


Who is the Puzzle maker?

Patient/Caregiver Perspectives on Navigating Health Services in Ontario

The Change Foundation Health Integration Report
June 2008

THE CHANGE FOUNDATION

HEALTH CARE DESERVES
OUR FINEST THOUGHT

Contents

"…you're sent for more tests, you're adding more doctors or specialists…and then you really sit back and you have to think to yourself from time-to-time, "Well, who is the puzzle maker? Who's getting all these pieces and putting them together?"

— Carmen, patient & caregiver in Toronto

Introduction

When The Change Foundation redefined itself in 2007 as a policy think tank focused on supporting health integration in Ontario, it set out to make a unique and useful contribution that would not duplicate the efforts of others.

The Change Foundation's first health integration report, *Who is the Puzzle maker? Patient/Caregiver Perspectives on Navigating Health Services in Ontario*, aims to do that in a meaningful, albeit modest, way. As our research shows, almost none of the literature on health system and services integration captures the experiences or perspectives of patients and their families. And as our literature review also reveals, while surveys of patient satisfaction with services from individual institutions and organizations abound, there is scant in-depth probing of patient and caregiver perspectives on how integrated they find their health-care system as they move between and among health providers and services. We also know little about the impact of a poorly coordinated vs. a well-integrated health system on health outcomes.

This report presents snapshots of the experiences of patients and caregivers navigating the system in Ontario and shares their insights about what changes would help create a better integrated health-care system organized around their needs. Their input is instructive for everyone committed to improving the integration of health services in Ontario.

Who is the Puzzle maker? draws on several sources: findings from focus groups with Ontario patients and caregivers who've navigated the health system in the past year; results from a general Ontario population survey asking about communication and information flow in the health-care system; a literature review on public expectation and patient experience of integration of health care; and a scan of who is measuring what in health integration in Ontario.

The Change Foundation offers this initial work as a resource to the people who plan, fund, design and deliver health services in Ontario. As the province begins in earnest to integrate health services under the umbrella of Local Health Integration Networks (LHINs), we need to keep the experiences and suggestions of patients and caregivers uppermost in our collective minds. The Change Foundation will continue its work on patient and caregiver perspectives on health integration, and will follow up this research with additional patient/caregiver engagement in the fall and winter.

The LHIN Landscape

When The Change Foundation moved from a granting organization to a "think tank," health integration seemed like a logical initial focus. Ontario was moving into a new era of health governance through the 2006 creation of Local Health Integration Networks (LHINs) while maintaining existing governance structures for health programs and institutions. LHINs and health organizations are now developing contractual relationships through accountability agreements. Hospitals have been the first to establish this new relationship; other community providers such as Long-term Care Homes, Community Support Services, Community Mental Health and Addictions Services, Community Health Centres and Community Care Access Centres are coming on board over the next couple of years.

What Did We Want to Know?

Better, integrated care, planned locally for defined geographic populations was the policy rationale for the creation of the LHINs. Given this goal, The Change Foundation identified integration as a topic that presented a significant opportunity to help improve health care in Ontario. Our questions were relatively straightforward:

1. Where might we focus to improve the integration of services?
2. Where are patients experiencing problems and where do they see success?
3. How would we measure and report on whether our health-care system is becoming more integrated, and what would be the best approach to doing so in the future?

What Did We Do?

Our background research included the following:

- A literature review conducted by a team at the University of Calgary reporting on the perceptions and expectations of patients and their families with respect to the ease with which they could navigate the health-care system;
- A survey of the general population in Ontario about information flow and communication across providers when they used the health-care system;
- 10 focus groups across the province with patients who use the health-care system fairly often (minimum of six interactions within the last year) and caregivers to capture their perceptions of how well integrated health care is in their communities;
- An environmental scan of work being done in Ontario to measure integration as we move forward with local efforts to integrate services.

"The difficulty was the coordination of care once she got home from hospital.… if the surgery's over and you're healed that's fine, but for someone with diabetes or another chronic disease that requires ongoing management…it's sort of willy-nilly. There just didn't seem to be a good flow of information between the specialists. And so it's a bit difficult to navigate. I thought it would be very helpful to have someone sort of helping us with that."

—Tanya in Kingston

What Did We Find?

As noted at the outset, there is lots of research describing integrated care—what it should look like, how to accomplish it, identification of barriers and critical success factors, etc. However, hardly any of it looks at the process through the eyes of patients and their caregivers. Therefore, the patient perspective became our focus.

When Ontarians are sick and searching for diagnosis, treatment, or test results, when they're trying to control their diabetes or cancer or asthma, and when they're looking for the support and services their ailing parents need to live at home, they turn to their health-care system for help. What do they find? And how do they fare? Do they know where to go, who to see, and what to do next?

The Change Foundation heard clearly from patients and caregivers that the lack of coordination and communication among various parts and players in our health-care system left them feeling frustrated, confused, and forgotten. And even when care or co-ordination was excellent, it sometimes seemed to patients and caregivers that it was **despite** the system—not because of it. They felt there was too much left to chance, too few protocols followed, too much dependence on the actions—or inactions—of individual providers.

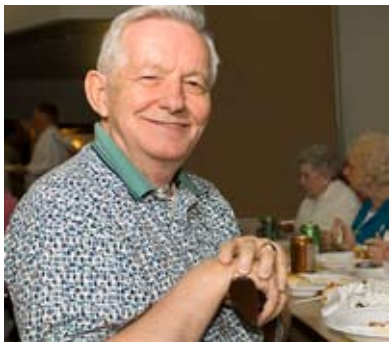
But patients and caregivers also praised the system—especially the continuity of care and coordination provided cancer patients. And those whose family doctor worked at a community health centre or were part of a multidisciplinary health team reported greater collaboration between their health-care providers.

The results below portray what patients are experiencing today. They have reasonable expectations of the system; they strongly support their health-care providers and professionals; they understand the government's concern about directing more and more resources to health care but they can also see where things break down. In the words of one citizen, "sometimes, the process just doesn't make sense. Couldn't it be just a bit more logical?"

Those of us working in, researching and writing about the system often use terms like episodic care but patients don't see it like that. For patients, there isn't really an end point. They are attached to the health-care system for life and our results underscore their feelings that at certain points, they have lost the attachment.

The results are not meant to assign blame or point fingers. Health-care delivery in Ontario in 2008 is complex: it involves many people in different physical locations all working flat out, a mix of providers, planners, case managers and health professionals all with different accountabilities, and multiple information systems that are not yet able to speak to each other. This is why LHINs and organizations like Community Care Access Centres have responsibility for improving the patient journey.





Four general themes flow out of our research—these are areas that patients identify as problematic:

- Navigating the system: knowing whom to call, what to ask, how to move from provider to provider and back again, connecting the hospital process with the community process, organizing services in one's home. Not so simple.
- Dealing with repetition, redundancy and delay: repeating medical histories, symptoms, medical records, tests. A common situation.
- Worrying about communication: wondering whether necessary information has been transferred from one provider to another or one setting to another, not being clear about what happens next in the care process—who is responsible for what.
- Getting lost in the transition: experiencing the problems described above at points of transition from one provider or organization to another, e.g. from hospital to home or a long-term care facility.

Navigating the System—Is Anybody Joining the Dots?

- 54% of people in the survey of Ontarians reported that they were not confident that there was a single, lead person in charge of coordinating their health-care services (Pollara, p. 10, 81). This figure is based on findings from a fairly healthy population; if the survey had targeted frequent users of the health-care system or people with chronic health conditions, it would likely be even higher.
- Research indicates that as people move across and receive care from a variety of settings, the patient and family often represent the only common thread and are often left to make their own way through the continuum of services without the skills or support or even just the confidence to do so (Spragins and Lorenzetti, p.20). This experience was particularly common among parents of children with special needs and other families dealing with chronic, debilitating illnesses.
- Patients recognize that they must shoulder some responsibility for managing their care but are looking for more of a partnership.

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"You are your own health advocate–you have to hustle your doctor–you can't take anything for granted."
(Keith in Toronto)

"…there's certain things that fall on yourself. You have to be responsible, but if you're in a hospital and you need some kind of therapy where you're going to another institution or someone has to come in for home care and things like that…there's very little you can do yourself to coordinate those kinds of moves."
(Carmen in Toronto)

- Patients receiving care in integrated clinics featuring multi-disciplinary health-care teams reported higher levels of satisfaction and less difficulty navigating services (Spragins and Lorenzetti, p. 20).
- Focus group participants echoed that finding. Those who received care from community health centres or through multidisciplinary teams reported more coordinated care and better communication among providers, patients and families.

"…the delivery of medical care at those community health centers is just phenomenal…You get the medical attention; you get the follow-up if you're diagnosed with diabetes…When I was diagnosed with my heart problem I was immediately referred to the Ottawa Heart Institute…I was part of the healthcare team. I got to see a physio. I got to see dietitians. I got to see a cardiologist. I got to see psychologist. I got to see a social worker. Instead of being left alone to figure it out."
(Phyllis in Ottawa)

- Focus group participants expressed concern for those who are not capable of advocating for themselves or don't have a family member to act for them.

"But for the elderly or people who are not functional or able to take care of themselves, that must be pure hell."
(Sudbury caregiver)

Dealing With Repetition, Redundancy and Delay–Could it be a bit more logical?

- 41% of people in the survey of Ontarians reported that they do not feel that the health system values their time (not seen at time of appointment, dealing with only one issue in each appointment, short notice for appointments during work hours) (Pollara, p. 9, 77).
- Common themes from the research literature include patients having to convey the same information repeatedly, being sent for duplicate tests (either because first results were not available or too much time had passed between the request for a referral, the tests, and seeing a specialist), appointments or treatments being postponed after the patient arrives onsite, rebooking an appointment

"Since November, I think that I have told my history with my daughter, if not 500 times, then not once."
– Sudbury caregiver

"They would both request a blood test—so my child would get blood work twice and this became a real problem until I put my foot down and said 'you guys have got to figure this out because this is unacceptable. There is no reason for him to be getting blood drawn twice when you work in the same office.' "
– Melissa from Ottawa

"My various bits and pieces are dealt with at different hospitals—and if I am scared or sick or out of it, I don't remember where the records are."
– Betty in Toronto

because the health professional did not have adequate information to undertake an assessment of patient at the time of the appointment (Spragins and Lorenzetti, p. 33).

- Focus groups highlighted a similar theme of repeat tests for different providers and having to retell their situation.

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(Melissa from Ottawa)

"With my dad, every time I've gone, and he's been to various places and I've been there, we have the big file. Now if I wasn't educated and he wasn't very organized… and now he's getting older so my sister's got to help… every time they go you have to fill in the forms again."
(Keith in Toronto)

- Focus group participants also talked about how much longer things take—they expect to wait but they also wonder about whether we have become less efficient.

"Years ago, the receptionist or nurse would pick up the phone and call the specialist and you would leave the office with your appointment. Now everything is done by fax…it may be weeks before responses are made and appointments are confirmed…the whole system seems to have slowed down."
(Linda in Ingersoll)

"…every time I go to the doctor it's mostly because of my blood pressure and my diabetes medication. I did not have a chance to discuss my asthma. I left it at that, because every visit the doctor allots a fifteen-minute time slot for each health condition and I have to get back to the doctor and say, okay I have multiple health issues, I need more time to discuss my problems… It is frustrating…my health condition is so connected, interrelated—my high blood pressure, my diabetes medication…So, he does have to discuss all of these issues with me, because the medication may counter-react with the other medication."
(Isabella in Toronto)

Worrying About Communication–Is Anybody Listening or Talking to me?

This was by far the greatest area of concern in the literature, the survey and the focus groups. Results relate to having the right information at the point of service, clarity for the patient and caregiver as to next steps

> "I actually had to go myself to the doctor's office, get the results and drive back to the specialist."
> – Georgina in Ottawa

> "I think what we should have also is a centralized health file, where all our health information, all our past health history, all our current medications and all our treatments are in that central file. So, if I go and get involved in an accident in a remote town somewhere, the people treating me can instantly know all my problems and they would now do a much better job on treating me."
> – Julius in Toronto

in their treatment pathway, and basic communication between and among health-care providers.

Information At Point of Service

- 41% of people in the survey of Ontarians reported that they were not confident that all their health-care providers had access to all the information, tests and records related to their health (Pollara, p. 79).
- Common themes in the literature: records were misplaced or not transferred in time or incomplete information was sent (medication list not up to date or some, but not all, lab tests received).
- Focus group participants described instances in which they delivered their own results to ensure they were received.

"I actually had to go myself to the doctor's office, get the results and drive back to the specialist."
(Georgina in Ottawa)

- Focus group participants also described feeling anxious when they were expected to relay information if it wasn't available at the time of receiving service.

"My various bits and pieces are dealt with at different hospitals—and if I am scared or sick or out of it, I don't remember where the records are."
(Betty in Toronto)

"I think what we should have also is a centralized health file, where all our health information, all our past health history, all our current medications and all our treatments are in that central file. So, if I go and get involved in an accident in a remote town somewhere, the people treating me can instantly know all my problems and they would now do a much better job on treating me."
(Julius in Toronto)

Clarity About Next Steps in Treatment

- 30% of people in the survey of Ontarians reported that they sometimes received instructions from a health-care provider about symptoms to watch for and 35% reported they occasionally, seldom or never received such instructions (Pollara, p. 73).
- 27% of people in the survey reported that they sometimes received instructions from a health-care provider about where to seek further care if needed and 30% reported they occasionally, seldom or never received such instructions (Pollara, p. 73).
- Focus group participants reported that they are often at a loss as to next steps in their health care, although cancer patients seemed to receive more coordinated care with clearer communication.

"Patients are expected to know more about what's happening, but they're not educated…The time isn't

taken to tell people what's happening and what's gonna happen next."
(Pam in Kingston)

"…as soon as they knew I had colon cancer—boom—it all happened. I learned on the Tuesday, I was in the hospital on the Saturday, I was operated on Tuesday, home two weeks later, started chemo a month later, 6 months later I was done. Bang, bang, bang…they set up homecare for me. They also gave me a drug card…And so I found the communication and the organization just wonderful."
(Hal in Ingersoll)

Communication Between Health-Care Providers

- Research studies highlight that patients' perceptions of how well their care is coordinated are strongly related to their understanding of the extent to which health-care professionals communicate with each other within and across sectors (Spragins and Lorenzetti, p. 23). The professionals themselves are highly valued but patients believe they are not communicating well with each other.
- Evidence suggests that this directly affects care and patient outcomes: "Quality of care and patient safety can be jeopardized due to incomplete or inaccurate information transfer between settings and practitioners, inappropriate or absent follow-up care. There is conflicting advice about illness management and difficulty reaching practitioners when questions arise." (Spragins and Lorenzetti, p. 24).
- Focus group participants reported a lack of communication between providers.

"Trying to organize it to get them all to work together was next to impossible. Nobody knows what the left hand is doing, kind of thing…"
(Krista in Kingston)

"My family practitioner did not even know that I had seen the specialist in January. He did not even know that I had been to the hospital and that he had sent me to see a specialist…He said to me: "Well, why did they not call that you were at least in the hospital?"
(Patient in Sudbury)

"I counted 22 different people who came into my little room and did this and that and the other. I'd have to say they all did it very well, but I scratched my head and wondered…'Who's in charge?' "
(Cautley in Toronto)

"…people are leaving the hospital and then they're kind of on their own. When they're out there's home care, but only for so long and then…it's unloaded deeply on families. Honestly if they don't have daughters or sons close by, you're on your own."
– Joy in Kingston

"There are gaps between the family doctor, the specialist and the hospital."
(Clara from Ottawa)

Getting Lost in the Transition–Who is the Puzzle maker?

Research indicates that the concerns around information flow and communication are particularly acute when a patient is moving from one provider or location to another (Spragins and Lorenzetti, p. 29). This is when the need for some support and assistance appears to be most needed.

Focus group participants also identified these transitions as most difficult because they felt they couldn't fulfill expectations and weren't sure where to turn for help:

"What's available for home support? What are the choices? We didn't feel as a family, that we knew what to do…I think that's the weakest part of the system. Dealing with and getting parents into proper, good care…There's not enough information given to the children."
(Shirley in Ottawa)

"…people are leaving the hospital and then they're kind of on their own. When they're out there's home care, but only for so long and then…it's unloaded deeply on families. Honestly if they don't have daughters or sons close by, you're on your own."
(Joy in Kingston)

"My father was in the hospital for two weeks, then they sent him home because they needed the bed and the home care showed up unannounced and two days late and handed my mother and I a bag of needles and the medication and said, 'When he's in pain, give him one of these.' And I said, 'Whoa! We can't do that, you need to come back and administer this.' But you know, that was an uphill battle."
(Caroline in Kingston)

"They asked my father 'Is there someone at home who could take care of you?' And he said, 'Yes, my wife.' But my mother is blind, she has mobility issues. I said, 'He cannot come home under these circumstances.' So they told me I was the primary caregiver."
(Carmen in Toronto)

What Can Be Done? Thoughts from the Public and Suggestions from the Literature

Patients and caregivers identified solutions to help connect the pieces of the health-care puzzle, so that good care and coordinated care are not left to luck:

- Speed up Ontario's implementation of electronic

health records–this was echoed by all groups, old and young alike, regardless of residency;

- Provide access to a professional 'care coordinator' or 'system navigator'. (The research notes the use of different terms for this function, including: care facilitator, transition coach, patient navigator or case manager. Regardless of the name, there is a need for a known and accessible individual responsible for coordinating care across settings and providers.);
- Increase multi-professional team work and expand the range of health providers such as pharmacists and nurse practitioners;
- Provide better support, information, and liaison for caregivers, many of whom felt overwhelmed by the responsibility of caring for a friend or family member;
- Co-locate services and establish linkages between primary care practices and other parts of the system to make it physically easier for people to access services;
- Support health providers to undertake process mapping with their institutional and community partners to reduce duplication and delay;
- Offer patients care maps that they can take with them when moving from one provider or location to another.

> "I think primarily we need better communication…everything from information sharing whether that's through computer files, from caregiver, hospital, other institutions, whether rehabilitation or social services or whatever. There really has to be a push to make that communication connect and in a timely manner. You know, not that you're arriving at one physician to find out that they haven't received reports from another or that blood work hasn't been you know, sent to them, etc., which is all time consuming and financially you know, a waste as well."
> – Carmen in Toronto

Measuring Health Integration

There are many efforts underway in Ontario to create performance measures and indicators. A scan of organizations currently working on these issues includes:

- Health System Performance Research Network (HSPRN), evolved from the Hospital Report Research Collaborative, focuses on measuring and improving integration across the health system, and will focus on performance measures related to transitions of care between sectors.
- Cancer Care Ontario (CCO) and the Cancer Quality Council of Ontario (CQCO) have developed the Cancer Services Integration Survey to collect provider feedback on the level of coordination and integration of cancer services. Areas for future work include: (i) better measurement of the patient experience with the cancer system; and (ii) interactions between primary care providers and the cancer system.
- Local Health Integration Networks (LHINs) are: (i) working with the Ministry of Health and Long Term Care (MOHLTC) to develop measurement indicators for the Ministry—LHIN Accountability Agreements; (ii) working together to develop an inventory of indicators for measuring their Integrated Health Service Plans; and (iii) starting to work on indicators for the Accountability Agreements with service providers.
- Ontario Health Quality Council (OHQC) reports annually to the public on Ontario's health system. Two aspects of integration of care were included in their recently released 2008 report: (i) use of rehabilitation services by people treated in hospital for stroke; and (ii) patients' knowledge of whom to

contact after discharge from hospital. The OHQC will be working over the next year on how to better measure patient-centred care.

- Joint Policy and Planning Committee (JPPC) formed a multi-stakeholder committee that recommended: (i) system integration indicators for the Hospital Accountability Agreements; and (ii) indicator development for hospital—Community Care Access Centre (CCAC) integration.

Some of these organizations hope to measure health integration. However, there is no agreement on what constitutes the ideal measures of integration, and patient-focused measures of integration are particularly underdeveloped.

The Change Foundation is working with the Ontario Health Quality Council, the Institute for Clinical Evaluative Sciences, and Cancer Care Ontario to facilitate the development of a measurement framework. The Foundation is especially interested in taking the lead on or partnering with organizations to create robust and valid measures of the patient's perspective of integration.

Next Steps

The Change Foundation will undertake the following priority projects in the coming year:

- Develop a plan to investigate the impact of poor coordination and communication on patients' health. Up to now, the focus has been on patient experience with process and structure. The next step is to learn about what happens to patients when they or their caregivers have problems with coordination and communication.
- Conduct another round of patient and caregiver focus groups to better understand integration challenges faced by communities with specific needs (e.g., mental health and addictions consumers, multi-cultural communities, etc.). Although there may be problems common to all who use the health-care system, there are also likely to be unique challenges for specific patient groups and assumptions about appropriate care and the care process that need to be questioned.
- Continue to support projects to improve patient transitions between parts of the health-care system. We will continue to partner with the Ontario Association of Community Care Access Centres on projects to improve the patient experience in the transition from hospital to 'home'.
- Survey providers, through a partnership with a provider association, to better understand the conceptual and practical applications of integration from a health-care professional perspective. Although our focus is understanding integration from a patient perspective, we are also going to "integrate" this orientation with more knowledge about integration from the provider perspective.
- Prepare international case studies so we can learn from countries that have reformed their health systems to achieve integrated, high quality, accessible and sustainable health care. We want to tell the story behind the reforms and extract lessons for Ontario as it moves forward with its integration journey.
- Continue to work with our partners to facilitate the development of an integration measurement framework. We are especially interested in developing robust and valid measures of the patient's perspective of integration.

Research Methods

Literature Review

A systematic review was undertaken by researchers at the University of Calgary using peer review articles and grey literature. Eleven multidisciplinary peer-reviewed databases were used along with key organization websites and reference lists from the major studies identified. Using inclusion and exclusion criteria, the search was limited to empirical studies of consumer expectations and patient experiences of integrated health care published since 1997. Fifty-three studies were selected for inclusion, twelve of which were Canadian.

General Population Survey

A general population survey was conducted by Pollara Inc. with 1,015 Ontarians aged 18 and older between April 29th and May 1st, 2008. Questions focused on information flow and communication, provider access to necessary information, coordination of care, and whether the health system values the time of patients. A survey of this size yields results that are accurate to +/- 3.1%, 19 times out of 20.

Focus Groups

Ten focus groups were conducted by Pollara across Ontario between March 26th and April 9th, 2008 with patients and caregivers. The groups lasted ninety minutes and were organized as follows:

- Toronto (2 patient groups)
- Ottawa (2 patient groups)
- Kingston (1 patient group and 1 caregiver group)
- Sudbury (1 French language patient group and 1 French language caregiver group)
- Ingersoll (1 patient group and 1 caregiver group)

Patients were men and women aged 18 years or older with a minimum of six interactions with the health-care system in the last year. At least one interaction had to involve a provider or service other than an interaction between a family physician and specialist.

Caregivers were men and women aged 18 years or older who had participated with a friend or family member (whom met the above criteria) in appointments and felt they could speak to the person's experiences with the system.

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Vision

To be Ontario's trusted advisor advancing innovative health policy and practice.

Mandate

To promote, support and improve health and the delivery of health care in Ontario.

Mission

To promote independent analysis and informed debate of current and emerging health issues.

To support outstanding research and policy analysis about health system integration.

To improve patient outcomes through innovative approaches to quality improvement and knowledge transfer.

Values

Excellence

We strive for excellence in all that we do.

Innovation

We take innovative approaches in developing new ideas.

Collaboration

We work in partnership with others to achieve success.

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