Patient Partnership in a Time of COVID-19: Wave 4 of COVID 19 – Supporting Emotional Well-Being and Mental Health of Patients and Families

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 April 28, 2020, CFHI hosted a webinar discussion about **Wave 4 of COVID-19: Supporting Emotional Well-Being and Mental Health of Patients and Families.** During this conversation, patient engagement leaders, patient and family partners, and health system leaders from across Canada discussed the importance of maintaining the lived experience perspective in decision-making circles including cultural safety and the importance of taking a strengths-based approach, discussed the ongoing fourth wave of the COVID-19 pandemic which refers to the ongoing psychological trauma and mental health impacts, and the importance of maintaining patient engagement during this time, the mental health and well-being of patients, families and caregivers, and explored and discussed how to partner and collaborative to build solutions.

During the discussion, three questions were posed for participations to share thoughts and concerns, as well as solutions they or their organizations have experienced. The following key themes emerged:

How have things changed for patients/families/caregivers since the beginning of the COVID-19 pandemic? Have those needs been recognized and what resources do we currently have in place?

Participants emphasized many changes that have rapidly occurred for patients, families and caregivers that have occurred since the beginning of the COVID-19 pandemic, including:

- Changes to policy and practice happened rapidly, with little communication to patients, families and caregivers. This has led to increased anxiety, trauma, and feelings of isolation and families and caregivers feeling like they have been forced out
- Patients, families and caregivers were not engaged in decision-making surround the policy changes that have occurred
- New practices that have emerged include enhanced virtual capacity to support appointments which are helpful in ensuring continuity of care and alleviating anxiety. However, there are important considerations surrounding access and equity when considering technological solutions

Participants also identified that many issues, particularly for those in underserved populations, are being exacerbated during this time. Many organizations are relying on technology to continue to facilitate care, which can be barrier to many. Additionally, due to restrictions on the ability of families and

caregivers to be in attendance with their loved ones within healthcare institutions, many patients are missing an advocate and partner in care at the bedside to help mitigate language or communication barriers, or to partner in their care These rapid changes surrounding policy and practice have greatly impacted the mental health and well-being of patients, families and caregivers.

How is your organization engaging with patients and families now to reduce the potential impact of Wave 4 of the COVID-19 pandemic? How are patients/caregivers/families mobilizing and what supports do they need?

In addition to the implications of the rapid changes in hospitals and healthcare to address COVID-19, participants also shared what formal engagement supports organizations are putting into place, as well as informal ways patients, families and caregivers have been engaging:

- Participants emphasized the importance of peer support programming that has been launched by organizations, including weekly virtual forums, virtual coffee chats, and check-ins
- Patients, families and caregivers shared that many informal networks of patient partners have been created to continue support, share ideas and stay connected
- Many organizations are facilitating virtual visits and connections with families and caregivers. This includes phone calls, check ins using social media platforms, and the creation of patient and family partners tables in order to engage within the COVID-19 response structures
- Participants also shared the ways they are remaining connected to community and care through food delivery baskets for youth and elders, over the phone tea-time for Elders with their traditional health team, and creating health promotion activities
- Participants indicated the need for a formal mechanism through which to share resources surrounding COVID-19 and engagement. Many organizations are working on creating resources, but have no central resource through which to share them

Though engagement has been happening in pockets across the country, participants emphasized the importance of returning to a partnership model within engagement and the importance of healthcare leaders and organizations bringing patient, family, and caregiver back to the table.

Now more than ever, patients and families may be experiencing trauma and barriers to care. How do we change what we do in engagement to hear those voices? How do we remove barriers to hear diverse voices and ensure safety in engagement?

The final question addressed the trauma and barriers being faced by those currently journeying through the healthcare system. Participants shared the following concerns and potential solutions:

- It is important to not understate the trauma being experienced by patients, families and caregivers. Participants emphasized the need for organizations to consider equity and access when engaging, including caution surrounding the potential for technology to cause trauma
- The need for increased awareness surrounding cultural safety and awareness when considering the impacts of trauma and pandemic for First Nations, Inuit and Métis communities. Participants suggested the use of cultural frameworks and practices to guide and enhance the support of the mental, emotional, physical and spiritual needs of communities

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- Participants identified the need for more peer support opportunities and the need for organizations to begin engaging again. Participants addressed the assumption of organizations that partners are unable to engage at this time. It is crucial to create a myriad of engagement opportunities, and to open the door and to allow individuals to self-select what engagement works for them

The impact of Wave 4 of COVID-19 and the evolving pandemic on the mental health and well-being of patients, families and caregivers cannot be understated. Participants emphasized the importance of peer support programming, considering equity when creating engagement opportunities, taking a strengths-based approach, learning about trauma-informed care, and examining cultural safety and awareness. Now more than ever it is crucial to engage and re-engage with patients, families and caregivers to consider the implications of excluding lived experience from decision making tables, and the lasting impacts of the fourth wave.

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