

# **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



## BACKGROUND

Between October and December 2020, patient partner leads from all Cohort 1 OHTs were invited to share their early experiences with patient, family and caregiver engagement and partnering through a series of short interviews covering a range of topics, including: the ways in which **patients and family caregivers are recruited** to OHTs; **structures and activities** established to provide opportunities for them to contribute, advise, partner or co-lead; **the influences of COVID-19** on engagement, partnering and co-design activities; **early assessments of impact**; **contributors and challenges** to successful engagement; and, recommendations for **supporting engagement and partnering** moving forward.

## WHO DID WE LEARN FROM?

Nineteen patient partner leads from fourteen OHTs participated in 20 – 60-minute interviews with a member of the PPEC research team. Four staff members were also interviewed in 3 additional OHTs where patient partner leads were either not in place or could not be reached. Most of the patient partner leads interviewed had previous experience as a patient partner, including past involvement in regional-level health organizations, affiliations with multiple organizations, in addition to lived experience as an informal caregiver, patient or both. Some joined their OHT during the application phase; others joined more recently.

## HOW ARE PATIENT AND FAMILY CAREGIVER PARTNERS BEING RECRUITED TO OHTs?

- OHTs are at various stages of recruiting their patient and family caregiver partners with a variety of strategies being used, including: i) OHT partner organizations; ii) advertisements (e.g., online, newspaper); iii) organizations serving target populations; and iv) follow up with individuals who participated in previous OHT activities.
- Recruiting a diverse complement of patient and family caregiver partners is both a focus and a challenge for OHTs; notable barriers to recruitment include the reduced opportunities that COVID-19 presented due to increased turnover of patient partners, generally due to COVID-related health issues, and the early challenges associated with online engagement.

## WHAT STRUCTURES ARE BEING USED TO ENGAGE PATIENTS AND FAMILY CAREGIVERS IN ONTARIO HEALTH TEAMS?

There was general agreement that patient partners should be embedded across all OHT governance structures. Common approaches include:

### ***Patient/caregiver members of OHT executive leadership and management committees***

- OHT executive governance committee (most); some patient partners chair/co-chair these committees (N=3)
- OHT operations committee (many); some patient partners decline due to heavy workload but receive regular updates on committee activities

### ***Patient/caregiver members of sub-committees and working groups*** focused on building blocks and priority populations:

- Working groups typically have a larger number of patient partners than executive-level committees (up to 5 – 10 per committee)
- Inclusion of at least one patient partner from the executive level on working groups/sub-committees ensures the integration of patient/caregiver input between working groups and executive level

### ***Patient and Family Advisory Committee (PFAC)***

- Twelve of the OHTs interviewed have established or are in the process of developing PFACs
- Members are often recruited from the PFACs of participating organizations
- A variety of names are given to this committee: Patient Partner Council, Community Wellness Council, Lived Experience Council, Partners for Better Care Council
- Two OHTs decided not to form PFACs to ensure that engagement is embedded within the OHT rather than as a separate entity (will reassess over time)

### ***Additional structures in some OHTs:***

- Some OHTs have established Community Engagement Groups to advise the OHT on how to effectively engage the community (these groups include many patient partners)
- Some have developed databases and lists of patient partners who can be contacted for specific work or activities

## HOW ARE PATIENT AND FAMILY CAREGIVERS BEING ENGAGED IN OHT ACTIVITIES?

Patient and family caregivers are engaged in a variety of activities and roles across OHTs.

Examples include:

### ***Policy and governance***

- Feedback on an accountability framework
- Developed the logo and mission statement for a working group
- Discussions around COVID policies
- Developed Terms of Reference for a variety of committees (e.g., governance committees, PFACs, working groups)

### ***Program planning and design***

- Flu shot clinic design
- Launch of a hotline service to support seniors in need at home
- Logistics and flow of the COVID assessment centre (e.g., answering the question “What should a clinic look like from a patient’s perspective as you walk in the door, as you’re greeted?”)
- Design of mental health & addictions walk-in clinic
- Advice on intake procedures and hours of operation

### ***Educational Activities***

- Hosting of a webinar to explain the health system and services for those who have difficulties navigating the system (e.g., new immigrants)
- Assisted with the development of communication tools for COVID assessment centres

### ***Supporting patient engagement***

- Development of frameworks and policies for patient engagement
  - Co-designed the mandate, goals and purpose of the patient engagement working groups/PFACs
  - Development of a survey to be distributed to OHT partner organizations to understand the PE activities underway in their organizations.
- Education and professional development activities

## WHAT IMPACT HAS COVID-19 HAD ON PATIENT ENGAGEMENT AND PARTNERING ACROSS ONTARIO HEALTH TEAMS?

- Most patient engagement activities were paused during wave 1
- Some patient partners provided feedback on COVID-related work (e.g., development of the COVID assessment centre, providing supports to COVID-positive patients)
- Engagement and partnering activities re-started in wave 2; for most, the focus remains on COVID rather than broader OHT activities
- Some viewed the wave 1 pause as a slow down; others viewed it as a full stop with the need to re-start – for some, this was an opportunity to revisit the way OHTs view patient engagement
- Now that PE is continuing through online formats, most feel this works well and allows the work to continue
- Some PE work is suffering (e.g., recruitment of new patient partners); some patient partners have resigned due to health issues, loss of interest after wave 1 or technical difficulties
- COVID has added a level of urgency to patient engagement and patient partner work (e.g., higher level of community interest in patient engagement); it has motivated some individuals to become involved as patient partners and has normalized virtual meetings/forums making it easier to engage the community through those strategies.

## WHAT ARE THE EARLY IMPACTS OF PATIENT ENGAGEMENT AND PARTNERING ON ONTARIO HEALTH TEAMS?

- Many identified early impacts they felt patient partners were having on OHTs, including:
- Process-related impacts (how patient partners were being successfully engaged):
  - Patient partners feel respected, involved and listened to; comfortable sharing their views
  - Sense of cooperation and collaboration (feel they are part of the team)
  - Appreciate hearing explanations when their suggestions aren't implemented or when a hybrid approach is taken.
- Outcome-related impacts:
  - Program brochure revision: patient partner feedback improved usability
  - Changes to governance structure resulted from patient partner input (call for patient engagement in governance for OHTs to be patient centered)

## WHAT ARE THE CONTRIBUTORS TO SUCCESSFUL PATIENT ENGAGEMENT AND PARTNERING IN OHTS?

- Trust: Some OHTs were established based on pre-existing working relationships between different organizations in the region; trusting relationships facilitated quick ramp up of patient engagement.
- Staff support: staff dedicated to supporting and advocating for patient partners in the OHT facilitates engagement opportunities, provides training and other supports.

## WHAT ARE THE KEY CHALLENGES TO PATIENT ENGAGEMENT AND PARTNERING ACROSS ONTARIO HEALTH TEAMS?

- **Organizational capacity for patient engagement:** PE is very new for some OHT partners; mandates without know how has led to tokenistic engagement
- **Recruitment of diverse voices:** difficulties engaging patient partners from diverse populations; need more explicit attention to and supports for this
- **Compensation:** concerns about unequal approaches to compensation and other financial supports offered to patient partners across OHTs; how to recognize different roles and activities (e.g., one-time roles, working group members, co-chairs) with fair and appropriate supports and/or compensation relative to role, workload and time commitments
- **Acronyms and jargon:** Challenging for patient partners to learn and understand during meetings; limits their ability to effectively contribute
- **Technical supports:** lack of access to personal devices for online engagement; technical challenges associated with external connections
- **Meeting scheduling:** mostly during the day, limiting participation of patient partners with other responsibilities such as paid employment
- **Heavy workloads** and **short timelines**

## HOW CAN OHTs SUPPORT PATIENT ENGAGEMENT EFFORTS MOVING FORWARD?

- Province-wide information and resource sharing to reduce duplication of effort and support consistency around core principles and activities, e.g.,
  - Terms of reference and engagement plans
  - Policies and procedures related to patient partner compensation and related supports
  - Understanding what is working well in OHTs; how others are dealing with COVID
- Networking opportunities for OHT patient partners (e.g., monthly meeting for OHT patient partners to share resources and learn from each other)
- Guidance about how to ensure OHTs adequately reflect a broad range of community perspectives in their work (e.g., different population groups, experiences with different conditions, etc.)
- Compensation and related supports for patient partners can remove some barriers to participation; important for the recruitment of harder to reach populations
- Education and support for patient engagement and partnering, including 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 (e.g., one OHT has a database that allows for calls for participation to go out to potential patient partners)
- Government-led public communications about OHTs – the public needs to learn more about OHTs
- Support for PE evaluation

*The Public and Patient Engagement Collaborative at McMaster University is pleased to be part of the Ontario Ministry of Health's Central Program of Supports for OHTs. The Central Program of Supports is designed to assist OHTs in improving their readiness to achieve OHT implementation deliverables set out by the Ministry. Our role is to support OHTs with Building Block #3: Patient partnership and community engagement, with a specific focus on supporting the evaluation and measurement of patient, family and caregiver engagement. For more information, please see our website: <https://ppe.mcmaster.ca> or contact Laura Tripp at [lauratripp@mcmaster.ca](mailto:lauratripp@mcmaster.ca).*