

# **Improving Processes Together** **Co-design with Seniors, Caregivers, Clinicians**

Presentation to the  
Association of Family Health Teams of Ontario  
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# Today's Lineup

- The Change Foundation: purpose, plan, progress
- What did ON seniors, caregivers say Loud & Clear?
- A patient perspective: primary care a la FHT
- Preparing for PATH – health leaders consultation
- PATH:** 1<sup>st</sup> system-wide patient/provider co-design
- Panorama:** embed patient/caregiver perspectives
- Over to **you** – how do you engage patients/families?





# The Change Foundation – take 1, & 2

- Endowed 1996 - independent, non-profit, charitable; Support, improve health & healthcare delivery in ON
- 10 yrs. as granting agency – funding array research, projects on drivers of local healthcare change
- 2007 – new function: health policy think tank – new focus: health integration, quality improvement



## Where we are now – implement plan



- Goal – improve people’s **experience** as they move in, out of, across healthcare system
- Focus - **seniors with chronic health conditions**, informal caregivers
- Locus – **transitions** across continuum of care, between providers & within sectors, services, settings

# Where Ontario is : Chances + challenges

- Deficits
- Demographics
- Drummond
- Difficult decisions
- Devil in the details
- Ontario's Action Plan for Health Care
- Emphasis on primary and community care – new integration levers?
- Evidence: improve quality!
- *Excellent Care for All* requirements

# How we work – methods align, augment

- Research and Policy Analysis

- Engagement (Loud & Clear;  
Panorama)

- Care redesign – PATH  
**Partners Advancing Transitions in  
Healthcare: a first *with* Ontario  
patients**



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# Key part of the plan - engagement



- With whom? Healthcare's stewards, stakeholders, **users – missing piece of puzzle**
  - ✓ Province-wide engagement (fall 2011)
  - ✓ Public engagement panel (2012-2015)
  - ✓ Province-wide engagement, round 2 (2014)
  - ✓ Summit (2015)
- Why? Premise and Promise



# Engaging seniors/caregivers across Ontario

TABLE 1:

Engagement Channel	Number of Participants
In-Person Participants	116
Dryden	23
London	13
Ottawa (pilot)	25
Peterborough	16
Timmins	18
Toronto	21
Online Participants	10
Webinar (pilot) Participants	12
<b>Total</b>	<b>138</b>

## Participant Profile

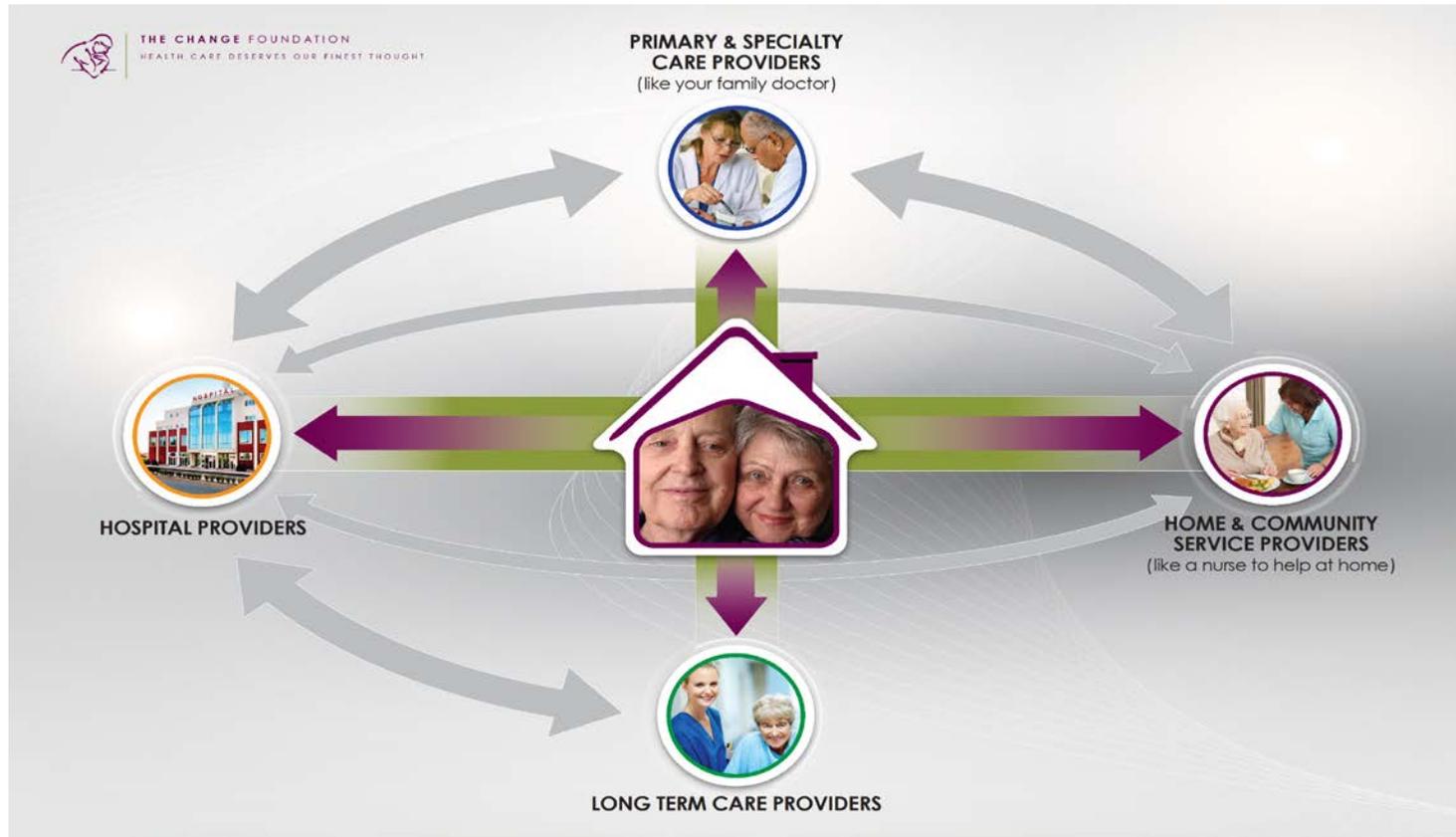
- 47.8 % -- Senior with chronic health condition
- 25% -- Caregiver of a senior with chronic health conditions
- 23.9% -- Both a senior and a caregiver
- 3.3% -- Other

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# Framing the conversation



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HEALTH CARE DESERVES OUR FINEST THOUGHT

## Discussion Topics

- Your experience navigating system: Transitions & Communication
- How your relationships with people affected your experience



10 questions on healthcare transitions

➤ 55% experienced problem navigating transitions; 16% said they had not.

➤ 52 % experienced care disruption due to poor communication between health workers

➤ 35 % said they could find information to navigate the next step in their care

## Five Themes Emerged

- **The primacy – and problems – of primary care**
- **The importance of connections and clarity about next steps**
- **The communication deficit**
- **The inclusion factor**  
— hey, what about us?
- **Issues of equity**



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## Embed Movie

APRIL 2012

# Loud and Clear

Seniors and caregivers speak out about navigating Ontario's healthcare system

This report is about their stories and experiences.

# Next – embedding patient/caregiver input

- The Change Foundation's engagement panel, launched Sept. 29-30, announced today
- **Panorama: A Panel of Ontario Residents Exchanging Views, Experiences and Advice to Improve healthcare**
- More on that later, but now.....
- Meet a member of Panorama – Kingston resident & patient who receives primary care via family health team
- Miguel Costa will share his healthcare story and experience

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# Welcome Miguel Costa





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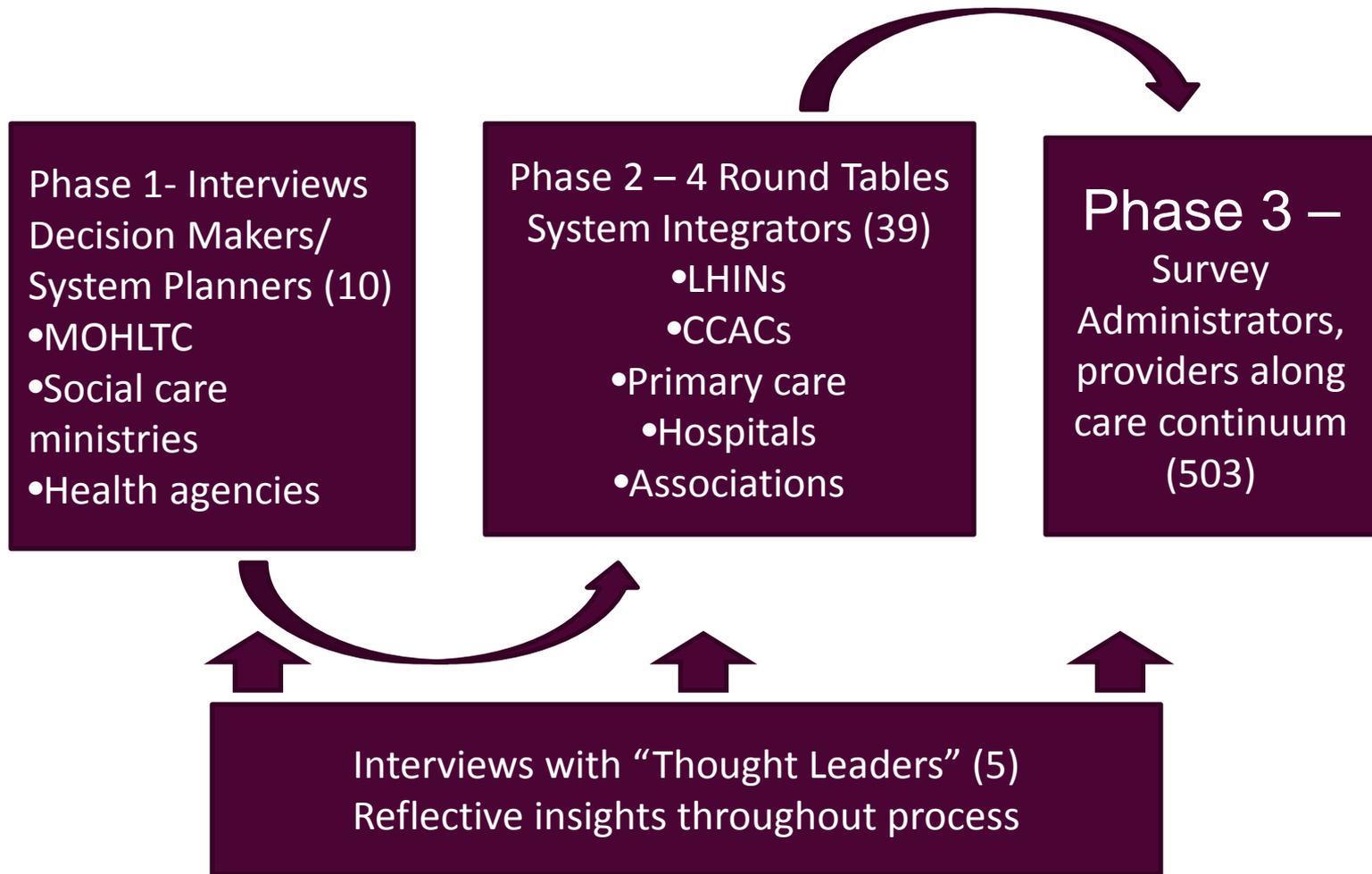


# Health System Leaders' Consultations

Consultations designed to solicit perspectives of health system “leaders” on:

- **Broader healthcare system** - What changes have impacted the healthcare system over the past two years (positively & negatively)?
- **Patient experience (seniors & caregivers) and transitions:** How do system leaders perceive the experience of seniors and caregivers as they transition in, out, across different parts of the healthcare system?
- **Barriers and enablers for transitions:** What do health system leaders perceive as the systemic barriers and enablers to integrated care for seniors and their caregivers?

# Health System Leaders' Consultations



# Health System Leaders' Consultations

Caveats on what we heard through the consultation methodology:

- Information, feedback is directional, not representative
- Feedback is qualitative input and provides a snapshot of perspectives
- Views, perspectives were often competing, and tended to vary depending on how distant the “leader” was from the interface with patients and caregivers

## General Observations

- Significant discussion at the local level about improving transitions but the focus is not restricted to seniors – focus was often on patients with chronic conditions regardless of age
- Better understanding of system integration issues after 5 years of the LHINs BUT the challenge is in translating what we know into real improvements in care
- Recognition of the need for alignment of LHINs and CCACs but different views on relative roles especially regarding patient navigation

## Areas of strong consensus

- Clear, repeated recognition that the delivery system does not do well at transitions of care – between providers, across organizations or sectors
- Strong support for primary care as the centre of the delivery system, playing a pivotal role in managing transitions
- Recognition of the need for better measurement of the patient experience across transitions of care – across providers, organizations, sectors
- Acknowledgement that the quality agenda is a great place to start and encourages a focus on patient experience, measurement & discussions about role accountability

## Areas of strong consensus (cont.)

- Strong desire that the province set broad direction but with flexibility for regional / local innovation according to community needs
- Emerging recognition that we need new accountabilities
- Broad recognition that seniors end up in the wrong place – in the acute care system; acknowledgement of the need to break the thinking that LTC is the only alternative
- Wide recognition that fundamental changes to the healthcare system are needed – very few leaders believe that only minor changes are needed. There is an appetite for change.

## Areas of tension:

- Should the focus be on chronic conditions (regardless of age) or on populations such as seniors?
- Should the responsibility for patient navigation sit with primary care? CCACs? Does the LHIN have a role?
- Does there need to be further alignment of LHINS and CCACs?
- How to reconcile the recognition that fundamental changes are required with a reported sense of powerlessness and risk aversion in decision-makers?

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**PATH**

**Partners Advancing  
Transitions in Healthcare**

A first with Ontario patients

## What is *Partners Advancing Transitions in Healthcare* ?

- A community based partnership between patients, caregivers and health care providers,
- A partnership who will work together to understand the experiences at key transitions between healthcare settings and services,
- A partnership to re-design transition processes,
- A partnership who will use The Change Foundation's resources for:
  - Building and supporting a patient, caregiver, provider coalition;
  - Engaging patients and their caregivers in **experience based co-design**;
  - Managing the PATH project work;
  - Providing process re-design and improvement expertise;
  - Measuring the changes that occur as a result of the newly designed processes;

## Key components/features of the PATH project

- Seniors with chronic health conditions
- One community partnership
  - Patients providers
  - Informal caregivers
  - Social support providers
  - Acute care providers
  - Home and community care
  - Primary care providers
  - Funders and other stakeholders
  - Mental health care providers
- Care transitions
- Patient experiences
- Patient led **experience based co-design**



Partners Advancing  
Transitions in Healthcare  
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## Goals of the PATH Project

- 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

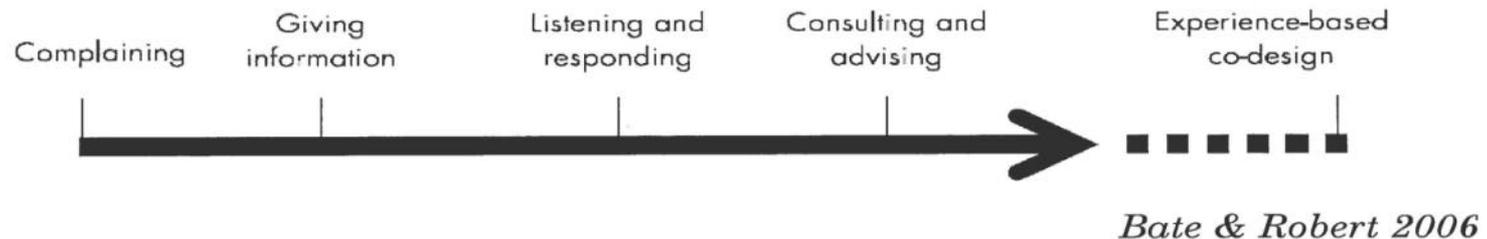
## What is Experience Based Design (ebd)?



- 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**.
- Focuses on **co-designing new processes together**.
- Measurement of improvements and benefits.

# What is Experience Based Design (ebd)?

## Scale of patient influence from the UK national Health Service



Reproduced from [Bate SP, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care*. 2006; 15 (5):307-10] with permission from BMJ Publishing Group Ltd.

# Evolution of patient, family, caregiver experience

Doing “to” patients

Doing “for” patients

Doing “with” patients

Barbara Balik, Common Fire, Meeting of the Minds June 2011

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



“ebd is about sharing and understanding the experiences of patients, carers and staff together to design better services.”

## ...Back on the PATH Timeline

July 2011	Letter of Intent call was issued; 27 received
November 2011	Letters of Intent reviewed; short list of five submissions determined
January 2012	Five communities invited to submit full project proposal
March 2012	Full proposals submitted to the Foundation
April 2012	Site visits by Foundation staff to all five sites
May 2012	Final determination of PATH community
June 5, 2012	Public Announcement of PATH community
Late June 2012	Experience Based Design and Quality Improvement Training for 56 PATH partner clients, caregivers, and clinicians

# Selected PATH Community



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## Northumberland

# PATH

**Partners Advancing  
Transitions in Healthcare**

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## *Why Northumberland ?*

- Patient/family/caregiver co-design central to proposal-came up with solutions
- **Northumberland Hills Hospital is lead organization & they attracted key partners**
- Successful track record of joint projects
- **Strong project management plans**
- Leadership commitment and alignment
- **Strong community partnership array**
- Solid evaluation, measurement and data collection
- **Excellent focus on community issues**
- Shared goals for community level improvement

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# PATH Partnership

- Patients and caregivers recruited from community
- Healthcare Providers
  - Northumberland Hills Hospital
  - Northumberland Family Health Team
  - NHH Comm. Mental Health Services
  - Central East Community Care Access Centre
- Community Providers
  - YMCA Northumberland
  - Community Care Northumberland
  - Golden Plough Lodge Long Term Care Home
  - Palisade Gardens Retirement Residence
- Others
  - Central East Local Health Integration Network
  - Health System Performance Research Network
  - Patients' Association of Canada
  - QoC Health

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**THE NORTHUMBERLAND COMMUNITY PARTNERSHIP  
MEMBERS**

# PATH Next Steps

- July-Sept. 2012** -PATH project supports being set-up
- October 2012**
- Attend Patient and Family Centered Care Conference (IPFCC)
  - Recruit patients/caregivers to share experiences, work on teams
  - Recruit for project positions in QI coaching, admin support, etc.
  - Draft Project Charters for improvement teams
- November 2012** -Patients/caregivers share stories that inform improvement team work
- December 2012** -Patients/caregiver and providers begin participating on project teams
- Feb.-Mar. 2013** -PATH Patients/caregiver and providers engage with Panorama
- Thru Jun 2014** -PATH co-design work in full swing

# PATH co-design work

- 4 project teams each working on a different transition improvement
- Project Teams with equal numbers of patients/caregivers and staff from PATH provider organizations; 8-10 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

# PATH Transition Improvement Ideas

## Awareness, Values, & Planning Ahead

- *Aging Well Kit, Aging Well Plan*
- Raising awareness in community

## My Health Story

- Life story
- Health Story

## Patient Centered Care Provider Model

- Building relationships w/ providers
- Person centered care transitions

## Transition Coaching

- Transition partners trained
- Matched w patients in transition

# PATH Summary

- Community partnership of patients and providers work on common goal
- Focus on improving healthcare transition experiences for seniors
- Partners work together in teams using experienced based co-design
- Measure how well the improved processes work
- Sharing the PATH successes with the rest of Ontario

# The Patient and Caregiver Voice of PATH....



“When a loved one is sick, we're at our most vulnerable and need the right information and support. PATH puts seniors and caregivers at the center of change and redesign; with PATH we will ensure that patients and caregivers are respected, informed, supported, and empowered...when they need it the most!”

Gayle Einarsson  
Caregiver

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# PANORAMA

- 32 members from across Ontario
- All have experience with chronic health conditions, personally/care giver; lots of interactions with different parts of healthcare system
- From every LHIN, different walks of life, range of lived experiences

# Panorama





# Panorama input

- Will provide ongoing input (online & face to face) to The Change Foundation for 2 ½ years
- Help inform thinking, decision-making— on PATH, emerging healthcare issues, our work, their priorities
- Already began discussion on primary care, transitions, Ontario Action Plan on Health Care
- Lively launch, probing questions, keen interest in using experience to improve healthcare for all

# How are YOU engaging patients and caregivers?



## Thank you

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