

# Panel Summary

Engaging with Patients, Families and  
Caregivers to Support Ontario Health Teams

18 March 2020



HEALTH FORUM



**EVIDENCE >> INSIGHT >> ACTION**



## Rapid-Improvement Support and Exchange (RISE)

RISE's mission is to contribute to the Ontario Ministry of Health's 'one window' of implementation supports for Ontario Health Teams by providing timely and responsive access to Ontario-based 'rapid-learning and improvement' assets.

### About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 14-16 citizens from different walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. A citizen panel can be used to elicit the values that citizens feel should inform future decisions about an issue, as well as to reveal new understandings about an issue and spark insights about how it should be addressed.

### About this summary

On the 18th of March 2020, RISE convened an online citizen panel on engaging with patients, families and caregivers to support Ontario Health Teams. This summary highlights the views and experiences of panel participants about:

- the underlying problem;
- three possible elements of an approach to addressing the problem; and
- potential barriers and facilitators to implement these elements.

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

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## **Summary of the panel**

On March 18<sup>th</sup>, 2020, the McMaster Health Forum and RISE hosted an online citizen panel to explore the views and experiences of 15 patients, family and caregiver advisors, 12 of which have been actively engaged as patient advisors during the development of Ontario Health Teams (OHTs) and three of which expressed an interest in contributing to the development of OHTs. This panel was a first step in producing advice to the ministry and OHTs about engaging patients, families and caregivers, and explored the challenges in meaningfully engaging patients, families and caregivers in the work of all OHTs.

During the deliberation, panellists focused on five challenges in meaningfully engaging patients, families and caregivers in the work of OHTs: 1) OHT partners lack a shared understanding of why patients, families and caregivers should be engaged as equal partners in the development of OHTs; 2) resource and time constraints influence the level of patient, family and caregiver engagement across OHTs; 3) there is a lack of clear expectations about patient, family and caregiver engagement in the co-design of OHTs; 4) there is a need to broaden patient, family and caregiver engagement in OHTs, including reaching more diverse and marginalized communities; and 5) there is a lack of coordination and opportunities for patients, family members and caregivers from across the province to learn from one another's experience and exchange tools and resources.

In discussing the elements of a potentially comprehensive approach to address these challenges, panellists discussed: strategies to support patient, family and caregiver engagement at all levels and stages of OHT implementation (element 1); engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs (element 2); and engaging patients, families and caregivers in co-designing the OHT building blocks (element 3). Several value-related themes emerged, including: the importance of legitimizing patient, family and caregiver experience; the need to build shared goals, values and tools across key stakeholders that could drive the co-design of OHTs; the need to develop robust partnerships at all levels of OHTs (and at all stages of implementation of OHTs); the importance of being solution-focused; and finding ways to support rapid learning and improvement regarding patient, family and caregiver engagement.

Panellists emphasized the need to focus on actionable next steps, including building a network of patients, families and caregivers involved in OHTs and the tools and resources that would be most useful in the coming months.



“To make sure that the culture is changing, [it] starts at the top. It is actually engaging with patients and caregivers at that top level that supports a different way of working.”

## **Discussing the problem:**

What are the most important challenges to meaningfully engaging patients, families and caregivers in the work of all OHTs?

Panel participants began by reviewing the findings from the pre-circulated citizen brief, which highlighted what is known about the challenges of meaningfully engaging patients, families and caregivers in the work of all Ontario Health Teams (OHTs) – and the causes. They focused on five challenges in particular:

- OHT partners lack a shared understanding of why patients, families and caregivers should be engaged as equal partners in the development of OHTs;
- resource and time constraints influence the level of patient, family and caregiver engagement across OHTs;

- there is a need to broaden patient, family and caregiver engagement in OHTs, including reaching more diverse and marginalized communities;
- there is a lack of clear expectations about patient, family and caregiver engagement in the co-design of OHTs; and
- there is a lack of coordination and opportunities for patients, family members and caregivers from across the province to share one another's experiences and exchange tools and resources.

We review each of these challenges in turn below.

## OHT partners lack a shared understanding of why patients, families and caregivers should be engaged as equal partners in the development of OHTs

The discussion initially focused on the perception that OHTs are not all at the same stage of reflection, development and implementation with regards to patient, family and caregiver engagement. Several participants highlighted the variation in levels of engagement (from limited engagement to more extensive partnership) and timing of engagement (from being engaged early in preparing the OHT application to initiating engagement later, once the application had been submitted and activities were underway). Panellists emphasized the importance of early engagement, but that this must be balanced with the potential drawbacks of not always having the appropriate organizational and governance processes in place to manage and benefit from patient input. Participants also stated that not all OHTs have fully recognized the value that engaging patients and caregivers can bring to their processes and outcomes.

Several panellists referred to the need to develop a shared understanding of why it is important to recognize and embrace the value of patient, family and caregiver engagement. Many emphasized that patients, family members and caregivers should be considered as equal contributors in the co-design of OHTs. Their unique perspectives can help to highlight areas for improvement as well as solutions to the pressing challenges facing the health system. However, some patients, family and caregiver advisors mentioned that OHTs need to address their own foundational questions of why patients, families and caregivers should be equal partners within an OHT before considering how to engage them.

Without this understanding, panellists felt concerns among key stakeholders (including providers and healthcare executives) around patient, family and caregiver engagement within the co-design of OHTs will not be addressed. As one panellist indicated: “Sometimes teams have only heard the gripes and there is a bit of stigma that professionals have [towards] patients.” A second panellist suggested that healthcare executives may not be comfortable receiving strongly worded feedback from patients, family members and caregivers: “You are going to have people who will be candid when they are expressing themselves. Thinking about the executive sitting at the top - they are not really prepared to receive some of that feedback yet.”

This cultural shift is not just about embracing the value of engagement, but also about new relationships that must be built with local communities, as well as new organizational and decision-making processes that must be put in place. As one panellist described: “There is the hesitation that we have been here before. It is the same leaders and I am trying hard to ensure that the same structures don’t happen.” Panellists emphasized that these shifts require time, resources and leadership at the highest levels, citing the importance of leading by example within OHTs as well as at the provincial level: “This is a whole different way of working and I am not sure the culture is ready for that – when you have to change how you are working, you need the time and ability to be able to do that and I don’t think the current healthcare workers feel that. To make sure that the culture is changing, [it] starts at the top. It is actually engaging with patients and caregivers at that top level that supports a different way of working.”



## Resource and time constraints influence the level of patient, family and caregiver engagement across OHTs

In addition to the need for a shared understanding around the value of patient, family and caregiver engagement, panellists highlighted two additional factors influencing engagement: 1) OHTs are being developed in fast-paced environments which limit their capacity to engage meaningfully; and 2) dedicated resources at the provincial level to support patient, family and caregiver engagement are limited.

The first factor identified was the fast pace at which OHTs are being developed, limiting their capacity to meaningfully engage patients, family members and caregivers. Referring to the first wave of OHTs that have been identified by the Ministry of Health, one panellist said: “This is evolving very quickly, and people are desperately trying to keep up. It’s not that people don’t want to engage, but it is that they don’t know how, they don’t have the tools or the training – being a whole different way of working – they just don’t have the experience. So, this is all new for them.”

The second factor related to the lack of dedicated resources, including human and financial resources, time, concrete tools and training, to support OHTs in general as well as specifically related to developing meaningful engagement activities. Some panellists highlighted the need to harness existing resources, tools and training in order to develop engagement guidelines and/or standards that are

### **Box 1: Key features of the citizen panel**

The online citizen panel about engaging with patients, families and caregivers to support Ontario Health Teams had the following 11 features:

1. it addressed a high-priority issue in Ontario;
2. it provided an opportunity to discuss different features of the problem;
3. it provided an opportunity to discuss three elements of a potentially comprehensive approach to address the problem;
4. it provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. it provided an opportunity to talk about who might do what differently;
6. it was informed by a pre-circulated, plain-language brief;
7. it involved a facilitator to assist with the discussions;
8. it brought together citizens affected by the problem or by future decisions related to the problem;
9. it aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. it aimed for open and frank discussions that will preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

tailored to the specific context of OHTs. As one panellist said: “There is a lot of good information out there to help the OHTs: courses, guides, how to recruit for diversity, how to co-design. But I haven’t sent these resources out to the rest of the Steering Committee on my OHT because I think they will just hit 'delete'. They have competing priorities and as someone said earlier, they are doing this OHT work on the side of their desk and it is a full-time job.”

Some participants shared that they felt a responsibility to broaden the representation of patients, families and caregivers working with OHTs. They highlighted the need for tools and processes to support new patients, families and caregivers such as clearly defined roles and responsibilities, and on-boarding processes. This would not only clarify the scope of patient, family and caregiver roles, but also make explicit the expertise that they bring to the table. As one participant shared: “If there is a standard screening tool for engaging patients and caregivers, for example criteria such as lived experience, solution or suggestion-focused and not just problems, etc., this may help alleviate the stress around having patients and families at the table . . . primary care would have a better understanding of “who” is in these roles.”

## There is a lack of clear expectations about patient, family and caregiver engagement in the co-design of OHTs

The discussion also explored how the lack of clearly defined expectations around the roles of patient, caregiver and family advisors in the co-design of OHTs may have contributed to the range of levels of engagement described above. Participants identified a need for minimum standards to guide OHTs in their engagement efforts, and for clear and consistent articulation of expectations around patient, family and caregiver engagement in the work of OHTs.

Panellists agreed that co-design can look different depending on the scope of work, but emphasized that for many, a collaborative approach early on in OHT processes has been the most rewarding and transformative. In particular, they highlighted the important role of patients, families and caregivers in helping to define the challenges facing OHTs.

Many panellists felt that establishing clear guidelines and standards to support patient, family and caregiver engagement in the co-design of OHTs would help establish norms and expectations. One participant described the potential for standard practices to support greater engagement within OHTs across the province: “Our Committee ensures patient and

caregiver representatives are compensated for transport costs, respite, an honorarium for time to enable people to participate - otherwise people will not be able to participate. This is essential and there should be minimum standards, guidance to ensure patients and caregivers are engaged, and that the practice extends equitably across the province.”

Some panellists suggested that these expectations should be established by organizations guiding OHT development. As one participant stated “If patients are truly first, wouldn't we be first at the table and wouldn't our priorities matter hugely? This is where the ministry and other organizations need to take a lead and set the expectations.” Other panellists felt that patient, family and caregiver organizations have the expertise and experience to develop the necessary standards and guidance for OHTs to inform and refine expectations. These approaches were not seen as mutually exclusive, but rather complementary strategies to meet a shared goal.

### **Box 2: Profile of panel participants**

The online citizen panel aimed for fair representation among the diversity of patient, family and caregiver advisors that are engaged (or likely to be engaged) with OHTs. We provide below a brief profile of panel participants:

- **How many participants?** 15
- **How old were they?** 25-44 (1), 45-64 (5), 65 and older (5), preferred not to respond (4)
- **Were they men, or women?** men (4) and women (11)
- **What was the educational level of participants?** 18% had completed post-graduate training or a professional degree, 27% had completed a bachelor's degree, 45% had completed community college, and 9% had completed high school
- **What was the work status of participants?** 18% working full-time, 18% unemployed, and 64% retired
- **What was the income level of participants?** 9% earned between \$40,000 and \$60,000, 45% between \$60,000 and \$80,000, 36% more than \$80,000, and 10% preferred not to answer
- **How were they recruited?** Purposefully selected among patient, family and caregiver advisors engaged with OHTs across the province and with the Ontario Caregiver Organization
- **How many were actively involved with OHTs?** 12 participants have been actively engaged as patient advisors during the development of OHTs and 3 expressed an interest in contributing to the development of OHTs

## There is a need to broaden patient, family and caregiver engagement in OHTs, including reaching more diverse and marginalized communities

Collaborative teams and trusting relationships need time to develop. In the context of OHTs, this includes a commitment and flexibility to reach broad community representation while ensuring appropriate supports and processes are in place to increase the breadth and depth of patient, family and caregiver engagement with OHTs. Panellists highlighted two components of broadening engagement. The first was around ensuring that all OHTs have a standard set of resources, structures and processes in place, including protected funding to support patients, family members and caregivers, formal and informal ways to recognize their expertise, and scheduling that accounts for the fact that many are juggling multiple responsibilities outside OHT work. Pressure to move and deliver quickly often doesn't leave time to engage effectively and can leave those patients, families and caregivers that are engaged with significant demands on their time and resources. As one panellist described: "Being the only patient and family rep is very time consuming. I am facing my own challenges managing my time".

When discussing the need to expand and diversify patient, family and caregiver engagement within OHTs, participants described two key barriers. The first was the lack of public knowledge about the role of patients, families and caregivers within OHTs, and therefore many people do not see a role for themselves. This also extended to raising awareness about OHTs in general, as stated by one panellist: "Broad communication about OHTs would help to demonstrate to citizens why they might want to be involved and how."

Diversifying engagement within OHTs also means needing to listen to broad and sometimes dissenting community voices, and not just those of patients, families and caregivers able to engage directly with OHTs. While there is often great value in building on existing relationships, careful and continued thought should be given to whose voices are not at the table.

This points to the second barrier to more diverse engagement within OHTs, which is the need to adapt outreach and engagement strategies, including engaging in ways that build on existing and community-specific ways of organizing. As one panellist described: "There is the hesitation that we have been here before. It is the same leaders and I am trying hard to ensure

that the same structures don't happen." Suggestions included listening to the needs and priorities of existing community groups, and creating stronger cross-organizational linkages to ensure patients, family members and caregivers already engaged in OHTs can better represent a range of community voices.

There is a lack of coordination and opportunities for patients, family members and caregivers from across the province to learn from one another's experience and exchange tools and resources

Participants highlighted the breadth and depth of expertise shared amongst themselves as a critical source of learning and insight. There was widespread interest among participants to continue sharing successes and failures, and exchange and adapt resources while also supporting one another in their work within individual OHTs. However, there was an acknowledged lack of coordination and opportunities to support the sharing of experiences, as well as the exchanging of tools and resources.

Throughout the discussion, several panellists shared examples of documents, templates and processes from their own OHTs, such as mentoring processes between seasoned and newly engaged patient, family and caregivers, and descriptions of roles and responsibilities of patient, families and caregivers within OHTs. They also shared plans to create communities of practice for patient, family and caregiver advisors that have not yet come to fruition.



“There are a lot of questions and unknowns and we can be partners in breaking down some of those fears.”

## **Discussing the elements:**

### How can we address the problem?

After discussing the challenges, participants were invited to reflect on three elements (among many) of an approach to engaging patients, families and caregivers to support OHTs:

1. supporting patient, family and caregiver engagement at all levels and stages of OHT implementation;
2. engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs; and
3. engaging patients, families and caregivers in co-designing the OHT building blocks.

Panellists were reminded that the three elements can be pursued together or in sequence. A description of these elements, along with a summary of the research evidence about them, was provided to participants in the citizen brief that was circulated before the event.

## **Element 1** – Supporting patient, family and caregiver engagement at all levels and stages of OHT implementation

The discussion about the first element focused on supporting patient, family and caregiver engagement at all levels and stages of OHT implementation. This is referred to as OHT building block #3. As outlined in the citizen brief, this could include:

- strategies to engage patients, families and caregivers at all levels of OHTs;
- strategies to engage patients, families and caregivers at different stages of implementation of OHTs; and
- strategies to support OHTs in the adoption of the Patient Declaration of Values for Ontario as a vision of what they are moving towards.

During the discussion about supporting patient, family and caregiver engagement, seven value-related themes emerged: recognition, inclusion, trust, cohesion, transparency, comprehensiveness and partnership (see Box 3).

Throughout this discussion, panellists referred to the *Patient Declaration of Values for Ontario*, which was shared in the panel’s briefing note and in the guidance for OHTs’ full proposal submissions. Some panellists were familiar with the declaration, while others were not. Given the continued relevance of the declaration to patient-centred care in Ontario, panellists recommended sharing it throughout the broader OHT community to ensure broad awareness. Panellists themselves agreed to share the declaration with their affiliated OHTs and other patient, family and caregiver advisors.

Building from the group’s discussion of the *Patient Declaration of Values for Ontario*, participants identified the seven value-related themes highlighted above, as well as actionable next steps to support effective and meaningful patient, family and caregiver engagement.

### **Box 3: Key messages about element 1**

#### **What are the views of participants regarding this element?**

- recognition
- inclusion
- trust
- cohesion
- partnership
- transparency
- comprehensiveness

## **Recognition, inclusion and trust**

The first three value-related themes (recognition, inclusion and trust) emerged during a discussion about legitimizing patient, family and caregiver experience. In describing their experiences of engaging with OHTs, some participants explained that they have been included in OHT decision-making tables early on, while others described feeling under-utilized or that they were present as a token rather than in recognition of their expertise. Several participants described the lengthy and sometimes bumpy road to establishing trusting and mutually beneficial working relationships within their OHTs. Critical to these experiences was both time and explicit recognition of different but complementary expertise that patients, families and caregivers bring to OHT discussions. Several participants emphasized the need to be included in discussions from the beginning, having patient, family and caregiver expertise “baked in”, as described by one participant.

Recognizing the contributions of patients, families and caregivers can be done in explicit and implicit ways that address both structural and process-related challenges to engagement. Several participants shared promising practices from within their OHTs, including compensation guidelines or support for patient, family and caregiver engagement, flexible meeting schedules, and including more than one patient, family and caregiver representative in any working group.

Many participants also recognized the challenges faced by those leading the development of OHTs to facilitate inclusive discussions and shared decision-making, including lack of resources, competing priorities and the required shifts in organizational and decision-making processes. Several participants emphasized that the co-design approach within OHTs requires groups to bridge differences in familiarity and use of technical language and decision-making processes, between patients, families, caregivers, providers and other health system partners. When done well, this often led to a ‘levelling of the playing field’ and contributed to building trust within OHT teams. Other participants described feeling as “the other” even with the best of intentions among their OHT partners, while another participant described the importance of attending to more implicit ways of recognizing patient, family and caregiver expertise and supporting inclusive discussions, stating: “If I was not the strong person I am, I would internalize the looks, comments and feedback – it would make me not want to participate.”



### **Cohesion and transparency**

Cohesion and transparency were the fourth and fifth value-related themes identified, reflecting the expressed desire of participants to build shared goals and values across key stakeholders that could drive the co-design of OHTs. There was broad agreement among panellists that OHTs presented an opportunity to build shared purpose and goals between providers and patients, families and caregivers, to redesign care around a health and social care system that improves both patient and provider experiences.

Participants highlighted the importance of transparency as a critical component of well-functioning teams. This included identifying and addressing fears or concerns from all groups involved in OHTs, including around issues of funding, independence, changing roles and responsibilities, managing expectations and privacy. Many participants empathized with providers and executives who are also navigating new roles, expectations and relationships, and recognized that often all OHT partners are adapting to a new way of working together. There was broad agreement that patients, families and caregivers can play an important role as allies to primary care and OHT leadership more broadly.

### **Comprehensiveness**

Panellists appreciated and generally agreed with the principles described in the *Patient Declaration of Values for Ontario* as identifying values underlying a patient-centred healthcare system for Ontarians, and describing what patients, families and caregivers expect from their healthcare system. Panellists cautioned, however, against universalizing declarations that largely represented only one group's perspective (in this case, that of patient, families and caregivers). Many agreed when one panellist shared: "The *Patient Declaration of Values* was written more to educate patients and caregivers than healthcare providers. We need more of a team approach that also incorporates the values and needs of healthcare providers."

Several panellists emphasized the need for a more comprehensive approach to health and social care, including those involved in home and community care, to define these shared goals and values. This was echoed by one panellist who stated: "There needs to be more inclusion outside of those funded by the ministry if there is going to be the types of impacts that are anticipated by the first-year goals – this has to include emergency medical services, public health and other community supports - not just medical care."

While panellists acknowledged the importance of the *Patient Declaration of Values for Ontario* in advancing patient-centred care in Ontario, nearly all panellists expressed an interest in adapting it to develop shared principles across all OHT partners (patients, caregivers, primary

care and other providers, social sector professionals, etc.) both at a provincial level and then further adapted for each OHT.

## **Partnership**

Partnership was identified as the seventh value-related theme, which emerged during a discussion about strategies to engage patients, families and caregivers at all levels of OHTs (and at different stages of implementation of OHTs). The citizen brief outlined a spectrum of engagement approaches originally from [Health Quality Ontario's patient-engagement framework](#), which distinguished between four approaches: 1) share (provide easy-to-understand health information); 2) consult (get feedback on a health issue such as a policy or decision); 3) deliberate (discuss an issue and explore solutions); and 4) collaborate (partner to address an issue and apply solutions). While a few panellists recognized the value of having complementary engagement approaches to inform the work of OHTs, others expressed concern that introducing this spectrum of engagement at this stage could undermine efforts to develop robust partnerships at all levels of OHTs (and at all stages of implementation of OHTs).

The importance of partnership was seen as essential to navigate the uncertainties and low-rules environment shaping the development and implementation of OHTs. Panellists highlighted that navigating these uncertainties while also redesigning organizational and decision-making processes to support effective engagement can create anxiety about the pace and extent of change both for themselves, and especially for those who work in health systems and community care. Some participants saw their role as partners in navigating that uncertainty together as part of OHTs, including addressing fears, managing unexpected events and developing shared understanding of expectations. The importance of trusting and collaborative relationships through that uncertainty was reiterated by several panellists, and articulated by one panellist: "It is an exciting time, but there are gaps that we probably aren't expecting – there is a role for our data and for our stories and those are going to be equally important as we help each other in this forum and our own communities."

## **Element 2** – Engaging patients, families and caregivers related to the year-1 priority populations identified by OHTs

While OHTs will be looking to provide services to various populations where gaps in services exist, several OHTs have focused on the following groups as their year-1 priority population:

- people at the end of life and/or needing palliative care;
- older adults with greater needs (meaning those at risk, with multiple chronic conditions, complexity and frailty);
- people with chronic conditions (including those with congestive heart failure; chronic obstructive pulmonary disease, dementia, diabetes, and complex-care needs); and
- people with mental health and addictions issues.

### **Box 4: Key messages about element 2**

#### **What are the views of participants regarding this element?**

- diversity
- inclusion
- adaptability

The second element focused on promising ways to engage these year-1 priority populations, as well as what could support or enable such engagement. While panel discussions focused to a lesser extent on element 2, three value-related themes emerged: diversity, inclusiveness and adaptability (see Box 4).

The first two value-related themes (diversity and inclusion) resonated with prior discussions about the need to broaden the range of voices that could shape the co-design of OHTs. This was particularly critical since many of the year-1 priority populations reflected individuals that are often isolated, marginalized and/or vulnerable.

The third value-related theme (adaptability) reflected the need to develop engagement processes and mechanisms that are adapted to the needs, preferences and expectations of these individuals (as opposed to using engagement methods that may reinforce systemic barriers). This led to discussions among panellists, many advocating for a partnership model, with a few being favourable to explore other types of complementary engagement mechanisms (including mechanisms that may be more consultative by nature) that could be used to bring in the voices of year-1 priority populations.

## **Element 3** – Engaging patients, families and caregivers in co-designing the OHT building blocks

The discussion about element 3 focused on the need to transition from identifying common challenges to engagement across the patient, family and caregiver community, to moving towards actionable tools, solutions and community development in order to support greater and more meaningful engagement in OHTs.

As outlined in the citizen brief, OHTs will initially need to learn and improve rapidly in the design of each of the eight OHT building blocks, which were called ‘OHT requirements’ in the ministry’s original guidance document. Designing these building blocks will require strategic choices in 58 domains, with some of these decisions needing to be made in year 1 and others coming later.

Panellists were asked to discuss which building blocks are the most important for patients, families and caregivers (and should be prioritized for co-design), as well as what role they would like to play (alongside other stakeholders) during the co-design and implementation of these building blocks.

Three value-related themes emerged during the discussion about element 3: solution-focused, urgency, and rapid learning and improvement (see Box 5). The first two value-related themes (solution-focused and urgency) emerged when some panellists indicated that they appreciated the opportunity to share their challenges, but felt strongly that solutions-focused next steps are needed. They expressed a sense of urgency in developing concrete actionable next steps to advance meaningful engagement in the work of all OHTs. As stated by one panellist: “Our healthcare system is in crisis and I feel fixing this is really a matter of life and death. Time is of the essence and we really must move forward to very practical, understandable, unambiguous steps that we can all take to engage patients.”

The third value-related theme (rapid learning and improvement) emerged during a discussion about the need to develop engagement guidance and standards for all OHTs. Given the breadth of expertise and extent of shared experiences among panel participants, many felt

### **Box 5: Key messages about element 3**

#### **What are the views of participants regarding this element?**

- solution-focused
- urgency
- rapid learning and improvement

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that panel participants are ideally suited to develop key guidance around patient, family and caregiver engagement for OHTs. Panellists also expressed an interest in regular opportunities for exchange and dialogue, as a way to amplify the role of patients, families and caregivers within the OHT community, as well as an important mechanism to develop shared tools and resources. Nearly all panellists expressed an interest in building on the panel's discussion, as shared by one panellist: "I believe there is common interest among a majority of members of the group in a continuing working group, expert-led, that could work in a coordinated way on developing common protocols, practices, resources, and tools that would facilitate the implementation of a cross-OHT framework for community engagement in the co-design of our healthcare system."

To support rapid learning and improvement, panellists emphasized the need to create opportunities for regular discussion and resource development. A community of practice dedicated to patients, families and caregivers engaged in the work of OHTs has the potential to build on group strengths and work towards shared goals and influence. This could be used as a platform to share and develop tools and adaptable templates (for example, how to bring in patients as part of OHTs, partnership and shared decision-making models, outreach strategies) as well as to ask questions and learn from the experience of others. Some panellists saw this as a way to advance their work within their own OHTs, as well as strengthen the provincial role of patients, families and caregivers. As one panellist said: "We have 24 health teams today and it feels like we are all going to be in our health teams and doing this on our own. Could this not represent an opportunity to embrace this in a provincial way?"

Such a community of practice could also support rapid learning and improvement at different levels of Ontario's health system. Panellists discussed building stronger linkages and participation in provincial patient, family and caregiver councils and initiatives, such as Ontario Health's Patient, Family and Advisors Network or a possible re-establishment of the Minister's Patient and Family Advisory Council.<sup>1</sup>

Lastly, panellists shared other examples of strategies that could support rapid learning and improvement, such as mentoring processes between seasoned and newly engaged patients, family members and caregivers, as well as clear descriptions of roles and responsibilities of patients, family members and caregivers within OHTs. Continuing to expand these tools

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<sup>1</sup> Since the convening of this citizen panel, the ministry has appointed a new chair for the Minister's Patient and Family and Family Advisory Council <https://news.ontario.ca/mohlrc/en/2020/06/ontario-appoints-new-chair-for-the-ministers-patient-and-family-advisory-council.html>

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and resources was seen as an important way to support rapid learning and improvement at the level of patients, family members and caregivers, as illustrated by one panellist: “One of the things that we really need to keep working on is that if you are going to bring a patient on, that they need to realize what they are getting into – it is way more time consuming than I had ever realized.”



“I am concerned about doing these activities separately which keeps the 'them' versus 'us' alive.”

## **Discussing implementation considerations:**

### What are the potential barriers and facilitators to implementing these elements?

After discussing the three elements of a potentially comprehensive approach for engaging patients, families and caregivers to support OHTs, participants examined potential barriers and facilitators for moving forward.

The discussion generally focused on actionable next steps and building the network of patients, families and caregivers involved in OHTs and the tools and resources that would be most useful in the coming months.

When turning to potential facilitators to moving forward, panellists emphasized building on the expertise of patients, families and caregivers and the extensive resources already available to support collaborative decision-making. Panellists described the importance of shared standards across the province that can be adapted to the context of each OHT.

Panellists also emphasized the need to develop and share practical resources, lessons and support for patient, family and caregiver engagement in an on-going way across the province. Administrative and facilitation support will be needed for this to succeed. Finally, while

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panellists expressed their interest in a collaborative space focused on patient, family and caregiver engagement, they also emphasized the need to create collaborative spaces together with providers and other health-system partners. As one participant shared: “I am concerned about doing these activities separately which keeps the 'them' versus 'us' alive.”

Panellists agreed that developing shared standards around engagement of patient, family and caregivers within OHTs would be a helpful next step. Standards and guidelines need to focus on actionable strategies and recommendations (for example, a minimum of two patient, family or caregiver representatives are required in every working group). The development of a terms of reference for patient, family and caregiver roles in OHTs at different implementation stages was also identified as an important resource. This would include expectations around role and length of commitment, compensation and/or recognition, as well as specific expertise or experience required.

Panellists also suggested the development of a document outlining the benefits and importance of patient, family and caregiver engagement, describing practical processes and strategies needed to support meaningful and sustained engagement, and how this can improve OHT performance. This would then allow patients, families and caregivers to support OHTs towards implementation of these processes.



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