Health Innovation Report

RAISING THE BAR ON HEALTH SYSTEM PERFORMANCE

Report #8: PATIENTS AS PARTNERS

Patient engagement: Why does it matter and how is it done?

" The patient is not just at the centre of care but is part of the care team, and is considered an actor of care. "

– Vincent Dumez, Faculty of Medicine, Université de Montréal

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" Patients bring energy for change. "

– Maria Judd, Canadian Foundation for Healthcare Improvement

Patient engagement leads to better healthcare solutions

There is a growing movement around the world to include patients directly in efforts to improve care and service delivery. What's this all about? Given the complexity of health care, can patients be actors and advise how the system needs to change? While definitions of 'patient engagement', 'patient and family-centred care' and the 'patient experience' may differ depending on the setting, organizations are starting to realize that including patients in the planning and evaluation of health service delivery results in new insights and better solutions.

As we designed our conference last fall, our planning committee felt we needed to address the "what is patient engagement?" before examining how it is, and can better be done. The stories shared on October 3rd revealed a number of important things: the current state of affairs in patient engagement; why patient or caregiver involvement changes how we think about care; the leadership needed from physicians, clinicians and healthcare executives to invite patient partnerships; and how patients are getting involved.

Most healthcare professionals believe they already engage patients in their care, however evidence suggests there is insufficient recognition of the experience-based knowledge of patients. Studies from the United Kingdom indicate that people with a chronic illness spend only about 10 hours per year with healthcare professionals, whereas they spend 6,000 hours self-managing their condition. Similarly, studies show that effective self-care management results in enhanced autonomy, improved patient outcomes and cost savings to the system.

On a positive note, patient engagement efforts are multiplying. In fact, this report offers an introduction to best-practice initiatives under way across Canada, the US and Europe, and, notably, in Montreal, at the Université de Montréal and the McGill University Health Centre. Patients are defining gaps in care, participating in hiring decisions at hospitals, improving the quality and safety of care processes, training health professionals and other patients around disease self-management and co-designing service improvements. This work is being accomplished at the micro level, one meeting, unit or class at a time, but it is also informing macro-level supports in accreditation and policy.

Additionally, patient experience surveys are providing information to guide improvement efforts about what matters most to patients and their families. The Canadian Foundation for Healthcare Improvement is currently providing funds, expertise and guidance to 22 pan-Canadian teams, which are implementing quality-improvement projects that include patients in the co-design process. The results of this program will advance our knowledge of how to do patient engagement well.

Finally, the vision of the care team on the cover of this report, with health professionals, patients and families forming a partnership to achieve better care and outcomes, should inform our actions on every level. It can guide us toward a more responsive, humane and effective health system.

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PATIENT ENGAGEMENT
Why does it matter?

1. Health needs have changed

Chronic diseases now account for 89% of deaths worldwide. Most cannot be cured and must be managed over the long term. A person with a chronic disease and his family spend five to 10 hours a year with their health professionals, and 6,000 hours providing care themselves. Outcomes depend primarily on care provided by patients and families. Not enough attention is paid to the 6,000 hours.

2. Care remains uncoordinated

Care coordination efforts led by professionals who compose the different silos of health care have limited impact. Only the patient and family can see how the pieces of the system fit together to provide the care they require and identify gaps that need to be filled.

3. Costs keep rising

Patients who cannot access the care and support they need for self-management in the community will have worse outcomes and will rely on existing and expensive health services, notably hospitals and emergency rooms.

4. Barriers to system transformation persist

Efforts to reshape the delivery of care are hampered by the vested interests and professional identities of those providing care. Including patients in transformation processes breaks down those barriers to focus squarely on improving patient experience and outcomes.

Figure developped by the Office of Collaboration and Patient Partnership, Faculty of Medicine, Université de Montréal

5. Medical education is not preparing physicians to manage chronic diseases

Medical education still centres on cure and is founded on asymmetric knowledge, which does not prepare physicians to work in collaboration with other professionals, caregivers and patients to manage chronic conditions. Training needs to include recipients of care and their families, and focus on building partnerships where professional expertise and the experience-based expertise of users are both valued.

6. The research enterprise limits the range of possible solutions

Evidence-based decision-making excludes options that lie outside the healthcare system researchers presently study. Research outcomes are defined by those providing services and do not account for the experience, capabilities and expectations of service users.

PATIENT ENGAGEMENT
How is it done?

1. Learn about the patient experience of care

Patient and family advisors are people who have a deep understanding through personal experience of the healthcare system and work with providers in healthcare organizations to improve the effectiveness and experience of care as well as care outcomes.

2. Measure the patient experience of care

The measurement of patient experience, an emerging field, provides valuable information about how to improve the quality and safety of care. One method involves surveying current and recent patients about specific aspects of the care experience rather than general satisfaction. The Canadian Patient Experience Survey, adapted by the Canadian Institute for Health Information to the Canadian context from the US Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey will be implemented in hospitals across the country in the next few years and will allow for benchmarking through the Canadian Experience Reporting System. A similar survey for primary care also exists.

3. Recognize the patient as an actor of care

Patients need to be seen as active partners in the care management team. Patient advisors can also provide training within schools of medicine, nursing and other health disciplines to develop provider skills in supporting patients' abilities to manage their illness. Educational programs designed with components for health professionals and patients deliver consistent messages to support self-management.

4. Dedicate resources to increasing patients' capacity for self-management

Patients require preparation and ongoing support for self-care. Services organized by healthcare establishments and communities offer inexpensive and cost-effective means of augmenting the self-management training provided by healthcare professionals. Trained volunteers are playing an important role in providing these services.

5. Include patient advisors in the co-design of health system improvements

Patient advisors have knowledge and insight into how the system can be changed to better meet needs and improve outcomes. Experience to date has shown that volunteer advisors can easily be recruited to work within organizations, be it in the areas of governance, policy, research or quality improvement. Organizations that are successful at patient engagement integrate patient advisors into the work of the organization at all levels, with processes in place to identify, recruit and support patient advisors.

6. Involve patients in defining research priorities and research design

Progress in medicine and the delivery of health care relies on the participation of patients not just as subjects of research but also in the definition of outcomes that matter most to them. Patient advisors are working on research governance and are being integrated into research teams to enhance research processes and the relevance of results.

The journey from modern scientific medicine to patient-centred care

Sholom Glouberman explains how it came to be that patients were not engaged for a very long time, what has changed and why they must absolutely be engaged today

SHOLOM GLOUBERMAN

is Philosopher in Residence at Baycrest, a Toronto teaching and research hospital, and President of Patients Canada, an organization he founded in 2007 (initially called the Patients' Association of Canada) that now reaches more than 10,000 patients and providers across the country. He holds a PhD from Cornell University, has been an adjunct professor at Toronto, McGill and York universities, and has acted as a health system advisor in Canada and the UK. Dr. Glouberman has led research on health policy for the Canadian Policy Research Networks and directed a Masters program in health management at McGill University. In 2005, Dr. Glouberman underwent major surgery, became a patient and wrote the book, *My Operation*, a vivid account of the gap between patients' experiences and institutional concerns.

Modern scientific medicine began with the possibility of dealing with infection and infectious diseases. Modern surgery was introduced after 1870 and, in 1880, Robert Koch and Louis Pasteur proved the germ theory and began to find the causes of infectious diseases. Many of our hospitals were built between 1880 and 1900. Then came great success with the discovery of vaccines for infectious diseases, and the beginnings of being able to deal with diseases like diabetes. Penicillin was introduced during World War II. In modern scientific medicine, patients were viewed as bodies brought to hospital for treatment. Doctors sought complete accuracy in the diagnosis and used a very clear recipe or protocol for every disease. Patients were meant to be completely compliant and expected very well-defined outcomes.

In England and in Canada, modern scientific medicine brought pressure to introduce publicly funded health care. Saskatchewan began to pay for hospital care in 1947 and in England, the National Health Service (NHS) was founded in 1948. Canada introduced National Medicare, covering hospitals and doctors, in 1966 and it reached all provinces by 1968–69. When the Canada Health Act was framed in 1984, its architects saw it as the beginning of an expanded healthcare system. However, it ended up erecting limits to public coverage: hospitals and doctors and medically necessary care. That is our healthcare system to this day. It does not cover drugs and covers very little care in the community compared to the UK and other countries that have more fully rounded healthcare systems.

What has changed

Public healthcare systems were introduced during the heyday of modern scientific medicine, but since then, disease has undergone a huge change. Between 1950 and the present day, mortality has shifted; the average lifespan in Canada is now over 80. The 2012 World Health Organization (WHO) Atlas reports that 89% of deaths are now due to chronic, non-communicable diseases, with fewer than 3% attributable to infectious diseases. In Canada, almost everyone over age 65 lives with at least one chronic condition, and more than 20% of people with chronic conditions have two or more. The health system, which has become more and more specialized and more divided, handles acute conditions extremely well and saves many lives, but it cannot really cope with the kinds of morbidity that are most prevalent today. It is not fit for purpose.

Research is also not fit for purpose. At a meeting on new ways of dealing with people post-stroke, wonderful research projects were presented on humane treatment in hospitals and rehabilitation centres. There is no research available on care in the community for this group. So when healthcare providers look for evidence-based protocols, they will only find evidence for humane stroke care in hospitals and rehabilitation institutes. Care in the community will not be con-

sidered as an option because there is no research and thus no evidence.*

Canada's narrow definition of Medicare is an impediment to coping with chronic diseases. Quality care for people with complex chronic conditions requires access to care before the situation becomes acute. It means a regular provider and team, ongoing multiplatform communication, assistance with transitions of care, partnership with patients and families, and lots of resources in the community for ongoing support. Instead, what we see are steadily increasing hospital budgets to deal with all the people who arrive there inappropriately because they lack community care. This vicious circle is depicted in Figure 1: increased pressure on urgent access and a need for more resources and money that have to come from other services, which means taking them away from non-urgent support.
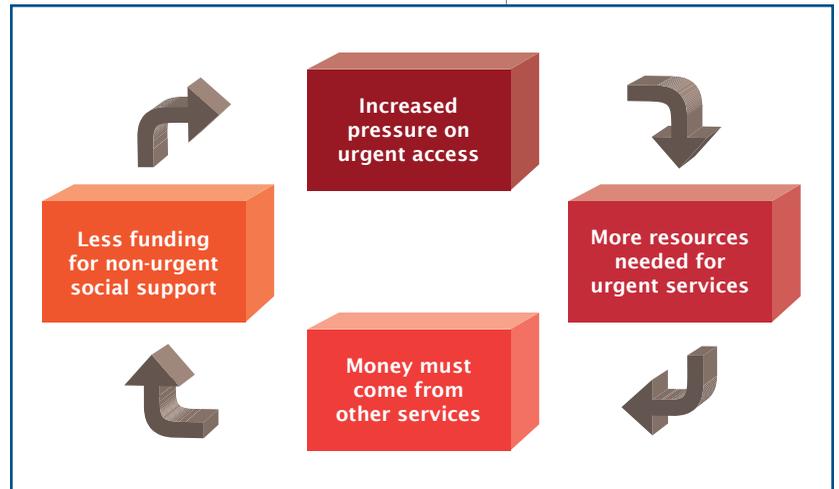
Patient-centred care

The actual structure of the healthcare system is the biggest impediment to patient-centred care. Everything from the providers in hospitals and primary care to the researchers and the structure of research makes it much harder for things to change. The definition of what constitutes a health system is so narrow that it does not recognize changes and needs that occur outside that rigid system.

We have to start to think about the healthcare system in a much broader way and recognize what is *not* there as well as try to improve what *is* there. This begins by acknowledging that Canada does not have universal coverage, as defined by the WHO. Then it becomes possible to start looking at what is missing by focusing on the patient.

Patients Canada

Patients Canada is committed to changing the healthcare system. We listen to patients' experiences and hold a monthly

Figure 1

A vicious cycle

Canada's narrow definition of Medicare is an impediment to coping with chronic diseases.

advisory panel meeting involving patients, researchers, sometimes doctors and leaders, to talk about what needs to be done to make the patient's experience better and try to understand the 'lacks' that patients express. What are the things that are missing? From that, we try and develop very clear and concrete things that can be changed to improve the patient experience, and we broadcast them.

Patient partners

Patient partnerships are blossoming across Canada, in medical education, research, hospitals, primary care and health districts. These efforts call for a particular type of patient partner. Patients Canada encounters three kinds of patient partners. Very typical patients are only concerned with their own condition. They ally themself with their doctor and their condition and sit on patient councils primarily to fight for their particular cause. That makes it difficult for the patient to get a

Universal coverage

The World Health Organization (WHO) defines universal health coverage as ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health service they need of sufficient quality to be effective while also ensuring that the use of these services does not expose the user to financial hardship.
— *Sholom Glouberman*

Figure 2
A virtuous cycle

From patient experience to key performance target

STEP 1: The patient experience

This experience involves a grandfather of five with type 2 diabetes who lives in the community with his wife. One day he looks pasty and feels tired and when his wife checks his blood sugar, it is 16, which is too high. She calls the family doctor but cannot get through. When she checks his blood sugar again, it has reached 23, which is much too high. She finally reaches the family doctor who tells her to bring him to the emergency room (ER).

The patient comes in through the ER in an ambulance, on a gurney. In triage there is no space for the wife, so he tells his story but the wife is not there to help. She can only be there for visiting hours and she follows the rules and brings no food. He hates the food and loses 25 pounds in three weeks. And he does not walk around much because he is wearing a hospital gown where his bum is sticking out. So he stays in bed. He comes home after four weeks in hospital, and his family wants to take him home by ambulance because he can hardly walk, but the ambulance would cost $500 so they stuff him into a taxi and bring him home. He is an invalid at home, with occasional visits to the ER. In the last week of his life he is brought to a nursing home and his family purchases a wheelchair at the drug store. Then he dies. They want to give the wheelchair to the nursing home but the home cannot take it because it is used.

STEP 2: Discussion

At Patients Canada, we discussed this story extensively and found all kinds of things that could be made better. One of the concrete things we extracted from the story was that there should be a third chair in the triage position. There is a chair for the nurse and one for the patient,

full picture and to really help the general patient movement. The second kind of patient is the one who becomes part of the establishment, for whom the doctor and hospital can do no wrong. The third kind of patient are those who want to give back because of the very good care they received and/or who do not want

> **The third kind of patient is somebody who wants to give back because of the very good care they received and/or who does not want anyone else to suffer the bad experiences they had. These people are good candidates for patient partnerships.**

anyone else to suffer the bad experiences they had. These people are good candidates for patient partnerships and Patients Canada, like other organizations, works very hard to involve them. We work with and develop the patient leaders based on a deep appreciation of the patient experience. Everything we do comes from patient experiences and we are developing a rich understanding of the system.

but most ERs do not have a chair for the family member. That is a concrete change that can be measured.

The rules about food in hospital should be changed so that family members can bring patients food from home. The Mayo Clinic has done this. There should be open visiting hours, as advocated by the Institute for Patient- and Family-Centred Care. Transport from the hospital should be provided. There should be support to retrofit homes for patients who are compromised. There should be much more support for family caregivers. There should be a clear way to contact the primary care team and make appointments online. A group of engineering students heard the story and proposed modular mobility supports, where pieces would be reassembled, and there would no longer be such a thing as a "used" wheelchair.

STEP 3: Create targets

Patients Canada creates key performance targets based on patient stories and works with organizations to see them implemented. The group is having an impact: working with Accreditation Canada to develop a new series of standards for patient-centred accreditation that will come into effect in 2016; contributing to the development of new primary care performance indicators at Health Quality Ontario; advising the Ministry about parking fees for patients and visitors. The Canadian Institutes for Health Research

is funding Patients Canada to develop key performance indicators, and some of these indicators have been adopted in patient-centred institutions — there is now a third chair in triage at the Kingston General Hospital ER.

Things are changing in bits and pieces. Canada Health Infoway is subsidizing family practices that allow patients to make appointments online; 800 practices have taken it up and a second tranche of funding is being released. In Nova Scotia, the Ministry is funding some primary care groups to give people access to their health records online. The aim is to move into a virtuous cycle (Figure 2 on page 8), where increased funding for social support leads to decreased pressure on urgent

> **It is not a matter of a massive restructuring, but rather about getting the money to flow in a different way.**

access, which stabilizes resources for urgent services and frees up money for other services. It is not a matter of a massive restructuring, but rather about getting the money to flow in a different way. Patients Canada is trying to get that to start with small interventions that will change the mindset of organizations so they become less demanding and start to recognize the changes that are needed, within and outside their walls. ■

* I sat on a Canadian Institutes for Health Research board where they were trying to introduce the accreditation of CLSCs (Quebec's local community health centres). I fought hard against it and succeeded in not having that research started at that time. But in the end, they completed the research and it became one of the evidence bases for the report that said that CLSCs were all different, were not standardized, and so could not be accredited properly and should be closed down. The researchers did not recognize the impact this would have or the fact that the CLSCs were a world-renowned piece of structure in Canada. To think that research has no consequences is a mistake. The destruction of the CLSCs in Quebec as independent community-based agencies was one of the biggest and most horrific changes to happen in Canadian policy.

Do you want to become a member of Patients Canada?

Membership is open to patients, family members, caregivers and providers. You are encouraged to contribute your experience with health care to help create a better understanding of how the health system should be improved.

Find out more: **www.patientscanada.ca**
Contact: **communications@patientscanada.ca**
Tel: **416-785-2500** ext. **5278**

Patients Canada
Make your experience count

Patient engagement to improve quality and performance

Ross Baker sees patient engagement as a key component in the transformation of our healthcare system

G. ROSS BAKER

Professor, Institute for Health Policy, Management and Evaluation, University of Toronto, Ross Baker, PhD, teaches and carries out research at the University of Toronto on patient safety, quality improvement, and leadership and organizational change. Director of the university's MSc Program in Quality Improvement and Patient Safety, his recent research projects include a study of patient engagement in leading organizations in North America and the UK; an assessment of governance in Ontario primary care; a study of contributing causes for medication and fall incidents in home care; and a synthesis of literature on physician engagement in healthcare organizations. He co-led the 2004 Canadian Adverse Events study, winner of the CFHI Health Services Research Advancement Award, and has been a board member of Saskatchewan's Health Quality Council since 2005. Dr. Baker has also served as a member of Great Britain's 2010-2011 King's Fund Commission on Leadership and Management in the UK National Health Service (NHS).

All healthcare systems currently face a challenge to improve the quality of health care without spending more money. This challenge requires that everyone, from system leaders to frontline staff, participates in reworking the design of healthcare delivery at a team level, an organizational level and a system level. This work needs to be aligned across the system, but it is the front line, in partnership with patients, that will make the biggest difference. Thus patient engagement is one of the critical issues in our healthcare system and one of the key components of the transformation of our system to fit the 21st century.

Health care has changed considerably in the last 40 years, but in many organizations there continues to be a resistance to reorganizing care, stemming from professional hierarchy and a commitment to the status quo. This resistance undermines our ability to reshape the delivery of care. However, these barriers will be broken down if the conversation includes informed patients — people who receive care and who are interested in the outcomes and the experience and not the titles of the people who are providing the care. Patient engagement is critical to the transformation and redesign of the system.

In 2001, the Institute of Medicine in the US released a seminal report, perhaps the most important report in this decade in terms of setting directions for healthcare systems around the world. The report, *Crossing the Quality Chasm*, identified six dimensions of quality in health care: health care has to be safe, timely, effective, efficient, equitable and patient-centred. Of those goals, creating patient-centred care has proven especially challenging. The website of every organization proudly proclaims that patient centredness is at the core of its mission, but the experience of patients on a day-to-day basis is often very different.

Figure 1

The continuum of patient engagement

Patient engagement is more than patient-centred care, it is the involvement of patients in the design of care, including participation in improvement projects.

Complaining — Giving information — Listening and responding — Consulting and advising — Experience-based co-design
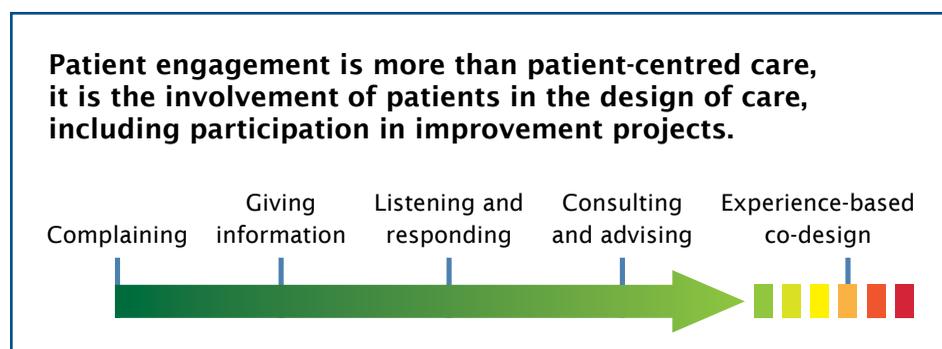
Bate and Robert, 2006

Achieving successful patient engagement

Despite the challenges, there has been a growing number of successful efforts to engage patients. Paul Bate and Glen Robert provide a useful way to categorize these efforts in a continuum (see Figure 1 on page 10) that describes how providers can interact with patients. On the left side are strategies to collect information from complaints or surveys. On the right are efforts to partner with patients to redesign the way in which care is provided within the organization. At the far right end of the spectrum is the engagement of patients in the design of care for people like them. For example, if you have multiple sclerosis, how can you help us design the care we are providing to all patients with multiple sclerosis? These more intensive forms of patient engagement were the focus of a series of case studies my team undertook to look at patient engagement efforts in Canada and abroad.[1]

The questions that guided our research included:
- What is unique about patient- and family-centred care and involvement in these different centres?
- Does the policy regime in these various countries make a difference to local efforts?
- What strategies are they using to engage patients?
- What impact does patient engagement have on service delivery?
- What factors contribute to the effectiveness of these different efforts?

Our high-level findings suggest that there are three critical processes that must be present in order to have true patient engagement for effective care (Figure 2). The first is that organizations have to develop processes to identify, recruit, orient and support patients who are coming to work with them on the redesign of care. Second, organizations that have been

Figure 2
Critical processes for patient engagement
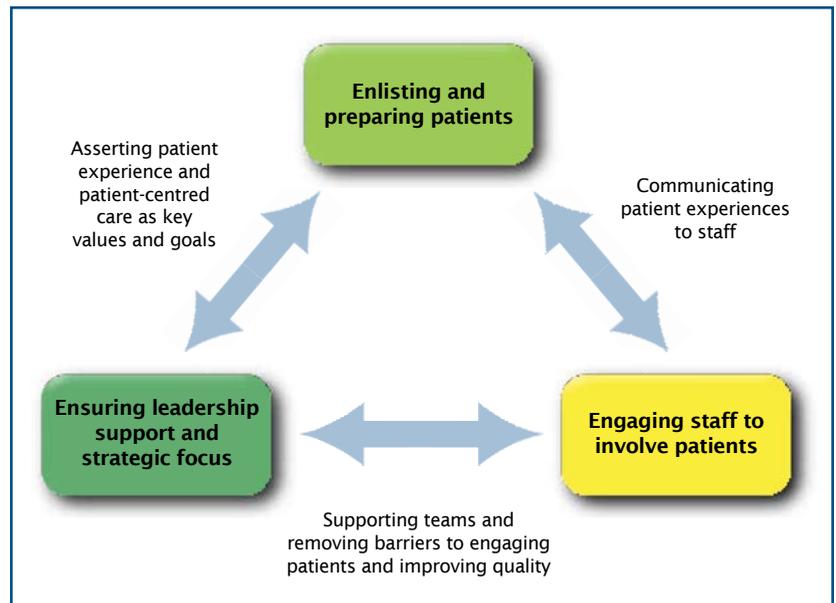
successful at patient engagement have developed staff or patient advisors who help to orient, support and integrate the work of patients into the ongoing work of the organization at all levels. Successful organizations help staff become full partners with patients, persuading them that

> **In many organizations there continues to be a resistance to reorganizing care, stemming from professional hierarchy and a commitment to the status quo.**

the way to a different future is by understanding how to have this deep conversation with patients. Experience-based co-design is a promising strategy that puts patients and staff together on improvement teams working to make a difference in the community and in hospitals. Third, and critically important, is ensuring leadership support for these efforts. Leadership is the glue that holds the rest of the pieces together. You can have isolated bright spots of performance without senior leadership support but you cannot have

REFERENCE
1. Baker, GR. Evidence boost: a review of research highlighting how patient engagement contributes to improved care. *Canadian Foundation for Healthcare Improvement Newsletter*, August 2014.

> **Experience-based co-design is a promising strategy that puts patients and staff together on improvement teams working to make a difference in the community and in hospitals.**

organization-wide engagement without the full backing of leadership. In leading organizations, patient engagement efforts are integrated into organizational work. There are patients on all committees, who are part of the important conversations and contribute to the key decisions.

Quality improvement opens the door to a new relationship between patients and staff because it provides the tools that allow people to understand how they are currently working and how they might work differently. Quality improvement training and projects offer an opportunity to level the playing field between staff and patients because they can learn together. The McGill University Health Centre's experience with the Transforming Care at the Bedside program (TCAB; see pages 20 and 41) has many of those elements: partnership between staff and patients, learning the tools, applying these tools to the local setting and then looking together at how to improve care. Cincinnati Children's Hospital has achieved enormous success in integrating patients into their improvement efforts across the organization. Similarly, the Saskatoon

Health Region has been integrating patients into their Lean rapid process improvement workshops so that the patient is a participant in those improvement efforts.

Leadership

What skills do leaders need to ensure successful patient engagement? Leaders need to create a coherent picture so that staff, patients and the community know where the organization is going, how it is getting there and what progress it is making. Leaders encourage and support staff in engaging patients and organizing improvement efforts. Leadership at the top is not enough; it must be distributed across the organization to make sure that nursing leaders, chiefs of medicine, heads of pharmacy and others are all aware of how their attitudes and efforts contribute to this larger work. As Ron Heifetz, a leadership expert at Harvard, says: "What interests my leader fascinates me." Everybody looks to the people who are their leaders to find out what is really important and that creates the environment needed to move forward.

Patient engagement efforts that make a difference in the care that is delivered to broader populations of patients are just beginning to take root. These efforts have the potential to transform our systems of care, creating better outcomes and better patient and staff experiences. ∎

Examples from the US and UK

One example of a system that has succeeded in engaging patients effectively is Georgia Regents Health System, a medical school and hospital in Augusta, Georgia. Georgia Regents has been working for 20 years on patient- and family-centred care and now has more than 200 patient and family advisors working throughout the organization, and staff who support those advisors. What has changed in Georgia Regents is the culture of decision-making. If a critical decision is being made in any area of the hospital, staff are asked: what do the patients think about this? What input do you have from them on the nature of this decision?

Another leading organization is Northumbria Healthcare Trust in Northeast England, where staff work with user groups, not just in the hospital but also in the community. In a project to improve stroke care, they discovered that change was needed not only in the hospital, but also once patients left the hospital in order to ensure a smooth transition. On one level this insight seems obvious, but many organizations in Canada and elsewhere are trying to convince their staff that they need to be responsible for the outcomes of patients after discharge. Engaging and understanding patients provides an important mechanism for achieving this new mindset.

The HCAHPS Survey: Measuring patient experience of care

Susan Usher traces the development and implementation of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey in the US, and its adaptation for use in Canadian hospitals

The Agency for Healthcare Research and Quality (AHRQ) launched the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program in 1995 in response to concerns about the lack of good information about the quality of health plans from the patient's perspective in the US. In 1998, the survey became part of National Committee for Quality Assurance accreditation, and Medicaid, the Federal Employees Health Benefits Program and the Department of Defense began requiring use of the CAHPS survey.

That first survey focused on health plans, however beginning in 2002, the Centre for Medicare and Medicaid Services (CMS) partnered with the AHRQ to develop and test the Hospital CAHPS or HCAHPS Survey. It was developed with public input and tested extensively with different groups. The survey, its methodology and the results it produces are in the public domain.[1]

HCAHPS provides a national standard for collecting information on patients' perspectives of inpatient care that enables comparisons of topics that are important to consumers across hospitals and over time. Public reporting of the survey results is designed to create incentives for hospitals to improve their quality of care and increase accountability for public funds.

With these goals in mind, the HCAHPS project has taken substantial steps to assure that the survey is credible and practical. A review of studies on HCAHPS published in 2005 confirmed that "the availability of comparative quality information on health plans and providers has

the potential to support and improve decision-making and quality improvement activities."[2]

In 2005, the National Quality Forum (NQF), an organization established to standardize healthcare quality measurement and reporting, formally endorsed the HCAHPS Survey and the Federal Office of Management and Budget gave its final approval for the national implementation of HCAHPS for public reporting purposes. The first public reporting of HCAHPS results occurred in 2008. Hospitals that provide government-paid services must collect and submit HCAHPS data in order to receive their full annual payment. The Patient Protection and Affordable Care Act of 2010 specifically included HCAHPS performance in the calculation of the value-based incentive payment. Use of the survey has increased substantially. In 2008, 2,421 hospitals publicly reported HCAHPS scores based on 1.1 million completed surveys. In 2013, 3,928 hospitals (of a total of about 6,000 in the US) publicly reported HCAHPS scores based on 3.1 million completed surveys.

HCAHPS in the McGill University Health Centre's TCAB program

When Patricia O'Connor, then Director of Nursing at the McGill University Health Centre (MUHC), initiated the Transforming Care at the Bedside (TCAB) program in 2010, she considered that the patient satisfaction surveys in use in Quebec provided little actionable information to help staff and physicians identify areas that required

The Survey

HCAHPS is administered to a random sample of adult inpatients between 48 hours and six weeks after discharge. The HCAHPS survey used in the US contains 32 questions and touches on 11 key topics:

Seven composite measures
1. Communication with doctors
2. Communication with nurses
3. Responsiveness of hospital staff
4. Pain management
5. Communication about medicines
6. Discharge information
7. Transition of care

Two individual items
8. Cleanliness of the hospital environment
9. Quietness of the hospital environment

Two global items
10. Recommend the hospital
11. Overall hospital rating

The survey also includes screening questions and demographic items, used for adjusting the mix of patients across hospitals and for analytical purposes. The survey can be administered by mail, by telephone, by mail followed up by telephone, or by interactive voice response.

HCAHPS results are publicly reported four times a year on the Hospital Compare Website at www.medicare.gov.

A demanding survey

As an example of the survey's demands, responsiveness is measured by two questions:

1. During this hospital stay, after you pressed a call bell, how often did you get help as soon as you wanted it? (never, sometimes, usually, always, I never pressed the call button).

2. How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted? (never, sometimes, usually, always).

Scores

The scoring system, referred to as "topbox," refers to the percentage of respondents who gave the highest response possible on the survey item. For example, to get a positive rating on responsiveness of care, the patient has to choose "always" on both of the items on that topic.

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1. www.hcahpsonline.org/files
2. Lake, Tim, Chris Kvam and Marsha Gold. *Literature Review: Using Quality Information for Health Care Decisions and Quality Improvement — Final Report.* Mathematica Policy Research. Cambridge, MA. May 6, 2005.
3. www.cihi.ca

improvement. She looked to the HCAHPS survey tool used in the US as a means of monitoring progress on patient experience of care. Accustomed to very good results on patient satisfaction surveys, the first results from the HCAHPS surveys at the MUHC were a reality check. "It was very humbling for us to see our results. We were far below the US benchmarks on items like communication with nurses and physicians. Yet, in other areas, we performed very well. This survey revealed 'the good, the bad and the ugly' and proved very useful in identifying problem areas that TCAB teams then targeted for improvement. The first wave of TCAB implementation achieved a 20% increase in staff responsiveness results."

In 2012, the MUHC became a beta test site (along with Harvard and the Boston Children's Hospital) for the pediatric version of HCAHPS, which was under development at the AHRQ when TCAB leaders were looking at an appropriate survey to use at the Montreal Children's Hospital.

HCAHPS comes to Canada

Interest in patient experience surveys has been growing across Canada over the past few years. In 2011, at the request of a number of provinces, the Canadian Institute for Health Information (CIHI) began development of an acute care patient experience survey, using the American HCAHPS survey as a base. CIHI worked with Accreditation Canada, the Inter-Jurisdictional Patient Satisfaction Group, the Canadian Patient Safety Institute and The Change Foundation in the development process.[3]

Called the Canadian Hospital Experience Survey (CHES), the questionnaire includes the 23-item HCAHPS survey, 19 questions that address key areas relevant to the Canadian context and seven questions to collect demographic information. It will provide standardized data on patient

The Canadian Hospital Experience Survey

HCAHPS domains
- Communication with nurses
- Communication with doctors
- Physical environment
- Responsiveness of staff
- Pain control
- Communication about medications
- Discharge information and care transition
- Ratings
- Rate hospital from worst to best
- Would you recommend this hospital to family and friends?

Additional domains
- Admission to hospital
- Person-centred care
- Discharge and transition
- Outcome
- Global rating
- Demographic questions

experience in hospital to guide quality improvement efforts internally and enable national comparisons.

CIHI has pilot-tested the survey in English and French, and four provinces (Alberta, British Columbia, Manitoba and Ontario) will be implementing it in 2014–15. The French survey was pilot-tested in New Brunswick. The CHES will not be mandatory, though Accreditation Canada has, since 2012, required that hospitals implement a reliable measurement of patient experience. ■

Patient experience, quality and safety

Dr. James Merlino describes efforts at Cleveland Clinic to understand how patients experience care

Five years ago, Kelly Hancock, our Chief Nursing Officer, and I started to focus on improving patient experience at Cleveland Clinic. We undertook two studies to help figure out the voice of the patient. In the first, we hired a company to go back to all patients who had completed a hospital stay and filled in the HCAHPS survey (see page 13), and ask exactly why they answered the way they did for every question. The second was an ethnographic study, conducted by researchers who sat on one of our worst floors and observed staff, patients and their interactions.

What do patients want?

Respect

One key finding from those studies was that patients wanted more respect. On the surface, that is not a very helpful finding, but when we delved into it, we found that respect meant being treated as individuals, and not being depersonalized during their hospital stay. They want us to know that they have spouses, families, kids, hobbies and a life. They want that because they think we will care more and will be more concerned about their safety.

Communication

Patients want us to communicate better, and that is not just the doctor or nurse communicating better with them: they want the nurse and the doctor to talk to each other. Patients are unsophisticated healthcare consumers, and what they do is judge us based on things they understand. If the doctor walks into a patient's room at 7:00 and tells him something and the nurse comes in at 10:00 and the patient asks the nurse "What did the doctor say?" or "What's the plan?" and the nurse does not know, the patient concludes that if the doctor and the nurse do not talk to each other, they cannot possibly deliver high quality care at the hospital. That is a proxy measure.

Happy people

If a doctor walks into a room and appears angry, patients are going to ask fewer questions or not engage because they do not want to make the doctor more angry. If a nurse walks into a room and is rushed, patients are not going to engage because they do not want to hold the nurse up, thinking they are going to make the nurse angry. So patients want us to be consistent.

Patients first

When we started thinking about improving things at the Cleveland Clinic, our CEO Dr. Toby Cosgrove coined this motto of Patients First. What he wanted to do was create a burning platform purpose for the people who come to work every day. His point was that if you come to the Cleveland Clinic to work it does not matter what you do, whether you are a doctor, nurse or maintenance person; you are there for patients, because that is what we do: we deliver care for patients. Today, health care is about high-performing teams of people working together because medical delivery is very complex and requires teams of people. The purpose of Patients First was to create that alignment of why we exist.

JAMES MERLINO

Chief Experience Officer and Associate Chief of Staff of the Cleveland Clinic health system, James Merlino, MD, is also a practising staff colorectal surgeon at the Digestive Disease Institute in Cleveland, Ohio. As a member of the executive team, Dr. Merlino leads initiatives to improve patient experience across the Cleveland Clinic's health system and heads efforts to improve physician-patient communication, patient access, relations with referring physicians and employee engagement. He is the Founder and current President of the Association for Patient Experience. In 2013, Dr. Merlino was named to *Health-Leaders* magazine's list of "20 people who make health care better" in recognition of his role as a world leader in the field of patient experience.

Figure 1
Interactions along the care trajectory
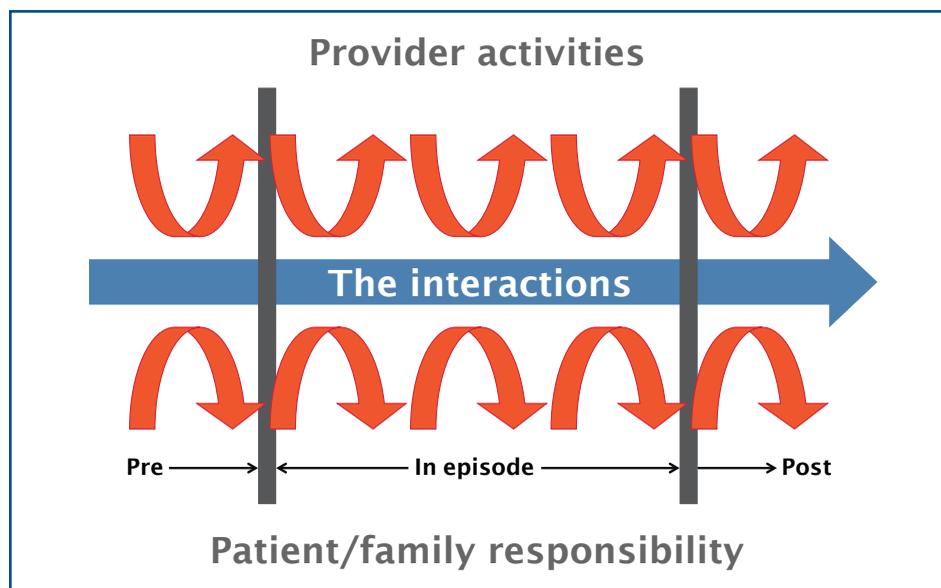
What is patient experience?

Patient experience is not about making people happy. It is about delivering safe, high-quality care, in an environment where patients and families are satisfied, to ultimately drive value and everything else we do in health care.

The HCAHPS survey, as it is administered and required in the US, has nine questions that relate to how providers communicate

> Patient experience is not about making people happy. It is about delivering safe, high-quality care in an environment where patients and families are satisfied.

to patients: three for physicians, three for nurses, and three around new medication. If the HCAHPS survey were about measuring happiness, certainly we would not need to ask nine questions about how we communicate. When we improve how nurses communicate at the bedside, medication errors go down, falls go down and pressure ulcers go down. And those are safety issues. When physicians communicate with patients more effectively, compliance with treatment goes up; when they

communicate with families, compliance goes up; and when physicians communicate and coordinate care with nurses, quality of care improves. These are obviously quality issues. And when we communicate better, patients are more satisfied.

When you introduce best practices that deliver on safety, quality and patient experience, you drive effectiveness, efficiency and better value. That is why Medicare in the US has rolled out the HCAHPS survey.

How do you improve patient experience?

Health care is full of silos and our responsibility is to get them to link together. It is taking what we do from a vertical perspective and turning it on its side so we understand how we connect to what the other person is doing (Figure 1). It is about driving better processes and tactics, aligning our people and culture, and bringing patients into the fold.

Driving improvement
Processes and tactics come in two forms. The first involves the everyday things that hospitals are required to do; and

figuring out how to fix broken processes. The second is identifying processes or tactics that should be added on to improve what is already being done.

Evolving culture

Aligning the culture is probably the most important thing we have done to effect change. Culture can be presented as development or evolution rather than change in order to make it less of a criticism and more of a way to plan for the future. You have to engage with each of the powerful (and, yes, tribal) healthcare provider groups to figure out what drives development and evolution, because they each respond to something different.

Engaging patients

There are all kinds of different terms to describe how we work with patients. We have talked about educating them, engaging them, empowering them, activating them. I like the term partnership because ultimately we need patients to help us be better. Imagine if every family member coming to visit a loved one in the hospital understood that healthcare providers not washing their hands causes infection. So that when healthcare providers walk into the room and do not wash their

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**Partner:
One that is united with another in an activity of common interest.** — *WEBSTER'S DICTIONARY*

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hands, the family member stops them and says "Wait a minute, you didn't wash your hands, don't touch my loved one." Imagine if every patient, before receiving a medication, asked the nurse "What is that medication for? What does it do? What are the side effects?" and the nurse responded.

Patient engagement is about changing the relationship (Figure 2), going from information asymmetry to information symmetry where patients have access to an electronic health record and help to understand how to use it. It is about going from passive recipient of information to active partner where patients are challenging us and participating in care. As a resident, I hated it when I walked into a patient's room and was asked a lot of questions. However, that makes us better. We should demand that patients ask us questions because it prevents us from forgetting things. We have to move from a model of paternalism to participation, incorporate what is important to patients and take the time to hear their voice. ■

Figure 2
Relationship change

OLD		NEW
Information Asymmetry	→	Information Symmetry
Passive Recipient	→	Active Partner
Paternalism	→	Participation
Patient Physician	→	Consumer Health Care Team
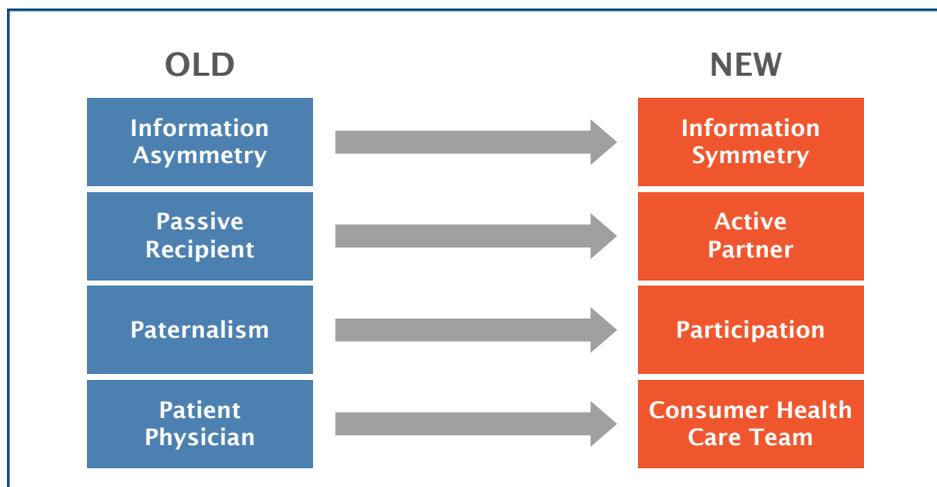
The Association for Patient Experience

Dr. James Merlino founded this organization, sponsored by the Cleveland Clinic, to seek, test and share solutions to improve the patient experience. The Association website presents case studies and best practices. Premium membership (US $75/year) provides access to webinars. In 2014, the Association launched the *Journal of Patient Experience*, available online, to provide practical information to healthcare providers and patients to improve the patient experience.

Find out more:
www.patient-experience.org

Association
for PATIENT EXPERIENCE

Patient engagement in hospital decision-making at Kingston General Hospital

Angela Morin describes the role of patient and family advisors

ANGELA MORIN

As Patient and Family Experience Advisor, Kingston General Hospital, Angela Morin, BA, has partnered with healthcare professionals and provided input into quality improvement, program development, and policy and facility design at Kingston General Hospital since 2011. She currently sits on the Kingston General Hospital and Southeast Regional Cancer Centre Patient and Family Advisory Councils, as well as Accreditation Canada's Client and Family-Centred Care Advisory Council. She is a faculty member for the Canadian Foundation for Healthcare Improvement's "Partnering with Patients and Families for Quality Improvement" collaborative.

I am one of approximately 60 volunteer patient and family advisors at Kingston General Hospital (KGH). In Kingston, we as advisors are partnering with our healthcare organization to help improve the patient and family experience and make the hospital care system safer and better.

What motivates someone with no healthcare background to volunteer hours every month to be a patient and family experience advisor? In my case, it was Bonnie, my friend who was diagnosed with breast cancer in 2010. For a year and a half, I went with her to her many appointments. I listened, monitored, recorded, tracked, supported, communicated and advocated on her and her family's behalf.

Bonnie and I started out frightened, stressed, intimidated and overwhelmed. We had to find our way through the healthcare labyrinth. The longer we were in that labyrinth, the more questions we had. In particular, why is this system so difficult to navigate?

The more we questioned the system, the less confidence we had in it. I voiced my concerns and frustrations to a friend, who connected me with Darryl Bell, the lead for patient experience at KGH. I was introduced to a way to use my experience and voice to make the system less frightening, less overwhelming and a lot more patient- and family-centred. I found a like-minded group of individuals, advisors who had valuable experiences to share and learn from. There were former patients and current patients with chronic conditions, family members who had lost a loved one, caregivers and survivors, all engaged in their own way, all wanting to make things better for those who follow.

Patient and family experience advisors have a sincere desire to help make the process better. We are not here to complain but to advise, to share our concerns and experience in order to make a positive difference in the healthcare system.

Hospital leaders, staff and stakeholders are now including us in the conversation, listening to our stories and soliciting our input. I have sat on operating room scheduling, staff education, patient support, employee hiring, website development and model of care committees. Last year, I participated in a forum presenting feedback to managers and staff directly involved in a surgical experience I had. I was able to tell my story to highlight what I felt had gone well or not so well. It was a unique opportunity to share my perspective, the patient perspective, and feel heard in a meaningful way.

As patient and family experience advisors, we ask questions, bring unique insights and often voice the reality of what is happening, not the intention. At KGH, we are encouraged to be bold. As the culture has changed, we have stopped being the patients they are afraid to hear from; now, we are the patients they want and expect to hear from. There has been a clear shift from the attitude of "Why would we engage patients?" to "How can we engage patients?" and "How can we do it better?"

> **We are not here to complain but to advise, to share our concerns and experience in order to make a positive difference in the healthcare system.**

Eleanor Rivoire looks at essential supports for patient engagement

Strategy

One of the winning conditions for effective partnership with patients and families at Kingston General Hospital (KGH) has been our strategy. It was developed in an engagement process that involved roughly 2,000 voices and is a living, dynamic tool. Our advisors and staff can speak meaningfully about what the strategy is and what is expected of them. It defines the principles that guide the behaviour of every person within the organization.

Improvement metrics

Within the organization, there is a performance improvement mindset. We focus on improvement initiatives where time, energy and resources are aligned to enable their success. The initiative to improve patient experience, for example, focuses on five specific organizational practices or standards as areas for improvement. Our Patient and Family Advisory Council defined these priorities, and we now have metrics that enable us to measure progress on specific changes and report back to the organization. That infrastructure, with clear accountabilities, is key to success.

Recruitment mechanisms

The three individuals at the inception of our patient engagement efforts became the architects of what our Patient and Family Advisory Council is today. They partnered in the design of the role description for advisors, and are now part of the recruitment of advisors, as well as staff. When the approach to partnering is seen and felt to be authentic, there is no shortage of candidates. The process needs to support recruitment of advisors who reflect the population the hospital serves.

Training

The organization must support advisors. When you want patient advisors to be part of a design team and you teach your whole organization Lean training or continuous improvement change, patient and family advisors are disadvantaged unless they receive the same learning. All of the voluntary advisors who are part of design teams share in the same training and expectations as other team members.

A place

Once we began partnering with patient and family advisors, we realized they needed a specific space in the hospital. Their office on a high-profile, highly trafficked hospital corridor sends a clear message of their standing, their value and what our organization is about.

Voice in policy

At KGH, all policies, from the board level to human resources to clinical practice, reflect the patient perspective. Typically, the teams making or revising policy include advisors or ensure consultation with advisors. Policies such as the family presence policy (visiting hours) have been strongly influenced by the patient advisors. The KGH made the commitment to include a patient advisor in every hiring decision. As a result, our role descriptions have changed to include the requirement to support the premise of patient- and family-centred care and patient partnership. As an outcome, the language and discussions within the organization have changed.

Distributed leadership

All staff are encouraged and taught to assume patient-centred leadership and incorporate learning from patients into their everyday routines: talking to patients, learning from their experiences, hearing opportunities, sharing those with someone who can influence change and taking on change themselves. This has helped staff stay connected to why they came to work in a hospital.

We used to talk about patients being the great untapped resource of the health system. At Kingston General Hospital, we have tapped into this resource. ■

ELEANOR RIVOIRE

Executive Vice President and Chief Nurse Executive, Kingston General Hospital, Eleanor Rivoire, RN, MSc, has more than 35 years of experience in the clinical, education and administrative domains of professional practice. Expertise in transforming patient experience has led her to a focus on patient engagement, patient- and family-centred care, and models of interprofessional practice and education. She is currently engaged in leading innovative changes at Kingston General, bringing about improved hospital quality and safety outcomes.

Patients as partners in co-designing care processes at the McGill University Health Centre

Patricia O'Connor describes how the Transforming Care at the Bedside program nurtures collaboration between staff and patient advisors

PATRICIA O'CONNOR

Senior Advisor for Patient Engagement and the McGill Nursing Collaborative, MUHC, Patricia O'Connor, RN, MScN, CHE, FCCHL, formerly the Director of Nursing for the MUHC, is an Associate Professor in the Ingram School of Nursing at McGill, a Certified Health Executive, and Past President of the Academy of Canadian Executive Nurses. She has completed fellowships with the Canadian Foundation for Healthcare Improvement (EXTRA program), the Canadian College of Health Leaders (CCHL) and the US Commonwealth Fund. In 2012, Ms. O'Connor was recognized as one of the Top 8 Women in Business in the Healthcare Sector in Quebec, and in 2014, she was awarded the CCHL National Nursing Leadership Award.

At the MUHC, The Transforming Care at the Bedside (TCAB) program (see also Case Study, page 41) has, between 2010 and 2015, touched 45% of the clinical units across its six hospitals. It provides patients and staff the opportunity to team up and improve quality of care, patient experience and staff work life. Frontline interprofessional care providers and patient representatives form each team, and together are trained in quality improvement and change management processes via structured learning modules over a period of 12 to 15 months. TCAB facilitators provide coaching support, encourage patient advisor participation and teach simple measurement tools that can be used to track progress. Every week, staff and patient representatives conduct tests of change as they introduce improvement ideas. Patient representatives also play a role in gaining feedback from current and recently discharged patients. In the words of one patient representative: "I feel as

> **Frontline interprofessional care providers and patient representatives form each team, and together are trained in quality improvement and change management processes.**

if my opinion is important in all the decisions that are taken (by the TCAB team). Together, we worked on the reorganization of the ward. It feels heartwarming to know that, as a patient representative, my opinion counts and that the healthcare professionals are working hard to improve

the hospital environment for patients and their families."

Mario Di Carlo, a patient representative, and Tina Kusaian, a TCAB facilitator, described TCAB work on improving admission and discharge processes in a stroke unit. It began with a process-mapping exercise to identify all the tasks undertaken in preparation for discharge, place them in relationship to each other and organize them into "swim lanes." The team voted on which areas to address first and worked to improve that step in the process. They determined that a discharge checklist was needed to help staff remain organized. The patient member of the team developed a plan to spread the teaching that staff provides to patients across the hospital stay rather than cramming it into 20 minutes immediately before they leave. That was enthusiastically adopted by the staff and, as Mr. Di Carlo states, "Patients leave much more confident about what they have to do."

Brenda MacGibbon, a patient representative who worked on the redesign of the family visiting room in the oncology unit, feels that "TCAB has really changed the culture of acceptance of patient representatives." Universally, staff appreciated patient advisor involvement. In addition, we saw significant growth in the leadership competencies of frontline staff to lead quality improvement. Scores on empowerment, global work satisfaction and team effectiveness also improved through the TCAB program. The nurses' union has been especially enthusiastic because the program addresses frontline nurses' experiences and builds their competencies and skills.

The TCAB experience showed that partnering with patients leads to different insights and better ideas. The investments to build improvement capacity with direct care providers and patients have led to shared responsibility and a distributed leadership model that contributes to operational effectiveness and improved performance.

Staff responsiveness, as measured using the HCAHPS survey (see page 13), improved by as much as 20% in some implementations. Time spent in direct care by registered nurses, a key objective of TCAB, increased. Data had never before been collected on how much time nurses spend in different activities. Use of personal digital assistants (PDAs) enabled us to create that data and improvements can now be measured against that baseline.

External funding was required to implement TCAB, notably to pay for protected release time. The Canadian Foundation for

> ## Universally, staff appreciated patient advisor involvement.

Healthcare Improvement, the Quebec Ministry of Health and Social Services, the Canadian Institutes of Health Research, the Max Bell Foundation, the Newton Foundation, the Roasters Foundation and the foundations of the MUHC hospitals all contributed to supporting the implementation of TCAB. ∎

Elements of success

Time taken to **build stakeholder engagement** before the program launch.

Direct involvement of patients with frontline staff in quality improvement efforts. Co-learning with patients meant that patients were better equipped to participate in teams, and staff were more willing to include them after they had gone through the teaching modules together. Patient advisors were recruited locally, and were present in all unit-based sessions.

Protected release time one day per week during the program for staff, so that their participation did not increase workload for the other staff.

Facilitator support: every unit had a TCAB facilitator to serve as a resource person and help teams determine measurements to track progress.

A structured approach: TCAB at the MUHC borrowed the best ideas from both the Institute for Healthcare Improvement's

TCAB program and the more structured Releasing Time to Care program in the National Health Service (UK). Four modules (eight to 10 weeks duration each) included workshops and weekly hands-on learning related to: rapid cycle improvement processes; Lean 5S to improve the physical environment; patient experience of care; and process mapping of admission and discharge processes. There were clear deliverables for each module. Teams learned how to do simple pre- and post-measurements that were meaningful to them, and monitor progress of a specific area of quality of care as they tested improvement ideas.

Senior leadership presence

Use of real-time data to assure that results were meaningful to the frontline care team.

Comprehensive program evaluation using quantitative and qualitative methods to provide evidence on patient, staff and organizational outcomes.

Patient engagement in medical education at the Université de Montréal

Vincent Dumez explains how patient leaders train students in collaborative practice that includes patients as full partners in care

VINCENT DUMEZ

Co-director, Office of Collaboration and Patient Partnership, Faculty of Medicine, Université de Montréal, Vincent Dumez, MSc, was the inaugural director of the Université de Montréal medical faculty's Office of Patient Partner Expertise (OPPE) in 2010. In 2013, the OPPE was reorganized, and Mr. Dumez became Co-director of the new Office of Collaboration and Patient Partnership with Dr. Paule Lebel. Prior to 2010, Mr. Dumez was an associate at one of Montreal's most influential consulting firms, where he specialized in organizational design and worked for 13 years as a strategic consultant helping to change large health sector enterprises.

I am an experienced patient. Living with hemophilia for 44 years, and blood contaminated by AIDS and hepatitis C in the early 1980s, I know a little bit about hospitals and clinics. I also have experience professionally as a management consultant and as an activist in the AIDS community.

In September 2010, the Dean of the Faculty of Medicine, Dr. Jean Rouleau, met with me. He had the first version of the *Strategy for Patient-Oriented Research* (SPOR) document on his desk. He said: "The CIHR [Canadian Institutes of Health Research] just produced the first version of a strategy for patient-oriented research and no patients were involved in defining the strategy!" He felt that the only way to change this mentality was to bring patients inside the faculty of medicine. He invited me to set up a unit, with funding and a seat on the governing board, to bring the patient's voice into medical education.

Teaching the patient perspective

In what is perhaps the first instance of a faculty of medicine giving patients a leadership role to integrate the patient perspective, the Collaboration and Patient Partnership Unit has become a model for educating providers to respond to the needs of today's patients. It is time for doctors to change. Unless doctors are engaged in partnering with patients, the efforts of other healthcare players will have only limited impact.

Faculties of medicine are ready to rethink their teaching of collaborative practice, for the simple reason that teaching students how to cure people will only enable them to benefit a small portion of the patients they see. The inability to cure the majority of patients is a source of frustration in medical schools. A whole other skill set is needed to manage chronic conditions. We have to change the way we teach collaboration, communication and professionalism. The doctor-patient relationship has changed. Patients arrive at their appointments not with symptoms but with a diagnosis, made through Internet searches that up to 90% of patients undertake before they see their doctor. That requires a different and longer conversation than the traditional five-minute visit and has consequences on the way doctors are trained. Non-compliance is another challenge; the numbers are high and cannot be attributed solely to a patient's lack of responsibility. Health professionals are challenged to understand why and to learn how to make sure that

Figure 1
From paternalism to partnership

PATERNALISM   PATIENT-CENTRED CARE   PARTNERSHIP OF CARE

INFORMING → CONSULTING → INVOLVEMENT → CO-BUILDING → CO-LEADERSHIP →
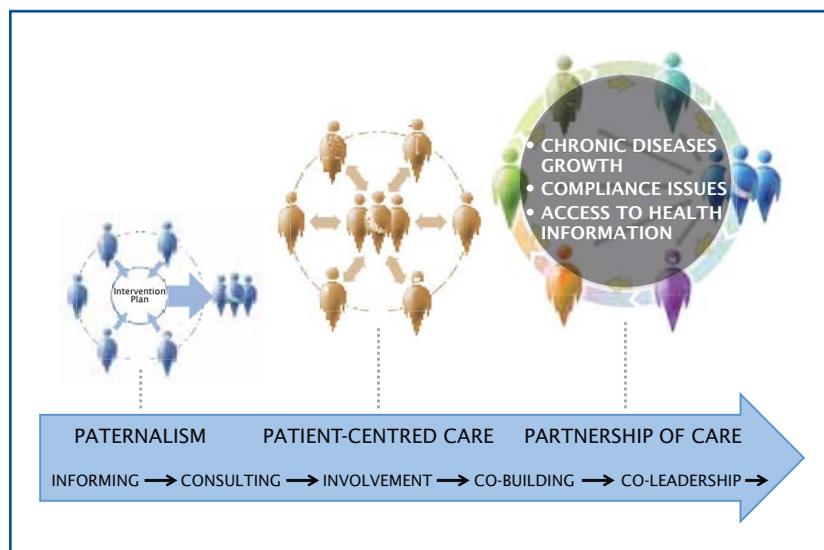
patients are well accompanied in the care setting and know how to take care of themselves outside the clinical setting.

Actors of care

At first, I was the only patient inside the faculty, but the Unit quickly grew to a 12-person committee made up of faculty and expert patients. We worked together to define a vision of collaboration that would guide our work in the faculty of medicine. Patient and family advisors proposed a vision where the patient is not just at the centre of care but is part of the care team, and is considered an actor of care (see Figure 1). Angela Coulter, a pioneer of patient engagement in the UK, has pointed out that over the course of a year, a patient with a chronic disease and his family will spend five to 10 hours with their health professionals, and 6,000 hours taking care of themselves. The focus of the system today is on the five to 10 hours and not on the other 6,000.

The vision of a circle of care that includes the patient and family as actors in care is at the heart of teaching at the Université de Montréal faculty of health sciences. Patients have been involved in redesigning the program for first-, second- and third-year training in the university's 13 health sciences disciplines.

The Unit has thrived, even with a change in leadership in the Dean's office. I co-lead the unit with Dr. Paule Lebel. Patients are being introduced at different levels within the faculty and in leadership positions on all committees where they can bring added value. There are now 120 patient trainers teaching collaboration, communication and medical ethics to students. They are also working with 24 hospitals in Quebec to involve patients in health quality-improvement processes. Figure 2 shows the structure and activities of the Unit. Selection and training processes for patient advisors have been established and patients are selecting, recruiting and training other patients, which is very efficient.

Figure 2
Collaboration and patient partnership unit
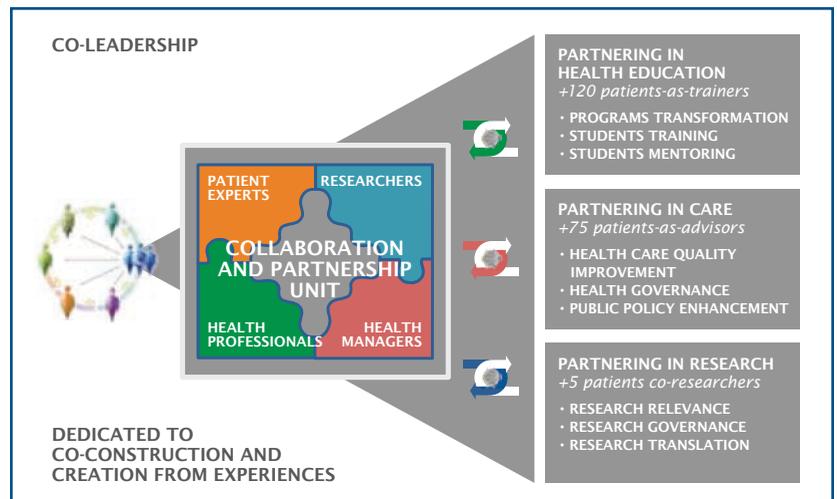
We are living partnership on a day-to-day basis in our team. That is the secret: not to invite patients to come at one particular moment and then disappear, but to have them in the operational functioning of the system. The Unit also collaborates with researchers who are helping to develop an evidence base from this experience.

We have worked in every kind of clinical setting, and are proving that patient partnership is possible in every area. The approach differs and a variety of methods are used to involve patients in quality improvement, but when it works, it becomes viral and people want to push ahead and multiply the experience because they consider it worthwhile.

Patient-centred research

Turning back to the original impetus for the Unit, we have been working with the CIHR for the last year and a half on its public and patient engagement strategy. The CIHR is convinced that we need more patients on research governance and we now have an opportunity to accompany Canadian research networks in arrhythmia, intensive care and transplantation to help them engage patients in their governance and projects. A meeting of the transplantation research network held in Montreal in August 2014 saw real co-creation take place. ◼

Chronic diseases require new skills and approaches to care

The four initiatives presented here recognize patients as care providers and equip them with the tools they need to improve outcomes

MARIO DI CARLO

T-Trainer, My Tool Box program, and Member, Board of Directors and Central Users' Committee, MUHC, Mario Di Carlo is a former board member of the Regroupement provincial des comités des usagers (RPCU) and of the Association québécoise de la douleur chronique (AQDC). He is Founder and President of the Butterfly Wings Foundation helping children with neuromuscular conditions.

DEBORAH RADCLIFFE-BRANCH

Director, My Tool Box Chronic Disease Self-Management Program, MUHC. Dr. Racliffe-Branch implemented this unique program in English and French across five MUHC hospital sites and has spearheaded the expansion and development of the Stanford Chronic Disease Self-Management Program in select McGill RUIS territories, several regions across Quebec and overseas. In 2014, Dr. Radcliffe-Branch received an award from the McGill Centre of Excellence on Aging and Chronic Diseases to implement and evaluate programming for seniors living with multi-morbidities.

My Tool Box: The MUHC's chronic disease self-management program
See also Case Study, page 36

MARIO DI CARLO: The My Tool Box program provides people with chronic diseases the tools and techniques to deal with their situation outside of the institution. It is not a support group or a place to talk about your problems. It is a place to learn how to self-manage your condition. The emphasis is on self-care but also on partnership with care providers, equipping people to better communicate with their physicians and care teams, and to navigate through the health system.

There is a vicious cycle of symptoms that involves the disease but also other things that affect a person's life — stress, emotional issues, fatigue, etc. So we teach people how all these things work together and offer them tools to reverse the cycle and relieve symptoms. The action plan and problem-solving are two pillars of self-management. The action plan involves how a person activates him or herself to meet objectives, and an important part of the program is teaching people how to set and achieve goals. Many patients with multiple chronic conditions or chronic pain are very discouraged. Achieving success in reaching a goal and building on it over six weeks sounds simple, but it is a very powerful experience. We see patients become activated.

DEBORAH RADCLIFFE-BRANCH: With an acute disease, the role of the professional is to choose and apply the therapy. With chronic conditions, because they occur over a long period of time and are rarely curable, patients really need to partner with their healthcare professionals. This is what we teach in the My Tool Box program. The goal is increased self-efficacy and confidence to improve clinical outcomes.

Traditional patient education is illness-specific and offers information and technical skills related to a specific illness. In comparison, self-management education provides problem-solving skills that are relevant to the consequences of chronic illness in general.

There is a good evidence base to suggest that people with chronic illness who self-manage their disease are more likely to appropriately use healthcare services, have fewer disease-related complications and experience greater quality of life and overall health.

Informed, activated patients understand the disease process and assume the role of daily self-manager, because they and their families are the ones who live with this every day, every year.

My Tool Box uses volunteer peer leaders who live with a chronic condition themselves. That is important because it makes the experience authentic. The people who are leading the course know what sort of challenges participants experience. The vast majority of patients we see at the MUHC's My Tool Box are living with complex chronic health conditions and really need the training and support the program offers. Unfortunately, despite increasing evidence of positive outcomes for patients and the healthcare system, support for self-management is still not an integral part of routine care for all Canadians with chronic illnesses.

Living well with chronic obstructive pulmonary disease (COPD)
See also Case Study, page 46

DR. JEAN BOURBEAU: I started developing the Living Well with COPD (LWWCOPD) program in 1997 with a nurse colleague, Diane Nault, at the Montreal Chest Institute. Our aim was to improve patients' ability to self-manage COPD. It started with comprehensive modules for patients and family members. Then we developed a guide for health professionals who worked with COPD patients that would help them deliver a consistent message and effective training in self-management. Materials for patients were developed for use in education sessions or by patients and families at home. The program filled an important gap.

A common source of reliable and up-to-date guidance helps health professionals deliver consistent messages and support patient self-management. Patients need motivation and health professionals need to learn how to provide that. The latest material being developed for LWWCOPD focuses on healthcare providers supporting patients in setting goals for disease management that reflect their priorities in life. The action plan empowers patients to cope with different manifestations (symptoms, medication, techniques of breathing, healthy habits) and day-to-day

management of the disease. The case manager/coordinator encourages effective use of health resources.

We have undertaken extensive studies of the program as it evolved over 15 years, including randomized controlled trials. Defining success for an intervention that was neither a drug nor a medical procedure was an important challenge. Compared to a control group, the LWWCOPD program brought a 40% reduction in both hospital admissions and ER visits and a 60% reduction in non-scheduled physician visits. The LWWCOPD program and website are constantly updated based on new knowledge from ongoing studies, new treatments (including new medications) and access to new resources such as telemedicine.

Ms. Jocelyne Goddard: When first diagnosed with COPD, I thought "Okay, that's done. We'll treat it and then get on with life." It took time for me to realize that chronic diseases did not work that way. Exacerbations landed me in the hospital and limited my activities.

I undertook the LWWCOPD program three times over seven years and learned how to take charge of my COPD. The pro-

JEAN BOURBEAU

Director, Respiratory Epidemiology and Clinical Research Unit, MUHC, Jean Bourbeau, MD, FRCPC, is a respirologist and Professor in the Departments of Medicine and Epidemiology & Biostatistics at McGill University. He directs the Pulmonary Rehabilitation Unit at the MUHC's Montreal Chest Institute, and the chronic obstructive pulmonary disease axis of the Respiratory Network of the Fonds de Recherche en Santé du Québec. He is President of the Canadian Thoracic Society, and Chair of the Dissemination & Implementation committee, as well as a member of the executive committee of the Global Initiative for Chronic Obstructive Lung Disease.

Figure 1
Evolution of Living Well with COPD

	1997–1998	1998–2000	2003 to date	2004–2006	2005–2008
Region	Québec	Québec	Québec	Canada	Canada
Milestones	LWWCOPD 1st edition	Studies: RCT		LWWCOPD 2nd edition	Studies: RCT
Knowledge translation	Program development in English & French	1st edition: 7 home education sessions, case manager support	Involvement of provincial health board	Development of new edition & website creation	PR* to be done at home (CIHR funded)
Context	Pilot project: 16 patients and 5 health professionals	Moderate to severe COPD	COPD clinics, PR* programs and home respiratory services	The program is used across Canada; QACN	Use as part of COPD Integrated Care programs & PR*

Study publications:
- Bourbeau 2003 Arch Int Med (Reduction of hospital utilization in patients with COPD)
- Bourbeau 2004 Patient Educ and Counseling (Self-management and behaviour modification in COPD)
- Gadoury 2005 Eur Respir J (Self-management reduces both short- and long-term hospitalization in COPD)
- Bourbeau 2006 Chest (Economic benefits of self-management education in COPD)
- Maltais and Bourbeau 2008 Ann Intern Med (Home rehabilitation: RCT)

* pulmonary rehabilitation

gram equipped me with simple but very effective tools to help control symptoms: an action plan to keep track of symptoms and respond quickly when they worsen; a case manager, to call when I need help, who can coordinate the activities of different care providers; strategies to help conserve energy; and instruction in the proper way to use inhaled medications. I became an active participant in my care. I am now more confident, more autonomous, and have less need of emergency hospital visits. People talk about sustainable energy — the LWWCOPD program has brought me sustainable benefits: I am much more resilient than I was before.

GRAEME ROCKER

Head, Division of Respirology, Capital Health, Graeme Rocker, MA, MHSc, DM, FRCP, FRCPC, is a Professor of Medicine at Dalhousie University in Halifax, Nova Scotia. He leads the INSPIRED outreach program for patients and families living with advanced chronic obstructive pulmonary disease (COPD). In 2013, Dr. Rocker was appointed Clinical Improvement Advisor to the Canadian Foundation for Healthcare Improvement (CFHI).

Results

Data on the impact of the INSPIRED program on hospital admissions and use of ERs and family physicians was published in October 2014 in *Clinical Investigative Medicine*. It found a 60% decrease in hospital stays and an 80% decrease in ER visits in the six months following the completion of the program compared to the six months prior to patients starting the program. INSPIRED was designated a leading practice by Accreditation Canada in 2014 and Dr. Rocker is now collaborating with 19 teams across Canada, funded by the Canadian Foundation for Healthcare Improvement and Boehringer-Ingelheim, to establish similar programs in hospitals in each province.

Implementing a Novel and Supportive Program of Individualized Care for patients and families living with REspiratory Disease (INSPIRED) COPD Outreach Program™

DR. GRAEME ROCKER: As a respirologist at Capital Health in Nova Scotia, I have devoted considerable effort to understanding the needs and desires of people at the end of life in order to improve care. I undertook a study of the end-of-life priorities of hospitalized patients with chronic diseases and investigated the experience of families in rural Nova Scotia and New Brunswick caring for someone with COPD. This work brought me into people's homes and provided tremendous insight into what it is like to live with a chronic condition in that individual's setting. There is an urgent need to improve care for this group of patients and their families and respond to their chief concerns: being able to deal effectively with breathlessness and have a plan for care at home upon discharge from the hospital.

We looked for places on the road to an emergency room visit where interventions could be useful. We found that patients have a poor knowledge of the disease, little or no support in their local communities and they deny what is going on when symptoms change or worsen. So they show up in the Emergency Room (ER) much worse than they needed to have been. That sets them up for worse physiological situation and a longer hospital stay. At the end of that stay, the classic discharge plan in many hospitals aims primarily to get that patient discharged because there are others waiting to occupy the bed; it is not a plan to keep the patient out of the hospital.

The INSPIRED program is designed to help remedy that situation. A patient who has been hospitalized for COPD is informed about the program and contacted about 72 hours after discharge for a home visit. The purpose is to figure out what they want to hear about and what they need. Action plans are valuable, and the patients all have these that tell them when to initiate treatment for a flare up. Advance care planning has been a major part of what we do. The extent of the existential distress expressed by patients and family caregivers mandated that spiritual care skills be incorporated into the program as well.

Patients receive home visits from respiratory educators and spiritual care advisors, followed by a monthly follow-up phone call for about three months. A critical element of the program is advance care planning because it builds on trust, and patients can work with caregivers toward some decision-making about the difficult things that are going to happen at some point with COPD. Patients told us they want these discussions because it breaks the silence that was always there in all their previous hospital admissions.

Evaluating the program
Qualitative and quantitative evaluations were undertaken. Patients reported feeling more confident managing their symptoms, were less anxious, and were willing to discuss goals of care, including end-of-life

care. Quantitative studies did not, on the whole, produce statistically-significant results. However, highly statistically significant improvements were found in the self-efficacy and self-confidence that a patient has in understanding his disease and knowing what to do with medications.

The action plan and having antibiotics and corticosteroids or prednisone available in the home meant that patients did not have to wait to get an appointment with a family physician to start treating an infection or exacerbation. Accessible education

> **Patients reported feeling more confident managing their symptoms and were willing to discuss goals of care, including end-of-life care.**

and simple resources (such as a hand held fan that blows cold air on the face) can help relieve breathlessness. The fact of having someone to call, and feeling cared for, made an enormous difference to patients. We have formed relationships with patients that did not exist before.

COMPAS: Improving services for people living with diabetes

BRIGITTE VACHON: The Département régional de médecine générale, in collaboration with the Agence de la Santé et des Services sociaux de la Montérégie (ASSSM) developed the COMPAS (Collectif pour les Meilleures Pratiques et l'Amélioration des Soins et services en médecine de famille) project to institute a series of reflective workshops for primary care health professionals working with people affected by chronic diseases. The COMPAS workshops aimed to promote continuous and concerted improvements in the quality of care and services.

Following success with this model, the COMPAS team worked in collaboration with local diabetes associations to initiate additional workshops for people living with diabetes. Seven workshops were held, involving 79 patients from the 11 Centre de Santé et Services sociaux in the Montérégie, who formulated recommendations about how services and care could be improved. These recommendations were then disseminated to about one hundred decision makers, managers and professionals in the region.

The needs and challenges identified by people living with diabetes can be grouped into seven themes:

1. Challenges related to accessibility and continuity of care
2. Motivation to adopt and maintain health-related behaviours on a long-term basis
3. Keeping knowledge about treatments up to date
4. Psychological challenges around acceptance of the disease and its progression
5. Economic challenges related to the cost of some services and insurability
6. Physical health problems
7. Linking the activities of primary and secondary care providers.

Proposed solutions targeted transmission of test results, information regarding available services, centralization of services, adaptation of services to evolving needs, and collaboration between professionals.

The workshops had an impact on people's knowledge of available services and on their intention to use services differently (see Figure 2). They also encouraged people to become more involved in improving services. Project results confirmed the importance of patient engagement in quality improvement processes. We are now looking to design workshops that will bring health professionals and patients together in improvement efforts. ■

BRIGITTE VACHON

Assistant Professor, School of Rehabilitation, Université de Montréal. Brigitte Vachon, PhD, is Assistant Professor of Occupational Therapy at the Université de Montréal's School of Rehabilitation. She is a researcher at the Centre de recherche Fernand-Seguin of the Institut de Recherche en Santé mentale de Montréal, and collaborator on the COMPAS project with the Agence de la Santé et des Services sociaux Montérégie.

Figure 2

COMPAS results
Patient empowerment
1 month follow-up (n=66)

● 78% have better knowledge of services available in their area
● 83% wish to make better use of services available
● 35% made a change in the way in which they use services
● 86% were better able to identify their own needs for different services following the workshop
● 93% improved their awareness of needs experienced by other persons suffering from diabetes

Measuring the patient experience of care coordination

The Nuffield Trust is undertaking the difficult work of finding ways to assess care integration from the patient's perspective. **Ruth Thorlby** describes the challenges encountered and what can be learned from them

RUTH THORLBY

Senior Fellow, Health Policy at Nuffield Trust, Ms. Thorlby's research interests include UK National Health Service (NHS) reform, integrated care, GP commissioning, accountability, international comparisons and health inequalities. Before joining the Nuffield Trust. Ms. Thorlby was a senior fellow at The King's Fund and a 2008-2009 Harkness Fellow at Harvard Medical School, where she researched how US physicians and healthcare organizations understand and tackle racial inequities in health service quality. A graduate of the London School of Economics (LSE), Ms. Thorlby was a broadcast journalist before moving into health policy, and worked for BBC News and the BBC World Service.

The UK Secretary of State for Health, Jeremy Hunt, has talked a lot about integration in the last two years. He said recently: "Integration is today what waiting times were a decade ago — the challenge that defines modern health care."

What is keeping Jeremy Hunt (and other policymakers) awake at night is the rise in emergency admissions to hospital. The UK has seen a 47% increase over the last 15 years, reaching five million admissions in 2013. A good proportion of these could likely have been prevented through better upstream care. One of the objectives that frames current work on measuring care integration in the community is to flatten and possibly bend the curve of the rise of hospital emergency admissions.

Terminology

The word integration is used in policy circles, but user groups prefer to call it coordinated care. National Voices, which is a coalition of over 140 health and social care voluntary sector organizations that involve patients and users, was asked to think of a way of explaining integration and immediately threw it out as a non-word. They redefined it as person-centred coordinated care. So that is the term we use and it signifies health and social care working better together to meet user needs.

System characteristics

The National Health Service (NHS), set up in 1948, is a universal service paid for by general taxation that is free at the point of use. There are some user charges for prescriptions (which 70% to 80% of people are exempt from paying) but on the whole, very little out-of-pocket contributions for health care. Social care was also established in 1948 but was not merged with the NHS. Social care is organized through local government; it receives money from central government, but is a means-tested, rationed service. Publicly funded social care is not available to everyone. Health and social care are two very different structures even though their work overlaps and, from a user perspective, people do not always distinguish between social care workers and healthcare workers.

Efforts to bring health and social care together are not new and there are places in the UK where the budgets have been brought together. Torbay, in Southwest England, has had some good results from budget pooling that enables them to invest in preventive social care, and this seems to reduce hospital admissions. However, these examples are unusual.

By way of explaining what the current system looks like, Figure 1 (see page 29) depicts something called a web of care and demonstrates graphically from a user perspective just how complex that system is. The boxes in red represent social care, and the health services in the blue boxes are often provided by a range of different bodies. In the figure, Malcolm has Alzheimer's disease and Barbara is his caregiver, and they are the only people who know how well these services are working together.

The reform agenda

When the coalition government came to power in 2010, it initiated very radical reforms to the NHS in England, including a reorganization of the purchasing bodies and a greater emphasis on competition to drive improvements in quality and efficiency. This produced an outcry, notably from professional associations, and there was an unprecedented pause in the legislation. Consultations concluded that the reforms also had to focus much more on integration. In 2012, the arguments were resolved and the Act was passed, assigning a duty to promote integration/coordination across different bodies in the NHS, including the regulator.

In the process of revising the Act, National Voices was charged with arriving at a common definition of coordinated care that would make sense from a user perspective. They consulted their stakeholders and asked what users would be able to say about their care if it was fully coordinated. The core sentence that resulted is: "My care is planned by people who work together to understand me and my care, put me in control, coordinate and deliver services to achieve my best outcomes." A series of statements, which are now known as "I" statements (Figure 2, page 30), were produced for different domains: goals, outcomes, communication, information, decision-making, care planning, transitions and emergencies. This is now the definition of coordinated care that is guiding work in England.

The impact of coordination projects

The immediate context of our work at Nuffield Trust was the need to measure the impact of projects aimed at improving the coordination of health and social care from a user perspective. After passing the Act in 2012, government provided assistance and training to 14 pioneer areas across England to accelerate their care coordination projects. Many focus on the people who are known to fall through the net of normal disintegrated care: older, frailer people, but also younger people

Figure 1
The web of care
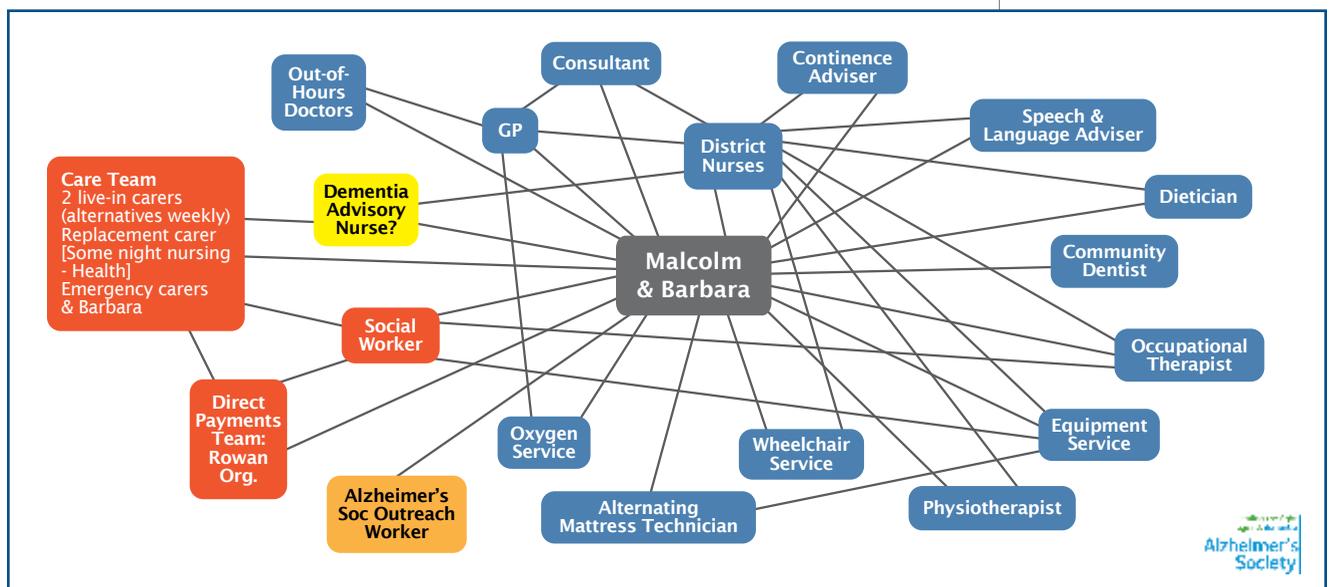
Figure 2
The "I" statements

Independence

I am recognised for what I can do rather than making assumptions about what I cannot

I am supported to be independent

I can do activities that are important to me

Where appropriate, my family are recognized as being ley to my independence and quality of life

Community Interactions

I can maintain social contact as much as I want

I'm still me

... a narrative for coordinated support for older people

Care and Support

I can build relationships with people who support me

I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me

Taken together, my care and support help me live the life I want to the best of my ability

Decision-Making

I can make my own decisions, with advice and support from family, friends or professionals if I want it

---

with severe mental health problems. Government has also established a Better Care Fund, worth 3.8 billion pounds (about 3% of the NHS budget) for health and social care integration projects. These projects are using proxy indicators to measure success: a drop in ER admissions,

> **Social care has always measured people's well-being, outcomes and capabilities, whereas health care mostly measures numbers of doctor visits and outcomes of a specific illness. Capabilities are still a difficult concept for many healthcare workers.**

decreased length of stay, fewer delays in discharge from the hospital. Alongside other research organizations, the Nuffield Trust was asked to develop questions around the user experience of integration that could sit within the existing national survey used to assess experience of inpatient, outpatient and GP care.

Local government and local NHS services insisted that the questions should

not only be geared toward performance management, but should also support quality improvement to help them improve services locally. So the Nuffield Trust is working with National Voices, Picker Europe (for all the technical work on survey development), the International Foundation of Integrated Care and the King's Fund, with funding from the Aetna Foundation, to develop a new survey to measure the experience of coordinated care from a user perspective. The initial effort focuses on people over age 65 with at least one chronic condition.

Developing a patient experience survey

First steps have included establishing an expert advisory group and conducting a literature review of surveys on coordinated care, continuity of care and transitions from hospital to community. The National Voices' "I" statements have been refined based on in-depth interviews, and questions are being cognitively tested in view of piloting the survey with about 3,000 older people across six pilot sites. They will receive a paper survey at their home

that asks them about all aspects of their health and social care.

The challenges included consideration of the different dimensions of continuity (relationships, management, behind the scenes, information)[1] and the key points in care (normal care that happens at home, planned transitions to an inpatient stay, emergency care, advice). There was an interesting debate about how to begin the survey. National Voices considered it important to include statements about the older person's sense of well being (this work has now been published)[2] such as: "I'm recognized for what I can do rather than making assumptions about what I cannot do"; "I'm supported to be independent." Some health professionals did not see how this type of question would help them improve service, while social care providers find it quite useful to know whether people are socially isolated and what they can do themselves. Social care has always measured people's well-being, outcomes and capabilities, whereas health care mostly measures numbers of doctor visits and outcomes of a specific illness. Capabilities are still a difficult concept for many healthcare workers.

The decision was to include these questions, partly because they send a powerful signal to the people completing the survey that this is about them and the outcomes that matter to them. The survey includes 39 questions around capabilities and well-being, day-to-day health, use and payment of social care services, use of health services, health status and demographic information.

Cognitive testing of the survey questions revealed some important challenges. In terms of communication, for example, people felt that they would not know if there had been a failure in communication between staff unless something went wrong. That shows the difficulty of measuring communication from a user's perspective.

Defining the end-game

Government regards integration as key to bringing health and social care budgets together and unlocking the money for upstream interventions. One problem is the heavy and increasing rationing of social care: there just is not enough state-funded social care and data are lacking on how well people provide care for themselves. Another is that there is no assurance that better coordination of care and more social care will accomplish the government's main goal of reducing hospital admissions. Very few community interventions to date have shown reductions over the short term.

Integrated/coordinated care projects are seeing GPs and primary-care teams stepping into the real lives of people. One example from a Greenwich project refers to a 52-year-old woman who has been in and out of Emergency and has an alcohol problem. When the primary-care team asked about her priorities, first on the list was a job or some voluntary sector work; second was to lose weight and feel better about herself; and third was to deal with her alcohol dependence. The reality is that priorities one and two need to be dealt with effectively before number three can be tackled. This is the very hard work involved in coordinated/integrated care, and results cannot be measured in the very crude quantitative sense of bringing ER admissions down.

If reducing emergency admissions stands as the primary objective behind care integration/coordination efforts, the projects currently under way may be doomed to fail. The measurement of care integration/coordination needs to capture how these efforts improve whole-person care and improve a person's life, and these need to be recognized as goals that are equally, if not more, important than bringing down emergency admissions. ■

The "I" statements for communication

If your care were well coordinated, you would be able to say:

- I was always kept informed about what the next steps would be.
- The professionals involved with me talked to each other. I could see that they worked as a team.
- I always knew who was the main person in charge of my care.
- I had one first point of contact. They understood me and my condition. I could go to them with questions at any time and that person helped me to get other services and help and to put everything together.

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Legal frameworks for sharing health information in coordinated patient-centred care

Ed Percy believes the increasingly "liquid" nature of health data will stress the regulatory frameworks around privacy and disrupt legislation dramatically

ED PERCY

Vice President, CGI Global Healthcare. Ed Percy, B Eng (Hons), is responsible for health care across CGI's worldwide operations, including managing the company's strategic portfolio, promoting its thought leadership, and providing strategic support for 400 offices in 40 countries from his base in Manchester, England. Trained as an engineer and a keen advocate of using technology to improve clinical efficacy and safety, Mr. Percy has worked in the field of health care for most of his career and been instrumental to the success of many critical eHealth projects around the globe.

The European Union (EU) is a federation of member states. Legislation in Europe dates back to the United Nations Universal Declaration of Human Rights in 1948, the establishment of the Council of Europe and the Convention for the Protection of Human Rights in 1953. This is where all of our patient legislation comes from.

The EU framework

Rights to health and social care were enshrined in the 1961 EU Social Charter. The first direct references to the rights of patients in health and care settings came in 1997 through the Treaty of Lisbon, and important legal constraints were imposed on healthcare delivery organizations through the Charter of the Protection of Human Rights and Dignity.

The Convention on Human Rights established the right to "respect for his private and family life, his home and his correspondence." Article 8 of the EU Charter of Fundamental Rights explicitly prevents the processing of personal data concerning, among other things, health and social care data, with some interesting qualifications (see Disruption ahead, page 34).

Legislative frameworks are just that, frameworks, and there are plenty of real life scenarios today where current legislation is grey. Disclosure after death and the nature of true ownership of data and the rights of citizens to access their data are significant considerations. With the increasing burden of elder care falling on younger relatives, the nature of consent and confidentiality between relatives who are caregivers will become a major concern, and we will see many interesting test cases.

Differences between countries

In the absence of a common EU-wide patients' rights legislation, the EU sets out a legislative framework and directives or instructions to member states to implement the legislation in their context. Here are four examples of how EU countries have defined these rights: Belgium passed a law on the rights of patients in 2002; Denmark introduced the Health Act in 2005; Finland defined the status and rights of patients in 1992 legislation; and in the UK, patients rights are not the subject of a specific Act, but rather are treated in Common Law, the Data Protection Act of 1998 and the General Medical Council.

The right to information concerning one's health

Belgium: A patient has the right to receive all information concerning his/her state of health. In exceptional cases, the health professional may withhold information about the patient's state of health if disclosure would cause great harm to the patient; this is called the therapeutic exception.

Denmark: Danish law does not regulate the right to information as a separate right, but includes this in the overall rights of involvement of patients as described in the informed consent part of the Act.

Finland: A patient will be given information about his or her condition, treatment,

alternative medical procedures and effects. This may include third-party persons, with permission of the patient.

UK: The right is intertwined with the right to informed consent assured by the General Medical Council, stating that the patient should receive adequate information about the treatment.

The right to access one's medical record

Belgium: The patient has the right to a medical record. The law, however, does not give a specific definition of a medical record. Patients have the right to access their own medical records.

Denmark: The act contains a provision regarding the duty of physicians to keep medical records. A provider may forward information regarding the history of the illness, cause of death, etc. of a patient to relatives, when this is not considered to be against the wishes of the deceased.

Finland: Healthcare professionals will record in patient documents the necessary information as defined in the Act.

UK: As laid down in the Data Protection Act of 1998, patients have the right to access their medical record at all times.

The right to privacy

Belgium: The subject of privacy is not covered specifically in the law on the rights of patients, as this is already embedded within the Belgian constitution. A distinction is made here between the privacy of patient data regarding health and protection and the obligation of the physician to assure the protection of confidence regarding the information the patient shares with the physician.

Denmark: The Danish Constitution provides for the protection of privacy. The Health Act indicates that hospitals are allowed to inform the patient's GP about treatment provided by the hospital without the explicit consent of the patient.

Finland: The Constitution states that detailed provision on the protection of personal data will be prescribed by Act of Parliament: patients must be treated in such a way that their human dignity is not violated and that their convictions and privacy are respected.

UK: Common Law covers the doctor-patient relationship and the need for confidentiality. Doctors are obliged to

> **With the increasing burden of elder care falling on younger relatives, the nature of consent and confidentiality between relatives who are carers will become a major concerns and we will see many interesting test cases.**

respect the confidentiality of patients. Common Law does not cover the right to privacy, which is protected by the Data Protection Act.

National law in a common market

Denmark is often perceived to be the leading health informatics society in the world. The Danes have had universal GP and consultant access to patient results for about 15 years through the MedCom platform. The Danish Health Act extends the Danish constitution with regards to communication between secondary and primary care, not involving the patient. Consent to share does succeed to the individual, so the patient may choose not

to have medical history divulged to relatives post-mortem. Finland has had electronic records in primary and secondary care for over 25 years. It has the oldest patient-rights legislation of anywhere in the world, with the right to privacy enshrined in a separate act of Parliament, not as part of the Finnish constitution. Almost all legislative frameworks today refer to national law, and yet the EU is a common market and patients and their information have no borders. Current legislative frameworks do not allow patient data to exit EU territorial boundaries.

Disruption ahead

The disruptive nature of technology and its incredibly rapid propagation through new business models will stress our legislative models in ways we can only vaguely imagine today.

Legitimate purpose is the concept that data can be shared and used for treatment or the management of care services. While patient networks based around conditions

> The security provisions in the UK data protection directive do not apply to data in transit. Various EU member states require their hospitals to encrypt data before transferring. However, what are the protections when citizens begin to exchange data and download their electronic medical record to a mobile phone to provide it to another care provider?

and diseases are great ways to generate behaviour change, our current legislation does not provide mechanisms for sharing that type of data across networks.

Secondary uses are difficult to define and predict with the emergence of partial and full genomic sequencing technologies. The challenge of accurately conveying what will be done with a patient's data — how long will physical specimens be kept, or to what extent will they be associated with electronic patient data — makes

the concept of "notice" for distributing and disseminating data appear impossibly complex.

Purpose limitation is laudable but impedes use of data held by hospitals that could prove immensely valuable in the development of precision medicines.

Access rights to health information are going to get very complicated. Do they apply to all data (notwithstanding the therapeutic exception) in an electronic record? Do they include data collected by patients on portable devices? This is sensitive data, but does it fall under the data protection directive?

The **security provisions** in the UK data protection directive do not apply to data in transit. Various EU member states require their hospitals to encrypt data before transferring. However, what are the protections when citizens begin to exchange data (as US veterans are now doing through the VISTA system) and download their electronic medical record to a mobile phone to provide it to another care provider? Universal use of Vista was legislated by government, but creates disruption to other legislative frameworks.

Years ago, when medical records were paper-based, the concept of **perpetuity** was not significant. Today with electronic medical records and the very cheap availability of storage, perpetuity is going to become an increasing concern and challenge.

Health care is the last of the great supply-driven industries. Other industries have transformed to be demand-driven, with services and data centred around the consumer. Access to health care is still determined by those who provide the service, but change is coming and it will be highly disruptive. Technology always moves faster than business models (though they catch up pretty quickly), with legislation lagging far behind. Challenges to existing legislation around health information will be a defining feature of progress toward patient-centred care. ∎

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CASE STUDIES

in patient engagement

Staff and patients at the McGill University Health Centre
(MUHC) are leading exciting programs that engage patients
in their own care and in care process redesign. Health
Innovation Forum explores how these programs work to
improve health system performance and outcomes and
looks at the challenges involved in perpetuating and
expanding them within existing healthcare structures.

Challenge

The My Tool Box chronic disease self-management program

A network of expertise has developed in Quebec around a program that works through volunteers to improve people's ability to manage chronic disease

The best health technologies and most dedicated teams of professionals can only do so much for chronic conditions. Patients are the main players in managing their own disease, and empowering them to do so is a central challenge in health care today. Education is one key aspect. Excellent programs have been developed to teach people about treatments and strategies that help disease management. Equipping people with the skills and tools they need for self-care, however, requires a change in mindset — they need to see themselves as part of the solution.

This challenge was recognized in 2006 by the patients' committee and staff at the McGill University Health Centre's (MUHC) Montreal Neurological Hospital (the "Neuro"). With a small innovation grant, they set out to pilot a self-management program for MUHC patients living with one or more chronic diseases. "Self-management fills the space between knowing something and being able to put it into practice," explains Mario Di Carlo, a patient at the post-polio clinic who was recruited early on in the project. "It helps people understand they need to get involved, and empowers them to do so." That's the key, according to Cheryl-Anne Simoneau, who has been living with chronic myeloid leukemia since 2000 and also answered the original call to participate. "How do you make people understand the ball is in their court? Regardless of what you've been diagnosed with, you still have a certain amount of control. If you don't empower patients, they can't be partners."

FIND OUT MORE

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My Tool Box website
www.mytoolbox.mcgill.ca

A My Tool Box workshop in session.

The program

The Neuro decided to adopt a proven self-management program developed at Stanford University that in six weekly workshops addresses what a person must do to live well with one or more chronic conditions. Its goal is to strengthen self-efficacy in order to improve clinical outcomes. Available to license, and already adapted to the Canadian healthcare context by a team led by Dr. Patrick McGowan at the University of Victoria in British Columbia (BC), the program is designed to be volunteer-run and uses a train-the-trainer model: course participants can take further training to be certified as workshop leaders and teachers. Mr. Di Carlo and Ms. Simoneau took part in the very first group, were impressed with the results and began long-lasting relationships with the program.

To run the pilot and later direct the program, the Neuro hired Dr. Deborah Radcliffe-Branch, an educational psychologist and assistant professor in McGill University's Faculty of Medicine. She had over 20 years of experience implementing and evaluating patient education programs and was familiar with the Stanford program's decade-old implementation in BC. She set out to identify patient volunteers with the right leadership qualities and brought in Dr. McGowan from BC to teach the first group of leaders, including Mr. Di Carlo and Ms. Simoneau. "We purchased a license from Stanford for $1,000 that allowed us to hold as many as 30 workshops a year," says Dr. Radcliffe-Branch. The MUHC's self-management program thereafter known as My Tool Box was formally open for business.

My Tool Box is promoted to patients throughout MUHC hospitals, in the community and through word of mouth. Participants sign up for six free weekly two-and-a-half-hour hour workshops involving 10 to 12 people with a range of clinical conditions or their caregivers. Sessions are led by a team of two volunteer leaders.

The My Tool Box office promotes the program, takes registrations, organizes sessions, provides materials, helps to select and vet prospective leaders, and arranges and pays for their training.

Distinguishing between disease management and self-management

Unlike programs offered by health professionals that focus on managing a particular disease, self-management starts with a personal action plan that specifies changes the person wants to make to improve life. The focus is on reducing the negative impact of disease. "The personal action plan is at the centre of the workshop," explains Mr. Di Carlo. "Each week, people review what worked and what didn't, and what they plan to do next." Classes are highly participative, and can often boost patients' confidence about ways to manage their health and maintain fulfilling lives.

The program focuses on developing competencies in problem solving, decision making, communicating, managing emotions, evaluating treatment results and coping strategies. Self-efficacy is enhanced and people gain confidence in their ability to put skills to work. Updated every five years, the Stanford manual, *Living a Healthy Life with Chronic Conditions*, is used by leaders to guide sessions.

Results

Program uptake

Dr. Radcliffe-Branch has attracted a pool of talented patient volunteers dedicated to making the program available to ever more patients.

Positive program results

The Chronic Disease Self-Management Program was developed by the Stanford Patient Education Research Center, whose programs, around since the 1980s, are currently in use in 24 countries.[1] The first randomized controlled trial of the Stanford program was completed in 1996 and included results for 1,000 people followed over three years. It demonstrated significant improvements in patients' ability to manage their chronic disease(s) and use healthcare resources effectively, with a cost-effectiveness ratio of 1:10. Results showed statistically-significant improvements in physical exercise, emotional issues, communication with physicians, control of anxiety, fatigue, incapacity and limitations in social functioning, along with decreases in unplanned hospital admissions and physician visits.[2] Results have been validated through successful implementation that produced similar results in different countries and populations, including Canada.[3]

My Tool Box
volunteer leaders at
an annual reunion

uate the program on an ongoing basis, assessing participants' general health, quality of life and usage of health services at the program's start, and six months after completion.

My Tool Box has brought statistically significant improvements in patients' ability to manage disease symptoms, physical abilities, exercise and communication with doctors. Statistically-significant decreases are evident in pain severity, illness intrusiveness, depression, fatigue and distress. My Tool Box has reduced participants' emergency room visits from 0.68 to 0.48 per year and cut by half the number of hospital days, from 1.67 to 0.82. Dr. Radcliffe-Branch estimates a decrease in healthcare costs of $3,900 for each patient enrolled in the program.

Mr. DiCarlo and Ms. Simoneau pursued further training to be certified as Master Trainers (responsible for training leaders).

Since 2007, the MUHC's My Tool Box program has completed 153 six-week workshops in English and French, and trained and certified 63 leaders, 30 Master Trainers, and two T-Trainers. Participants can be referred to the program by a health professional, but word-of-mouth referrals are also common. More than 1,900 people living with an average of 3.3 chronic conditions (pain after surgery, chronic musculoskeletal pain,

> **My Tool Box has reduced participants' emergency room visits from 0.68 to 0.48 per year and cut by half the number of hospital days, from 1.67 to 0.82.**

diabetes complications, chronic obstructive pulmonary disease, multiple sclerosis, arthritis, cancer, depression, etc.) have participated in the MUHC's My Tool Box program. Participants meet at the My Tool Box office or in a community venue. They receive the course manual, a workbook and a CD which provides a set of easy-to-follow exercises.

Outcomes
In terms of measuring results, the Stanford program includes questionnaires that all have high alpha reliability coefficients. Dr. Radcliffe-Branch uses a selection of nine questionnaires to eval-

Adoption in Québec
The MUHC's My Tool Box has become a centre of expertise in chronic disease self-management across Québec. "In the early days of My Tool Box, Patrick McGowan would come to Montreal to train our leaders and trainers," says Dr. Radcliffe-Branch. "Now we're independent, with two T-Trainers, Mario Di Carlo and Louisa Nicole, who can train leaders and Master Trainers in both French and English."

My Tool Box produced the first French translation of the Stanford materials, including the participant book and training manuals. "When Stanford issues program updates every five years," explains Dr. Radcliffe-Branch, "Dr. McGowan's team in BC completes the Canadian adaptation. The Tool Box team at the MUHC then plays an important role in assuring the translation and adapting material slightly to address certain features of Québec's health system."

The MUHC's My Tool Box has provided training, materials and support for self-management programs that have been provided to the Abitibi-Témiscamingue Health and Social Services Agency or ASSS (2010), the ASSS Lanaudière (2012), the Family Medicine Unit and Health and Social Services Centre (CSSS) in Chicoutimi (2013), and Bruyère Continuing Care (Ottawa, 2010). An especially close relationship has evolved between the My Tool Box program and the Abitibi-Témiscamingue ASSS.

In 2009, the Abitibi Témiscamingue ASSS'

Director of Public Health, Dr. Réal Lacombe, and Health Promotion Advisor, Céline Hubert, visited the MUHC to see first-hand how My Tool Box worked. They were impressed and asked Dr. Radcliffe-Branch to provide a training session in Abitibi-Témiscamingue. Mr. Di Carlo and Ms. Nicole trained a group of volunteer leaders, enabling them to begin offering the program. Two of these leaders came to My Tool Box to receive Master Training certification so they could teach additional leaders at home. Today, the Abitibi-Témiscamingue program is able to perpetuate itself. "The MUHC team is very important to us and others in Québec," asserts Ms. Hubert. "They are the pioneers in this province. They work in French and English, and provide guidance and advice when we need it."

Since 2010, 70 workshops have been held in Abitibi-Témiscamingue, with 628 participants, 80% of whom completed at least four of the six sessions. The region now has two Master Trainers, 40 volunteer leaders and five coordinators, one in each CSSS. Ms. Hubert, who is a patient, nurse and advisor at the ASSS, has become a close collaborator with My Tool Box's Mr. Di Carlo in producing French-language materials.

Expanding participation

"My Tool Box reached a tipping point about a year ago and we rarely have to advertise any more," says Dr. Radcliffe-Branch. "Volunteers continue to supply posters to hospital clinics. Health professionals and patient word of mouth keep up the flow of participants. We know they are not finding this type of support elsewhere: less than 20% of patients registered for My Tool Box courses have visited a CLSC (local community health centre) in the past year."

Ms. Simoneau thinks doctors should play a more active role talking about My Tool Box. "It helps motivate patients. My Tool Box should be integrated into the patient care pathway and emphasized as essential. The program enables patients to advocate for themselves and improve their quality of life."

In Abitibi-Témiscamingue, Ms. Hubert says some CSSS have been wildly successful in attracting participants and volunteer leaders, while others have had more difficulty. "The coordina-

Who's who in the Stanford program

- **Participants:** People living with one or more chronic diseases and those caring for a loved one with one or more chronic disease.
- **Volunteer leader/facilitator:** A person who has taken the workshop as a participant, undergone a selection process and completed training with a Master Trainer.
- **Master Trainer:** To become a Master Trainer, the volunteer leader/facilitator must have led at least two workshops and completed a four-and-a-half-day certification course (offered by the My Tool Box team in Montreal, facilitated by two T-Trainers).
- **T-Trainer:** Master Trainers take a four-and-a-half-day apprenticeship under supervision of a Stanford-approved T-Trainer and train at least one group of Master Trainers independently to receive T-Trainer certification from Stanford.

tor's role is very important in sustaining volunteer energy," she notes, and adds they are learning from high-performing centres.

Maintaining volunteer energy

Witnessing patients regain enjoyment in life keeps volunteers devoted to the program. Mr. Di Carlo recalls one chronic pain sufferer who arrived at the workshop looking to escape a rut. Her action plan was to start playing the piano again, something she had once enjoyed but had to give up because of pain. "By the end of the six weeks, she was not only playing again, but had started getting together with people and enjoying life. Her whole perspective changed and her health began to improve," recalls Mr. Di Carlo. "People arrive

> **Witnessing patients regain enjoyment in life keeps volunteers devoted to the program.**

with a certain mindset about their condition. By the end of the six weeks, you see a real transformation that positively impacts their health and, often, their treatment options."

The program is self-perpetuating as volunteer leaders emerge from participating in the program. "The group leaders get to know participants through the six weeks and can make recommendations about suitable leaders to myself and the coordinator," explains Dr. Radcliffe-Branch.

"We then screen and interview potential candidates and if the person is interested and deemed suitable, we offer to provide them the training required for certification as a leader. They're not strangers anymore."

Dr. Radcliffe-Branch believes there is more than enough enthusiasm in the volunteer community to grow the program further, but recognizes that adequate funding is key to sustaining that energy. "My Tool Box is appealing to volunteers as an evidence-based program overseen by a professional, with standardized material, in which volunteers become trained and valued as 'expert patients' who then 'pay it forward.' They have the opportunity to foster empowerment and actually see the transformations in people from the start to the end of the program."

Funding self-management support

In the US, the Stanford program is supported by government. The US Administration on Aging, in collaboration with the Centers for Disease Control and Prevention (CDC), provides funding to 45 states for the establishment of disease self-management networks.[4] In 2011, New York State counted 361 program sites, and websites are used to direct people toward programs in their neighbourhood.[5]

In Canada, the Stanford program has been implemented in eight provinces and one territory. Funding can take various forms. Self-Management BC is a Ministry of Health Patients as Partners Initiative administered by the University of Victoria, which implements and evaluates the program in the province's health regions. In Yukon, it is a permanent government-run program. In Ontario, the program is well established and its funding is shared, in some cases, between the Local Health Integration Networks (LHINS) and the Ministry of Health and Long-term Care, with occasional additional private-sector funding.

In Abitibi-Témiscamingue, Ms. Hubert says Public Health saw the program as secondary prevention, which justified taking on the preparation, management and financing of the pilot project from 2010 to 2013. This year, the program was incorporated into the service agreement between the Abitibi-Témiscamingue ASSS and the five CSSS on its territory, which are now obliged to hold a certain number of workshops per year. The ASSS provides additional funding to the CSSS for the program: as of 2014, its budget now includes an annual $30,000 that goes to each CSSS to cover a two-day per week coordinator and the cost of running workshops. The ASSS buys the program's yearly license from Stanford for $1,000 and coordinates the program at the regional level, playing a pivotal part in training, motivating and equipping CSSS coordinators and volunteer leaders. Ms. Hubert organizes a meeting each year to present the annual report and strengthen ties between volunteers from different locales.

At the MUHC, funding for My Tool Box has so far come from hospital and foundation sources along with private donations and some funds from pharmaceutical companies. A request for funding from Montreal's Health and Social Service Agency (ASSSM) was denied earlier this year. While the My Tool Box program attracts patients from across Montreal, no other hospital or health services centre has yet initiated the program. The question of who is best placed to "own" the program in the Montreal area is still up for debate. Some think ASSSM ownership would help the program expand its availability to the community at large. Others see a benefit to being based in the hospital, which reaches people with multiple chronic conditions who can really benefit from the program. "Ideally," concludes Dr. Radcliffe-Branch, "each health centre would make this program available." ∎
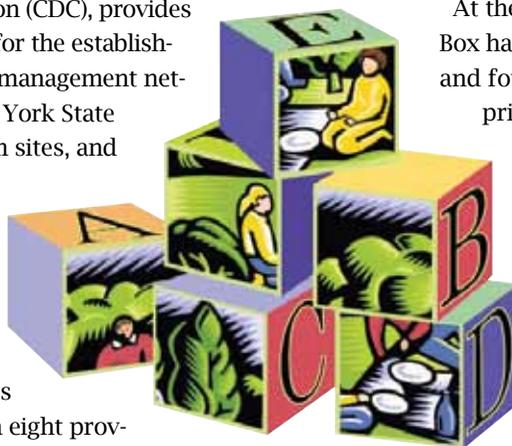
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This case study was prepared by Health Innovation Forum with contributions from Ms. Patricia O'Connor, former Director of Nursing; Dr. Alain Biron, Assistant to the Director, Quality, Patient Safety and Performance; and Ms. Brenda MacGibbon, patient representative on the TCAB team, MUHC.

Challenge

Transforming Care at the Bedside

MUHC program empowers frontline staff, patients and families to improve quality, safety and performance

Quality improvement in the hospital setting is an ongoing challenge. Major organizational changes receive a lot of attention, with multidepartmental committees and large investments. Less visible are the small changes at unit level to improve work processes and environments that affect staff and patient experience of care.

Patients and frontline health workers have the clearest understanding of how things could be improved but often lack the skills and mechanisms to propose and effect change. Current and former patients can make an important contribution to identifying problem areas as they experience the effects of good and poor design most immediately. Simple changes can often result in measurable improvements. While collaboration between staff and patients in continual quality improvement of hospital care sounds good, there is little guidance available on how to bring it about in real-world hospital settings.

The program

Transforming Care at the Bedside (TCAB) is a program developed by the Institute for Healthcare Improvement in the US, which engages nurses to lead process-improvement efforts aimed at patient outcomes and the work environment. It focuses on teaching frontline staff how to use rapid-cycle-improvement processes with the Plan-Do-Study-Act (PDSA) model and enables each unit to identify and accomplish measurable improvement projects. Currently used in over 200 American hospitals, TCAB has demonstrated very clear improvements in patient safety, quality of care and quality of work life.

Ms. Patricia O'Connor, then Associate Direc-

tor of Nursing (Neurosciences) of the MUHC, encountered the TCAB program at the ThedaCare health centre in the US (Appleton, Wisconsin), as part of her work on the U.S. Commonwealth Fund Harkness Fellowship program (2008-09). ThedaCare's TCAB innovations were part of a far-reaching transformation at the organization. "Change was no longer solely the responsibility of formal leadership," recalls Ms. O'Connor. "Every single employee in the organization was being trained and empowered to bring about improvements." She heard nurses say that for the first time in their careers they actually had time to practise nursing in the way for which they were educated instead of wasting time in non-value-added activities.

Shortly after her return, Ms. O'Connor became the MUHC Director of Nursing and was successful in obtaining funds from the Canadian Foundation for Healthcare Improvement (CFHI) to pilot TCAB at the MUHC. "I was able to show the hospital administration and other stakeholders what TCAB could do and how that would align with organizational goals to improve effectiveness, efficiency and patient flow," says Ms. O'Connor. In August 2010, the program was launched on five units in three MUHC hospitals. The MUHC added an innovation by introducing patients as partners on TCAB teams in order to under-

FIND OUT MORE

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stand what improvements were needed from their perspective. A number of patient representatives volunteered to join TCAB teams. "No TCAB organization had yet directly embedded patients in the training and redesign work," says Ms. O'Connor.

Three main objectives guided TCAB work at the MUHC: understanding care through the eyes of patients and families and improving the patient experience of care; inviting patients and families to work with staff to redesign care processes that respond to their real needs; and increasing nursing time spent on direct care.

"We knew we didn't have very good information about the patient experience of care," says Ms. O'Connor, who made a point of building measurement into the heart of the project. At the very start, she worked with the Quality, Patient Safety and Performance department to introduce the HCAHPS (Hospital Consumer Assessment of Healthcare Provider and Systems) patient experience of care survey. Information about nursing use of time was also lacking; she obtained software from the Institute for Healthcare Improvement (IHI) that enabled nurses equipped with personal digital assistants (PDAs) to track the time spent on different activities and establish baseline data.

Uptake

The first units to participate in TCAB in 2010 were internal medicine, neurosurgery, gynecologic oncology, psychiatry and a multiservice general surgical unit. Further units at all hospital sites of the MUHC joined in subsequently. A TCAB team composed of frontline caregivers from different disciplines, managers, assistant managers, patient representatives and a TCAB facilitator was created on each unit. Patient representatives were recruited from the hospital's patient committees, whose members are either former patients or former patients' family members.

The MUHC's TCAB program is delivered in four learning modules of about 10 weeks each. Workshops, combined with hands-on learning one day per week with the teams, focus on developing skills in four areas:

1. Rapid-cycle-improvement processes using PDSA;
2. Improvement of the physical environment using Toyota LEAN 5S methods (sort, set, shine, standardize, sustain) and waste walks;
3. Three specific strategies to improve the quality of care and patient experience, e.g. whiteboards at the bedside, assessment of needs questions and comfort rounds; and
4. Process mapping to improve admission and discharge processes.

"In addition to the US TCAB model," says Ms. O'Connor, "we stole shamelessly from the UK's National Health Service (NHS) Releasing Time to Care program, which is more structured and includes protected release time for staff to learn new skills." In addition, each unit chose a quality indicator such as medication errors, falls or reducing hospital-acquired infections that needed improvement, and tested new practices to find ones with the best outcomes. This helped teams take ownership of the improvement effort, set specific goals, design measurements and evaluate results. Dr. Alain Biron, Assistant to the Director, Quality, Patient Safety and Performance at the MUHC, worked with TCAB teams to ensure that the proposed changes led to improvements that could be measured. "Measurement was embedded even at the stage of identifying what the teams wanted to change," he says, "and TCAB facilitators were available to help units design and collect those measurements."

Evaluation tools

At the end of each improvement project, TCAB

TCAB in action at the MUHC

SEBASTIEN DORVAL-GAGNON/GLOBAL NEWS

teams from each unit presented their specific results to the other teams, senior management and funders. They also received feedback on the impact their projects had on broader project goals such as patient experience, nurse responsiveness, team effectiveness and work satisfaction. Front-line RNs, patient attendants and unit clerks, along with patient members of the team, presented what they had done to improve care on their unit and showed their "before and after" results. "That's what impressed senior leaders within the hospital more than anything," asserts Ms. O'Connor. "It was a very fundamental shift in accountability where frontline staff became the owners of the improvement capability."

Dr. Biron was charged with finding and developing appropriate measurement tools to assess specific practices and their cumulative impact on the three main project objectives. "The HCAHPS patient experience survey used throughout the US gave us a much more concrete measurement than the patient satisfaction surveys traditionally used in Quebec. For the first time at the MUHC, we were comparing ourselves with others in terms of patient experience," says Dr. Biron. "We found that we weren't actually doing so well. When we were doing patient-satisfaction surveys, everyone was quite happy with the results and scores were quite high. However, when we changed the question from "Are you satisfied with the information you received?" to "Did we give you written information upon discharge?" as a yes or no question, results changed."

Patients played a central role at different levels, participating in TCAB leadership, as well as on each of the unit teams. The patients brought fresh eyes and kept teams focused on the patient experience. On the units, TCAB patient representatives would talk to inpatients and get their feedback on proposed improvements. They also conducted post-discharge interviews, along with a research assistant, in patients' homes. "Patients were probably more open with us than they might have been with one of the nurses," says Brenda MacGibbon, a patient representative who joined the TCAB team on the gynecologic oncology unit. "While some staff were hesitant at first about opening up the closed universe of their unit to 'outsiders,'" says Dr. Biron, "they came

Time spent searching for wheelchairs on MNH 4S
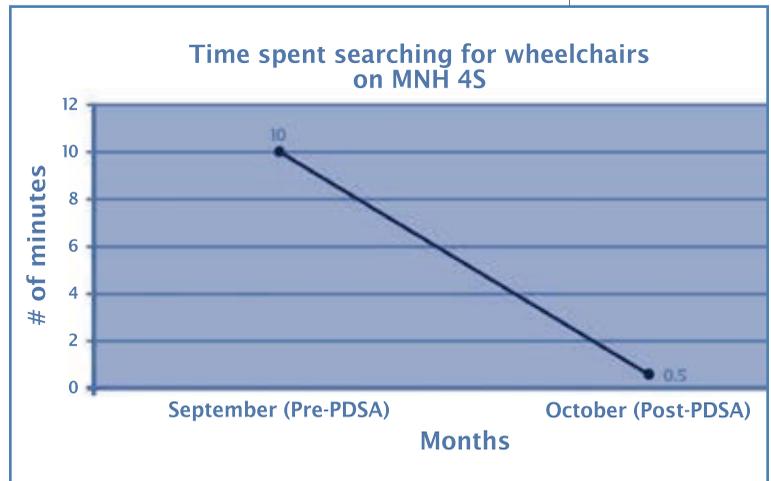
to value the different perspective that patients contributed to discussions."

Results

Initially implemented on five units, the TCAB initiative has now been spread to 19 units across the six hospitals of the MUHC. Between 2010 and 2014, approximately 45% of clinical staff (1,400 persons) were exposed to the learning. TCAB results have been studied from a number of different angles. First, the impact of each unit's improvement project is assessed to gauge how effective the process was at addressing the problem identified by the team.

On the psychiatric unit, for example, serial admission interviews by the physician, social worker, occupational therapist and nurse were replaced by a team interview with the patient. This cut admission time down from over four hours to just one hour, which avoided repetition and long waits for patients and families, saved considerable health professional time and improved communication between the team members. This improvement was recognized by Accreditation Canada as a Leading Practice in 2014. Patient satisfaction doubled.

TCAB efforts to improve the physical environment took on a different focus in each unit: nursing stations, medication rooms, family visiting rooms, treatment rooms, supply rooms, staff lounges and patient dining areas were all redesigned through a collaborative process involving staff and patient TCAB participants. Clocks were installed in all patient rooms. The clean-up of

storage rooms resulted in returning an average $3,000 worth of equipment per unit to Biomedical Engineering. Designated spaces were created for equipment, which reduced the average time nurses spent looking for equipment from 220 seconds to 26 seconds — a savings of two full-time-equivalent nurses per year. Staff and patients benefited from remodelled spaces that were better adapted to their specific purpose. A room turnover project, using visual cues such as coloured magnets to indicate room readiness after discharge of a patient, improved communication between team members and housekeeping and significantly shortened the time to prepare the room for the next patient.

Patient experience of care was improved in different ways. All units provided whiteboards by each patient bed to enable patients and their families to communicate with the care team and provide support and encouragement to each other. Comfort rounds every one to two hours were introduced, focused on managing pain, preventing pressure ulcers (by turning the patient), helping the patient to the bathroom (preventing falls) and ensuring that all items are within reach. Staff members were trained to ask three basic questions on each shift to find out the patient's priority for the day: What is your greatest concern right now? What information do you need that would be the most helpful? What do you need from me right now that would help

Whiteboards

you? On the hemodialysis unit, these questions led to an increase, from February to April 2012, in the proportion of patients who received their blood results from 40% to 100%.

Patient contributions

Throughout these projects, patient representatives identified needs that staff never would have recognized. The family room on the gynecologic oncology unit was actually a source of pride to nurses and staff. It took the patient reps to point out that patients with cancer really did not want to look at walls covered with cancer posters and pamphlets while they were visiting with family. As well, there were sharps containers in the room, which was also used to prepare patients for surgery. "Today the walls are painted and art hangs where the pamphlets used to be," says Ms. MacGibbon. "Surgical preparation has been moved to a room previously used for storage that we cleared out across the hall."

Overall, TCAB improvement efforts increased the percentage of time nurses spent on direct and value-added care activities and improved HCAHPS results on nurse responsiveness (e.g. immediate response after pressing the call button) and communication with nurses. Staff reactions to TCAB and patient involvement in redesigning care have been consistently very positive, as has the nurses' union. Patient representatives were highly engaged and felt valued. Ms. MacGibbon noticed how young patients involved in TCAB became increasingly committed to volunteer work at the hospital following the experience.
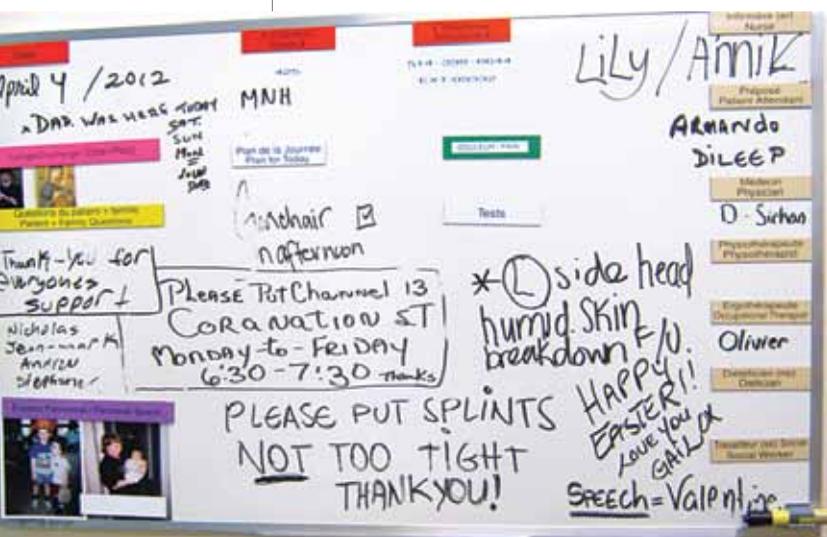
Potential for expansion

TCAB was supported by external funding from multiple sources (the CFHI, the Canadian Institutes of Health Research [CIHR], the Newton Foundation, the Québec Ministry of Health and Social Services, the Roasters Foundation and MUHC hospital foundations). The main expense was in obtaining protected release time to enable frontline staff to participate in TCAB training one day per week. It became apparent in the first year that staff could not undertake TCAB work alongside their regular duties. These funds also supported skilled facilitators who worked with the

teams. The development and adaptation of new measurement methods were covered by grants initially, but are now integrated into MUHC Quality, Patient Safety and Performance expenditures.

A culture change

In 2015, TCAB will see its final wave of intensive roll-out on inpatient units and in operating rooms, an ER and a dialysis centre. Future efforts will focus on shorter implementation cycles. Staff has acquired skills to lead improvement efforts at the unit level and to measure their impact, resulting in improved team effectiveness and increased accountability in taking ownership of problems and working to resolve them. In other words, a culture change has occurred. Units that have not officially participated in the program seek out TCAB facilitators or members of participating units for coaching, especially around ways to improve the physical environment. "Around 2012," remarks Ms. O'Connor, "we started hearing a number of departments in the hospital say 'We need to TCAB this': it has become a verb." In 2014, Accreditation Canada recognized the TCAB program as a Leading Practice.

TCAB introduced new methods of assessing quality at the MUHC and these have been integrated into the organization. "HCAHPS is now part of the MUHC's Quality and Performance dashboard for the entire organization and we're comparing ourselves against US benchmarks," says Dr. Biron. US results are the only ones available publicly at this time, though Canadian comparisons will soon be possible following the Canadian Institute for Health Information's decision this year to adopt the survey in Canada. All provinces save Québec will now be introducing HCAHPS in their institutions. The MUHC TCAB team actually contributed to expanding HCAHPS, by beta testing a new pediatric version in collaboration with Boston Children's Hospital, Harvard University and the US Agency for Healthcare Research and Quality.

"We've built organizational capacity for quality improvement," says Ms. O'Connor. In 2013-14, Infection Control partnered with Nursing and Housekeeping, to use TCAB methods to tackle *Clostridium difficile (C. difficile)* and vancomy-

Equipment parking lot

cin-resistant *enterococci* (VRE) rates that were the second worst in the province. "Efforts to reduce the MUHC's very high infection rates had not been successful in producing significant results," says Ms. O'Connor. "We targeted the six worst units and brought staff through the rapid-cycle improvement and 5S processes and added training in hand hygiene, precautions and environmental cleanliness." For the first time, housekeeping was given protected release time to participate in training alongside nurses, patient care attendants and unit coordinators. In eight months, these six units achieved an impressive 30% reduction in rates of *C. difficile.*

TCAB demonstrated to staff, leadership and the patient community that there were important benefits to working in partnership to improve the patient experience of care. The MUHC is now embarking on further organization-wide initiatives to embed patient engagement into its various structures. Ms. O'Connor will use the lessons from her leadership, as Director of Nursing, of the TCAB project to work in a newly created position to sustain and spread patient engagement throughout the organization. Patients will now be integrated, using standardized mechanisms for recruitment and involvement, into all quality improvement initiatives at every level.

"TCAB accomplished a lot of mythbusting about who was supposed to make changes and how," Ms. O'Connor reflects. "It proved we have enormous untapped talent at the front lines just waiting for that opportunity to learn new skills in order to improve patient care." ■

Challenge

Living Well with COPD

A solid foundation for interdisciplinary patient-centred disease management

"As a physician," says Dr. Jean Bourbeau, "you hear about where the needs are, from both patients and healthcare professionals, and you see the gaps that need to be filled." Effective support and management of individuals with chronic obstructive pulmonary disease (COPD) demands a comprehensive and patient-centred approach.

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Living Well with COPD website **www.livingwellwith copd.com**

Fifteen years ago, when he arrived at the MUHC's Montreal Chest Institute from Québec City, Dr. Bourbeau saw a clear need to have physicians, health professionals and patients working off the same page to manage COPD. "That meant getting the team working together and with the patient to improve disease management." He looked to experience in diabetes, chronic heart failure and asthma that seemed to point the way.

Interdisciplinary care models were in their infancy, and Dr. Bourbeau felt that the first step in coordinating care was to develop evidence-based material that could guide the efforts of a range of professionals to provide best care and patient education. He collaborated with a respiratory care nurse, Ms. Diane Nault; with a grant from the pharmaceutical company Boehringer-Ingelheim, they worked with focus groups and expert advi-

sors to develop the original Living Well with COPD material and structure a self-management education program.

COPD affects between 4% and 13% of Canadians over age 35 (between 1.5 million and 3 million people).[1] The disease (also known as emphysema and/or chronic bronchitis) causes the airways to become inflamed and narrow. COPD is progressive and leads to symptoms of breathlessness, cough and frequent respiratory infections. Acute exacerbations are frightening episodes (as fatal as a heart attack), during which breathing is severely compromised. According to most recent Statistics Canada figures, COPD is the fourth leading cause of death in Canada and the leading cause of hospital admissions. The total cost of COPD hospitalizations alone is estimated to be over $2 billion a year in Canada. One hospital admission often leads to another: 18% of COPD patients who were hospitalized for COPD are readmitted, often more than once, within the year. Emergency room (ER) visits following discharge are higher among COPD patients than for any other chronic condition.[2]

Complex management

Managing COPD relies heavily on patient knowledge, skills and motivation to take medications properly and implement strategies on a day-to-

day basis to minimize symptoms and use health resources effectively. It also depends on physicians, nurses, respiratory therapists and other health professionals working from a common knowledge base and using a team approach to deliver consistent educational messages to equip patients for self-management.

A number of strategies and medications can help people control symptoms of the disease. Medical therapies include bronchodilators to help open the airways and reduce shortness of breath, anti-inflammatories (either inhaled or taken orally) to reduce inflammation in the bronchi, antibiotics to treat respiratory infections and home oxygen for chronic respiratory failure. Healthcare professionals require expertise to carefully select the best options for each individual in a constantly evolving therapeutic landscape. Patients need to develop skills around when and how they should be administered, as well as master breathing techniques, exercise routines and anxiety-reduction and energy-conserving strategies.

The program

"The original pilot of Living Well with COPD in the late 1990s showed promising results, but before encouraging its adoption we wanted to test it further and build solid evidence that it was doing what we expected," says Dr. Bourbeau. With a research grant from the Fonds de recherche du Québec-Santé (FRQS) and additional funding from Boehringer-Ingelheim, Dr. Bourbeau conducted a clinical trial in seven hospitals in three cities across Québec that randomized over 200 patients to receive either usual care or the Living Well with COPD program. The educational intervention consisted of one hour per week of teaching at home for seven to eight weeks, followed by weekly telephone calls for 8 weeks, then monthly calls. Nurses or respiratory therapists acted as case managers, working in collaboration with the treating physician, and were available to patients by telephone throughout the study period. Care providers all worked from the Living Well with COPD materials.

Proven effectiveness

The results of this study, published in the *Archives of Internal Medicine* in 2003 showed that hospital admissions for exacerbations of COPD were reduced by 39.8% in the Living Well with COPD group as compared to usual care, ER visits by 41.0%, and unscheduled physician visits by 58.9%.[3] "It was a landmark study internationally and the first major study to establish the benefits of disease management," says Dr. Bourbeau. Further studies confirmed these benefits, established the program's cost-effectiveness and identified components, notably the written action plan, that contribute strongly to positive results.[4,5,6] Since 2003, there have been over 20 publications on Living Well with COPD[7], and the program has been adapted and implemented in Québec, Canada, the US and countries in Asia, the Middle East, Australia and Europe.

Continued support from Boehringer-Ingelheim, Pfizer and other pharmaceutical companies (GSK, AstraZeneca, Novartis) over the years has allowed for the development of additional materials and the creation of a website, livingwellwithcopd.com to make them widely available in English and French to health professionals and patients. The materials are updated regularly under the direction of Dr. Bourbeau and evaluation of the program is ongoing. There are more than 10 research projects currently under way supported by the Canadian Institutes of Health Research (CIHR), the respiratory health network of the Fonds de recherche du Québec-Santé (FRQS) and unrestricted grants from the pharmaceutical industry.

COPD is an important area of drug development research at Boehringer Ingelheim and the company has seen a number of different respiratory medications approved in the past decade. Suzanne Kimmerle, Healthcare Affairs Manager at Boehringer-Ingelheim, believes the key to Living Well with COPD's success is that "it has evolved continually as we discover better ways to manage COPD. It is updated regularly to incorporate advances, whether in drug therapy, pulmonary rehabilitaton or exercise regimens." It also incorporates feedback from program users.

How it's used

Health professionals create a user account on the website to access full-length versions of materials, all free of charge, which they can then print for

Living Well with COPD

Materials available on the Living well with COPD website:

Pamphlets and brochures
· Patients plan of action
· Get moving… breathe easier
· Summary of the program

Modules
· Being healthy with COPD
· Integrating long-term oxygen therapy into your life
· Integrating an exercise program into your life
· Integrating a plan of action into your life
· Managing your stress and anxiety
· Managing your breathing and saving your energy
· Preventing symptoms and taking your medication
· Keeping a healthy and fulfilling lifestyle

use in education sessions and to hand out to patients. They can work directly from the website to teach patients, and patients can also access the material independently. Registration enables the Living Well with COPD team to track where the program is being used and to keep users informed about updates as they are produced.

The resources include training for health professionals in disease management, pamphlets, flip charts and posters to use in patient coaching, and comprehensive materials for patients. However, health professionals need to know how to navigate the site and find material that's most appropriate for a given patient and situation. "You

> **"Our priority is to assure that patients hear the same message from the beginning to the end of their trajectory: during doctor visits, with their nurse educator, in learning centres and when receiving care from respiratory therapists."** — *PATRICIA CÔTÉ, QACN*

can't just give someone a pamphlet, call that education and expect behaviour change," says Ms. Kimmerle. Dr. Bourbeau stresses this point. "The Living Well with COPD program is not about just bits of material; it's a how-to guide for inter-professional collaboration."

The program offers educational content for patients and a reference framework for health professionals," says Isabelle Ouellet, clinical nurse coordinator for the Centre-West region and at

the Montreal Chest Institute. "Living Well with COPD enables me to base my interventions around proven materials and approaches and serves as a guide when providing individual or group patient education."

Living Well with COPD is effective at increasing not just patients' knowledge but also their motivation to manage their condition. Ms. Jocelyne Goddard, a patient at the Montreal Chest Institute, points out: "It's one thing to learn how to do an exercise, but quite another to integrate it into your daily routine. Once you do, you see the benefits." Ongoing contact with the care team helps keep her motivated and education helps her manage symptoms. "Knowing how different exercises and medications work makes me much more confident that I can act before a crisis occurs," she says.

In fall 2014, Dr. Bourbeau will be launching an expanded patient portion of the site, supported by the Québec Asthma and COPD Network (QACN), the respiratory health network of the FRQS and the CIHR, as well as industry partners (Almirall, AstraZeneca, Boehringer-Ingelheim, GSK and Novartis). Living Well with COPD recently became a not-for-profit corporation to assure its sustainability and the team has expanded to include full-time staff and consultants from different fields, from behavioural science to information technology, working to keep the program up-to-date with the latest evidence.

Uptake

The QACN stands as an innovative mechanism to spread disease-specific best practices on a provincial scale. It is unique in providing continuing education to a wide range of health professionals. "We offer a three-day training program geared for all those caring for people with COPD," says Ms. Patricia Côté, Executive Director of the Network, "and one full day deals with patient education, using the Living Well with COPD materials." The training program is accredited by the orders of nurses, respiratory therapists and kinesiologists. Funding for network activities comes from both the Québec Ministry of Health and Social Services and pharmaceutical companies.

"Our priority," asserts Ms. Côté, "is to assure

that patients hear the same message from the beginning to the end of their trajectory: during doctor visits, with their nurse educator, in learning centres and when receiving care from respiratory therapists. The QACN promotes use of the Living Well with COPD program so that people don't spend their time reinventing the wheel. It's an indispensable tool." The educational flip chart is a favourite: on one side are the key educational messages the professional wants to relay, while on the other are images that help the patient understand the messages. Home care providers carry the materials around with them to share with their COPD patients, according to Ms. Côté. The Network recently recruited regional delegates to serve as spokespeople and help disseminate the Living Well with COPD program and additional modules.

Potential for expansion

"The QACN has been instrumental in seeing the program adopted across the province," says Dr. Bourbeau, who sits on the Network's scientific committee and is President of its Board this year. "The QACN a very good example of how professional societies and non-profit organizations, with industry and government support, can collaborate to promote better approaches to care."

Ms. Côté is very optimistic about the Québec Ministry of Health and Social Services' recent emphasis on chronic disease self-management. Its current strategic plan strongly encourages healthcare organizations in Québec to take action on self-management of chronic disease.

Other provincial governments are also emphasizing self-management and integration of care in hopes of reducing the very high hospital admission and readmission rates for these patients. In April 2014, the Canadian Foundation for Healthcare Improvement (CFHI) launched a pan-Canadian collaborative, supported by Boehringer-Ingelheim. Its aim is to help healthcare organizations implement supports for COPD patients and their families to facilitate self-management and reduce the need for acute services. For patients with advanced COPD, the INSPIRED (Implementing a Novel and Sup-

portive Program of Individualized care for patients and families living with REspiratory Disease) program, developed by Dr. Graeme Rocker at Capital Health in Nova Scotia, provides a hospital-to-home, coordinated and proactive approach to care. The CFHI collaborative will enable this approach to be implemented in other hospitals.

"INSPIRED, which is the first pan-Canadian collaborative program with 19 sites across the country, seeks to significantly increase the current level of care for COPD. Both INSPIRED and Living Well with COPD aim to bring patients the highest possible quality of life while managing their disease," says Martina Flammer, Vice President Medical and Regulatory Affairs, Boehringer Ingleheim (Canada) Ltd.

Dr. Bourbeau will be collaborating with Dr. Graeme Rocker in Nova Scotia to examine how the INSPIRED program can best encourage use of Living Well with COPD and provide a collaborative framework for interprofessional care across the trajectory.

As the health system has become increasingly integrated and coordinated, Living Well with COPD has been incorporated into the training and work of community health centres, home care workers and specialized pulmonary rehabilitation centres." All those pieces have come together in the evolution over the past 15 years," Dr. Bourbeau remarks. He is still working hard to promote its use in all the places people with COPD receive care, including ERs and medical wards, and is undertaking a project with the Montreal Health and Social Services Agency (ASSS) to adapt the program for primary care.

Dr. Bourbeau sees three main challenges in the coming years. The first is collaboration to enhance and spread proven practices and programs. "The second challenge," says Dr. Bourbeau, "is to implement levers, through government, service agreements and accreditation requirements, to encourage health professionals to focus on disease self-management. The third challenge is to sustain research and evaluation of the programs we are implementing. This is the only way we will improve quality and cost-effectiveness in our healthcare system." ■

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The future of patient engagement

Canadian organizations take action to focus on service users

Accreditation Canada

Karen Kieley, Accreditation Product Development Specialist, describes how the organization is changing to recognize the growing importance of patient engagement.

Accreditation Canada includes client-centred services as one of the eight dimensions of the quality framework. Standards have always contained items about understanding the client, understanding client needs, providing education and information to clients when they need it, and engaging them in service delivery and service design. During onsite surveys, evaluators talk to patients as they are going through their journey, and try to follow the path of the patient to gain a sense of the horizontal movement. A client experience requirement is being introduced by service in a phased approach, starting with acute care, long-term care and correctional services. This new requirement will help ensure organizations are monitoring the experiences of those using their services and using the results for quality improvement.

Accreditation Canada is re-examining the language it uses in all of the standards to move away from paternalism. The shift is from a perspective of "doing to" (i.e. "educating clients about," "giving information to the client") to "doing with," which captures real partnership with clients in their care and in the design of the system. Accreditation Canada is further developing content about partnering at every level, particularly in leadership, and is working to reframe the quality dimensions of its standards in terms of what the patient really wants. As a next step, Accreditation Canada is looking at ways its own practices can reflect partnership with patients and families. This may mean including patients as evaluators on the team during the accreditation survey and including patient representatives on standards working groups.

Accreditation Canada has a role in advancing client- and family-centred care. It has already noted improvements in some of the Required Organizational Practices (ROPs) around client- and family-centred care since these were introduced in the accreditation standards. Some examples are giving clients safety education, teaching them about their role in their own safety, and medication reconciliation.

Canadian Foundation for Healthcare Improvement

Maria Judd, Senior Director, Patient Engagement and Improvement, focuses on engaging patients and families in the Foundation's healthcare improvement work.

The Canadian Foundation for Healthcare Improvement

(CFHI) is a not-for-profit organization funded by the Government of Canada, dedicated to accelerating healthcare improvement. CFHI recognizes patient and citizen engagement as a critical lever for healthcare improvement. CFHI's Partnering with Patients and Families for Quality Improvement Collaborative, launched in 2014, focuses on harnessing the tremendous potential of patient and family engagement to drive quality improvement in health care. The Collaborative provides funding, coaching and other support to help 22 teams from Canadian healthcare organizations engage patients and families in designing, delivering and evaluating healthcare services, with the goal of better patient care and outcomes. Teams span the continuum of care, from community organizations right through to regional health authorities and government organizations, with diverse projects focusing on self-management of chronic conditions and transitions in care, etc. The teams were selected in summer 2014 and held their first meeting in Montreal on October 2 to coincide with the MUHC-ISAI conference.

Aligning with this vision of collaboration, CFHI is the exclusive Canadian partner of the Institute for Patient- and Family-Centred Care's Better Together Campaign, a campaign that aims to change the concept from families as visitors to families as partners in care, by replacing restrictive visiting hours policies with family presence policies in Canadian hospitals.

Finally, CFHI has developed the Patient Engagement Resource Hub to share learnings and best practices. The Resource Hub, available on the CFHI website, is a collection of practical, open-access resources that support engaging patients and families for quality improvement.

CFHI's earlier support to 17 organizations, through the Patient Engagement Project (PEP) initiative, resulted in improvements to patient-provider communications, patient experience and other quality domains. The experience of the PEP teams has been analyzed by Ross Baker from the University of Toronto, and holds important lessons about the elements required for successful patient engagement.

HealthCare*CAN*

Bill Tholl is founding president and CEO of HealthCareCAN, whose mandate is to speak on behalf of Canada's healthcare community in order to advance organizational health system performance. HealthCareCAN is interested in finding ways to support the community in moving toward patient centricity and engagement.

HealthCare*CAN* is committed to strengthening the voice of

patients. Following the MUHC-ISAI conference, it was agreed by the Transitional Board to assign two places on its permanent Board for patient representatives.

We are also interested in partnering with other groups to establish a clearinghouse of initiatives in patient engagement, to enable organizations to see how others have overcome barriers and succeeded in truly integrating patients into decision-making. The repository should include contact information for project leaders so that people can learn from each other.

There is an opportunity provided by the Innovation Panel established by the federal Minister of Health and led by Dr. David Naylor, to make patient- and family-centred care one of the five game-changing innovations in Canada's health and health-care system.

Finally, HealthCare*CAN* acquired Vocera's Experience Improvement Framework and Mapping and Design Methodology and is adapting these for insertion into the Canadian curriculum. We will be looking for people to help adapt and adopt these patient-centred approaches that seem to be working fairly well in the US. HealthCare*CAN* offered its first course in Experience Mapping and Design in 2014. It involves a six-month program of workshops, webinars, coaching calls and application of the methodology within the organization.

Hoffman-La Roche

Janice Selemba, Vice President, Customer, Value and Strategy, describes Hoffman-La Roche's current efforts to become truly patient centric.

The first step is understanding that patient centricity is more than just providing treatments that produce positive health outcomes. Hoffman-La Roche's challenge is to integrate patient perspectives (in an industry that does not permit direct access to people) into the solutions we provide. Small shifts in perspective, such as speaking about ensuring that "treatments do not fail patients," rather than "patients do not fail treatments," point to different directions. Hoffman-La Roche's purpose statement, "Doing now what patients need next," implies knowing what patients need. The company is now looking at ways to involve patients in defining those needs. This can start to implicate everything from product development right through to the end delivery of treatments.

There is a challenge in defining what patient centricity is in such a way that it becomes useful to guide actions within the organization and create sustainable partnerships to promote patient engagement and empowerment. Understanding what impacts the patient (person) and their family is part of that. Recognizing the growing circle of care and the tools they need is another part. Hoffman-La Roche has scientific, educational and business capabilities that can be put to use in optimizing benefit for patients and their caregivers along their journey, before, during and after the

point of access to treatment. We are eager to take up this challenge, which we consider vital to ensuring the company's continued relevance in a changing environment.

Government

Dan Florizone was Deputy Minister of Health in Saskatchewan until 2013, when he became Deputy Minister of Education. He engaged the Patients First review in 2009, was an early proponent of Lean to improve efficiency and chaired the Health Quality Council, which has led the way in supporting evidence-based patient-centred care. In 2013, he launched the Students First initiative.

The alignment of policy and governance with the patient engagement agenda is essential, not because we need to rely on government to introduce change, but because government can either promote or abruptly stop any good initiative under way. We have a problem in those public services that we either fund or deliver directly through government, and we are finally waking up to the need to focus on those we serve and look at improvement from their perspective.

> "I believe we are on the cusp of a Copernican revolution where providers, doctors, hospitals, are not at the centre of health and health care, but patients truly are." — BILL THOLL

This involves looking at the whole continuum, whether in health care, social services, education or justice, finding the touch points, and involving the people we serve in identifying where and how government services can make a positive difference. The framework that emerged at the MUHC-ISAI conference provides the litmus test: If an initiative or change does not make a difference to providers and patients at the point-of-care delivery, is it really an improvement or is it the most important improvement?

Step 1 in a 12-step program is admitting you have a problem. In order to move forward, we have to understand and collectively agree that the status quo is no longer serving us well. One of the biggest failings we have as a country is to think, because we are proud of Medicare, that we have the best system in the world. Success breeds complacency when what we need is continuous improvement.

Patient engagement has changed our discourse. We can no longer claim to be the experts in what patients want and need, because the patient is right there. Our advantage in the service sector is that the people we are talking about engaging are right there, through the care journey, at those touch points; in fact, you could almost envision that we are having conversations about the patient and the patient is sitting there thinking: "Just ask me." ∎

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