patient at a time until the end of the day, then going home. Generally, their job does not involve what the patient experienced before and after seeing them. But it should.

The patient experience as a whole must become a consideration for Canadian physicians, and indeed all health care providers. This includes considering whether patients could be better served at a hospital that’s closer to their home, or whether they know of any patient support groups that could help people better cope with the psychological and other effects of their illness.

In short, physicians need to listen to their patients, and the system needs to respond to both. It’s a matter of quality care, and it’s a matter of patient safety. Luckily, as we found out, there is no shortage of engaged patients who want to be heard, and who want to have a voice.

“The nuance of how to get doctors on board is the final frontier to patient-centred care.”

## Measuring for patient engagement

Too often, patient engagement is not supported by health administrators or governments because it is perceived to not be measurable and it does not offer any tangible results to the public. To be taken seriously, patient experience should be measured at all levels of the health care system and used to set targets for higher quality care that is in keeping with patient experiences and expectations. In our *Progress Report 2011: Health Care Renewal in Canada*, we found that governments made the most progress on the accord themes when specific goals and targets were set out up front. In 2014, governments have an opportunity to include patient engagement as a performance objective. As we learned from Dr. Brian Golden and Heather Fraser in their presentation based on their work in the Systematic Therapy Treatment Centre at Princess Margaret Hospital in Toronto, the system must be designed like it's a business, and businesses listen to their customers.

## In conclusion: what we know

Patient engagement and patient-centred care require changes at all levels. They can be seen as a daunting task or as an opportunity to support Canada's publicly-funded health care system. It is possible with solid leadership, as demonstrated by several jurisdictions that have actively engaged citizens in shaping future health care, and that have put patient engagement as part of performance management at the hospital level. It will not happen overnight. However, as long as all actors in the health system are headed in the same direction, progress will be made.

It's very easy to get stuck in the negative and highlight what is wrong with the system. Instead, we should build on the positive and ask others what is working. At the symposium, we learned about a handful of initiatives from across Canada that are working to put patients first, such as the Patients are Partners in Improving Experiences and Outcomes of Care program at Montreal's St. Mary's Hospital Centre, The Saskatchewan Union of Nurses' Patients and Families First Initiative, and Ontario's Patient Journey Project. They are described in the symposium proceedings report that is available online at [www.healthcouncilcanada.ca](http://www.healthcouncilcanada.ca). We have highlighted one such initiative, British Columbia's Patients as Partners project, as a "promising practice" in patient engagement (see page 14). We encourage you to read the report and to be open to learning from others.

**"Start with what is working. Find all those examples, then ask: 'How can we get more of that? How can we help the best to spread?' As the best spreads it begins to isolate the worst. People can get engaged with developing the best. People can become very discouraged just trying to fix problems."**



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## Promising Practice: British Columbia's Patients as Partners

The Health Council of Canada's symposium included presentations of a number of approaches to patient and public engagement that could be highlighted as promising practices. One that illustrates three aspects of patient engagement—policy influence, cultural change, and a methodology to improve practice—was the presentation on Patients as Partners.

Patients as Partners is both a policy and philosophy of the British Columbia Ministry of Health. The unofficial motto of Patients as Partners is "nothing about me without me." It offers an opportunity for patient engagement in redesign through the partners who deliver Integrated Primary and Community Care: health authorities, non-governmental organizations (NGOs), and physician collaboration committees (partnerships with the BC Ministry of Health and the BC Medical Association). This includes the General Practice Services Committee, Shared Care Committee, and the Specialist Services Committee.

In 2002, the General Practice Service Committee (GPSC) was formed to enable the BC Government and primary care physicians to work together on strategies: "Focusing on what is best for patients, not best for physicians or best for government...". Among other things, the GPSC "...is responsible for new initiatives, including clinical incentive payments, maternity care bonuses, training modules to enhance clinical and administrative skills, and the creation of Divisions of Family Practice to coordinate and support family doctors at the regional level."<sup>5</sup> This shift created an environment where physicians were supported to spend more time with their chronically ill and complex care patients. Over time, this has led to



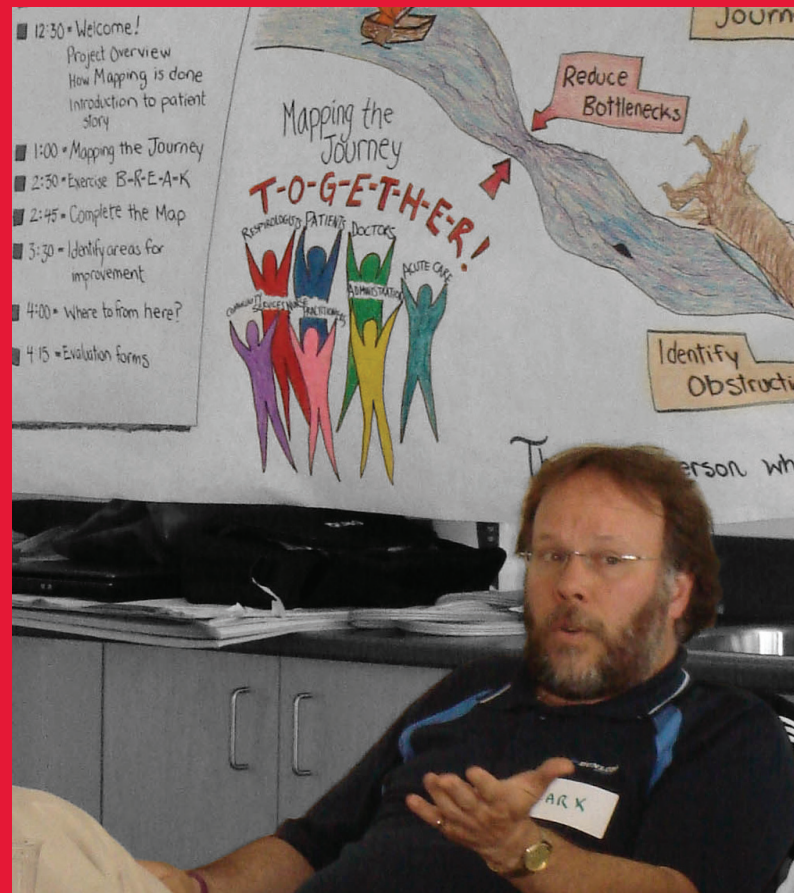
a change of culture where patients are more often seen as partners in the management of their care. In fact, according to Kelly McQuillen, Director Patients as Partners, BC Ministry of Health, “Physicians now ask ‘how many patients are on this consultation call today or involved in our redesign approaches?’ ”

## How it works

Patients as Partners collaborates with health authorities, NGOs, physician collaborative committees, and other key stakeholders to identify opportunities for patient and public engagement in program and service design, and system and community health care transformation. Patients are engaged through the Patient Voices Network, a mechanism to recruit, train, and support patients, families, and caregivers to participate in health care changes at the individual (patient to provider), program and service design, and community and system levels.

The network helps patients to constructively share both positive and negative experiences as a voice for improvement through support, training, and coaching. Patient voices for improvement are leveraged to ensure patient experiences can inform system, program, and practice improvements. More than 80% of patients are already reporting that they find participating in their engagement opportunity is a meaningful and valuable experience.<sup>6</sup>

Patient experience measures are central to the overall Integrated Primary and Community Care evaluation, accountability, research, and quality improvement framework. Patients as Partners will know that patient and public voices in the change process have ‘stuck’ when they see an improvement in population health, an improved patient and provider experience of care, and lower per capita costs overall. And, patients will be engaged in the design of the provincial evaluation framework. Could patient engagement be the catalyst to move primary health care to the next level?



Physicians now ask ‘how many patients are on this consultation call today or involved in our redesign approaches?’





# Key messages from the National Symposium on Patient Engagement

Additional material on the National Symposium on Patient Engagement is available in a companion document, *National Symposium on Patient Engagement: Proceedings Report*, available at [www.healthcouncilcanada.ca](http://www.healthcouncilcanada.ca).

## IMPROVING THE PATIENT EXPERIENCE THROUGH DESIGN

**Dr. Brian R. Golden**, Sandra Rotman Chaired Professor in Health Sector Strategy, University of Toronto & University Health Network; Professor, Strategic Management, Rotman School of Management; Executive Director, Collaborative for Health Sector Strategy

**Heather Fraser**, Director, Rotman DesignWorks and Business Design Initiative, Rotman School of Management

This presentation was based on the work the researchers did using the Rotman Creative Design Process to redesign care and the patient experience in the Systematic Therapy Treatment Centre at Princess Margaret Hospital in Toronto.

### Key messages:

- There are “three gears of business design”—empathy and deep human understanding, concept visualization, and strategic business design—which correspond with the “three gears of health care”—patient care satisfaction, clinical experience and outcomes, and responsible capital investments and spending.
- Empathy and deep human understanding require broadening the lens and appreciating the patient’s journey. There is a need to define the patient’s unmet needs (i.e., social, physical, identity, communication, emotional) to help personify them and contextualize their needs.
- Concept visualization requires exploring new possibilities to create a richer multi-dimensional patient experience. There is a need to consider what and how people, objects, environments, media and messages, and services can enhance the patient experience.
- Strategic business design involves defining the enterprise system. Enriching the patient experience will improve organizational operations.

## TIPPING POINT: MY JOURNEY TO BECOMING AN ENGAGED PATIENT

**Daniel Stolfi**, Patient and Writer/Performer, *Cancer Can’t Dance Like This*

Daniel Stolfi is an actor, comedian, and cancer patient advocate who told the story of his battle with cancer, which also forms the basis of his one-man show, *Cancer Can’t Dance Like This*.

### Key messages:

- Stolfi described his personal experience as a cancer patient. The tipping point for him in becoming an engaged patient was when he experienced a medical error.
- Stolfi stressed the importance of building a relationship with his physician and needing to feel that he was part of a health care team.
- He described how health care providers need to understand that for patients, cancer is a “new” experience. They also need to appreciate the journey from the patient’s perspective.
- He talked about the need for peer support groups, in particular for young adults with cancer. Patients need to “reverse prescribe” online communities to health care providers because they are often unaware of what peer supports are available for patients.

## IDEAS CAFÉ: WHAT IF PATIENTS WERE EQUAL PARTNERS IN THE DESIGN OF THE HEALTH CARE SYSTEM? IS THE HEALTH CARE SYSTEM FLEXIBLE ENOUGH TO ALLOW FOR MEANINGFUL PATIENT ENGAGEMENT?

### Moderator:

**Cathy Fooks**, President and CEO, The Change Foundation

### Participants:

**Nimet Karim**, Family Member, CHEO Family Forum

**David Wells**, New Brunswick Patient Advocate; Former Chair, New Brunswick Surgical Care Network Advisory Committee

**Durhane Wong-Rieger**, President, Canadian Organization for Rare Disorders; Chair, Consumer Advocare Network

**Sholom Glouberman**, President, Patients' Association of Canada

**Adalsteinn Brown**, Assistant Professor and Chair in Public Health Policy, Dalla Lana School of Public Health, University of Toronto

**Stéphane Robichaud**, CEO, New Brunswick Health Council

Patient/caregiver representatives and health system design representatives took turns imagining a health care system where patients are equal partners in the design of the health care system.

### Key messages:

- Karim and Brown described the top three things they feel need to change within the health care system to make it more responsive to patient and caregiver needs. Karim discussed the need for a coordinated system of care with enabled technology; improved transitions of care; and integration of natural or alternative medicines into the health care system. Brown described how patients need to have a role in governance of health care organizations; the system needs to be designed from the patient's perspective; and health care needs to be delivered by a team that includes the patient and family.
- Wells and Robichaud described their ideas for achieving greater involvement of patients and caregivers in decisions around health policy and service delivery. Wells described examples of inward and outward aspects of patient engagement. An example of inward patient engagement is the creation of impact statements. An example of outward patient engagement is the Southcentral Foundation in Alaska, the NUKA system of care, where patients are seen as "customers or owners" of the health care system and are educated to take ownership of their own health and health care decision-making. Robichaud described how the focus needs to be on a "few key whats" where everyone is working together on a common purpose. There is need for leadership, purpose, and accountability around patient engagement.
- Wong-Rieger and Glouberman described potential actions that might be taken to support patients and caregivers in their involvement in the development of health policy and service delivery. Wong-Rieger stated that patients' voices have to count, but for patients to make a meaningful contribution in this area, they need to get educated and informed about the system and have commentary that will help shift the discussion. Financial resources are also needed to support patient involvement. Glouberman described how the current system needs to change from being focused on acute care to chronic disease management. He also said that institutions are risk-averse, which can affect their ability to be patient-centred.

## KEYNOTE ADDRESS: MAKING THE CASE FOR PATIENT ENGAGEMENT: DEFINING, MEASURING, AND RECOGNIZING PATIENT-CENTRED CARE

**Susan Frampton**, President, Planetree

Dr. Frampton “made the case for patient engagement” from both her personal position as the daughter of a patient, and as president of Planetree, a not-for-profit organization that globally promotes and provides education in patient-centred care.

### Key messages:

- Frampton described the Planetree patient-centred model of care. She noted Canada’s lack of measurement tools and public reporting methods related to institutional and practitioner report cards for patients to make decisions about quality of care. Patient-centred care not only improves the patient experience, but is essential for quality and safety.
- Frampton provided international examples of organizations that have been recognized for excellence in patient-centred care.

## ACHIEVING A CULTURE CHANGE IN HEALTH CARE: TOWARDS PARTNERSHIPS BETWEEN PATIENTS/ FAMILIES AND HEALTH PROFESSIONALS

**Mary Ferguson-Paré**, Former Vice President, Professional Affairs and Chief Nurse Executive, University Health Network

**Danielle Martin**, Physician, Women’s College Hospital and Board Chair, Canadian Doctors for Medicare

In this session, presenters discussed shifting to a more patient-centred organizational culture, aligning employees with new initiatives, and influencing physicians as independent contractors to accept patient engagement.

### Key messages:

- Remember that participants used “compassion” and “communication” to describe their most positive personal experiences with the health care system.
- Use appreciative inquiry to create organizational change.
- Include everyone in patient engagement.
- Use measurement and tie money to outcomes.
- Provide feedback on performance since it engenders a desire to improve.
- Ask health care providers what would make work life easier. Patient engagement is related to quality of work life and job satisfaction.



## IMPROVING PATIENT–PROVIDER COMMUNICATION: A FOCUS ON HEALTH LITERACY AND CULTURAL COMPETENCY

**Bernice Downy**, Principal, Minoayawin – Good Health Consulting

**Gail Sloane**, Senior Policy Analyst, Nova Scotia Department  
of Health and Wellness

**Janet Rhymes**, Consultant, Logical Minds Consulting

This session focused on increasing awareness of the importance of facilitating culturally safe health literacy approaches to achieve improved health outcomes for patients.

### Key messages:

- Remember that low health literacy is a barrier to patient engagement.
- Promote health literacy for indigenous populations through personal agency and self-determination. Acknowledge and integrate culturally congruent socio-political contexts and decolonize educational approaches to improve the potential for health literacy. In essence, health care providers need to meet patients where they are at and understand the context and lens from which they seek care. Patients need to have a strong self-identity to take personal responsibility for their own health and to be able to actively engage with the health care system.
- Follow the Government of Nova Scotia's cultural competence guidelines (available at [www.healthteamnovascotia.ca](http://www.healthteamnovascotia.ca)). Use the cultural competence and health literacy tool, Messages for All Voices, to specifically help implement Guideline 9, which deals with health materials, forms, and signage (available at [www.gov.ns.ca/health/primaryhealthcare/healthliteracy.asp](http://www.gov.ns.ca/health/primaryhealthcare/healthliteracy.asp)).

## PATIENTS AS PARTNERS: THE KEY TO SYSTEM TRANSFORMATION

**Kelly McQuillen**, Director, Patients as Partners, Primary Health Care and Specialist Services Branch, British Columbia Ministry of Health Services

**Archie Allison**, Volunteer Patient Advisor, Patient Voices Network, British Columbia

This session highlighted British Columbia's journey towards Patients as Partners in individual care, system redesign, and quality improvement (see Promising Practice, page 14).

### Key messages:

- Encourage the practice of patient engagement in three domains: individual care; program and service design; and system and community.
- Support change initiated by patient and public engagement; it involves a paradigm shift, one that may challenge health care providers' and administrators' training and professional socialization.
- Use mechanisms to recruit, train, and support patients and their families to participate in health care changes for authentic engagement.
- Include patient voice, choice, and representation as part of improvement teams to lead to creative ways of thinking and accelerate improvements.
- Ensure successful engagement through rigorous planning, skilful execution, and following a series of steps. Patient and public engagement requires champions at all levels of the organization. Like any other significant change, patient and public engagement requires resources.
- Couple information and patient and public education as elements of engagement with meaningful opportunities to participate.
- Use effective patient and public engagement to transform people, relationships, and organizations.

## SHARING EXPERIENCE WITH PATIENT ENGAGEMENT: LESSONS FROM AN ONGOING COMMUNITY HOSPITAL PROJECT IN MONTREAL

**Bruce Brown**, President, Professional Services,  
St. Mary's Hospital Centre

This session provided an overview of the work to date on the Patients are Partners in Improving Experiences and Outcomes of Care at SMHC project.

### Key messages:

- Remember that one size does not fit all. The specific contexts of patient care in different clinical areas of a hospital require recognition of and flexibility in approaches to patient involvement in care organization and delivery.
- Listening to patients is instructive and offers lessons that are sometimes counter-intuitive.
- Give patients the opportunity to participate and give feedback, but keep in mind that they resist being labelled as "representatives" of all patients.
- Keep things moving to show tangible results between meetings to motivate continuing participation.
- Use the science of measurement of the patient experience as a source of credible information for guiding services, but remember it is not the same as assuring patient engagement [Patient Reported Outcome Measures (PROM) focus]. Patient satisfaction surveys are not often used, but when they are, they serve as barometers.
- Support a sustainable engagement by including ownership and partnership between patients and front-line hospital workers.

## PATIENTS AND FAMILIES FIRST: INNOVATION AND COLLABORATION FOR QUALITY HEALTH CARE

**Amber Alecxe**, Director, Patients and Families First &  
Government Relations, Saskatchewan Union of Nurses

**Lynne Telfer**, Clinical Support Nurse, Saskatoon City Hospital

This presentation described the Saskatchewan Union of Nurses' Patients and Families First Initiative that is aimed at engaging patients and their families; collaborating with key stakeholders; providing professional education and support; and addressing the gap between the reality of nursing practice environments and the theoretical and clinical research that supports nursing innovation and patient-centred care.

### Key messages:

- Find creative ways to involve patients/families/the public from the beginning.
- Provide a forum for administrators and also front-line providers to learn from experiences of patients and their families.
- Consider strategies for sustainability at the outset of project development to ensure an ongoing community of patient and practitioner innovators.

## QUALITY IMPROVEMENT GUIDED BY THE PATIENT EXPERIENCE IN PRIMARY HEALTH CARE – THE PATIENT JOURNEY PROJECT

**Tanya Spencer Cameron**, Co-Lead, Quality Improvement and Clinical Integration, Health Quality Ontario

This session presented a patient engagement strategy focused on the primary health care patient experience from the system level to the practice level.

### Key messages:

- Be intentional and engage patients in a meaningful way.
- Use the patient experience to optimize quality improvement initiatives.
- Move beyond the data to listen to patients and their families.
- Include patients as active members on quality improvement teams.



We can learn from one another, share what others are doing well, and, more importantly, not be afraid to ask them how they did it. The ideas for change are out there. By sharing what we learn from those actively involved in health care, and putting that knowledge into practice, we can start to turn ideas and experience into a better reality for all Canadian patients.



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