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Health System Navigators: Band-Aid or Cure?

A PRIMER WITH REFLECTIONS FROM THE CHANGE
FOUNDATION'S PANORAMA PANEL



Acknowledgements

The Change Foundation's unique and abiding partnership with our PANORAMA panel serves as a model of community engagement. It also deepens and enriches our work. PANORAMA is a panel of more than 30 Ontario patients and caregivers who are drawing on their own experiences – good *and* bad – of moving across the healthcare system, to help improve everyone else's.

The Change Foundation acknowledges and thanks each PANORAMA panelist for inspiring and informing us. Their stories, ideas and wisdom help our thinking evolve on how to advance a patient-centred healthcare system in Ontario.

About this Report

This is the first in a series of PANORAMA reports presenting the diverse and collective views of The Change Foundation's standing panel, along with the Foundation's own analysis on game-changing ideas to advance a patient-centred healthcare system in Ontario. We hope these reports, integrating the frequent, lived healthcare realities of more than 30 Ontario patients and caregivers, will spark meaningful public policy discussion and inform system-level change.

What's PANORAMA?

PANORAMA is a standing panel of more than 30 Ontario residents exchanging views, experiences and advice to help The Change Foundation in its work to improve the patient/caregiver experience. The panel is reflective of a growing proportion of Ontario's population who are living with chronic health conditions or providing care for someone who is.

“I got a list of referrals for surgeons from my doctor, but didn’t know how to decide what is best, how the surgery will affect my life, how long rehab will take or where I can get rehab.”

“People are so very individual and circumstances are unique to each of us, so I fear that the desire for one model to act as a template for all navigation will work poorly. Can all possibilities be anticipated?”

“Most people have adequate caregivers in friends and family, and for them a navigator would be unnecessary and prohibitively expensive for the system, and may even be an annoyance. The navigator should concentrate on the small group that really does need help, to keep costs from getting out of hand, but also not to spend a lot of effort needlessly.”

PANORAMA panel members



INTRODUCTION

Why health system navigators?

Ontario's healthcare community has begun to fully absorb the consequences of an unintegrated healthcare system. Individuals seeking care can get lost as they move among different healthcare providers who are not connected to one another. At times, this can have a serious effect on clinical outcomes, and it frequently duplicates efforts, wastes everyone's time and increases costs.

(Boling, 2009; Boyd et al, 2007; Golden et al, 2010; Lin et al, 2006; Naylor, 2004; Simpson, 2002).

Of late, increasing emphasis is being placed on what is called health system navigation. In the current Ontario context, the focus is on navigation at points of transition, as patients move from one provider to another. This is generally thought to mean movement between unconnected organizations or providers (although transitions within the same care team under one roof can sometimes prove just as difficult).

A potential policy fix that is currently being developed is the introduction of *health system navigators*, sometimes called *patient navigators* or *transition coaches* – people who would help “navigate” the moving around. Enterprising healthcare professionals have even started businesses that can provide these services for a fee (Wilkinshaw, 2011).

Some important questions are raised:

- Is this a sensible system solution (Parker et al, 2011) or another “work around” for an overly complicated system (Robinson-White et al, 2010).
- Does the existing evidence, which is based largely on cancer system navigation, translate to other patient populations with chronic disease?
- If we assume that the research to date (still a small amount, and from other jurisdictions) applies in Ontario, what implementation issues would need to be considered?



This primer looks at how the concept of navigators developed, summarizes some of the research done and provides reflections from The Change Foundation's [PANORAMA](#) panel on what would need to be considered in the Ontario context.

As many of the recently established provincial [Health Links](#) are thinking about some sort of navigation model, we hope this primer can contribute to the discussion.¹

History and evolution of the health navigator model

The first patient navigator program was developed in 1990 at Harlem Hospital in New York City for African American women with breast cancer. Its founder, Dr. Harold Freeman, could see that poorer, black patients faced more barriers getting screened, diagnosed and treated. In a recent interview, he says the term came to him as he was “thinking of a metaphor for what patients have to do to negotiate the medical system; it’s like being on a small boat in the South Seas when you can see an island in the distance but there are rocks in between. And if you hit them, you’ll

sink and possibly die. But let’s say there is a navigator on board who can chart the course and get you there safely” (Fayerman, 2011).

Peer navigators were used – people from the same culture or community and/or cancer survivors. Trained to provide support, they helped people organize their care, overcome logistical barriers such as insurance or transportation problems, and helped them feel empowered to take an active role in sorting out their care options.

The results were very positive, with improved access leading to earlier diagnoses and greatly improved five-year survival rates (Freeman et al, 1995).

Patient navigation is now well established in the US, assisted by a \$25-million grant program established by the Bush administration in 2005 (over five years) for hospitals and other healthcare providers to recruit and train “patient navigators” to help underserved populations navigate the system.

Peer navigators were used – people from the same culture or community and/or cancer survivors.

¹/Health Links is an Ontario program that funds/ supports groups of providers in designing coordinated, efficient and effective care for patients with complex needs. www.health.gov.on.ca.





Panorama panelists en route to Cobourg (Ont.) to meet face-to-face with The Foundation's Northumberland PATH participants.

Patient navigation has been an accepted part of breast cancer accreditation programs run by the American College of Surgeons since 2008 and since 2012, it has applied to other types of cancer as well.

In Canada, Nova Scotia was one of the first jurisdictions to introduce a navigation program into its cancer care system. The program was first implemented by three of the province's district health authorities in 2001, and a 2004 evaluation report from Cancer Care Nova Scotia confirmed that it "has significantly benefited cancer patients and their families in dealing with the emotional turmoil, informational needs and logistical challenges associated with having cancer.

It has resulted in more efficient use of clinical time for physicians and more appropriate use of community health professionals. It has contributed to overall improvements in the cancer care system itself by addressing problems related to integration, coordination and continuity of care. There is strong evidence to support the implementation of patient navigation in the remaining health districts [of Nova Scotia]" (Corporate Research Associates, 2004).

Other provinces have followed suit, with developed (cancer related) programs in Quebec, Ontario, British Columbia and Newfoundland and Labrador, all with their own unique features and target patient populations.

It is important to note that Canadian programs initially focused less on underserved populations and more on people living with cancer in general (CPAC, 2010). More recent programs have taken a culturally targeted approach, for example, a Toronto-based program for the Chinese Canadian community, and one for Asian Canadian and First Nations communities in British Columbia.



Benefits and challenges of navigation programs

An implementation guide compiled by the Canadian Partnership Against Cancer (CPAC) reviewed the evaluation literature on navigation programs in the cancer field and summarized the following benefits and challenges (CPAC, 2010):

BENEFITS OF NAVIGATION PROGRAMS

FOR PEOPLE LIVING WITH CANCER

- Increased understanding of their cancer and treatment plan
- Important source of emotional, informational and logistical support
- Improved recognition of barriers and possible solutions
- Improved diagnostic waiting times
- Improved access to services
- Improved coping skills
- Improved preparation for consultations and treatments
- Increased compliance with treatment

FOR HEALTHCARE PROVIDERS

- Identification of system-related problems
- Improved collaboration and increased interest in teamwork
- Improved workplace satisfaction
- Improved satisfaction with care provided

FOR THE SYSTEM

- Increased patient satisfaction
- Improved management of oncological emergencies
- Enhanced coordination between hospital and community-based services
- Reduction of service duplication
- Potential improvement in continuity of care
- Improvement in quality and consistency of community cancer care

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CHALLENGES OF NAVIGATION PROGRAMS

- Role requires training
- Initial resistance to new role as it requires a work culture that takes an active approach requiring teamwork
- Navigators may have limited capacity to encourage cooperation (particularly when they are peer navigators)
- Lack of clarity in roles when navigator is integrated into an established team
- Lack of decision making autonomy for navigators
- High burnout and/or compassion fatigue

It is important to remember that these findings are in relation only to navigation programs for cancer patients. In Canada, cancer services in most provinces are organized through a central provincial agency working to standardize care delivery across the province. One could argue, then, that there is a more organized approach to cancer care delivery than to other healthcare services, and that navigation can therefore be integrated into it more easily. To give a bit more context: in cancer care, the provincial agencies that organize the care path as a whole *also* support and manage the navigation programs, while in *other* care scenarios, multiple actors are involved and no single body holds the reins.



Panorama panelist Douglas McRonney.

It is also important to note that as the programs evolved, the function often became “professionalized” and was taken on by healthcare professionals – usually, though not always, nurses or social workers (Manderson et al, 2012; Parker, 2011; Sofaer, 2009). In the 2012 edition of its guide to navigation, CPAC provides a detailed set of competencies for professional navigators and outlines the various steps that must be undertaken to implement a program (CPAC, 2012).

Shifts in emphasis – from cancer to chronic illness, and from patient to system

As the lens widened from cancer care navigation to chronic-disease management overall, the emphasis shifted – rather than a singular focus on the patient’s needs, stated goals are now often more system-related, such as (Manderson, 2012):



- tighter case management to prevent hospital admissions or readmissions
- acceleration of hospital discharges
- more effective use of health system resources
- better patient education

Therefore, *health system navigator* has become a more accurate term than the more-limited sounding *patient navigator*, and the distinction between navigators and other staff members such as case managers, discharge planners, health promotion experts and health advocates is less clear. A number of research studies have commented on the lack of consensus about how navigation is defined for these groups (Wells et al, 2008).

This widening of the lens has led to a *narrowing* of focus in one respect. The time from discharge-from-hospital to home is increasingly seen as the window of time in which navigation services are available. Once the patient is back home, the need for the support is presumed to be over.

A recent systematic review of literature looked specifically at *transition navigation* programs for older adults with multiple chronic illnesses, and identified nine programs that fit its search criteria (two in Canada, six in the US, and one in Australia). Five of the programs reported positive economic outcomes, two reported higher satisfaction with care for providers and patients, and five reported increased patient quality of life or functionality. The authors concluded that there was mixed support for the effectiveness of the role but sufficient promise to warrant further development and evaluation (Manderson, 2012).

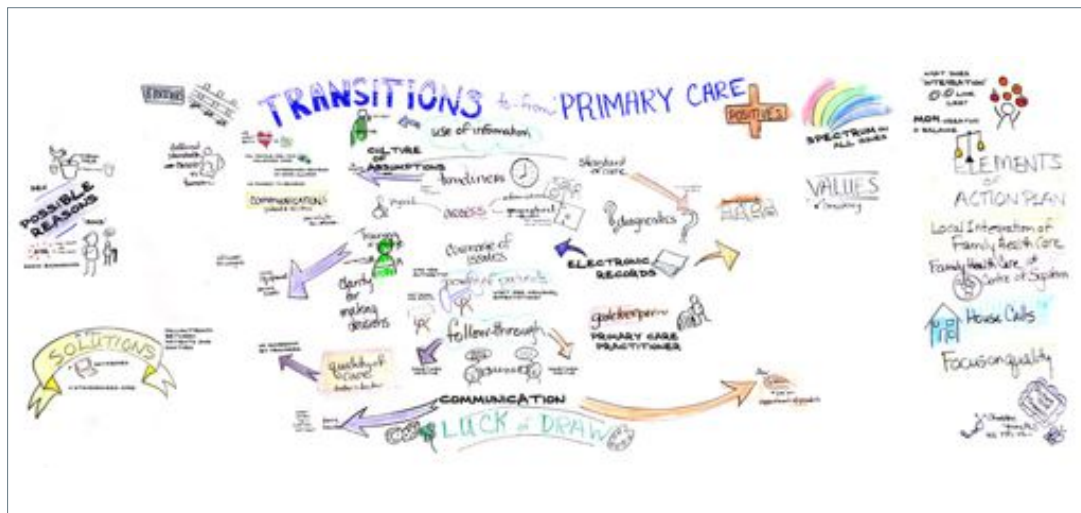
A question of context – and of integrated care

It is important to remember that the need for patient navigators stemmed from a system of care that was not well organized – was, arguably, not a system. Programs of care that are well integrated have demonstrated a positive benefit on the quality of care on

The question for Ontario then becomes:

Are we looking at the idea of health system navigators because our delivery system is disorganized and unintegrated or would a more integrated system of care eliminate the need for navigators in the first place?





Graphic mural captures images of how Panorama panelists visualize our healthcare system from Toronto launch event, September 2012.

a variety of measures (Coleman et al, 2004; Kripalani et al, 2007; Ouwens et al, 2005). Agreed-upon components of integrated care programs usually include:

- support for patients and families in the self-management of disease; this includes tools to routinely monitor and assess the patient's health
- access to clinical follow-up; this means regular follow-up from a member of the healthcare team, often a nurse case manager, in person or electronically
- active case management, where explicit responsibility is given to an individual or a team for guiding the patient through care processes
- a multidisciplinary team

A solution for Ontario?

So the question for Ontario then becomes: Are we looking at the idea of health system navigators *because* our delivery system is disorganized and unintegrated or would a more integrated system of care eliminate the need for navigators in the first place?

At [The Change Foundation](#) we turned to our citizens panel, [PANORAMA](#), for input.

We had established the panel in 2012 as a reflective body to help us think through ways to improve the patient experience; 32 people from across the province, ranging in age from 24 to 82, agreed to volunteer their time and work with us. One of the first issues they identified was the difficulty they had encountered when navigating



local healthcare services, either as patients with chronic disease or as caregivers for family members with chronic disease.

On the question of health system navigators, we structured a series of online and in-person dialogues to ask them:

- a) Is the introduction of health system navigators a good idea?
- b) If so, what should be taken into account when thinking about implementation?

Is it a good idea? Their answer, in short: *Maybe.*

At the start of our discussions, panel members expressed mixed feelings about the use of health system navigators. As we moved through our deliberative process, their questions and reasons for caution emerged.

Panelists who liked the idea felt that navigators could make it easier for the following individuals to use the healthcare system: those with very complex health issues requiring a lot of time and effort to coordinate care; those with difficulty advocating for themselves (or a low comfort level with it); those with limited geographic access to services; and those with communication barriers, language or otherwise.

Panelists who were less keen on the idea thought it would lead to another level of bureaucracy that patients would have to navigate. They were more in favour of improving existing communication and coordination channels among existing healthcare providers.

The panel was clear in supporting a flexible approach, based on its belief that the need for a system navigator depends on the circumstances. It was not supportive of a one-size-fits-all approach. In the panelists' words, they wanted to see solutions that were "needs-based, providing what is required for clear, compassionate, person-centred care and a smooth transition for the patient, but not more than what is required. The service should not be wasteful or obligatory, and it should be well understood and promoted so that people who need the services know about them, and those who do the referring must be aware of their availability."²

²/This quote comes from a work in progress by The Change Foundation: a summary report of the PANORAMA panel dialogue on health system navigation.



As the dialogue unfolded, it was clear that two different roles were being discussed: a potential role for peer navigators (probably volunteers who had experienced similar health issues) to provide support and advice; and a second, more formalized role for professional navigators who would provide hands-on coordination and case management.

Our discussion focused on the second role, partly because, as mentioned previously, navigation is becoming professionalized.

Implementation must-haves if Ontario does adopt a navigator program

We asked the panel what they felt would be important to consider if a health system navigator program were to be implemented province-wide. They said the following:

- The role would need to be clearly defined and performed by someone who has met provincial training requirements and meets a standard of practice.
- Navigators should not be expected to do it all, and, regardless of who filled the role, it would be important to clearly define the role in relation to other healthcare providers.
- The navigator would need to have the necessary authority to communicate, and to initiate action, across the various points of care.
- The role should not replace that of an informal caregiver, or decrease the responsibility of the patient or informal caregiver for taking care of the patient's health needs.
- The role should not replace that of primary care providers or decrease their responsibility to fulfill their professional obligations.
- The role should not replace that of CCAC care coordinators or decrease their responsibility to fulfill their professional obligations.
- The potential for existing members of the care team to take on the role should be the starting point.
- Whether a generalist or specialist approach would be more effective should be discussed.

The role would need to be clearly defined and performed by someone who has met provincial training requirements and meets a standard of practice.



- Any new health system navigator solutions should be culturally sensitive, and provide a process for matching navigators and patients that will foster trusting relationships.
- Any new health system navigator solutions should focus on providing only what is needed, without introducing unnecessary additional costs or making navigation obligatory for patients or caregivers.
- Evaluation of the success of the health system navigator role should be linked to indicators that measure impacts such as changes in health outcomes, improved patient experience and more efficient use of health services.
- Would they be paid? If so, to whom would they be accountable – the patient or the employer?
- If they weren't paid and were volunteers, would anyone pay attention to them?
- What sort of training would be required? Who would organize it?
- How would navigators interact with patients' existing care teams or individual providers? Would they be considered team members? How would disputes be resolved?
- How would personal health information be protected? Would they have access to patient health records?
- If navigators didn't belong to a regulated health profession, how would they be regulated professionally?

Questions for future consideration

As the panelists had mixed views about the introduction of health system navigators across Ontario, we asked them what questions they would need answered before they could formulate advice. Here is their list:

- Who would the navigators be?
- Who would appoint them?
- Would patients have to consent to having a navigator included in their care?

All good questions.

Closing reflections

Evaluation of the success of the health system navigator role should be linked to indicators that measure impacts such as changes in health outcomes, improved patient experience and more efficient use of health services.



Some might argue that health system navigation is just a new buzzword – a glorified term for good case management. Perhaps, but we think there’s more to it than that. Research has shown that strong care coordination does improve resource allocation, compliance with treatment protocols and overall health outcomes. Yet people still say they find the system hard to navigate – even when there *is* good support for case management to improve coordination.

Perhaps our current siloed governance structures get in the way. Perhaps our siloed funding models don’t support provider interaction. Perhaps our siloed delivery organizations can’t find mechanisms to cross organizational boundaries. Perhaps it is all of these

things. Whatever the reasons, when patients and caregivers talk about what happens to them as they use Ontario’s healthcare system, we come back to where we started. The navigation is too difficult.

The use of health system navigators is just one idea. A group of committed citizens – our PANORAMA [panelists](#) – gave it a serious look. We hope their reflections, and ours, will prove useful for decision-makers who are interested in giving health system navigation a try.



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The Change Foundation's PANORAMA panelists reflect Ontario's rich diversity in age, gender, geography, and cultural and socio-economic backgrounds.

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