Patient Partnership in a Time of COVID-19: Embedding Patient Partnerships Across the Healthcare System

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.

On June 25, 2020, CFHI hosted a webinar discussion exploring **Embedding Patient Partnerships Across the Healthcare System**. During this conversation, presenters from the Saskatchewan Health Authority and Hotel Dieu Grace Healthcare shared their journey to ensure patient engagement and partnership was firmly rooted during the time of COVID-19 and embedded in emergency response processes. The presenters explored and identified the characteristics required of a healthcare system to ensure engagement and partnership were entrenched within institutions and its structures and processes, and discussed how to align management and leadership teams to value, engage with, and embed the patient and caregiver voice.

Carole Ann Alloway, a family caregiver, opened the discussion by reflecting on her experience of the evolution of the role of the caregiver to become an integral member of the healthcare team, and the impact of COVID-19 on the care of her husband and her ability to act as caregiver. COVID-19 has exposed the fragility of patient and family partnerships in care. Carole Ann emphasized the importance of caregivers to be recognized as essential care partners as part of the circle of care and especially during times of crisis.

Felecia Watson (Executive Director of Patient and Client Experience, Saskatchewan Health Authority [SHA]), Kevin Belitski (Patient Partner, SHA) Kathy Quinlan (Manager of Quality and Co-Chair of Patient Family Advisory Council, Hôtel-Dieu Grace Healthcare [HDGH], Ontario), Lisa Raffoul (Patient Advocate, HDGH), Barb Masotti (Co-Chair of Patient Family Advisory Council, HDGH) and Joe Karb (Vice President of Restorative Care, HDGH) shared how they have maintained and sustained patient partnerships within their organizations and within their COVID-19 response.

Within the SHA, there is a strong culture of Patient Family Centred Care and engagement with more than 600 patient and family advisors engaged across the organization. They are committed to the collaboration and co-design of programs, services, policies and strategies. At the start of the pandemic, they created an Emergency Operations Centre to coordinate and plan the continued response. At that point, the existing structures for engagement were temporarily paused or interrupted. However, through the integrated response structures, members of the Patient and Client Experience team were redeployed and able to support engagement by embedding Patient Family Advisors in four Integrated Health Incident Command Centres. They were involved in the development of key communication messages and tools, active members of teams that developed and actioned pandemic plans, included as expert panel members to co-design

family presence guidelines and members of the team to facilitate appeal processes for patients and families. Patient and Family advisors also provided consultations for providers with questions about the family presence guidelines. The lessons learned through this process have been applied to make amendments to ensure engagement is embedded in any future pandemic and emergency response structures. Information is available via their website.

Hotel Dieu Grace Healthcare shared the history of their patient and family engagement work, which has been deeply rooted within their leadership and organizational structures. The Patient and Family Advisory Council was engaged immediately to work on the COVID-19 response, engaged to co-design communication, signage, messaging around family presence and other policies, and connected with staff on the incident response team and as part of the COVID-19 ethics committee. Hotel Dieu Grace emphasized the importance of the Coordinated Care Program (CCP) launched in response to COVID-19, which includes the creation of a Designated Care Partner role. This role was created to ensure the supportive care provided by families and loved ones was recognized, and that family caregivers continued to be integral members of the care team. The purpose of the CCP is to provide patients, staff and DCPs with a planned and coordinated approach to include family in the care of the patient. DCP receive training on infection control practices, as well as an understanding of their roles and responsibilities.

Patients who would benefit by having a DCP at HDGH are identified as:

- Those who are planning for discharge whereby a DCP is required for health teaching
- Patients who have language barriers, patients who are non-verbal, patients with cognitive, emotional and/or physical disabilities who require additional support beyond family presence.

It is important to note that a DCP is not an alternative to or synonymous with a patient visitor.

During the discussion, questions were posed for presenters and participants to further explore how best to ensure patient partnerships remains central to institutional processes across the healthcare system. Below we highlight key points of discussion.

What was the thought process at your organization and within your team when you began your engagement work surrounding COVID-19?

Presenters were asked to reflect on and share how their engagement work became rooted within responses to COVID-19:

- The pre-existing culture of partnership and engagement at both organizations supported the ongoing integration of this way of working from the outset, with consideration as to how to ensure successful and meaningful engagement for patients, families and caregivers

- Appropriate processes were put in place to support continued engagement, using different structures and methods for engagement, to ensure a direct link to the work.

Additional questions by the audience prompted discussions related to creating tiered visitation approaches; the continued training and education of staff that emphasized the importance of engaging with patients, families and caregivers; the expectations of the roles of patient and family partners during this time; and implementation and sustainability of lessons learned during this time of COVID-19. Presenters and participants spoke of families and caregivers as the constant in the lives of patients, with healthcare providers as the guests and visitors in their lives, emphasizing the shift required in language, from visitor to a designated or essential partner in care.

What challenges did you experience while ensuring engagement remained within your organizations during the time of COVID-19? Did you experience organizational push back or support?

Presenters were also asked to reflect on any challenges or barriers they experienced in embedding engagement within their COVID-19 emergency response structures. Both organizations spoke of their supportive cultures that enabled ongoing engagement efforts, including:

- Newly created pandemic response roles helped to overcome shifts in organizational structures to support continued engagement. This included the creation of a rapid response advisory group of patient partners that had the ability to respond quickly

- Leadership support and endorsement for engagement from the outset with immediate and ongoing communication and support to patient and family partners.

Presenters and participants also explored what action can be taken by patient partners when organizational support for engagement during this time is not present. The importance of supportive leadership and ongoing commitment to engagement, as well as the opportunity to build and develop trusting relationships was emphasized. Additionally, participants discussed the crucial role family and caregivers play in ensuring patient safety throughout the care journey.

Name three characteristics required within healthcare organizations to ensure patient partnerships are embedded across the system.

To end the session, presenters and participants were asked to reflect on what they would consider to be the three most important characteristics within a healthcare organization to ensure patient partnerships are embedded across the system. The following key points emerged:

- Leadership support and involvement was viewed to be the most critical factor in determining whether an organization would have partnerships and engagement embedded across the system. Leadership is crucial to cultivating a culture of engagement within the organization.

- Documenting and recording the care that is provided by family members and loved ones was also seen as important to recognize the integral role of family caregivers as part of the care team.

- Development of trust and relationships between leadership and patients, families and caregivers was also seen as critical to ensure the foundation of partnership and engagement within the system.

- A desire to learn and grow together. Having an inquisitive spirit is key to learning and growing together. We must have a high level of mutual respect knowing that we all have expertise that we bring to conversation.

- Clear and open communication was consistently identified as a crucial characteristic.

Participants further identified transparent processes, evaluation, education, and equity as being important characteristics that would need to be present within a healthcare system to maintain and strength partnership and engagement.

Throughout the webinar series, Patient Partnership in a Time of COVID-19, participants from across Canada have shared their concerns that the COVID-19 pandemic has revealed the fragility of patient engagement within the health system and that during a crisis, engagement and partnership efforts need to be maintained and strengthened, not put on hold. Participants emphasized the importance of not repeating the same mistakes and lessons learned from previous pandemics such as SARS, which included the importance of families and caregivers as integral members of the care team.

The development of an organizational culture that has unwavering leadership support, that also recognizes the integral role of essential care partners, is crucial to create a system where engagement and partnership are truly embedded.

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: What advocacy happens when a 'designated care partner' would not work to take the place of the family/caregiver presence during COVID?

A: DCP does not take the place of the family/caregiver. A DCP is someone who is chosen by the patient. The patient defines what "family means to them; it could be a relative, close friend, neighbour, or whomever the patient chooses. At HDGH, we have a family presence policy, where family is welcomed at any time and is considered to be part of the care team. Due to the infectious nature of COVID-19, strict restrictions were put into place and *family* presence was only available for end of life and palliative reasons. The value of *family* presence is well understood at HDGH and the DCP program provides training and education for infection, prevention and control, as well as an understanding of their role and responsibilities as part of the care team. The intention of this accountability is to not restrict family/caregiver into hospital if the predicted "second wave" comes upon us, or for any other reason.

SHA has been updating their family presence guidelines to align with current public health orders, and have tried to be as open and responsive to patient/family needs as possible, while maintaining safety for all. As of July 7, 2020, all patients and residents can designate two family members/support people to be present, one at a time. Two people may be present at one time for end of life, critical care, and maternal services. Although essential care giver/designated care partner language has not been used in the SHA family presence guidelines, when developing family presence processes within each unit/facility/home, those family members who were regular caregivers prior to pandemic are prioritized if phasing in family presence or scheduling is required.

Q: Earlier in the conversation, a question was raised about equity. I would love to hear from the two organization how they ensure EVERY patient experience is safe and the unique needs of diverse people are met in an unbiased way.

A: Each patient is unique and we make every attempt to listen to and respond to what the patient requires.

The SHA is committed to hearing from our diverse population and recruiting Patient Family Advisors who can bring different perspectives to the work that is done to co-design and improve programs and services. It is important to uphold a culture that supports diversity, continually works to do better, and learns from any mistakes that are made.

Q: Past research on family presence pointed to the essential role families have in preventing safety incidents like medication errors, falls, and safe transitions in care. I wonder if anyone is building the case for families as essential partners using the patient safety at the point of care argument. How is it working?

A: Yes. This is a key discussion point around all our meetings about visitation guidelines. A patient's personal caregiver is their primary advocate, helps reduce errors in treatment and care, alleviates some of the load off staff providing care, and contributes to the overall health and well-being of the patient. It is a very difficult service to quantify and place a measurement to, but unfortunately there are many stories of a patient's health declining once all visitation was restricted due to the pandemic, so it is apparent the more we can open up those restrictions (while remaining to the guidelines) the better.

Q: To visit my loved one in long-term care, I must provide a recent negative COVID-19 test (within 14 days). Is this required of designated care partners presently?

A: At HDGH, a DCP does not have to provide a recent negative Covid-19 test result. All DCPs go through a screening process, including temperature check, each time they come to hospital. DCPs are provided with a surgical mask as well as a face shield which they are required to wear at all times, and to practice good hand hygiene and infection control as per training. At this time, DCPs are not participating in any aerosol generating procedures.

The SHA does not require COVID testing for designated family members and support people. Similar to what has been described above, family members/support people would be screened including temperature check, required to wear a surgical mask, and practice proper hand hygiene. Physical distancing is also encouraged. Family members/support people would be asked to leave the room during aerosol generating procedures. In end of life situations, exceptions may be made in consultation with Infection Prevention and Control.