The Change Foundation (TCF) is an independent health policy think-tank that works to inform positive change in Ontario’s health care system. With a firm commitment to engaging the voices of patients, family caregivers and health and community care providers, TCF explores contemporary health care issues through different projects and partnerships to evolve our health care system in Ontario and beyond. TCF was created in 1995 through an endowment from the Ontario Hospital Association and is dedicated to enhancing patient and caregiver experiences and Ontario’s quality of health care.
ACKNOWLEDGEMENTS

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First and foremost, our sincere thanks to the patients and family caregivers who shared their stories, worked tirelessly on the co-design teams and project committees, participated in the testing of PATH solutions and, on so many levels, helped us learn.

We thank the PATH partner organizations – and the leaders and health care providers within those organizations – for their commitment to the project and to improving the experience of patients and family caregivers in the west Northumberland community.

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郭-design team: The teams of patients, caregivers, providers and partners that came together to develop solutions for each of the five project elements. Also referred to as the project element teams.

Experience Based Co-Design (EBCD): An approach that enables staff and patients (or other service users) to co-design health care services and/or care pathways, together in partnership. EBCD was central to the PATH project.\(^1\)

PATH community: West Northumberland region of Ontario.

PATH lead partner: Northumberland Hills Hospital (NHH) was the lead partner in the PATH project – they received the financial transfer from The Change Foundation and housed the PATH project team.

PATH partner organizations: The health and community care organizations in west Northumberland that came together to create the PATH partnership.

PATH partnership: The full group of 12 partner organizations and the 39 patients and family caregivers that made up the partnership.

PATH patients: The patients and their caregivers who were enrolled in the PATH project to use the My Health Experience mobile technology tool.

PATH portal: The My Health Experience mobile technology tool that patients used to keep all the information about a patient’s evolving life and health story and fill in real-time surveys about their health care experiences. It also facilitated secure two-way communications between patients/caregivers and health care providers.

PATH project: Partners Advancing Transitions in Healthcare (PATH) project.

PATH project elements: The five project components that were included in the west Northumberland PATH proposal.

PATH project team: A small administrative group, housed at NHH that provided project management and operations support to the PATH project.

\(^1\) http://www.kingsfund.org.uk/projects/ebcd/experience-based-co-design-description
**PATH providers:** The health care professionals who were involved in the PATH project that worked at any of the partner organizations.

**PATH solutions:** The solutions developed by the project element teams (also referred to as co-design teams) using experience-based co-design (EBCD).

**PATH volunteer peer coaches:** Formally trained volunteers who coached seniors and their caregivers in using the My Health Experience portal, helped seniors connect and communicate with providers and access resources in the community, and provided support and encouragement.

**Project element teams:** The five teams made up of the PATH partnership (patients, caregivers, providers, administrators) that worked on the five project elements to develop patient-driven solutions.

**RISE team:** The Respect, Information, Support and Empowerment (RISE) team - a group of 15 patients and caregivers who were involved in the five project teams, and who also met independently throughout the project to provide advice to all aspects of the project.
THE ORIGIN OF PATH

The Change Foundation’s 2010-2015 strategic plan, *Hearing the Stories, Changing the Story*, was focused on patient engagement and improving the patient experience in Ontario. The Partners Advancing Transitions in Healthcare (PATH) project was one of two showcase engagement projects that formed the basis of our work and our learnings over that five-year period. PATH was a made-in-Ontario patient engagement project, developed in partnership with the west Northumberland community. The premise of the PATH project was to create an environment conducive for patient engagement at every level of the local health care system – engaging with, working alongside and truly integrating patients and family caregivers into the health care fabric.

Charting a New PATH is a three-part report that describes what the Foundation has learned as participants in, and funders of, the PATH project. Given the complexity of the PATH project, that required a leap of faith by all those involved, we learned a lot. We have reflected on the major achievements, the unexpected opportunities that emerged, but also on the ambitions of the project that weren’t fully realized. And even though we didn’t achieve everything we set out to do, we don’t see that as failure – we see it as a learning and growing opportunity. It’s in that spirit, that we share our findings.

We believe our reflections and commentary can help inform the work of others in the health care sector who are in the midst of or about to embark on patient engagement activities in their organizations, communities or regions.

These reports are aimed at those who are interested in pursuing these concepts more deeply and more widely.

1) PART 1 — Redefining Patient and Provider Partnerships: Proposal and Project Development
2) PART 2—Creating Meaningful Partnerships in Care: Lessons From West Northumberland
3) PART 3—On The Horizon: PATH’s System Lessons
PART 1: REDEFINING PATIENT AND PROVIDER PARTNERSHIPS: PROPOSAL AND PROJECT DEVELOPMENT

THIS REPORT IS THE FIRST OF A SERIES OF THREE THAT MAKE UP CHARTING A NEW PATH. IN REDEFINING PATIENT AND PROVIDER PARTNERSHIPS: PROPOSAL AND PROJECT DEVELOPMENT, WE REFLECT ON OUR LEARNINGS GAINED THROUGH THE PROPOSAL PROCESS AND PROJECT SET-UP PHASE.

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That is where our PATH journey began. In 2010, The Change Foundation (TCF) released a new strategic plan: *Hearing the Stories, Changing the Story*. The plan committed us to devoting our resources and energy to really listening to patients and their family members. We knew it would change how we saw the world of Ontario health care. We listened. And our view definitely changed.

We were influenced by the work of Barbara Balik, a senior faculty member at the Massachusetts-based Institute for Healthcare Improvement and head of Common Fire, a health care consulting firm. She spoke about how the philosophy of “partnership with patients” was evolving – moving away from an approach of doing *to* – “I talk, you listen, you do” – to an approach of doing *with* – “we talk together and you decide”. We were also influenced by the work of the Point of Care Foundation in the UK, which works with patients, families and health care providers to research, test and share new approaches to patients’ experiences.

From the outset, our intent was clear: to improve people’s experience as they moved in, out of, and across Ontario’s health care system.
We called the project Partners Advancing Transitions in Healthcare, or more simply: PATH. We decided to find and support a community willing to roll up its sleeves and create a partnership between patients, family caregivers and health care providers. We were looking for a partnership that would:

• give equal weight to patients’ views;
• engage in some out-of-the-box thinking about the local health system; and
• embrace the opportunity to demonstrate to the wider health care community that this new way of working – truly working together with patients and families – would improve patient experience and, in the longer term, patient outcomes.

PATH marked a new approach to funding by The Change Foundation (TCF). We understood that the status quo was not going to achieve the depth of excellence and innovation that we were aiming for. With endorsement from the TCF Board of Directors, we made the strategic decision to make a significant financial investment in one community with a focus on one change initiative. Prior to this, TCF had typically awarded smaller grants to a number of organizations, using a more traditional grant funding process. As a result, the PATH project was the largest and most complex project we have ever funded.

At the time that PATH was being conceptualized in 2010, patient experience and patient engagement work was beginning to gather steam in Ontario. A number of groups were actively working to engage with patients as a pivotal component to their operations. As well, a desire for integrated care and collaborative delivery models was being proposed as a way forward.

Because the beginning of the PATH project coincided with this shift in the system, the possibility of the impact of this project was even more significant. Both the opportunity and the risk, including the potential for failure, were profound.

We designed a logic model (see Appendix 1) to guide our thinking, which later also shaped our evaluation questions. However, it was ultimately the voices of patients and family caregivers that helped us hone in on what mattered.

Our first step was to put out a call for proposals for the PATH project. We were charting a new path, so we had more than a few anxious moments. What if no one understood or embraced this shift in philosophy? What if no one came to our party?
In the end, we received 27 submissions, and 24 made the cut for review. After an extensive review process, we selected the west Northumberland community. Their proposal embraced the notion of embedding patients and family caregivers in all aspects of the work. Seniors and caregivers played a key role in the on-site presentation, and it was evident that they had been involved in the proposal development. They really got it.

“Northumberland showed the smarts, the heart, the team, the ideas, and the experience to set PATH up for success.”

CATHY FOOKS
CEO, THE CHANGE FOUNDATION

However, this proposal and project development process was a huge learning experience for TCF—one with many key lessons along the way. The following pages of this report review some key lessons and suggestions that emerged out of this process.
STRATEGIC DECISIONS TAKE TIME

Our strategic decision to go deep in one community was a significant shift for us, and we knew we had to take the time to get it right. We were about to begin our journey of learning how to become a significant community partner in a concentrated change initiative. Our decision was the result of paying careful attention to trends in the health care environment. We held consultations with health system leaders, and we organized eight face-to-face workshops with seniors and their caregivers to truly understand their needs and issues.

It took us 22 months to release our Strategic Plan and the subsequent Implementation Plan, including:

- a logic model to guide our work,
- a framework for understanding our strategic focus (the experience of individuals and caregivers), and
- a four-year plan for achieving strategic directions.

SEEK OUT OPPORTUNITIES FOR LEARNING AND DISCOVERY

At the outset of our Strategic Planning process, we put together an external advisory sounding board. We selected people who were not necessarily “the usual suspects”, but rather those who worked in community and social service organizations that intersected with the formal health care system. The sounding board had no governance authority, but they enhanced our opportunities for learning and discovery, as they exchanged ideas and gave us advice on different points in our Strategic Planning process. Specific to the PATH project, they provided guidance on our PATH Request for Proposals (RFP), our selection process and our early thinking on evaluation. Given the diversity of the experience, knowledge and networks of our sounding board members, their input and reflections were incredibly valuable.

While PATH was being designed, we launched a complementary initiative – the PANORAMA advisory panel. The panel had 31 members from across Ontario, all either living with long-term health conditions or caring for someone who was. For two-and-a-half years, they advised us in our work toward improving the health care experience. Over the course of the two projects, we arranged two face-to-face meetings of the PATH and
PANORAMA groups, to encourage further collaboration and learning. The province-wide perspective of the collective PANORAMA panel was key. Specifically, we were able to hear, regularly, whether the challenges and solutions playing out in the PATH community (west Northumberland) resonated with people in other regions.

USE A SELECTION PROCESS THAT IS COMPREHENSIVE, FAIR AND TRANSPARENT

We used a two-part competitive process to identify our community partnership: an open call for Letters of Intent (LOI) and a subsequent targeted Request for Proposals (RFP). Our RFP prescribed exactly what we were looking for – an experience-based co-design (EBCD) coalition of partners – as well as our expectations for the role we would play. Specifically, we would be the funder, but we would also provide overall project direction. We were clear and transparent about the project principles and our expectations.

We contracted with an external, independent Fairness Advisor to provide oversight of the selection process to choose the successful PATH proposal, at the TCF Board’s suggestion. Given the Board’s potential for conflict of interest, they were not involved in the development of the application process or the selection of the successful proposal. However, they still had a responsibility to guarantee that appropriate procurement practices were followed. The Board viewed the involvement of a Fairness Advisor as an important risk mitigation strategy to ensure openness, fairness, transparency and impartiality in the community selection process. The Advisor provided two reports directly to the Board – one on the selection of the short list, and one on the selection of the winning proposal.

A review panel of three Foundation staff and three external members (from another province) met to review the applications and select the short listed communities. Three of the original 27 submissions did not meet the submission requirements and were deemed ineligible to proceed. From the remaining 24 submissions, five were invited to submit a full proposal in response to our RFP. We offered them a $5,000 financial stipend to complete this process, which four of the five organizations accepted.

3 The Change Foundation’s Board Members are members of the Ontario health care community. Any number of our Board Members could have been from organizations that may have submitted a proposal for the PATH project. As a result, the details of the selection needed to be blind to the Board to ensure no potential or perceived conflict of interest would jeopardize the project.
VISIT SITE LOCATIONS TO DO YOUR OWN ASSESSMENT OF COMMUNITY READINESS

We conducted site visits to all five locations. We chose to do site visits based on the experience and advice of the Point of Care Programme at The King’s Fund. Site visits were not part of their selection process for their experience-based co-design (EBCD) work, but they felt they would have been incredibly valuable. The site visits gave us a chance to see nuances in the relationships within the proposed partnerships, and to determine the level of commitment to patient and caregiver co-design. We wanted to see if what was said in the proposal seemed to be playing out on the ground. The site visits were critical in assessing the readiness of the community to take on an innovative project of this scale, with its associated risks and opportunities. In west Northumberland, seniors and caregivers played a key role in the on-site presentation, and it was evident that they had been involved in the proposal development.

BUILD IN PARTNERSHIP COMMITMENT EXPECTATIONS

In our RFP, we included an expectation that each partner organization would provide in-kind contributions, as an indication of commitment to the project. To ensure that the in-kind contributions were made once the project was underway, the PATH project team was required to document and detail the in-kind contributions in their regular reporting back to The Change Foundation. In the end, the in-kind contributions from all the PATH partners amounted to close to $400,000.

DEVELOP A SUPPORTIVE INFRASTRUCTURE IN COLLABORATION WITH YOUR PARTNERS

In collaboration with the PATH partners, we developed a structure and governance model that facilitated ways for TFC to be involved, but also to limit our ability to interfere with the partners’ process. A funding agreement, a governance structure, terms of references for committees, and a project charter helped to clarify roles and responsibilities. The establishment of a governance structure that could adapt and adjust to the emerging needs and feedback of all partners – patients and caregivers, front-line providers, administrators – was a critical success factor.
We aimed to create a project reporting process that would be reasonably straightforward for the lead partner (Northumberland Hills Hospital) to complete, while still being thorough about accounting and auditing. We created a budget monitoring system that allowed the community partner to track their activities while accounting for financial resources. The project reporting process was designed to be an avenue to hear about what was working and what was not, as we needed to learn, and course-correct, as the project progressed.

We established an Executive Lead position at the Foundation, responsible for managing our relationship with the lead partner and other PATH partners. Since this was an uncharted approach for us, we had to be careful not to delve too deeply into local issues and maintain appropriate boundaries as the funder. The Executive Lead had to balance our need for clarity, timeliness and accountability on one hand, with the relatively unpredictable unfolding of the PATH project in the community, on the other.

That challenge was to be responsive, and answer the PATH project team’s questions, while transferring knowledge diplomatically. Once the project launched and as things moved along, the Executive Lead played a variety of roles: planner, coach, evaluator, mediator and facilitator.

CREATE A MULTI-PRONGED EVALUATION FRAMEWORK FROM THE BEGINNING

TCF’s theory, from the start, was that whatever happened in the PATH community could contribute to system-level learning. We also knew that we would need our own evaluation of the project’s impact in relation to influencing the system, separate from the local-impact evaluation, which would belong to the PATH project team itself. Both evaluation frameworks were considered from the outset.

Local Level Impact
The PATH project team set up a research partnership with the Health System Performance Research Network (HSPRN). This enabled them to collect data using a standardized set of indicators in real time, as patients used the local health system. The data was uploaded into a secure portal, analyzed and fed back to the PATH project team on a weekly basis.
The second report in this series, *Creating Meaningful Partnerships in Care: Lessons From West Northumberland*, provides more detail on the local level evaluation and impact.

**System Level Impact**

While we were very interested in local improvements, we knew that it would not be the specifics of PATH’s innovations that would help us with strategic- and system-level learning. For that, we needed to reflect on what we learned through doing the complex and messy work of co-design. We hoped that this would then enable other communities to undertake similar culture change and create their own local solutions. For our system-level evaluation, we asked two simple but hard to measure, questions:

- What was the **value and impact of involving patients and family caregivers** in initiatives to improve care?
- What was the **value and impact of working through a broad partnership** of health and social care organizations to address problems with care?

Given the nature of the work – real time delivery with real patients and providers – we decided a form of developmental evaluation would be the best approach. We needed an inside look at how the work progressed as it happened, otherwise we would not understand how things unfolded as they did. We were mindful that while the project was underway, people still needed to access health care services and that the work of the evaluation team could not get in the way.

The third report in this series, *On The Horizon: PATH’s System Lessons*, provides more detail on the system-level evaluation.
FINAL THOUGHTS

Overall, the PATH team in west Northumberland showed the smarts, the heart, the team, the ideas, and the experience that made the project a success. By including patients and family caregivers from the start, it was clear that west Northumberland understood the objectives and the potential for collaboration inherent in the proposal.

However, the process of developing a proposal for such an innovative project, and then development the actual initiative, provided TCF with key lessons that now have strong influence over our current work. These lessons, reviewed here, can help any organization looking to meaningfully engage with patients, family caregivers, and providers.
APPENDICES:
THE CHANGE FOUNDATION
QUALITY IMPROVEMENT THROUGH CO-DESIGN: GETTING TO IMPACT THROUGH PATH

A1. Assessing Readiness and Context

  - A2. Involving patients & caregivers (p/c) as equal partners in care redesign
    - Inviting p/c participation
    - Providing learning opportunities
    - Providing space and supportive environment for connecting and processing
  - A3. Engaging broad partnerships of providers in redesign
    - Listening to and learning from p/c stories
    - Engaging in joint analysis, planning and shared decision making
  - A4. Contributing to the Process (Role of the Funder)
    - Making financial investment
    - Building capacity for design and implementation
    - Providing input and support
  - A5. Designing Solutions
    - Activating Project Element Teams
    - Identifying touch points for improvement
    - Co-creating and testing solutions (pilot)

- 01. Positive, respectful, productive relationships
- 02. Greater use of Experience-Based Knowledge in shaping decisions & solutions
- 03. Stronger and closer network between p/c and providers
- 04. Pilot outcomes
- 05. Generativity and “spin-off” solutions
- 06. Organizational Environments that support enhanced p/c experiences
- 07. Improved patient/caregiver experience transitioning between healthcare settings/providers
- 08. Improved healthcare experience
- 09. Improved quality and individual outcomes

LEGEND
- Activity Streams
- System Outcomes
- Local Outcomes
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