

Patient and Family Engagement in Action: Overview, Objectives and Ontario Examples

Moderator: Sine MacKinnon, Director of Communications and External Relations, The Change Foundation

www.changefoundation.com

Presenter Disclosure

- **Session Name:** Patient and Family Engagement in Action: Overview, Objectives and Ontario Examples
- **Presenters:** Sine MacKinnon (moderator), Jonathan Kerr, Jill Adolphe, Sydney Graham, Joanna MacPhail, Esther Green
- **Relationships with commercial interests:**
 - Not Applicable

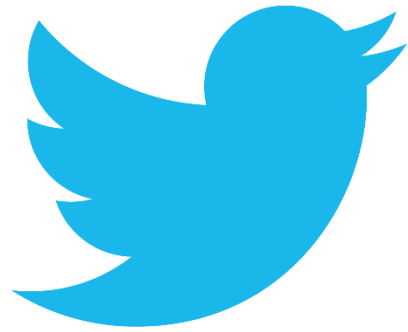
Disclosure of Commercial Support

- This session has received no commercial support

Mitigating Potential Bias

- Not applicable

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Engagement Overview

- Definitions/Distinctions
- Different publics and roles
- Different levels and latitude
- Different purposes – clarify and frame upfront
- Objectives/Methods
- Different tools and approaches
- Align methodology with objectives
- Why it matters – a word on outcomes/evaluation

Start with Simple, but Essential Questions

- **Which “public”?**
 - Citizens, Patients, Family or Friend caregivers, different combinations?
 - What essential characteristics, conditions, relationships do you want to examine to better understand?
- **Which role/s?**
 - To advise, offer opinion/information, provide feedback, validation?
 - To ID and rank priorities, seek consensus?
 - To draw on experiences and informed discussion to offer solutions, ideas?
 - To reflect values, preferences, consider trade-offs?

Key Questions to Assess, Answer Upfront

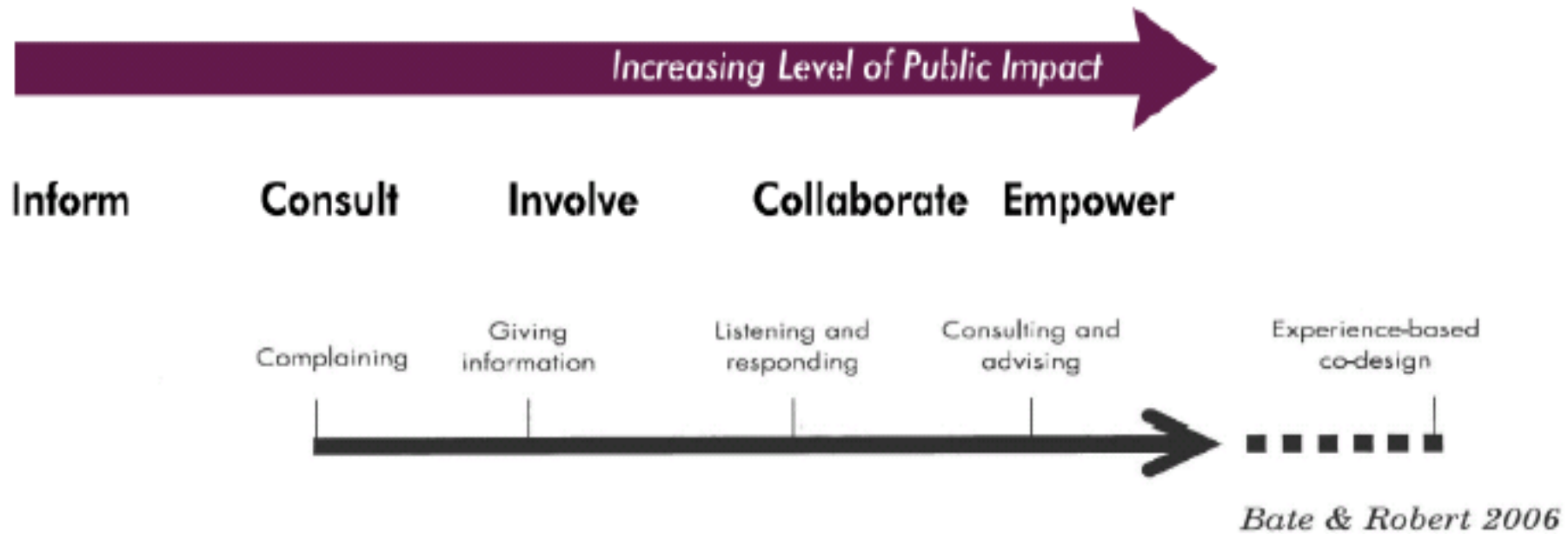
- Is there common understanding internally about intent of patient/family engagement; agreement at senior levels how it will be used, weighted?
- Is engagement clearly framed so patients understand purpose of process/weight of input? Inform → Empower(IAP2) Consult → Partner(Carman)
- Is there a decision/s to be made?
 - What role does patient/family input play in determining it?
 - What are other sources of input?
- What happens with patient input?
 - Reported back, reflected in public product, responded to, acted on?

More Early Decisions, Distinctions

Where/what to target? Problem (opportunity) prompting change?

- Interactions between patients/families and clinicians **delivering care** –and how they impact experiences, health, costs?
- Rules instituted in some, all parts of **healthcare organization**; how **decisions are made**, and by whom? Products, services that fail because of language, look, access?
- Lack of communication and co-ordination among providers and **across services - and with** patients/families. How to redesign systems?
- Bumping up against legislation, regulations, **policies** that make things worse for patients, harder to provide patient-centred care?
- Funding allocation choices for services and regions that reflect values, preferences of citizens?

Engagement – The Continuum



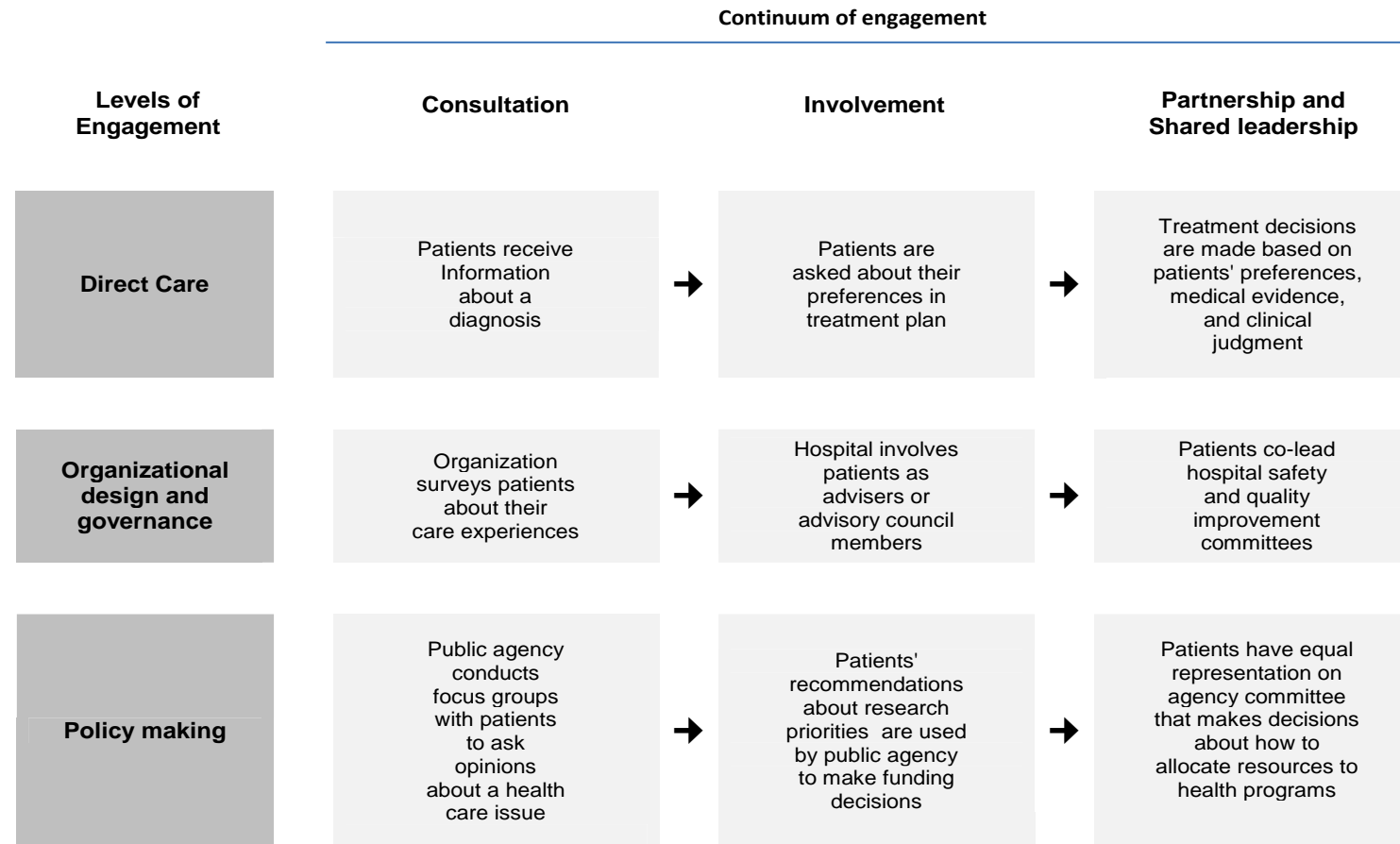
Doing "to"

Doing "for"

Doing "with"

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

A Multidimensional Framework for Patient & Family Engagement in Health & Health Care



Source: Carman 2013

Examples of Patient/Family Involvement

- United Kingdom
 - Experience Based Design (EBD): Patients, providers co-design health care
 - The Change Foundation's Northumberland PATH project (uses EBD)
 - Citizens' Council of the National Institute for Clinical and Health Excellence
- Canada
 - British Columbia's Patient Voices Network
- Ontario
 - Citizens assemblies, e-Health Consumer Panel, Citizens' Council (Public Drug Programs), Citizens' Reference Panel on Health Technologies, Patient & Family Advisory Councils ...



Panorama: A Panel of Ontario Residents Exchanging Views, Experiences & Advice to Improve Health Care



THE CHANGE
FOUNDATION

panorama

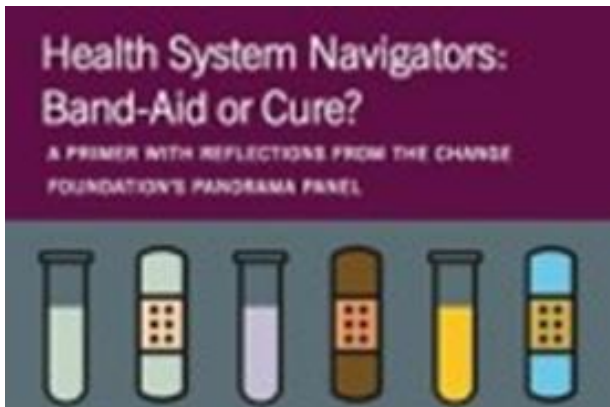


Patients Probe System Navigators, Co-design Health Services

“The use of health system navigators is just one idea. A group of committed citizens – Our [The Change Foundation’s] 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.”



Patients and caregivers partner with providers across the community and system to co-design changes to improve health care transitions and experiences. A first for Ontario, the project shifts who and what drives health care change, and tests the difference it delivers.



- From *Health System Navigators: Band-Aid or Cure? A primer with reflections from The Change Foundation’s Panorama Panel*



The Change Foundation's Northumberland PATH Project

[Click for Video](#)

A Word on Outcomes

Patient Experience Example

Data display that patient experience is positively associated with clinical effectiveness and patient safety, and support the case for the inclusion of patient experience as one of the central pillars of quality in health care. It supports the argument that dimensions of quality should be looked at as a group and not in isolation. Clinicians should resist sidelining patient experience as too subjective or mood-oriented divorced from the “real” clinical work of measuring safety and effectiveness.

Source: Doyle C et. al. (2013) A Systematic Review of Evidence on the Links Between Patient Experience and Clinical Safety and Effectiveness. *BMJ Open*: 3:e001570

Engagement in Action - Speakers

- **Jill Adolphe and Sydney Graham**
Co-Founders and Partners, Care 2 Collaborate
- **Joanne MacPhail**
Patient Co-Chair, Patient and Family Advisory Council, Cancer Care Ontario (CCO)
- **Esther Green**
Provincial Head of Nursing and Psychosocial Oncology, CCO
- **Jonathan Kerr**
Primary Care Lead, South East Local Health Integration Network

Patient Engagement: Approaches to Ensuring the Patient is Part of the Care Experience

Jill Adolphe and Sydney Graham



CARE 2 COLLABORATE
Advancing Partnerships in Care

Patient and Family Engagement



Source: Smart Health Messaging

Patient and Family Centred Care (PFCC)

- **Mutually beneficial partnerships**
- **Equal members** of the partnership
- **A direct and intentional** effort
- **Distinct** and **valuable** individuals
- Doing **with** vs. **to** or **for**

PFCC Core Concepts



Source: Making Every Contact Count, National Health Service Yorkshire & Humber

Information Sharing

“Two words, **information** and **communication** are often used interchangeably, but they signify quite different things. **Information** is giving out; **communication** is getting through.”

Sidney Harris

Collaboration



Changing a Culture



Implementation

“Without sustained patient/family participation in all aspects of policy, program development and evaluation, the care system will fail to respond to the real needs and concerns of those it is intended to serve.”

Institute for Patient- and Family-Centred Care

The Importance of Measurement

“That which gets measured, gets done.”

Covey



Evidence-Based Outcomes of Patient & Family Engagement

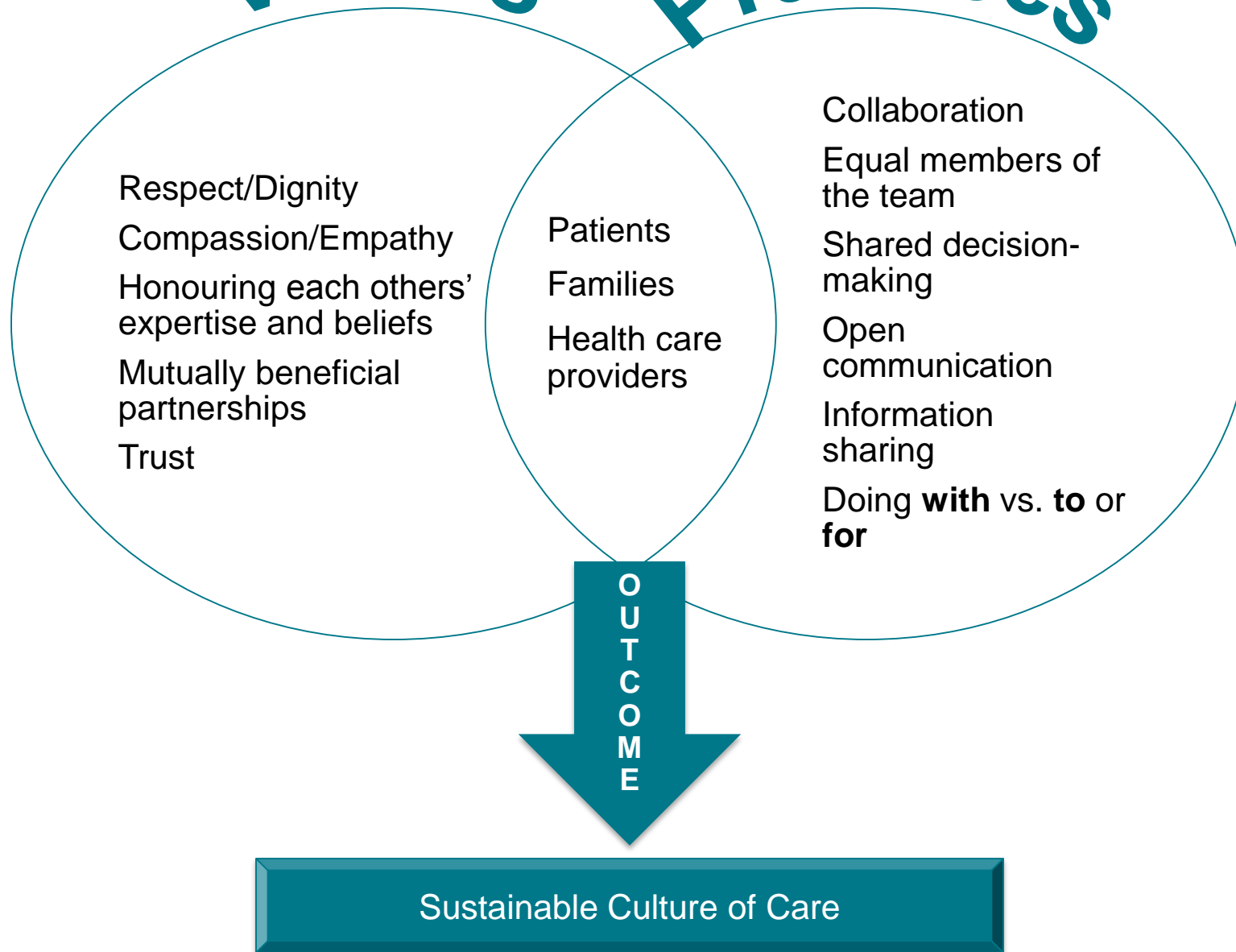
Improved

- Earlier discharges
- Patient safety/quality
- Patient satisfaction
- Patient/staff relationships
- Positive perceptions of the workplace by staff
- Psychological adjustment of patients
- Psychosocial well-being of families
- Staff ownership and protection of culture

Reduced

- Average cost per patient
- Length of Stay
- Medical errors
- Readmissions
- Staff vacancy and turnover

Values Practices



In Conclusion

- Patient and Family Engagement, encompassing the core concepts of Patient and Family Centred Care, is a transformational care model, based upon collaborative partnerships among health care providers, patients and families.
- To ensure a sustainable culture of excellence and improve the patient experience, it is imperative that this evidence-based model be reflected at all levels of an organization.

Contact Information

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A photograph of a woman with dark hair, wearing a grey jacket over a green shirt, smiling warmly. She is holding a baby in a stroller. The background shows trees and a building, suggesting an outdoor setting. A semi-transparent white box with blue text is overlaid on the right side of the image.

Transforming Health: How Cancer Care Ontario Leveraged its Patient and Family Advisory Council for Improvement

November 21, 2013



Ontario
Cancer Care Ontario
Action Cancer Ontario

Three Models

“Doing To”

- Clinicians and administrators decide what’s best for patients
- Patient experience is not taken into account

“Doing For”

- Patients are kept in mind in design of facilities or programs
- We design, then ask, rather than partner with patients from the outset

“Doing With”

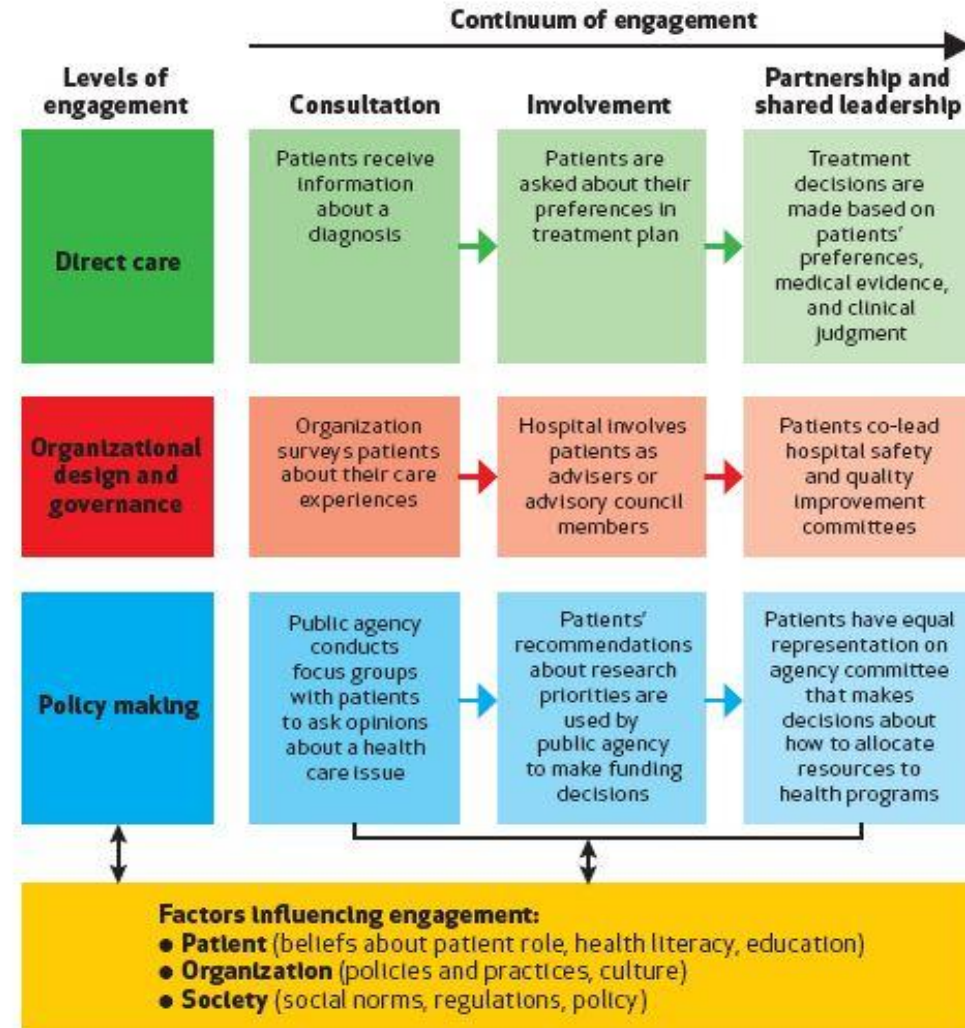
- Health care providers and patients partner
- Patients and family members are involved in the design and improvement of care
- Patients and families are kept well informed

Source: Balik, B. Healthcare Quarterly, 2012.

Moving to “doing with”

EXHIBIT 1

A Multidimensional Framework for Patient and Family Engagement in Health and Health Care



Joanne's Story

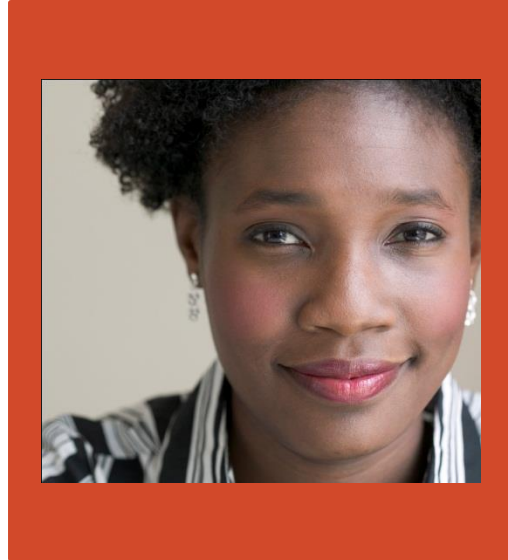
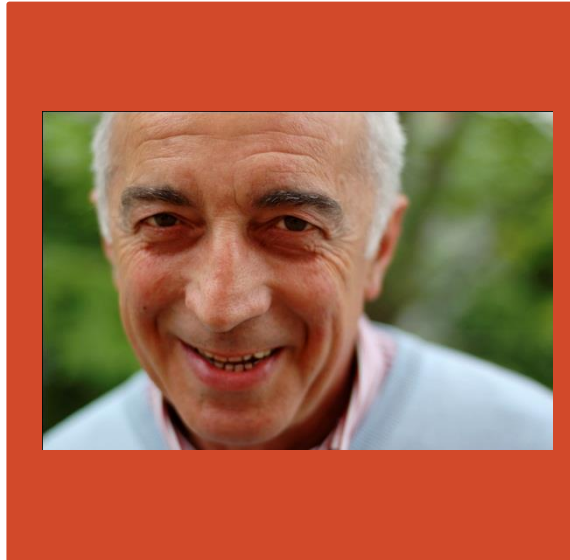


Our Commitment

Care is organized around the person to support their health



Patient & Family Advisory Council (PFAC)



Intent: Recruit patient and family advisors from across the province to form a PFAC.

What is PFAC Trying to Achieve?



Bring patients and families to the table, enabling them to become part of the decision making process about their own care.



Allowing us to gain insight into the cancer journey from those who have experienced it first hand.



Partnering with patients to continue to advance a patient centred approach to health

Putting patients at the centre of everything we do

What Key Priorities Were Identified?

Cancer Journey	Prevention/ Screening	Diagnosis	Treatment	Recovery/ Survivorship	End of Life
Priority	Stressing prevention and encouraging the population to take responsibility for their own health with support of healthcare providers so others don't get cancer.	Navigators and mentors throughout cancer journey. Consistency and standardization of what is good (e.g. supports, protocols) across all cancer centres.	Knowledge regarding: treatments, how to avoid re-occurrence, and for rare forms of cancer. Right support for the right person, particularly emotional support after treatment.	Helping patients deal with fear of dying & re-occurrence. Post-treatment pathway – emotional support and plans shared with clients.	End-of-life support/ transition for patients and caregivers. Awareness that healing goes beyond just curing the disease.
	Expand on our ideas so that advisors can be integrated all cancer centres.				

Patient and Family Advisor Orientation Package



"We, the patients along with our families, are the 'Face of Cancer'. We experience the drugs running through our bodies; have had the surgeries and the radiation; experienced the side effects... dealt with it all. We have a story to tell and share. If you think of this partnership for just one moment – with the people who have the knowledge, research and training plus the patients and their families who have experienced or are experiencing the cancer journey – the care can only get better and better. This is our hope and this is our passion."

- CCO Patient and Family Advisor

Broad & Targeted Recruitment

Cancer Care Ontario
Action Cancer Ontario



Join CCO as Patient and Family Advisors

Help build the best cancer system in the world.

Who are we looking for?

- People who are going through the cancer journey currently who want to share the story about their personal experiences.
- People who are family members/ caregivers who have supported loved ones, family, friends through the cancer system and would like to share their stories and experiences.

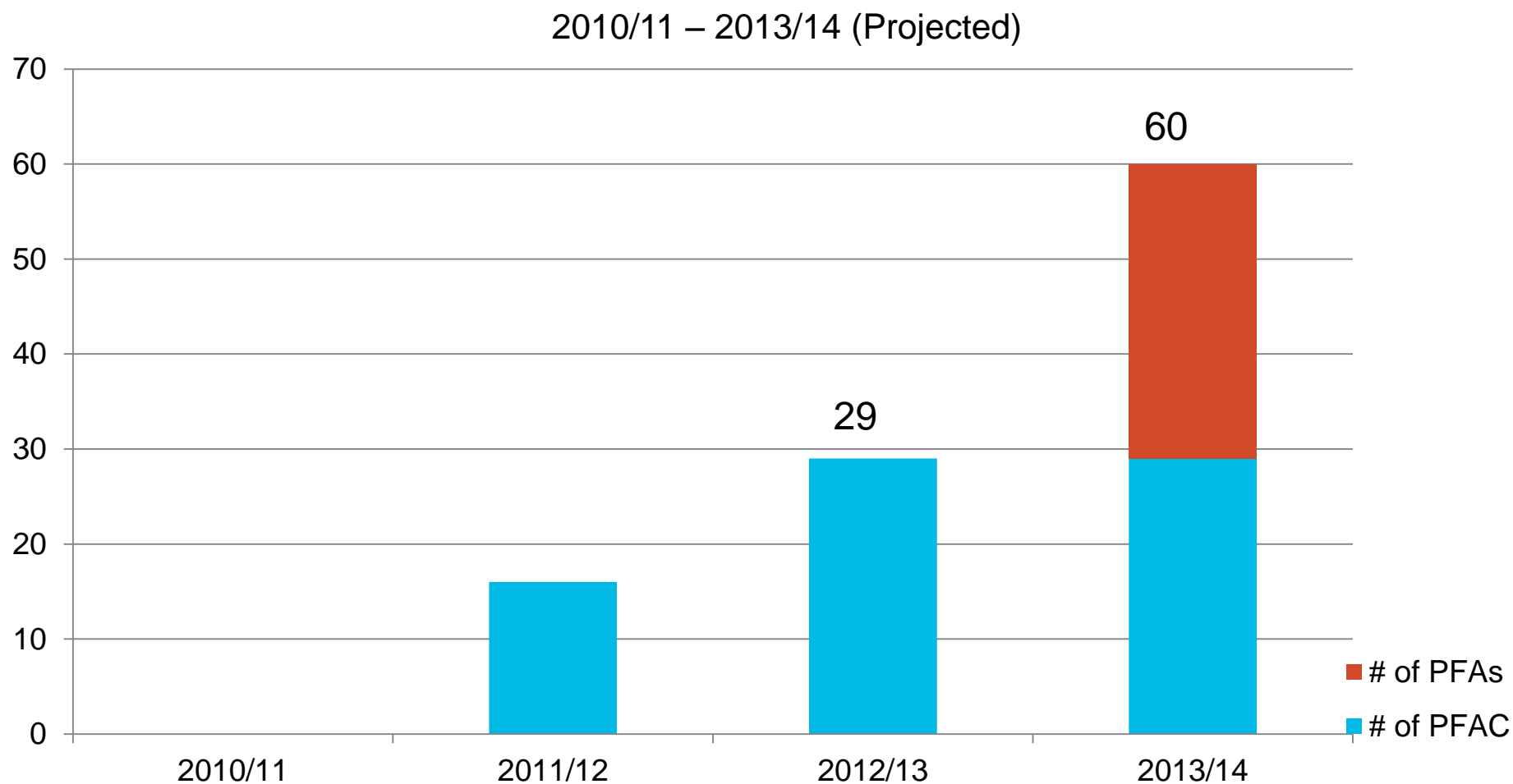
How can you contribute as an advisor?

- Help with reviewing materials that are sent to patients/families.
- Join a committee or working group.
- Participate in focus groups.

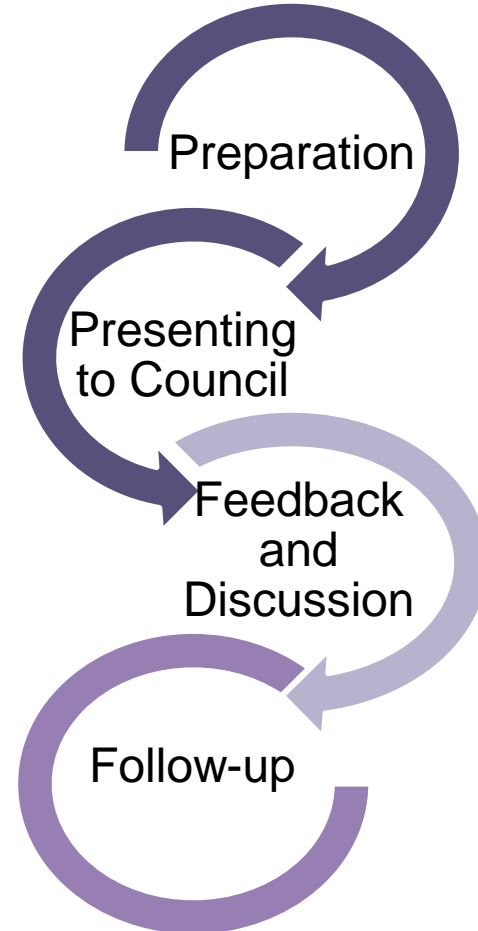
For more information and to download an application, please visit www.cancercare.on.ca or email patientfamilyadvisors@cancercare.on.ca



Growth of Patient & Family Advisors



Patient & Family Advisory Council: Staff Preparation Guide

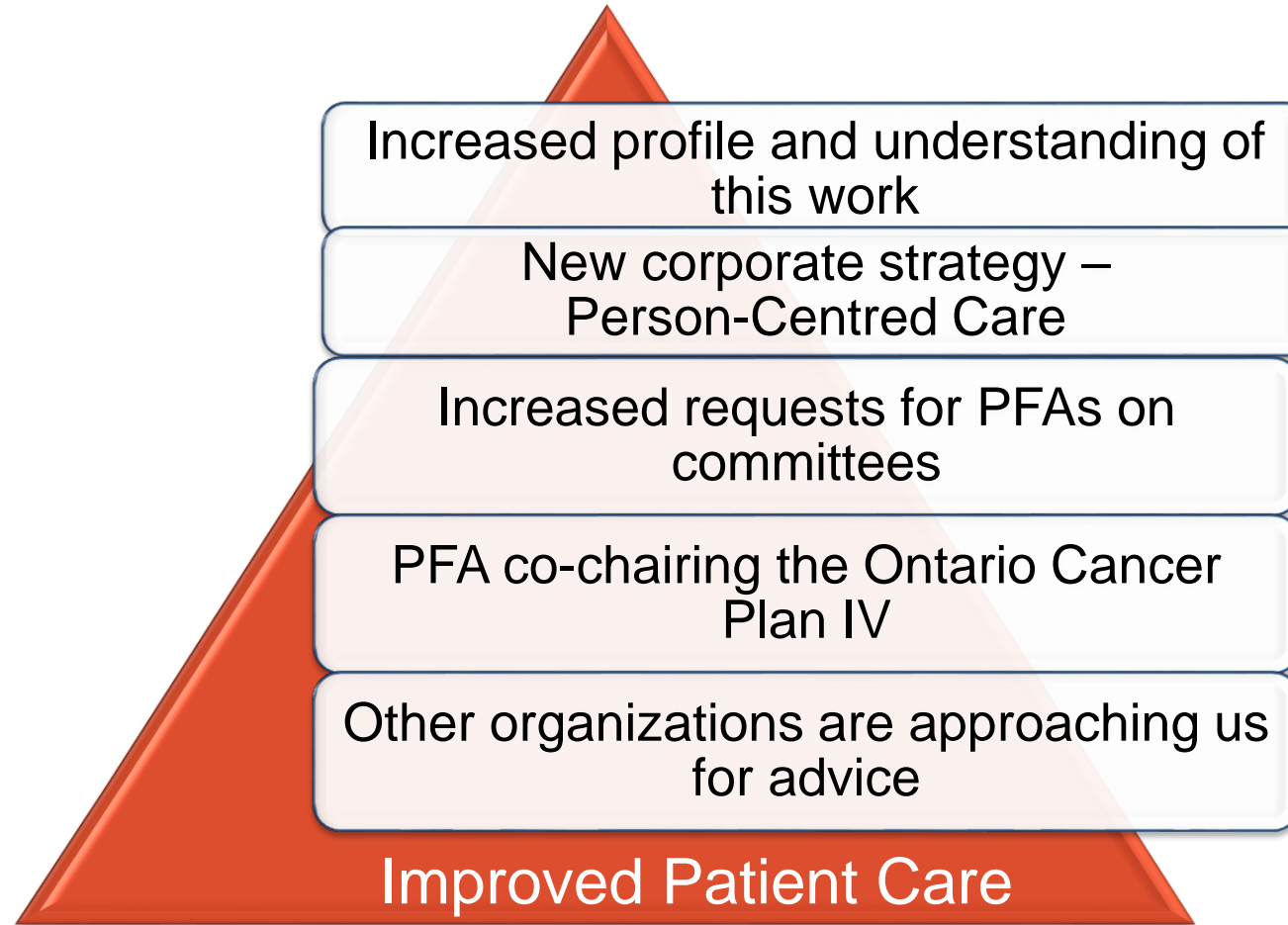


Lessons Learned

- Engage advisors early
- Learn from stories
- Actively pursue advisors with different perspectives
- Staff & advisor orientation is critical
- Use a continuous improvement approach



What Have We Achieved?



Contact Information

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Co-chair, Patient and Family Advisory Council,
Cancer Care Ontario

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Patient and Family Engagement in Action

Dr. Jonathan Kerr

- Primary Care Lead – South East Local Health Integration Network
- President-elect – Ontario College of Family Physicians

Topics

- 1. Who's job is it to do patient engagement?**
- 2. What do family doctors think about patient engagement?**
- 3. Patient Engagement activities in the South East Local Health Integration Network (LHIN)**
 - Primary Health Care Council
 - Primary Health Care Forum
 - Kingston General Hospital – Patient Experience Advisors
 - Primary Care Teams
 - Health Links

Audience Question #1

What do family doctors think about patient engagement?

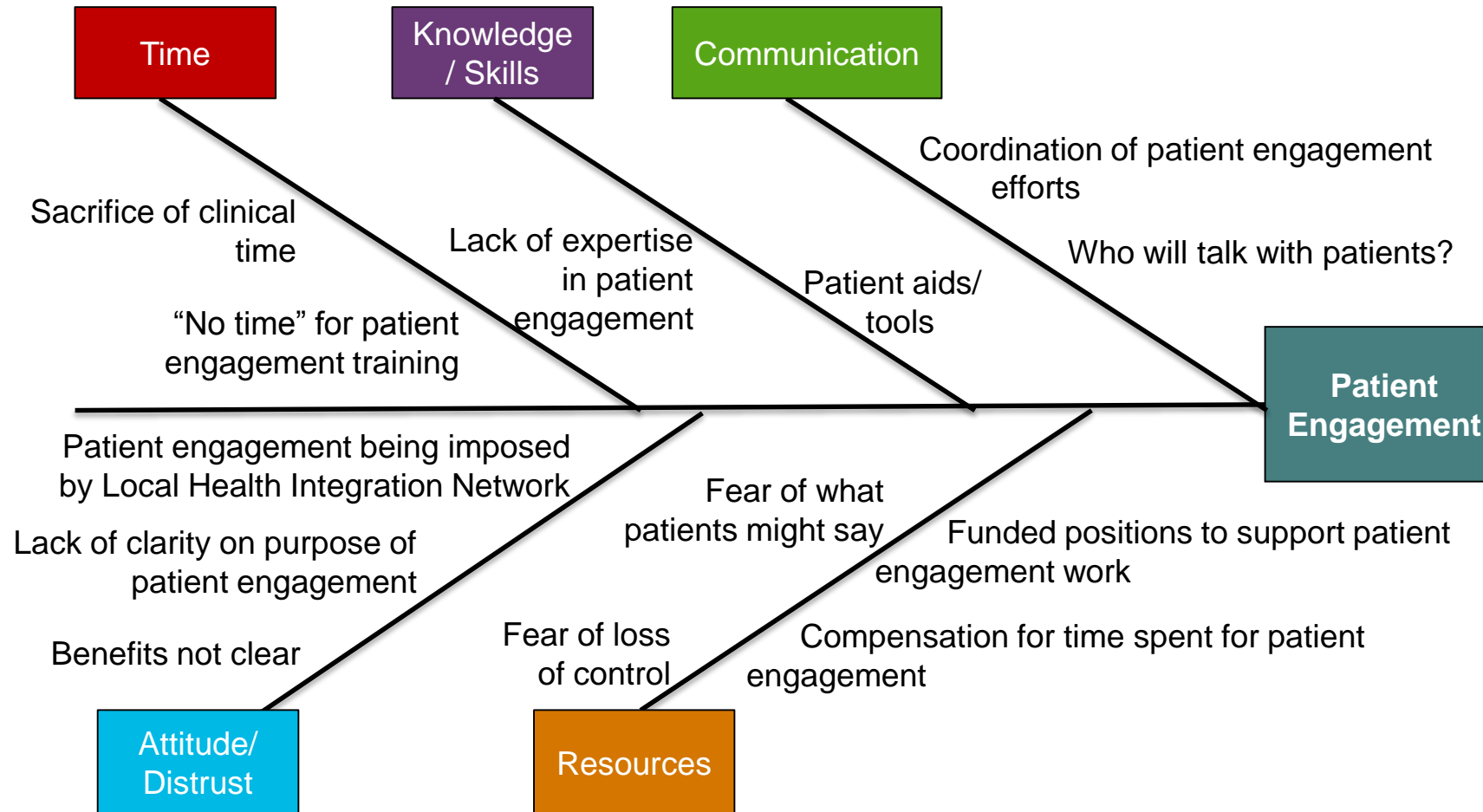
- a) I already do patient engagement every time I see a patient
... 30 times a day!*
- b) Sounds great, but I'm not ready for this yet.*
- c) What's patient engagement?*
- d) Is this about patient surveys?*
- e) That's someone else's job.*



***“When we want your opinion,
we’ll give it to you.”***

Source: Tapia, Felix J. pharmacoserias.blogspot.ca

Potential Barriers to Patient Engagement by Physicians



Audience Question #2

Whose job is it to do “patient engagement”?

- a) *Nurses*
- b) *Doctors*
- c) *Administrative staff/receptionists*
- d) *Local Health Integration Networks (LHINs) / Ministry of Health & Long-Term Care*
- e) *All of the above*

Whose Job is it to do “Patient Engagement”?

- Answer = e (All of the above)
- Different Roles:
 - **Leadership**(LHIN, Champions)
 - **Strategy** (Health Links)
 - **Training** (HQO, Change Foundation, etc.)
 - **Implementation** (Health Links, Family Health Teams, Community Health Centres, etc.)
 - **Evaluation** (All)



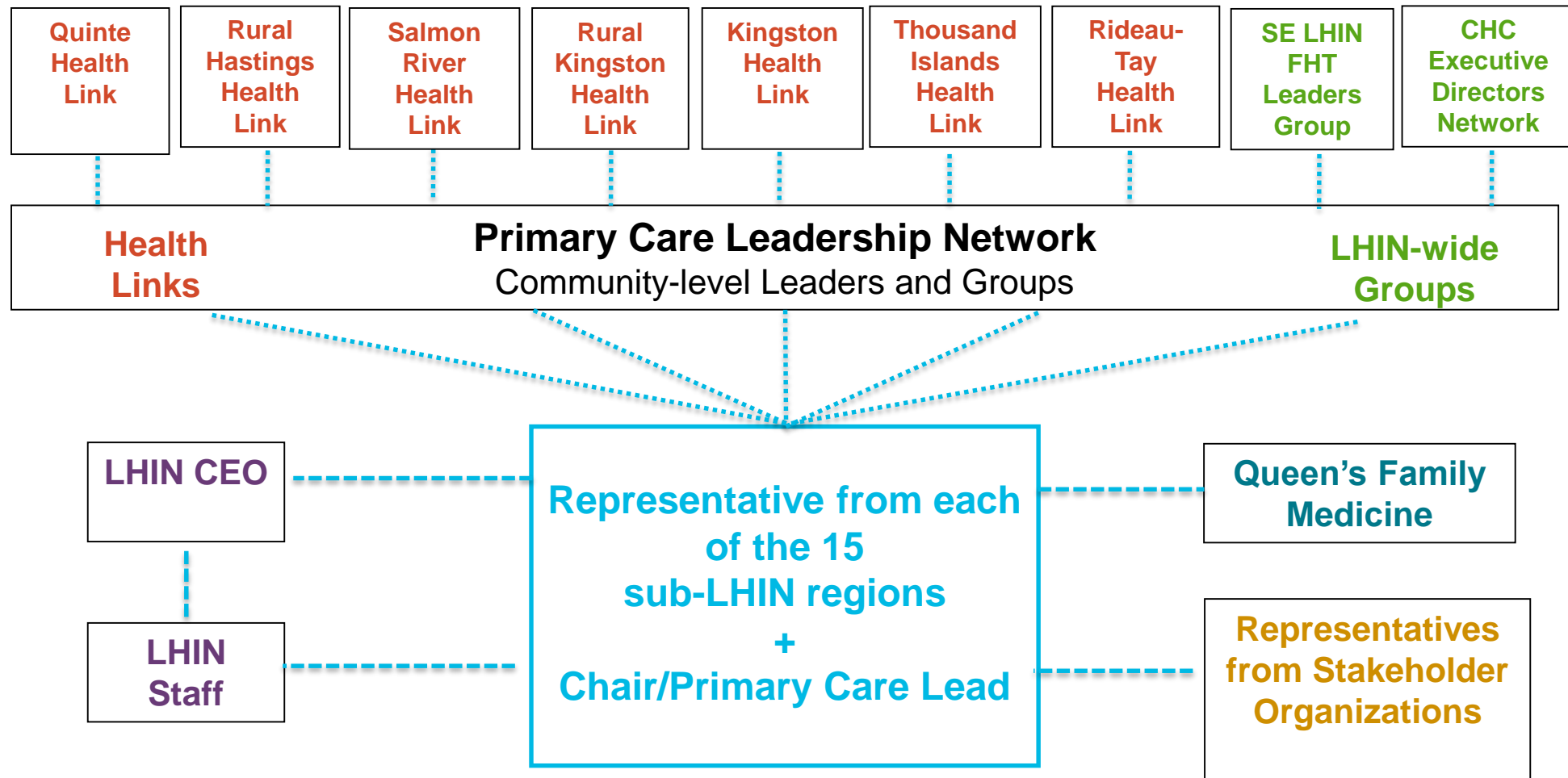


Source: Smart Health Messaging

Patient Engagement Activities in the South East LHIN

- Primary Health Care Council
- Primary Health Care Forum
- Kingston General Hospital
 - Patient Experience Advisors
- Primary Care Teams
- Health Links

Primary Health Care Council South East LHIN

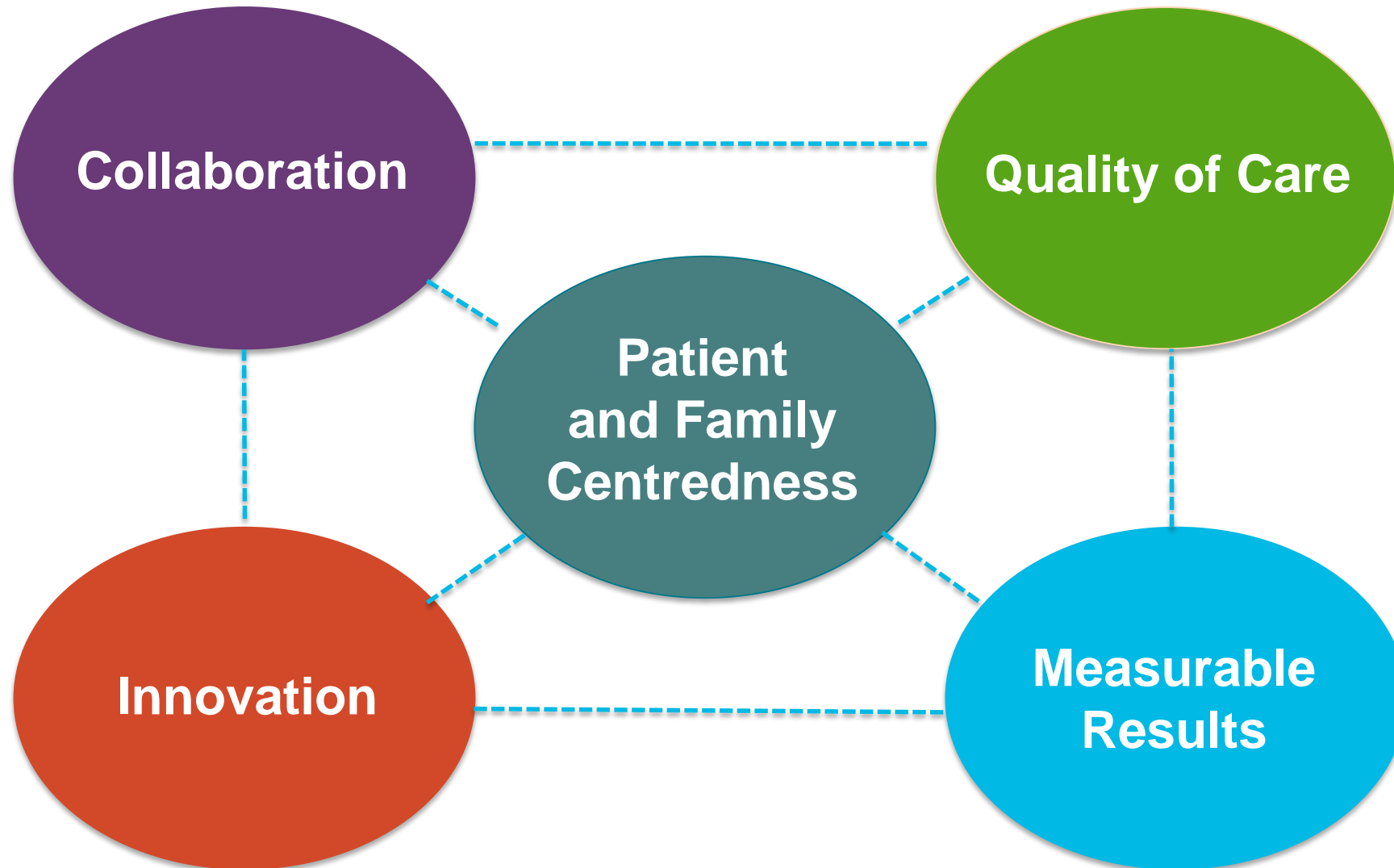


Stakeholder Organizations

- Jackie Redmond Community Care Access Centres
- Kieran Moore Public health
- Ken LeClair Community mental health
- Julia Niblett Cancer services
- Ingrid Harle Palliative care
- ★ **Jennifer Dee** **Patient Advocate**
- Mary Woodman Nurse Practitioner
- Sarah Sherwood Nurse Practitioner
- Elizabeth Grier Developmental disabilities
- Hugh Langley Southeastern Ontario Health Collaborative & Cancer Care Ontario
- Ruth Wilson Maternal health and intrapartum care
- David Barber Long-term care
- Hersh Sedhev Community health centres
- Sherri Fournier-Hudson South East Family Health Team Leaders Group & Association of Family Health Teams of Ontario
- Lynne Poff Association of Ontario Health Centres
- Wynand Bekker Community Pharmacist
- Catherine Donnelly Rehabilitation services
- Renee Fitzpatrick Child and adolescent mental health
- Michael O'Connor Emergency medicine
- Veronica Mohr Ontario Medical Association, Section of General and Family Practice
- Vacant Ontario College of Family Physicians



Primary Health Care Council Values



Vision



Primary Health Care Council's Vision

Collaborative primary care leadership towards an integrated, patient-centred, high quality health care system.



“What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?”

Primary Health Care Forum

November 19, 2013

Theme/Title:

- Engaging Patients in Health Links: Focusing on What Matters

Workshops by:

- The Change Foundation
- Health Quality Ontario
- Centre for Innovation and Collaboration
- Kingston General Hospital (patient advisor panel)

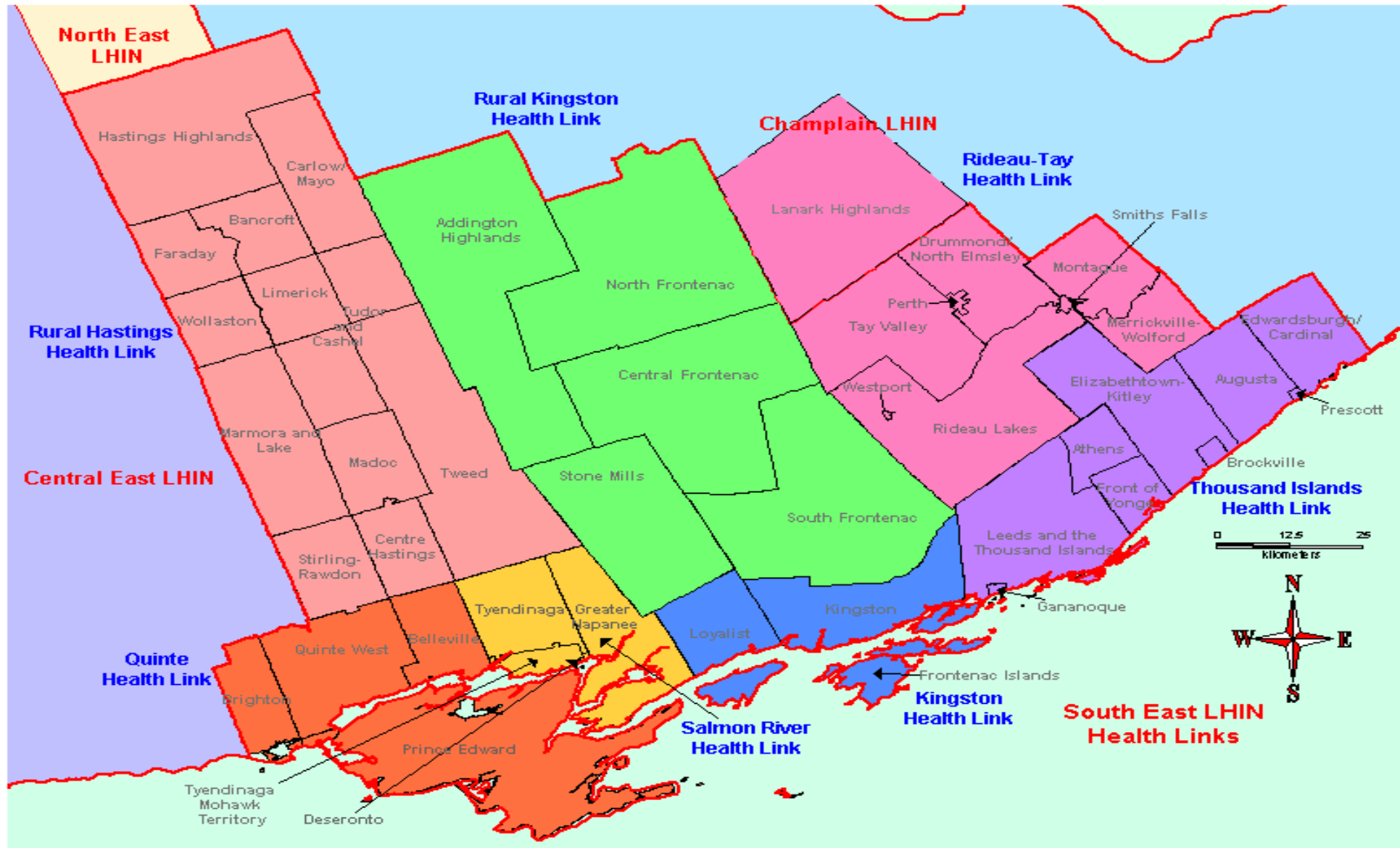
Hospitals & Primary Care Teams

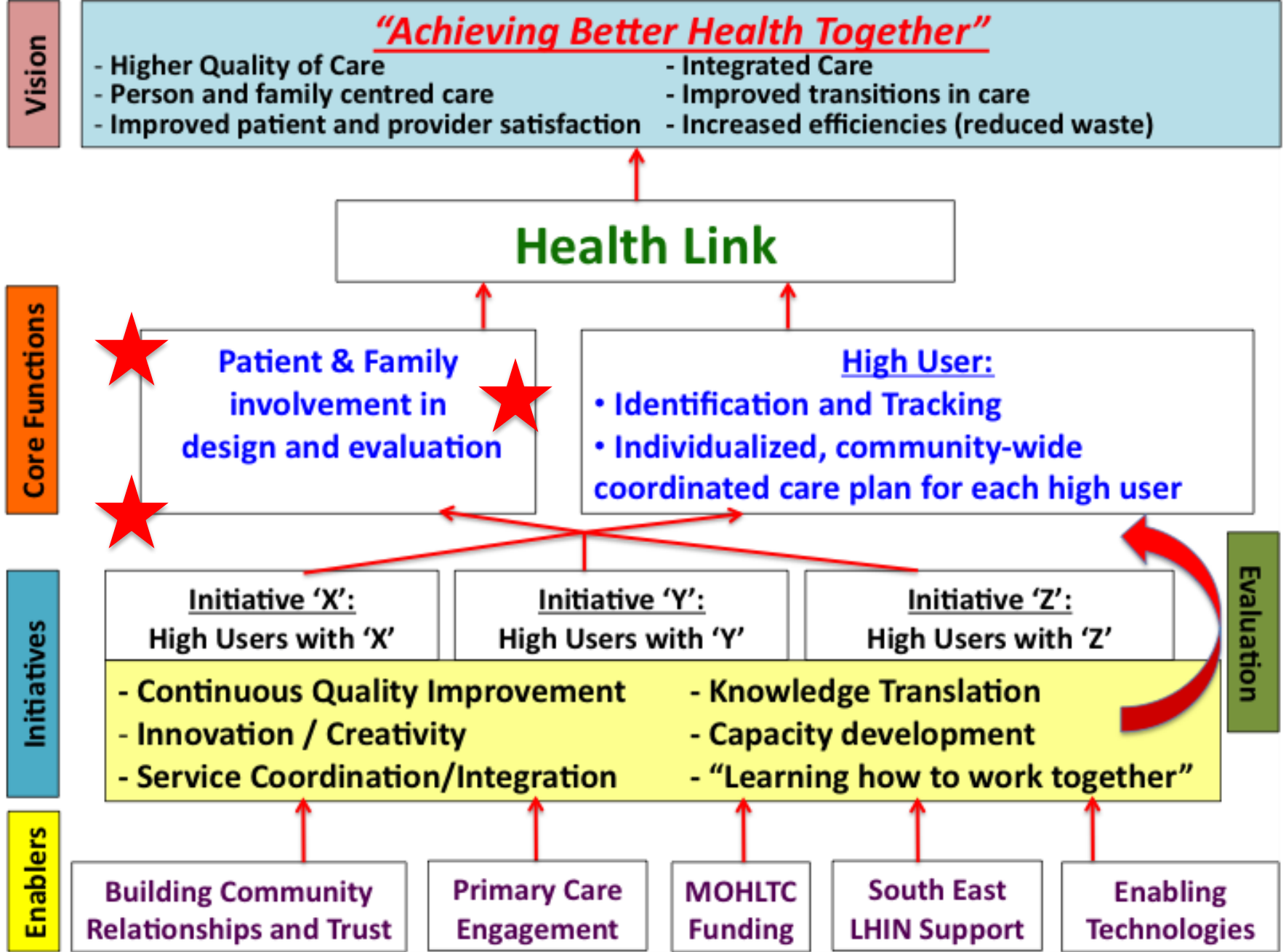
- Kingston General Hospital
 - Patient Experience Advisors

- Primary Care Teams
 - Family Health Teams & Community Health Centres
 - Community Boards
 - Patient Advisors

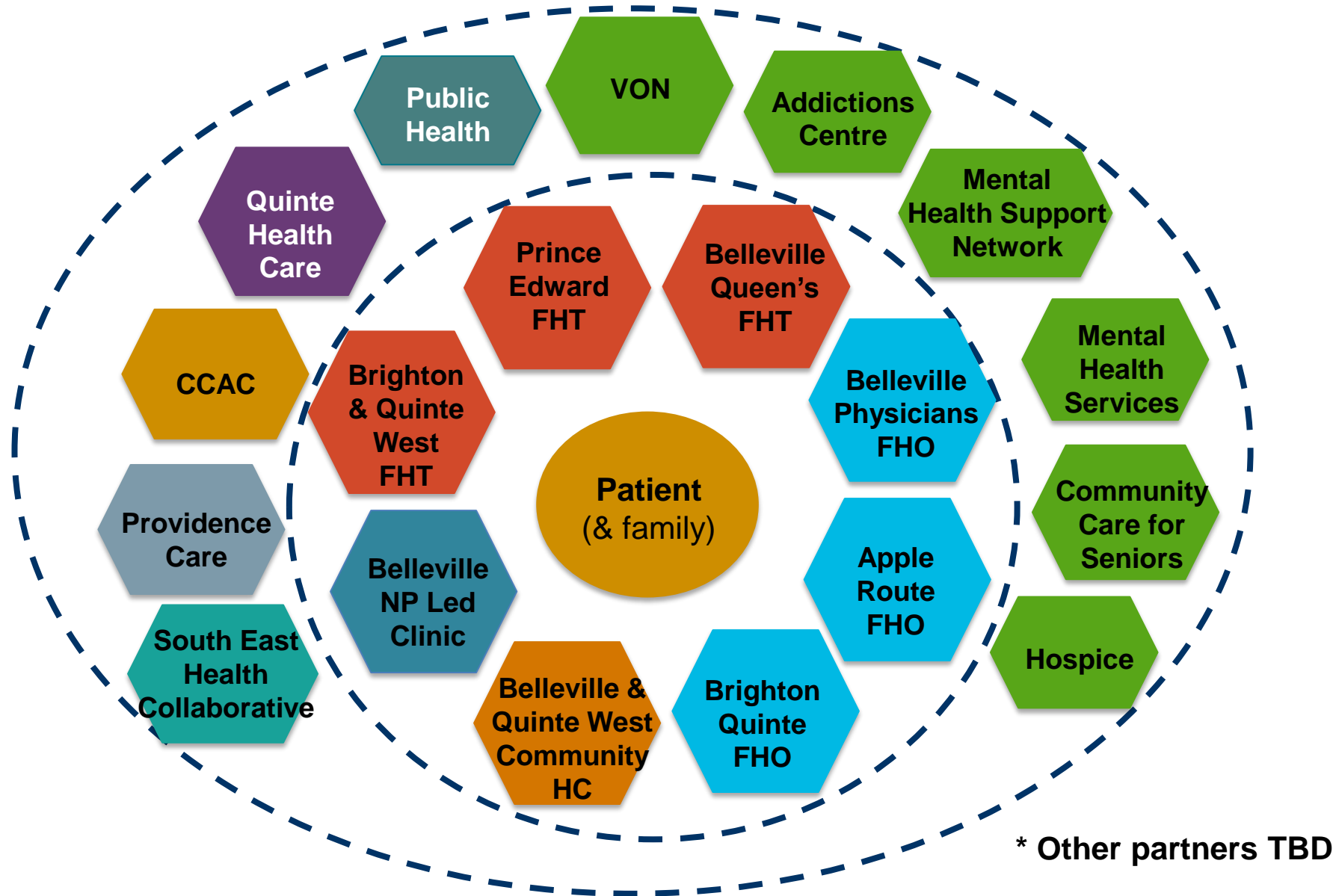
Health Links

Patient and Family Engagement
in both
Design
and
Evaluation






Quinte Health Link



Deliverables of Health Links

1. Increase the number of complex and senior patients with regular and timely access to a primary care provider.
-  2. Ensure the development of co-coordinated care plans for all complex patients.
3. Reduce the time from primary care referral to specialist consultation for complex patients.
4. Reduce the number of 30-day re-admissions to hospital.
5. Reduce the number of avoidable ED visits for patients with conditions best managed elsewhere.

Deliverables of Health Links

6. Reduce time from referral to home care visit for patients.
7. Reduce unnecessary admissions to hospitals.
8. Ensure primary care follow-up within seven days of discharge from an acute care setting.
9. Reduce the average cost of delivering health services to patients without compromising the quality of care.
10. Achieve an ALC rate of nine per cent or less.
11. Enhance the health system experience for patients with the greatest health care needs.

South East LHIN



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Questions and Discussion



Wrap Up

- Thank you!
- Reflections
- Resources
 - Patient/Family Engagement Resources (The Change Foundation, November 2013) available. Contact: smackinnon@changefoundation.com