

# Supporting High Quality Patient, Family and Caregiver Engagement: Principles and Practice

October 5, 2021

**Ontario**






PUBLIC AND PATIENT  
ENGAGEMENT  
COLLABORATIVE

McMaster  
University 

## Learning Goals:

In this workshop participants will:

-  Learn about principles, values and enablers of high quality patient, family and caregiver engagement.
-  Explore approaches to implementing purposeful engagement in practice.
-  Discuss challenges, barriers and solutions to effective patient, family and caregiver engagement.

**Note:** The workshop will end off with considerations to measure and evaluate impact.

## Speakers:

### **Julia Abelson, Professor, McMaster University; Lead, Public and Patient Engagement Collaborative**



- 20 years in public and patient engagement field
- Motivated by a desire for health policies to reflect the values and priorities of intended beneficiaries -- citizens, taxpayers, and service users
- Academic and service work focuses on supporting governments and organizations in Canada and around the world to understand how to rigorously and respectfully involve citizens and service users in a wide range of activities at all stages of the health system
- Specific expertise in design, implementation and evaluation of approaches for involving citizens and patients in system- and policy-level decisions
- Support OHT Building Block #3: Patient partnership and community engagement

## Speakers:

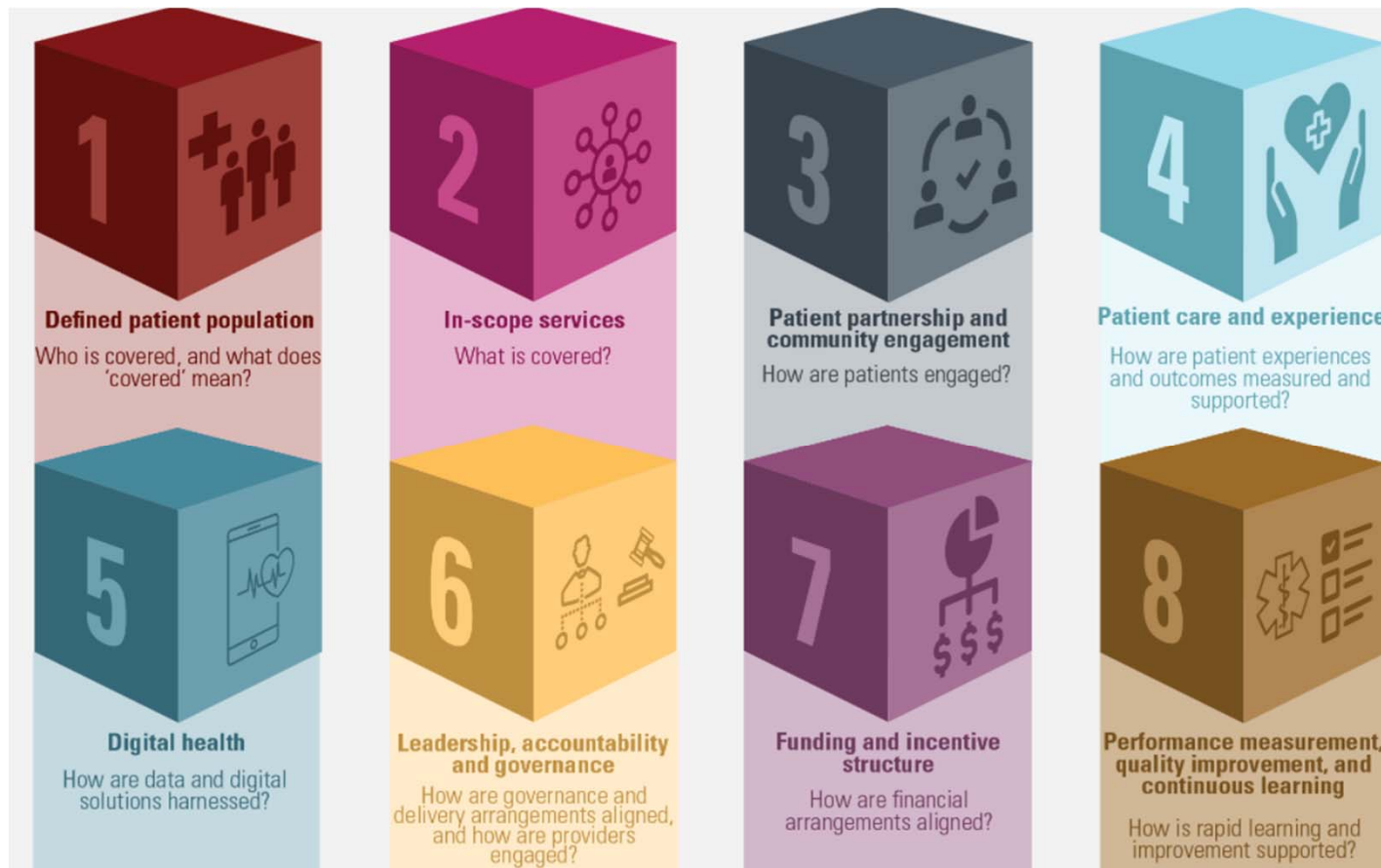
### **Betty-Lou Kristy, Chair, Ontario Provincial Health Minister's Patient and Family Advisory Council**



- Bereaved mother, in recovery for almost 20 years from alcohol/multi-drug addictions, trauma and mental health issues.
- Lost Pete, her 25-year-old son with concurrent disorders to an accidental opioid overdose in 2001.
- Has spent 15 years as a provincial system-level, lived experience and family – advisor, educator, and advocate – helping to frame policy, governance, and programming. Previous to this journey her background was in corporate marketing.
- Extensive board governance training and experience.
- Completed 3-6 year terms being a board director for Bereaved Families of Ontario, Canadian Mental Health Association Halton-Peel, Halton Alcohol Drug and Gambling Assessment Prevention and Treatment Services, Glen Mills Co-operative Housing Corporation and Addictions & Mental Health Ontario.
- Director at the Centre for Innovation in Peer Support that is embedded in Support & Housing-Halton.

# Building Blocks of the OHT Model

Patient partnership and community engagement is a foundational building block to the OHT model. It is core to improving the outcomes and experience of service recipients.



## Role of Building Block #3

- Capacity and competency around patient, family and caregiver engagement (and community engagement) is key to integrated care implementation readiness.
- Listening to and engaging patients, families and caregivers in health care system design works to increase efficiencies in the system, resulting in better quality care and better health outcomes.
- Continued patient, family and caregiver engagement is necessary to sustain partnerships in local care populations.

# Supporting Patient Engagement and Partnership through the Minister's Patient Family and Advisory Council (MPFAC)



Patient, family, and caregiver partnership continues to be a key pillar of the Ontario Health Teams model that speaks to the commitment to create a truly patient-centred health care system.



As part of the full application review process, virtual visits provided a unique opportunity to hear firsthand where teams are at with respect to their engagement efforts and how this work is progressing.



While some teams have demonstrated long histories of meaningful and robust patient partnership, others are just learning how to engage at a broader system level.



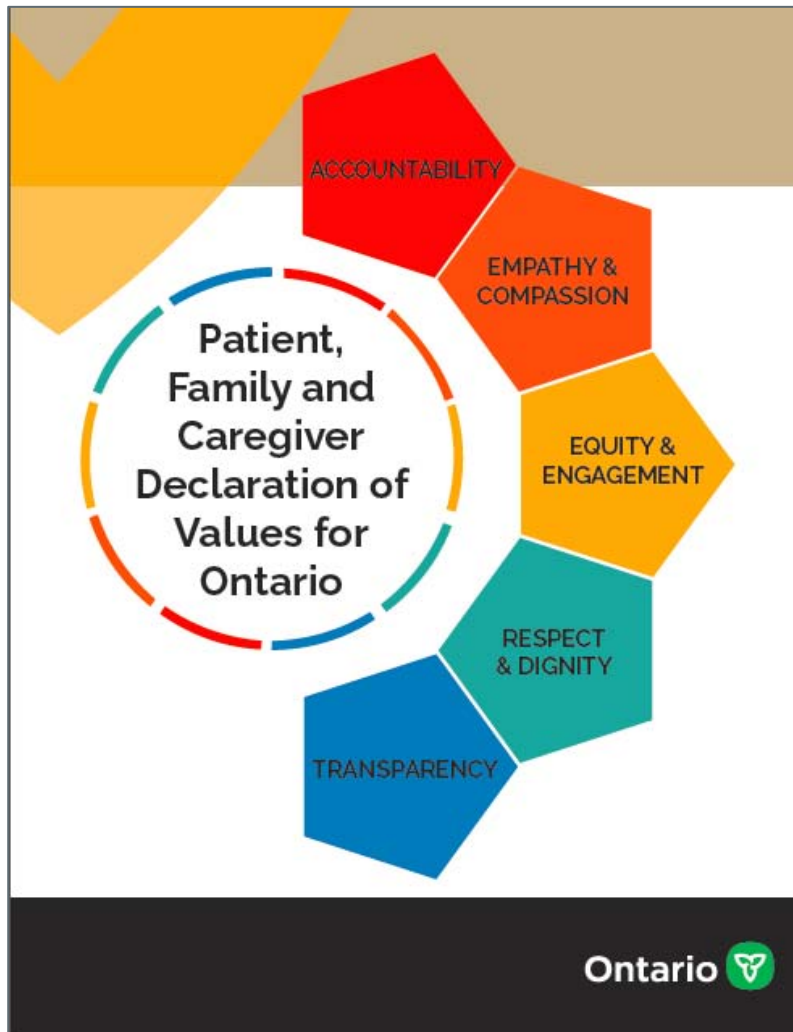
A key priority area Minister's PFAC is helping to advance this work to ensure appropriateness and alignment of patient engagement activities across Ontario Health Teams in order to maximize their quality and impact.



There is a great opportunity to learn from the successes of teams that have found a way to truly build effective patient, family, and caregiver engagement into the core of their Ontario Health Teams work and spread those learnings across all teams.



# Patient, Family and Caregiver Declaration of Values for Ontario (PFCDV)






The PFCDV for Ontario outlines patient, family and caregiver expectations for the health care system

- Authored by the MPFAC, the document sets a provincial standard which OHTs will seek to embody in their work.
- Key themes are grouped under five key values-based umbrellas:
  - Accountability
  - Empathy and Compassion
  - Equity and Engagement
  - Respect and Dignity
  - Transparency
- Recent amendments to the PFCDV highlight the importance of anti-racism, accessibility, equitable care delivery, and partnering with patients, families and caregivers.
- **Webpage:** <https://www.ontario.ca/page/patient-family-caregiver-declaration-values-ontario>



## Key Concepts

-  Who are we engaging and partnering with?
-  What do we mean by engagement, partnership and co-design?
-  What are our goals for these activities?

Different **people** in...  
different **roles** for...  
different **purposes**

## Who do you want to engage or partner with?

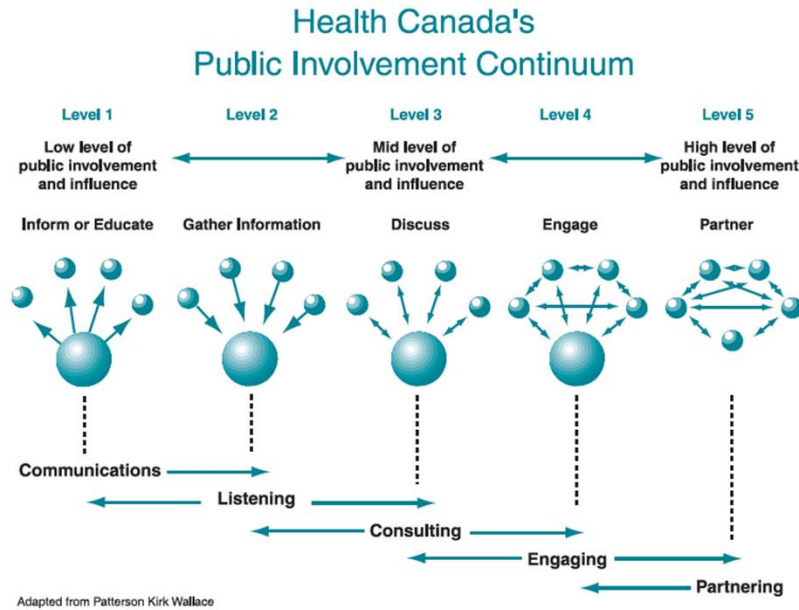
**Those who are directly affected** – Individuals with experiential knowledge in a specific area (e.g., disease, condition or aspect of care) who can provide a specific set of perspectives

**General or specific population groups** – Individuals/groups with shared identity (e.g., geography, stage of life, vulnerabilities or limitations); may or may not have specific experience to draw from

**Stakeholder groups** – Groups with organized interests in the area (e.g., advocacy groups, provider organizations)

(Abelson et al. 2016; Gauvin et al. 2014)

# What do we mean by involvement, engagement, partnership and co-design?



## IAP2 Spectrum of Public Participation



IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

INCREASING IMPACT ON THE DECISION					
	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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## Design Thinking Process



# What are your goals for engagement and partnering?

## Start with WHY

Why are you doing this? What do you hope to achieve?

## Then decide on WHO

Whose perspectives are important to have?  
Who will be most affected by the outcomes of the initiative?

## Then choose HOW

Broad consultation to inform at an early stage?  
Collaborate around shared goals?  
Co-design together?

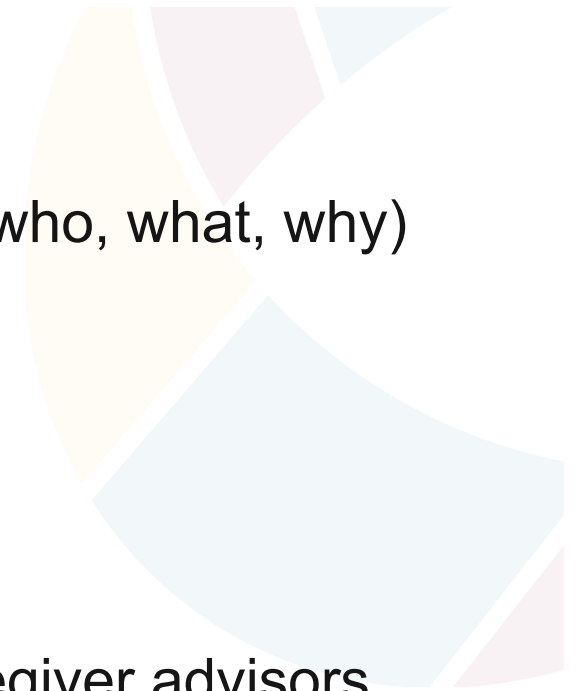
# From principles to practice:

## *What does high-quality engagement and partnering look like?*

- Lots of resources to choose from
  - Ontario Health – Quality Division (Formerly Health Quality Ontario)
    - <https://www.hqontario.ca/Patient-Partnering/Patient-Partnering-Tools-and-Resources>
  - Patient Engagement Resource Hub, Healthcare Excellence Canada
    - <https://www.cfhi-fcass.ca/innovations-tools-resources/patient-engagement-resource-hub>
  - Equity and Diversity resources
    - <https://www.ontariohealth.ca/sites/ontariohealth/files/2020-12/Equity%20Framework.pdf>
    - <https://www.hqontario.ca/Patient-Partnering/Patient-Partnering-Tools-and-Resources/Resources-for-Health-Care-Providers/Build-Equity-and-Diversity-Into-Your-Engagement-Activities>
  - Toolkit: Sharing Your Personal Journey for Public Speaking and/or Advisory Engagement. An Expertise for Co-Designing Person Directed Services & System Transformation. (Support House)
    - <https://supporthouse.ca/wp-content/uploads/2021/03/Toolkit-Sharing-Personals-Journeys-Public-Advisory-Engagement-FINAL-Mar-2021.pdf>

## Key Areas to Work Through

- Scope and level of engagement/partnership (who, what, why)
- Recruitment and selection
- Clarification and negotiation of roles
- Compensation
- Orientation and support for patient/family/caregiver advisors and organizational staff



## Scope and level of engagement or partnership: *What roles and responsibilities will they have?*

- In the overall **collaborative decision-making structure** of OHTs?
  - as members of the Executive Committee, Advisory or Operations Committee?
  - as members of a User Engagement Committee?
- As **partners in different stages** of the OHT implementation journey (e.g., clinical pathways, dissemination of information, recruitment of additional patient, family and caregiver advisors)?
  - as ad-hoc consultants or members of planning and implementation committees
  - training, research, or providing personal narrative



# Identification and selection of patient, family and caregiver partners

## Key considerations

- What perspectives, experiences, population or community characteristics are you looking for?
- How many user partners or contributors do you need to achieve your goals for engagement or partnership?
- Recruitment into OHT structures and activities vs. engaging where people are (through existing organizations and networks)

## Commonly used sources

- Existing patient, family and caregiver advisory groups within OHT collaborating organizations
- Additional community organizations and networks representing communities or populations of interest
- Health charities and disease-specific organizations
- Market research firms and online panels (e.g., Asking Canadians)

## Clarifying and Negotiating Roles

- As early as possible and check in periodically
- Clarify expectations for involvement at all stages
- Allow enough time for discussions about roles to show respect and commitment to meaningful involvement



# Compensation

- Similar to advice about negotiating roles
  - Initiate discussions early and in an open and respectful manner
- Don't assume anything
- Expectations will vary

## Resources:

Change Foundation – *Should money come into it?* <https://changefoundation.ca/patient-compensation-report/>

Richards D, Jordan I, Strain K and Press Z. Patient partner compensation in research and health care: the patient perspective on why and how. *Patient Experience Journal* 2018. <https://pxjournal.org/journal/vol5/iss3/2/>

# Orientation and Support

## What do patients, families and caregivers need to contribute meaningfully?

- a good understanding of the **policy/implementation goals and process**, and their **roles** in it (including timelines)
- basic understanding of **relevant terminology and concepts** needed to carry out their roles
- sense that they are a **respected** member of the team
- a **supporting infrastructure** for their participation (mentoring, administrative support, social/health support)

## How can integrated care partners facilitate this?

- invest in **early support of PFC members** in their roles
- on-going **communication**
- **respect for their roles and contributions** and any **limitations** related to health conditions, mobility, vulnerabilities



# Patient, Family and Caregiver Engagement in Ontario Health Teams: Learning from Early Experiences

Public and Patient Engagement Collaborative | MARCH 2021

Laura Tripp | Jeonghwa You | Maggie McNeil | Julia Abelson



# Key findings: Recruitment and structures

## Recruitment

- **OHTs at various stages of recruiting PFC partners**
- **Key strategies used:**
  - OHT partner organizations, advertisements, organizations serving target populations, participants in previous OHT activities
- Recruiting from **diverse populations** is a focus and a challenge

## Structures (how PFCs are embedded within OHTs)

- members of **OHT executive leadership and management** committees – highly valued approach; some are co-leading
- members of **sub-committees and working groups** (all OHTs doing this)
- **Patient and Family Advisory Councils** – some are doing this; others have chosen not to establish separate PFACs to ensure that PFC partners are embedded throughout the OHT
- **Other approaches:** Community engagement groups, databases of PFC partners

## Challenges

**COVID-19 (initial stages)** - most activities paused; changing focus; shift to virtual; greater level of urgency around engagement work

**Organizational capacity for patient engagement**

**Recruitment of diverse voices**

**Compensation**

**Acronyms and jargon**

**Technical supports**

**Meeting scheduling**

**Heavy workloads and short timelines**

## Enablers

**Trust** among patient partners and staff (esp. with pre-existing relationships) facilitates PE ramp up

**Staff support** and advocacy for patient partners facilitates engagement opportunities and other supports



## Support for OHTs Going Forward

- **Province-wide information and resource sharing** to reduce duplication of effort and support consistency around core principles and activities
- **Networking opportunities** for OHT patient partners
- Guidance for OHTs to adequately reflect a **broad range of community perspectives** in their work
- Guidance around **compensation** and related supports
- **Education and support** to include training and coaching for patient partners, OHT leadership and health care providers
- **Database of patient partners** who are willing and ready to engage in each region
- **Public communications** about OHTs
- Support for **PE evaluation**
- **Toolkits, briefs and research** on best practices in patient, family and caregiver partnership and engagement

## The importance of evaluation

- Helps with **goal setting and benchmarking** (early on)
  - What are we trying to achieve with our engagement and partnering work?
  - Where are we now? Where would we like to be?
- Supports **continuous learning and improvement** (on-going)
- Helps to **assess the impact of your work**
  - on people, programs, organizations and health system

## Getting started



What are our goals for evaluation (and whose goals are they)?



What aspects of engagement are you evaluating?



What are the most appropriate tools for the job?

# Evaluating Patient and Caregiver Engagement: Summary of what we know



Good handle on measuring *process and experience* of engagement (was engagement well designed and executed?)



Measuring *impact* has been more challenging

- \*Recent developments in health research (not easily transferable)
- \*Stories or perceived impacts (e.g., what has changed as a result of my/our engagement?)
- \*Lack of tracing between PE activities and outcomes/impacts



Range of approaches being used

- Surveys and interviews
- Document reviews and observations
- Case studies
- Trials and interventions

## Selected Evaluation Resources

### Public and Patient Engagement Evaluation Tool (PPEET)

<https://ppe.mcmaster.ca/our-products/public-patient-engagement-evaluation-tool>



### *Coming Soon...* **Impact Evaluation Toolkit**

A toolkit to support the evaluation of the impact of patient, family and caregiver engagement (details to follow on PPEC website)



# Appendix

# Contact Information

## Julia Abelson, PhD

- Professor, Department of Health Research Methods, Evidence & Impact (HEI), McMaster University; Lead, Public and Patient Engagement Collaborative <https://ppe.mcmaster.ca> (email: [abelsonj@mcmaster.ca](mailto:abelsonj@mcmaster.ca))
- Staff contact: Laura Tripp (Email: [lauratripp@mcmaster.ca](mailto:lauratripp@mcmaster.ca))

## Betty-Lou Kristy

- Chair, Provincial Health Minister's Patient and Family Advisory Council
- Email: [patientengagement@ontario.ca](mailto:patientengagement@ontario.ca)



# Supports Available to OHTs and How They Can Be Accessed and Used

- What the PPE Collaborative offers OHTs:
  - Technical advice and support around patient engagement, partnership and its evaluation, including guidance on appropriate supports for, and approaches to, evaluation at different stages of maturity
  - Tools to evaluate patient engagement and partnership (e.g., the Public and Patient Engagement Evaluation Tool (PPEET))
  - Leading a province-wide Evaluation Working Group that is developing a toolkit to support evaluation of the impact of patient engagement and partnership across the Ontario health system, including OHTs
  - **Note:** Additional information and materials are available on our website: <http://ppe.mcmaster.ca>
- Ministry of Health - Ontario Health Teams – Webpage
  - <https://health.gov.on.ca/en/pro/programs/connectedcare/oht/>
- Rapid-Improvement and Support Exchange (RISE) – Webpage
  - <https://www.mcmasterforum.org/rise/learn-about-rise/overview>
- Supports are available for all OHTs across the development spectrum