# Northumberland Community Partnership

*COBOURG, ON*

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**Background**

In 2011, the Change Foundation, an independent healthcare think tank in Ontario, launched an ambitious funding competition in pursuit of its strategic goal: to improve people's healthcare experiences as they move in, out of and across the healthcare system. Known as the Partners Advancing Transitions in Healthcare (PATH) project, the competition's goals were to improve healthcare experiences and transitions; seek solutions to the real needs of patients and caregivers; test co-design methods (a totally new approach for Ontario); and prompt system-wide change (The Change Foundation 2011).

Through the PATH project, the Change Foundation committed $3 million over two years to engage and support a community coalition of cross-sector providers and patients/caregivers to co-design how care is delivered, addressing healthcare transition problems that they identified. After a rigorous one-year selection process, the Northumberland Community Partnership, which includes 12 organizational partners in Northumberland County, was selected to receive PATH funding, announced in June 2012 (The Change Foundation 2012). The Northumberland Community Partnership (Northumberland) includes the following partners:

- Patients and their caregivers
- Healthcare providers: Northumberland Hills Hospital (NHH), Northumberland Family Health Team, NHH Community Mental Health Services
- Community providers: Central East Community Care Access Centre, Community Care Northumberland, Golden Plough Lodge Long-Term Care Home, Palisade Gardens Retirement Residence, YMCA Northumberland
- A patient advocacy organization: Patients Canada
- A regional partner: Central East Local Health Integration Network (Central East LHIN)
- Organizations with expertise in evaluation and technology: Health System Performance Research Network, QoC Health Inc.

## Patient Engagement

Patient and public engagement appeared to be part of the Northumberland community mindset already, with previous efforts led by the chief executive officer of the local hospital amidst healthcare restructuring efforts. Patients and families were part of the development of the Northumberland funding proposal, and partnerships had already formed with patients and families across a number of organizations in the community.

The Northumberland coalition emphasized the need to improve transitions in care for a community that has a high concentration of seniors with chronic health conditions. It assembled a wide cross-sector community partnership with a strong primary care presence and an innovative technology component. Northumberland also demonstrated an enviable track record of meaningful public engagement and involved seniors and caregivers from the onset of developing its proposal – all of which made it a winning team at the PATH competition. As a senior Change Foundation leader noted, "I think that groundwork was very helpful to people feeling empowered and particularly the hospital understanding that this project was going to be treating patient and caregivers as equal partners to providers."

## Key Strategies to Support Patient Engagement

One of the essential ingredients throughout all phases of Northumberland's PATH initiative was the central role played by patients and caregivers in co-designing – with local providers – transitions in healthcare. The team embraced a patient-centred, bottom-up approach to change, using experience-based design together with structured improvement methodologies. Key to the success of the partnership was the time taken by Northumberland PATH leaders to develop the governance structure for such a large coalition; to define terms of reference, roles and responsibilities for each of the partners; and to set expectations for how the partners would work together. While a time-consuming task up-front, leaders felt that the time was well spent to ensure PATH's smooth working through its many projects and with its multiple partners. Recruitment of seniors and caregivers was done primarily through building relationships and one-on-one discussions in the community and in seniors' homes, rather than through widespread

public advertising for patient partners. This strategy helped Northumberland PATH project teams find seniors and caregivers well-suited for the tasks involved, and helped with the retention of partners throughout the duration of the projects (the coalition had very low attrition rates).

Anticipating that patient partners might require support and coaching throughout the project, the PATH team had developed, in advance, the Respect Inform Support Empower (RISE) team, which focused on supporting seniors and caregivers as equal partners within their project teams (PATH News 2015a). Partnership was also buttressed by the structure of the project teams themselves: for each of the project teams, the goal was to have equal representation of seniors/caregivers and healthcare providers, which helped to develop an environment in which the patient voice was valued and heard. Interestingly, while the RISE team's support was available, participating seniors and caregivers did not often access it, as they reported feeling they were equal partners from the beginning and did not require further assistance.

From the outset, Northumberland PATH's defined project areas were a key enabler to support the engagement of seniors and caregivers, and their recruitment to these specific areas. However, those projects continued to grow due to the co-design methods used, posing some challenges to Northumberland's ambitious plan for completion within the two-year time period. The five key areas of focus that the Northumberland PATH project teams worked on were the following:

- *Building Awareness, Changing Values and Planning Ahead*: To build awareness and tools that empower seniors and their caregivers to shape how they age and access care and community services.
- *My Health Story*: A My Health Story document allows people to present themselves to the healthcare system as a whole person with a history, enabling them to build relationships with their providers and shape their care.
- *Person-centred care provider model*: Redesigning how care is delivered and organized for seniors as they move across a wide range of services, so that the quality of their experience – and their lives – comes first, consistent with gerontological best practices.
- *Peer transition coaching and advocating*: Coaches or "transition partners" who act as "warm hands" during transitions, to ensure that seniors do not get lost or confused.
- *Funding model*: Exploration of a patient-centred funding arrangement consistent with Ontario's *Excellent Care for All Act*, in partnership with the Central East LHIN.

Prior to the start of these projects, the Northumberland PATH teams had opportunities to learn together, which helped to set the tone for ongoing relationships within the teams. Project teams were invited to a patient engagement workshop hosted by the Institute for Patient- and Family-Centered Care and to another workshop on

Experience-Based Co-Design, co-hosted by the Change Foundation and Cancer Care Ontario. Through participation in these workshops, over 60 team members, including seniors and caregivers, had opportunities to learn engagement and co-design methods together. This created a *bona fide* sense of moving forward together.

Beyond these specific projects involving seniors and caregivers, PATH offered a range of other opportunities for patient partners to take part, depending on their time, capacity and interest. For example, patients and caregivers were involved in developing the original grant proposal, informing research, and providing input into new processes and technology solutions. As well, many of the ongoing patient partners also sought out opinions of their friends and neighbours, thereby attempting to represent many patient voices within their project teams.

## Impact

The co-design strategies, while time-consuming, offered a way to gather insights from all project team members, ultimately contributing to the richness of the final products. For example, a lot of time was spent on determining measures for many of the projects to ensure they reflected team members' criteria for success for their project areas. As well, there was a large technological component developed as part of PATH, which evolved with patient input, and, in the end, reflected their needs.

To ensure the technology was user-friendly and to maximize its use, transition partners were employed to help seniors use it in their own homes. Indeed, the technological devices played a large role in enacting many of PATH's foci, allowing seniors to provide information about their needs and issues in real time to healthcare providers, to self-monitor their health status and to communicate results directly to healthcare providers from their homes. Transition coaches assisted them not only with the technology, but also through all points along the continuum of care. The technology developed as part of PATH provided dynamic capability and the ability to personalize seniors' information needs for their healthcare providers. Seniors also expressed a need for educational resources and, therefore, co-designed a new website (www.pathwaytoagingwell.com), which is a comprehensive guide containing general information and localized for Northumberland County.

Evaluation of the Northumberland project has involved a broad range of quantitative and qualitative methods, examining both the outcomes of engagement (e.g., outputs of engagement; changes/ideas generated, implemented, spread and sustained), as well as the outcomes of changes implemented as a result of the co-design processes at individual (e.g., self-management and patient activation, patient outcomes, patient experience of care, patient–provider communication) and systems levels (e.g., readmissions, emergency department visits, coordination of care). Engagement processes have also been evaluated, from the perspectives of seniors and their caregivers, healthcare providers and project leaders. While local evaluation is currently ongoing, early results indicate providers are paying greater attention to patients' needs, goals and how they

are managing at home; in essence, taking into account the larger environment in which a senior is situated and, thus, evaluating the ability to provide care in ways that meet the needs of that person. For seniors, there have been indications of an increased sense of empowerment (stemming from their ability to use the technology developed through the PATH initiative to take control of their health), and to communicate effectively with their care providers while they are in the community.

PATH has also provided structures that have facilitated the development of relationships (not only between health service and community partners, but also between patients and providers), many of them enabled by the development of the technology to support information exchange among these partners. As a senior Change Foundation leader observed, "I think really it's the relationship with the providers and the patients and/or the caregivers that's everything. That's what makes patient-centred care principles go, it's what makes patient engagement go, it's what makes patient experience go. The one common thing of all those terms is that it's the … respect, information, being listened to. … So, putting structures in place to facilitate the relationship building and listening, I think is what will be the success of the project."

Early results of the Northumberland PATH initiative were presented in March 2015 at the Change Foundation's Capstone Summit. That event brought together all the PATH players to draw on what had been learned and to engage with other healthcare stewards, stakeholders and users on key recommendations for healthcare change in Ontario and beyond (PATH News 2015b). The Summit brought together all the PATH players to draw on what had been learned and to engage with other healthcare stewards, stakeholders and users on key recommendations for healthcare change in Ontario and beyond. The Change Foundation is currently completing its evaluation of the PATH project with results expected to be released in early 2016 (http://www.changefoundation.ca/charting-a-new-path/).

The Foundation's evaluation focused on two key questions: What difference did it make having patients and family caregivers as part of the project structure? And What difference did it make working in cross-sectoral collaborative teams? As of fall 2015, Northumberland Hills Hospital and QoC Health have been able to support continued use of the technology platform and the peer coaches. A business case was submitted to the Central East LHIN and the Ministry of Health and Long-Term Care to spread the program to other parts of the LHIN. The PATH project team hopes to secure ongoing funding for future expansion of the program. Also, in December 2015, PATH was one of five partnerships to receive an Ontario Centres of Excellence grant to support work aimed at improving remote patient monitoring and care (OCE 2015). This will allow further development of the technology platform.

**Summary**

The Northumberland Community Partnership is an example of whole-system change, focusing specifically on seniors with chronic health conditions who were engaged in

broad partnerships across all health sectors to address issues of transitions in care across the continuum. Using experience-based co-design methodology as a structured approach to develop and implement change, one of the most important partnerships developed involved bringing patients and their caregivers together with providers.

While there were challenges along the way, PATH was successful in co-designing many strategies to support seniors in the community. Those strategies relied on technological advances and educating seniors on how to use that technology to manage their health at home, to empower them in the self-management of their conditions and to enable communication with their care providers. Evaluation focused on both process and outcomes of engagement, and on outcomes of the changes implemented at both individual and systems levels.

The Change Foundation was purposeful in its funding competition, choosing a partnership that demonstrated maturity in its ability to partner with patients and caregivers from the outset, and with organizations that could tap into the potential and skills of community members. In the end, PATH's work created local champions in the community for ongoing work in this area. A culture of engagement was also created in the community, where health organizations will no longer consider improvement work without the significant voices of patients and caregivers represented on their teams.

This case study was researched and written in 2015 as part of research commissioned by the Federal Advisory Panel for Healthcare Innovation to inform their report: *Unleashing Innovation: Excellent Healthcare for Canada* (http://www.healthycanadians.gc.ca/publications/health-system-systeme-sante/report-healthcare-innovation-rapport-soins/index-eng.php).

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