

Patient Partnership in a Time of COVID-19: Maintaining and Strengthening Patient/Family/Caregiver Partnerships

The Canadian Foundation for Healthcare Improvement 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 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 26 2020, CFHI hosted a webinar discussion exploring **Maintaining and Strengthening Patient/Family/Caregiver Partnerships**. The conversation was hosted by : Claire Snyman (Patient Partner, British Columbia) and Carol Fancott (Director, CFHI) and guest speakers were Caroline Wong (Executive Manager, Centre of Excellence for Partnerships with Patients and the Public, University of Montreal) and Vincent Dumez (Co-Director, Centre of Excellence for Partnerships with Patients and the Public, University of Montreal).

During this conversation, patient engagement leaders, patient and family partners, and health system leaders discussed current innovative and creative approaches to patient partnerships, what has led to strengthened engagement and partnership, the accompanying challenges, and the impacts of COVID-19 on the patient engagement landscape moving forward and in the future. Claire Snyman opened the discussion by sharing with participants her experiences and observations of the shifts that have occurred in patient engagement due to COVID-19 and emphasized the importance of continued engagement. She shared how examples of mobilization from patient partners across Canada were utilized to create a plan on patient partner engagement that she recommended to a local health authority, with the intent to ensure patient experience and expertise is maintained through times of crisis. The COVID-19 crises have highlighted that patient partners are ready to engage, and the need to ensure infrastructures are created now to ensure that engagement does not fall off the radar in times of future crisis.

Exemplars were shared from the Centre of Excellence on Partnership with Patients and the Public (CEPPP) on how they have worked to continue partnership and mobilize patient partnerships during the crises, including maintaining connection to the community of patients and families through regular surveys, the involvement on a Tactical Ethics Committee for COVID-19, the creation of a rapid response committee, continued partnership with regional health institutions and hospitals, and partnering in the launch of a COVID-19 specific provincial research network.

During the discussion, three questions were posed for participants to weigh in on their experiences with patient/family/caregiver partnerships during the time of COVID-19, and with their own comments and questions. The following key themes emerged:

What innovative and creative approaches have you seen in patient engagement practices during this time of COVID-19?

Participants shared examples of innovation in patient engagement during this time, in addition to the areas they have found engagement could be improved:

- Participants continued to emphasize and identify technology as a unique and creative way to adapt patient engagement and facilitate virtual connection. Technology has also facilitated the creation of communities of patient partners during this time. Participants viewed technology as an opportunity to acknowledge the missed opportunities surrounding engagement in the early days of the pandemic.
- At the same time participants shared caveats and concerns about the growing reliance on technology to support engagement. Technology may eliminate barriers for some, but can continue to exacerbate and create them when accessibility and equity are not considered.
- Participants shared that existing and trusted relationships between patient partners and healthcare professionals or organizations have allowed for the continuation of engagement during this time. However, many participants also noted that the sudden exclusion of patient partners has led to feelings that engagement and partnership have gone backwards, with trust being broken in many ways.
- COVID-19 and the emergency response has highlighted how fragile systems that support patient engagement are and emphasized the need for robust strategies moving forward to create the necessary and permanent infrastructures that allow ongoing involvement of patient partners, especially in times of crisis. This includes continuing to build a foundational culture of engagement within healthcare institutions, and to embed partnership and engagement strategies at all levels of healthcare, supported by research and evidence.
- In some cases, staff and other resources were re-diverted to address issues related to the pandemic and as a result, engagement activities were reduced/halted.

What has enabled the strengthening of patient engagement and partnership during this difficult time? What challenges remain?

Participants continued the discussion by examining what has strengthened and enabled patient engagement during the time of COVID-19, as well as exploring the remaining challenges.

- Existing leadership structures have served as both an enabler and a challenge for patient engagement and partnership during this time. Where leadership has continued to be vocal and support patient engagement and partnership, engagement has continued, and where this support has been lacking, engagement has not been a priority with leaders continuing to work in silos.
- During this time, patient partners have mobilized and are continuing to be pro-active across the country through both peer-to-peer support and are part of the staying power to continue the dialogue surrounding the need for engagement across the healthcare system.

- Challenges identified included the need to make decisions quickly without the necessary infrastructure to support rapid engagement, and the ability to be nimble and responsive as a continued challenge
- Participants continued to emphasize the importance of communication and trust during this time, and the development of relationships as foundational to the strengthening of engagement. Participants again echoed the need to revisit the foundational pillars of engagement to rebuild trust and relationship through empathetic communication and transparency.

Though engagement has continued through various means such as technology, participants continued to emphasize the need to re-examine and rebuild trust and their relationships with patient partners. Participants felt strongly that the foundational pillars of engagement have been crucial to supporting engagement during this time and are required to continue to strengthen partnerships during the time of COVID-19 and beyond.

How do you think this time of COVID-19 may have changed the patient engagement landscape moving forward?

Participants explored how COVID-19 has changed the patient engagement landscape within Canada, and what structures are required to move forward.

- Participants felt that a shift to virtual options for engagement, and for healthcare, would help to continue to facilitate timely engagement and care. Virtual engagement does present an opportunity to reduce barriers, but participants emphasized the importance of moving beyond simply replacing face-to-face engagement with virtual opportunities and creating better techniques.
- Work remains to create equitable and accessible engagement opportunities for patient partners, particularly when considering a shift to virtual engagement
- Moving forward, participants indicated it would be crucial for patient partners to sit at COVID-19 (and other emergency response) tables to ensure patient perspectives and experiences remain central to decision making.
- Patient partners have mobilized and have created peer-to-peer support opportunities to share engagement ideas and practices and need to be included in knowledge translation and knowledge sharing moving forward.
- Participants emphasized the need for a shift in healthcare towards shared leadership, and the importance of embedded partnership structures.

Overall, participants emphasized the notion of building leadership capacity was crucial to continue to advance patient engagement, with the need to demonstrate the value of partnership through evidence. The need to find more patient engagement and partnership support at the political level and other areas where public policy is informed by patients is considered paramount to continued engagement in healthcare institutions, and to ensure engagement is not removed from the equation in the future.

The time of COVID-19 has highlighted many gaps in the existing leadership structures that support patient engagement and evidenced the need for continued work and research to advance the field of engagement. Many participants shared the fear that the gains made in patient engagement

have disappeared and require that structures be firmly embedded in healthcare organizations and leadership to support patient engagement and partnership moving forward, as well as during future times of crises.

Please see below for additional questions that were posed for the speakers, and their responses. For more information on future webinars on “Patient Partnership during this time of COVID-19”, visit the CFHI [website](#) for more details.

Presenter Question and Answer

Q: Patient partners are keen to engage. How can we support organizations if they are less keen as a result of all the impacts of COVID-19?

A: Remind organizations of the key benefits of patient engagement and that engaging with patients, families and caregivers is evidence based and offers unique and important perspectives on barriers, gaps, and solutions for challenges being faced across the healthcare system, especially during times of crisis. During times of crises, such as the COVID-19 pandemic, challenging environments for carrying out patient- and family- centred care (PFCC) are created. By actively engaging patients, families and caregivers, it allows organizations to ensure PFCC is maintained and supported. Provide examples of positive patient engagement models during COVID-19 to organizations for them to find motivation from.

Q: How do we embed/institutionalize caregiver partners so hospitals don't shut us out in the future?

A: As everyone starts to move from response to recovery mode, a key part will be looking at the learning we can take forward. Starting with enhancing the role of patients as partners in care and stating the benefits of engaging with patients, families and caregivers is integral to building a solid foundation. Bringing together key stakeholders in the patient engagement process within the organization and determining: what patient engagement means to the organization, what is going well, what didn't go well during the initial COVID response, and how this can be prevented in the future is important. Putting structures and processes in place now from senior leadership to frontline workers will help support continued patient engagement during a crisis – even if it takes a different avenue.

Q: How did you overcome barriers at higher organization levels to involve partners during crises?

A: This goes back to having a solid patient engagement foundation as well as a senior executive leader who will champion the role of patient engagement, especially during a crisis. Working through middle management and frontline staff to showcase the importance and benefits of involving partners during a crisis through a meaningful pilot project, can help overcome barriers at higher organization levels.