

Patient and Caregiver Experience & the PATH Project

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The Change Foundation

Leading Practices in Improving the Patient Experience

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Focus for Today

- How we think about understanding and acting upon patient experience
- What we are hearing from patients and their informal caregivers
- The Partners Advancing Transitions in Healthcare (PATH) Project

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The Change Foundation

- Established in 1995 by the Ontario Hospital Association as a endowed, charitable foundation
- Spent ten years as a granting agency
- Rebooted in 2007 as a policy think tank focused on system improvement
- Currently focused on patient experience and integrated care as a priority

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Elements of a “good” patient experience

(Adapted from US IOM (2001), Shaller (2007), Lewis (2009), Dagnone (2009))

- **Clear, consistent, reliable communication and exchange of information:** patients and caregivers understand next steps, feel listened to, and have access to needed information
- **Coordinated and connected care:** patients and caregivers are connected to the appropriate professional or service and are confident that their providers are collaborating
- **Comprehensive care:** patients and caregivers feel their needs are being met – not just some needs, some of the time

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Elements of a “good” patient experience

(Adapted from US IOM (2001), Shaller (2007), Lewis (2009), Dagnone (2009))

- **Engaged in care:** patients and caregivers are active participants in decision making about their care
- **Respectful, empathetic and considerate care:** patients and caregivers feel their time and perspectives are respected, they are given time to ask questions, and they are treated with dignity and respect
- **Timely and convenient care:** patients and caregivers receive support they need in a timely way, in a way that is convenient for them

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What does this mean for the way we deliver care?

- Different communications
- Different definitions of performance
- Different ways to value time

S. Lewis, AOHC, 2012

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How the System Would Communicate

NOW

Short & Frequent Visits

In-person Is Default

See the Doctor

Parallel & Unsynchronized

Talk Much, Listen Little

THE FUTURE

Longer & Fewer Visits

Multi-Mode

See Anyone Competent

Streamlined & Coord.

Listen First, Then Talk

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How We Would Define Performance

CURRENT

% of Pop. Screened

Low Wait Times

Access to Specialists

Quality of Technology

System-Defined Outcomes

FUTURE

% of Needs Addressed

Avoided Interventions

Primary Care Reduces
Referrals

Quality of Communication

Patient-Defined Outcomes

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How the System Would Value Time

CURRENT

My Time is Not Considered

Travel Time Is Pt's Problem

Non-Direct Care Time Is Overhead

Schedules Months in Advance

FUTURE

My Time Worth As Much As Profs

Travel Time a Burden to Avoid

Learning Time Is Essential

Schedules Open and Flexible

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What we are hearing from patients and their informal caregivers

Loud and Clear

Panorama

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Loud and Clear – Hearing From Seniors

- Six focus groups across Ontario with patients and caregivers
- Tell us about your experience
- Tell us what worked well
- Tell us what didn't work well
- Tell us what could be done to improve

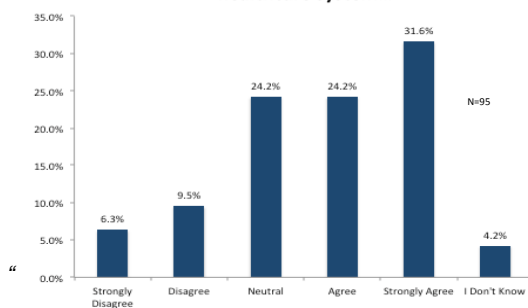
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The numbers on navigating healthcare transitions

The majority (55%) of the participants in our in-person and online engagements told us that they had experienced problems navigating transitions; less than one-fifth (16%) said that they had not.

I have had problems navigating a transition in the healthcare system...

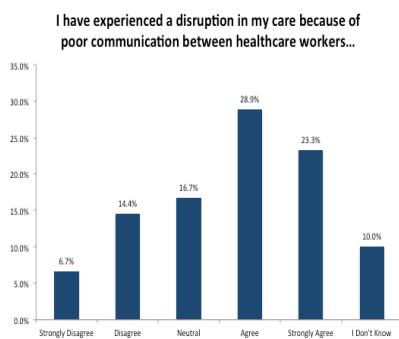


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.. On disruptions in care due to poor communication

Over half of participants said they had experienced a disruption in their care because of poor communication between health workers



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PANORAMA – A Panel of Wise People

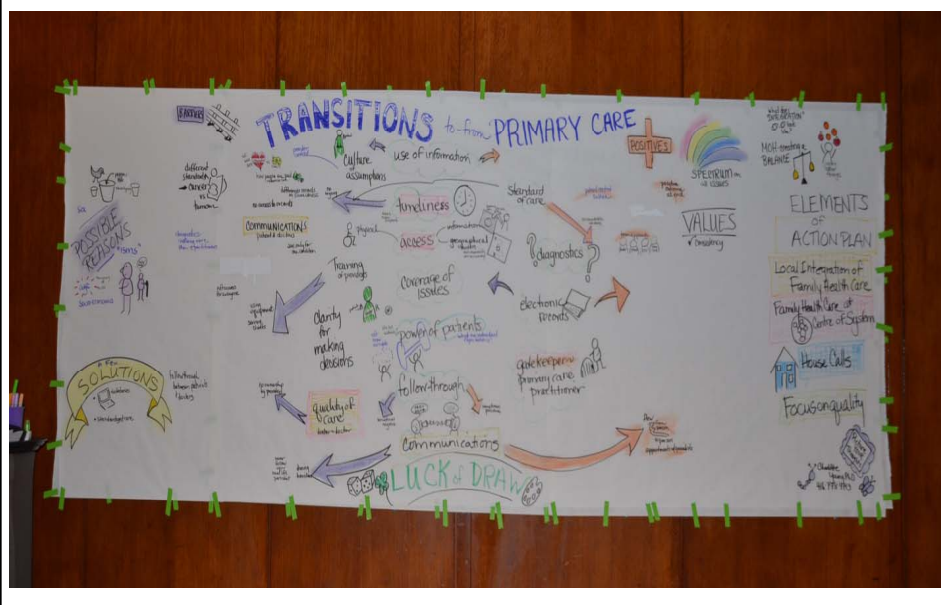
- 32 Ontario residents – 2 from each LHIN plus members from aboriginal communities and first language other than English or French
- Patients and caregivers – all ages
- Work with us for two years to reflect on their journey as we go through ours

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Visualizing the Health Care System



How do they visualize the health care system?

- **A balanced scale** – to show the two sided experience of good service/bad service and that the level of service is not the same across the board
- **A big doctor with his arms around his chest and behind him a little person** – to show the patient feeling they are without authority or rights
- **Two health care professionals talking through a tin can** – to show the outdated way of sharing information

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How do they visualize the health care system?

- **A safe with a patient trying to crack it open** – to show limited patient access to their own health care information
- **A question mark around the word diagnostics** – to reflect doubt in waiting for, or interpreting, test results
- **A deck of cards, dice or a lottery ticket** – to show that patient experience can be the luck of the draw
- **A hamster running on a wheel** – to show the challenges of accessing uncoordinated services

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PATH: Partners Advancing Transitions in Health Care

- Change Foundation is investing in a two year, multi partner quality improvement project focused on using patient experience as a way to improve care in an Ontario community
- Goals of PATH:
 - Improve people's experience as they move in, out of, and across Ontario's healthcare system by engaging and supporting a community partnership
 - Demonstrate the value of **experience based co-design** for the broader system

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Key components/features of PATH

- Patient led **experience based co-design**
- Seniors with chronic health conditions
- One community partnership

-- Patients	-- Home and community care providers
-- Informal caregivers	-- Primary care providers
-- Social support providers	-- Funders and other stakeholders
-- Acute care providers	-- Mental health care providers
- Care transitions
- Patient experiences

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Patient Centered, Experience Based Co-design

- It's a **partnership** between patients, caregivers and staff
- The emphasis is on **experience** rather than opinion or attitude
- Story telling is used to identify **touch points in the health care journey**
- The emphasis is on **co-designing better processes together**
- Systematic **evaluation** of improvements and benefits

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Evolution of Patient Experience in Healthcare

Doing "to" patients	Doing "for" patients	Doing "with" patients
<small>Barbara Balik, Common Fire, Meeting of the Minds June 2011</small>		
To	For	With
Provider makes rules and controls all schedules	Patient/family have some input	Patient/family as source of control
Information not shared with patients	Some transparency, public data	Shared knowledge and decision making
"I talk-you listen"	"We help you"	"We walk together"
Compliance focus	Improvement focus	Co-design focus
Unilateral	Benevolent	Partnership

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PATH Partnership

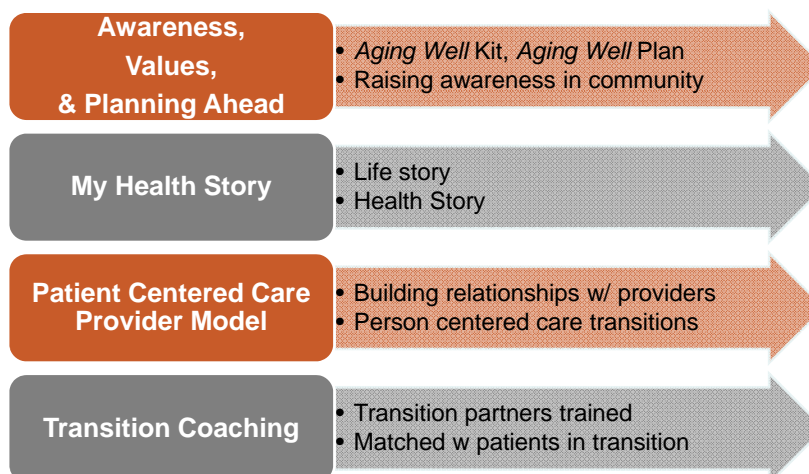
- **Patients, families and caregivers**
- **Providers**
 - Northumberland Hills Hospital
 - Northumberland Family Health Team
 - NHH Comm. Mental Health Services
 - Central East CCAC
- **Community Providers and Supports**
 - YMCA Northumberland YMCA
 - Community Care Northumberland
 - Golden Plough Lodge Long Term Care Home
 - Palisade Gardens Retirement Residence
- **Others**
 - Central East LHIN
 - Health System Performance Research Network
 - Patients' Association of Canada
 - QoC Health



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PATH Transition Improvement Ideas



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Summary of PATH co-design work

- Gather and analyze patient, caregiver and provider transition stories
- Assemble project teams each working on a different transition improvement, informed by the stories
- Project Teams with equal numbers of patients/caregivers and staff from PATH provider organizations; 10-12 per team
- Teams will test out solutions on small scale, refine ideas, and re-test
- Successful solutions will be tested on a larger scale with seniors in the community
- Success of the solutions will be measured all along the way
- Timeline: now through Fall 2014

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Hearing the stories, changing the stories.....

"When I called the hospital to explain the problems with the transitions, because I believe **problems like these are gifts for improvement**, all I got was "I am sorry you feel this way about your dad's discharge, but he was ready to go." Great, then why was there no home safety assessment prior to getting home? **Why was there no clear information** about what was going to happen for my mom to understand. ..."

I've never been asked as a **caregiver**, 'What's convenient for you?' or 'How would this work in your family?' Instead, it's 'This is what we're going to do for you.' **There's no discussion of collaboration.**"

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The future is here

PATH IS.....

- Focusing on those who need and use health care the most
- Built on collaboration across all sectors
- Understanding patients' and caregivers' experiences
- Using those experiences to improve care transitions and
- Providers working in partnership with patients to design a better future

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