

# ONTARIO HEALTH TEAMS' EXPERIENCES DEVELOPING PATIENT, FAMILY AND CAREGIVER ENGAGEMENT AND PARTNERSHIP STRATEGIES

Meaningful partnership and engagement with patients, families and caregivers is central to the transformation of Ontario's health system, primarily through the creation of Ontario Health Teams (OHTs). As of late 2021, there were 50 approved OHTs, achieving 82% coverage across the province. In the Fall of 2021, each OHT approved in 2019 (e.g., cohort 1 OHTs) developed a Patient, Family and Caregiver Engagement and Partnership Strategy. A group of patients, family and caregivers working with OHTs, and convened through a provincial community of practice (CoP), identified an opportunity to learn from the experience of developing this strategy to inform future engagement and partnership activities within and across OHTs. This document summarizes these learnings gathered through a

survey distributed through the CoP and contextualized as part of a community discussion among patients, families and caregivers as well as OHT staff.

The survey was distributed to all CoP members following the November 2021 community call when the Muskoka and Area OHT shared their experiences of developing their Patient, Family and Caregiver Engagement and Partnership Strategy. Twenty people completed the survey. Survey results were compiled and shared at the December 2021 meeting of the OHT Patient, Family and Caregiver Engagement and Partnership CoP. CoP members discussed the findings, adding their own insights and experiences. This summary presents the results of the survey and the learnings from that discussion.

## KEY INSIGHTS



OHT engagement strategies were a **critical tool** to guide OHT engagement-specific initiatives and across all OHT work and an opportunity to **build on shared understanding and collaborative processes**



Support and resources for meaningful engagement needs to be **intentional and systemic** across the province and within and across OHTs



Highlights the **demands for patients, family and caregivers' time and expertise**; suggests need for **sustainability, recruitment retention strategy** for patients, families and caregivers within OHTs, including greater clarity on roles and responsibilities and **sustained and sufficient funding** for engagement and partnership



**Align roles, responsibilities and expectations** for engagement and partnership with:

- OHT needs
- Interest and expertise of patient, family and caregiver members, including where they would like to **focus their influence**
- Health system entry point (e.g., health system planning, care pathway design)



Invest in building **strong, sustainable and rewarding** engagement and partnership opportunities. While many people report positive and/or improving experiences, it is a **collective responsibility** to support those not feeling heard and/or valued

*The following sections present survey findings organized by questions around **who, how and what** related to the development of OHT engagement and partnership strategies.*

## WHO

Who **led the development** of the strategy?

- 5 patient, family and caregiver partners (range: 0-16)
- 5 other OHT and partner organization staff (range: 0-46)
- 2 OHT engagement staff (range: 0-7)

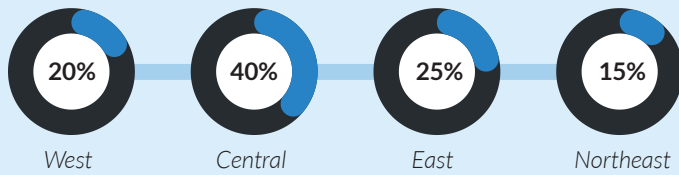
Other: 3 external consultant/facilitators; 1 advisor to author the strategy; 1 student

Who **were consulted** on the strategy?

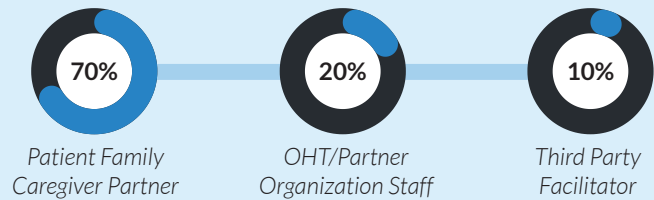
- 11 patient, family and caregiver partners (range: 3-50)
- 12 other OHT and partner organization staff (range: 2-46)
- 3 OHT engagement staff: (range: 0-7)

Other: 2 external consultants; 2 full executives, 1 collaborating organization

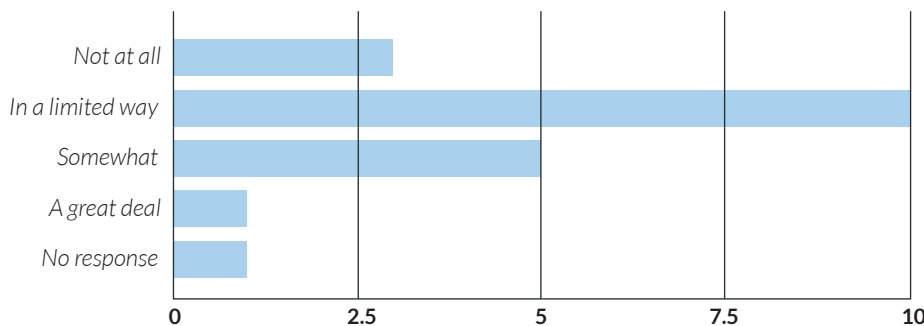
Respondents' **Location**



Respondents' **Role**



To what extent were **under-represented and under-served populations engaged** in the development of your strategy?



Engaged PFC partners who were already working with partner organizations; diversity depended on who was already engaged (4)

Engaged diverse groups through partner, community organizations (2)

## HOW

How were decisions made regarding **who was involved** in this work, how they were involved, and what would be included in the strategy?

- 7 patient, family and caregiver partners initiated and/or led the work
- 4 partner organizations determined who would participate based on capacity/expertise
- 3 full steering committees were engaged - collaborative approach
- 1 CEO led the work

"I pushed for this work to be done but we also had a deadline to work to. Unfortunately, there was no bandwidth (or interest) to assign staff or resources so it was done primarily by myself and my co-chair."

How were decisions made regarding who was involved in this work, how they were involved, and **what would be included in the strategy?**

- 9 decisions were reached via consensus
- 5 working groups took on the project
- 1 Outside facilitator managed the work
- 1 Leadership determined what was included

"Our PFAC initiated the work...[staff] prepared the initial plan and facilitated the discussions. All members participated in the drafting of the document section by section. We invited partners from across sectors to participate and co-design the content with us. We presented the work-in-progress to our partners for feedback."

How will you **deploy or operationalize** your strategy?



Use to inform other areas of OHT work



Expand and/or formalize engagement



Implement our strategy



Identify how to evaluate and be accountable to strategy



Develop resources and tools to support strategy



Unclear

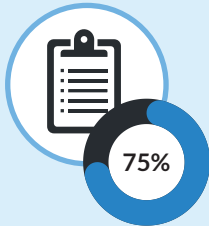
*"We will find implementation far more challenging as we lack sufficient dedicated resources"*

*"Keep accountability for deployment of the strategy within the OHT in the steering committee"*

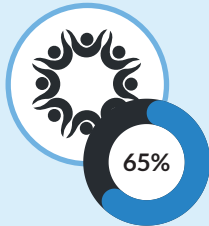
*"Keep the strategy front and center at meetings and in working groups; we won't keep our strategy on the shelf! We are committed to keeping it as a living document."*

## WHAT

What **resources** were used to support strategy development?



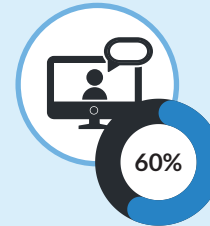
Ministry Guidance Document



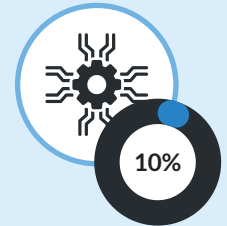
OHT Patient, Family Caregiver Community of Practice



Ontario Patient, Family and Caregiver Declaration of Values



Ministry Webinar on Strategy Development



Central Program of Supports partners

What were the **greatest challenges** you faced through this process? What would have been helpful to you when working through these challenges?



**Limited time (Impeded meaningful engagement/Impeded broad engagement)** — *"For effective community engagement by the OHT, dedicated resources are needed. OHTs are stretched thin from a dedicated resources perspective, especially now with the pandemic."*



**Needing a shared foundational understanding of what was required and why** — *"The process felt rushed since it was a new group of advisors. ....there was a gap in their knowledge and skills and what was required to have a meaningful discussion around the different elements of the strategy."*



**Lack of guides and resources** — *"We needed more time and orientation to the OHT concept for community members."*



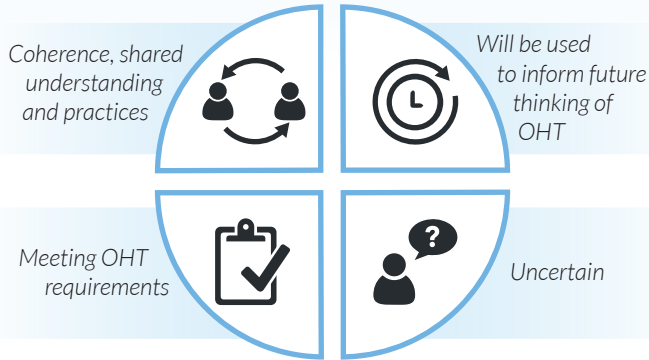
**Lack of clarity of roles, responsibility and assigned expertise for strategy development** — *"We needed clearer communication from the MOH about who should take the lead on this deliverable."*



**Being heard and feeling valued** — *"I attend [many meetings as part of OHT work]. I attend additional meetings [and related activities, investing my time] to understand what other OHTs are doing. This work is a full-time job and I get a paltry sum and no recognition. It is not sustainable."*

What **outcomes** did you achieve through the development of your PFC engagement strategy?

What **learnings or insights** did you gain from the process of developing this strategy that could be helpful for future and on-going engagement and partnership within OHTs?



- ✓ Need for clear expectations and accountabilities
- ✓ Need for strong advocates to lead the work
- ✓ Value and respect are needed
- ✓ Importance of selecting the lead for this work carefully
- ✓ Value of online tools
- ✓ Need for adequate, dedicated resources and sufficient time

*"It gave us something that we were able to wrap our hands around and be able to see what was missing in the processes."*

*"We wrote a strategy which we can't implement because we don't have the funding, time, resources."*

*"There is still lack of understanding of the role of PFACs for OHTs. Most PFACs operate in individual healthcare organizations and can see a direct link between their input and the improvement of the services (direct care or program development). It comes as a disappointment for some of the members that the role of OHT PFACs is somewhat removed from influencing direct care (patient experience) and the focus is really on program development (integrated care) and policy / strategy development."*



This work was led by members of the OHT Patient Family Caregiver Engagement and Partnership Community of Practice, the Public and Patient Engagement Collaborative (PPEC), McMaster University and Rapid Improvement Support and Exchange (RISE).

