

Patient Partnership in a Time of COVID-19: Access to Care and System Navigation

CFHI is hosting a series of webinars to explore **Patient Partnership in a Time of COVID-19** and facilitate pan-Canadian conversations about patient engagement during this time of pandemic. The discussion webinars bring a patient partnership lens to specific and emerging issues, policies and practices that are rapidly developing and being implemented in response to COVID-19. These issues have direct impact on patients, families and caregivers with implications on the quality and safety for both those receiving and delivering care. Our aim is to provide a place for discussion about these critical issues and for participants to share and learn from each other as they respond to the evolving pandemic.

On May 12, 2020, CFHI hosted a webinar discussion surrounding **Access to Care and System Navigation**. During this conversation, patient engagement leaders, patient and family partners, and health system leaders from across Canada discussed the challenges and barriers surrounding access to care and system navigation as a patient, and the importance of continued partnership to ensure appropriate and equitable access to care and system navigation. Two patient partners grounded participants in the reality of accessing and navigating care during COVID-19, highlighting the lived reality of fear for patients, families and caregivers, and the need for clear and transparent communication from healthcare organizations about current processes. Further, they identified the ways that the pandemic has exposed gaps within the healthcare system and the successes in the adaptation of care, such as virtual visits. Exemplars were shared from the Children's Hospital of Eastern Ontario about the pivots to programming and care that have occurred to continue to facilitate access, including virtual care, virtual rounding and a virtual emergency department. These new methods of care delivery were designed through engagement and partnership with patients, families and caregivers.

During the discussion, three questions were posed for participants to share their thoughts and comments, as well as their experiences with the reorganization of access to care. The following key themes emerged:

What are the challenges and barriers to accessing care as a patient in the time of COVID-19?

Participants shared many challenges and barriers to accessing care as a patient or family member/partner in care, and emphasized the following:

- The lack of consistent and clear communication surrounding access. This includes when patients and families should be accessing care, what is safe, and a lack of clarity on what services are available. Through clear and consistent communication about the current process and reality, fear could be alleviated for patients and families. Participants further identified that communication should be empathetic, supportive and trauma informed. Patient Partners should also be included in communication strategies to ensure that both the information and modality is patient friendly.
- The blanket visitor restrictions that have been applied since COVID-19 have created additional barriers in accessing care for patients. Participants identified fears and concerns of accessing care without their family, caregivers or partners in care. This was also a concern for any

individual accessing care who may have additional barriers and need a family member or partner in care to advocate for them.

- Participants identified gaps in the continuity of care, including no access to follow-up, such as testing or imaging. Further, many participants shared they were unable to access testing that was a regular part of their care, such as routine bloodwork and monitoring.
- Participants shared the current reality of fear in accessing care, which includes the fear of contracting COVID-19, the unknown of how care is currently being delivered, and the fear that as a family member or partner in care, they will not be welcomed.

Participants emphasized the importance of clear and transparent communication to address challenges and barriers and indicated that clear communication about processes and decisions would help to alleviate the stress for patients and families. Further, not only was communication important to address the current reality of care during COVID-19 but is pivotal as access begins to increase when restrictions are eased.

[How have you partnered with an organization or with patient/family/caregiver partners to reorganize access to care?](#)

Beyond the challenges and barriers that are currently being experienced, participants also shared how they are currently partnering with organizations, and what is important for organizations to consider when they are partnering with patients and families during this time:

- Participants emphasized the importance of trauma informed care when organizations are considering how they are supporting patients and families during COVID-19, and the need to consider access to mental health services, and the increases in needs surrounding mental health care
- Many participants emphasized ways how partnership has continued, which included working with organizations to develop communication tools for patients and families, and ongoing informal communication between patient partners. In addition, participants identified new roles as navigators for current patients, families and caregivers experiencing care during COVID-19. Further partnership around developing organizational COVID-19 responses has also occurred.
- However, many barriers exist to continued partnership, with many participants indicating that partnership with patients was not a current priority of many healthcare organizations
- Participants recognized that with the rise in virtual visits and care appointments, a shift in the power dynamic typically experienced by patients and families has taken place. Through virtual care, patients have not had to leave their own environment and can access care in their own home instead of an institution, which may lead to increased comfort
- Finally, participants identified that not only has access been limited for patient partners to receive care and to partner with organizations – but access to care and partnership also involves families and partners in care. These partnerships are crucial, and due to blanket restrictions, many families and partners in care have no access to partner during COVID-19

Though engagement and partnership work has emerged and continued in response to COVID-19, participants emphasized the importance of ongoing partnership to create and adapt new models that

work to further access to care, and the need to continue to partner with patients and families during the time of COVID-19 to create solutions that work.

What should we carry over as tools/techniques to support access to care for patients? Are there specific considerations we need to be aware of?

The final question explored what has changed within care delivery, and what tools and techniques should be carried into a post COVID-19 world to support access and navigation in care:

- Participants spoke out strongly in support of virtual care as a requirement to support continued access to care, and indicated that this a care delivery mechanism to be utilized where appropriate and when desired by patients, emphasized the importance of meeting patients and families where they are at, and ensuring there were capacity building opportunities for patients and families to engage effectively in virtual care
- The importance of engaging with patients, families and caregivers on what adaptations to care went well, and what didn't. Patients, families and caregivers need to be embedded in all future policy planning, and embedded in the decision-making process for next steps as restrictions surrounding care begin to ease
- Participants also shared the importance of offering a suite of tools for patients and families to access care, including but not limited to virtual care. There are many considerations that surround access that go beyond receiving an appointment.
- Finally, participants emphasized the importance of patients, families and caregivers being embedded into government policy and decision-making planning tables to ensure that policies and restrictions are not made without collaboration

Overall, participants emphasized the need for healthcare organizations and governments to learn how to carry engagement through into a pandemic, and how to create policies that remain supportive of patient engagement during a pandemic or crisis.

The realities of COVID-19 have created additional challenges to access and navigation in care for patients, have removed access for families and partners in care, and have led to new mechanisms of care delivery, such as virtual visits. Participants emphasized the importance of communication to address the current reality of fear patients, families and caregivers are experiencing, continuing virtual care and virtual access, and the importance of creating policies that support patient engagement that can continue during a time of pandemic and crisis.

For more information on future webinars on "Patient Partnership during this time of COVID-19", visit the CFHI Website for more details.