

Who Knows? Essential Care Partners Do: A second set of eyes, ears, hands, and voice

A summary of audience comments and questions

October 27, 2021

The Canadian Patient Safety Week webinar was well-attended with 407 participants joining in on the discussion from across the country. The audience was engaged, and ongoing discussion via the chat box continued throughout the session. Below is a high-level summary of themes that emerged through the chat discussion, and we provide responses to common questions posed through the chat box.

Themes:

Appreciation for the panelists sharing their experiences and acknowledgement of the power of stories.

There was a lot of gratitude expressed and many participants felt their own experiences were reflected through those shared by the panelists. Many participants also shared their own experiences through the chat, highlighting the essential nature of care partners as part of the care team and required contributors to health system design. Stories shared in the chat box reiterated the harm caused by restrictive visiting policies for essential care partners during this pandemic.

"Essential to feel safe, essential to be safe and should be welcome" This really resonated with me. Your experience is all too common.

Recommended resource: The patient and caregiver advisory group for the Essential Together program created a package of stories designed to bust myths and bring evidence to life: <u>Bringing Evidence to Life and Busting Myths through Stories (healthcareexcellence.ca)</u>

The importance of education for essential care partners and staff

The importance of and need for education was a theme that came through clearly in the chat. Essential care partners should be provided with training to support them in their essential role. Healthcare professionals should receive training on how to partner with and support essential care partners. Participants noted that education should include cultural nuances and necessary skills such as communication. Essential care partners and patients should be included in creating and delivering education. "Communication is key and essential in the training of healthcare providers."

Recommended resource: The Essential Together learning bundles include curated education resources from organizations across the country for essential care partners and staff: <u>Essential</u> <u>Together Learning Bundles (healthcareexcellence.ca)</u>

Positive energy and affirmation to learn from past experiences to create patient-family-oriented change moving forward

Participants felt that discussions offered by the webinar panel provided an opportunity to reflect upon and learn from our individual and collective experiences to enable the creation of essential care partner policies that are "crisis-proof" for the future to ensure care partners are never locked out again. Such policies also need to consider the identification and presence of more than one care partner. Embedding such policies requires a culture change in a system that is often resistant to change. Hearing the experiences of patients, residents and their caregivers, and including them at decision-making tables to create the necessary change. Participants noted that it is important for policy makers to learn from these discussions, and that clear definitions, terms of reference, and legislation would also be helpful.

"Hoping creative solutions that work for patients and caregivers will be sustained and that we will learn from mistakes made."

Recommended resource: The Essential Together pledge, where organizations can pledge their commitment to including essential care partners in policy development, is accompanied by a change package including links to resources and policy guidance: <u>The Essential Together</u> <u>Pledge (healthcareexcellence.ca)</u>

Questions:

I have concerns about making vaccinations mandatory for caregivers/visitors, since there is a Ministry directive for staff. What are thoughts on this?

Due to the effectiveness of vaccination against COVID-19, organizations across the country are contemplating or enacting mandatory vaccination for visitors and, in some cases, essential care partners. Guidance and practices vary across the country and should take an equity-oriented approach to decision making. Where mandatory vaccination exists for essential care partners, there are exceptions in certain situations.

Recommended resource: The Essential Together huddles are open sessions to come together and learn from each other. The upcoming huddle on November 24 will feature a bioethicist who will be discussing the ethics involved in considering vaccine mandates for essential care partners and visitors. Register for the huddle here: <u>Essential Together Huddles:</u> <u>Connecting for peer-to-peer learning and support (healthcareexcellence.ca)</u>

How do we create rules that aren't rigid and balance safety and patient and family experience?

Balanced and safe policies are necessary to prevent harm that arises from restrictions to essential care partner presence. Being guided by the evidence allows us to take a balanced approach. The emerging evidence through this pandemic has demonstrated that when infection prevention and control practices are in place, essential care partners are not sources of transmission within health and care settings. Evidence of harm as a result of blanket restrictions also needs to be considered, including harm to patients and residents, their caregivers, and to staff. Healthcare Excellence Canada created policy guidance for the safe reintegration of essential care partners through a rigorous policy lab process based on many perspectives, including from those that make policy, implement policy, and those most impacted by policy.

Recommended resources: The co-created policy guidance focuses on the key areas of identification and preparation of essential care partners and entry to facilities: <u>Policy Guidance</u> for the Reintegration of Caregivers as Essential Care Partners (healthcareexcellence.ca)

The evidence brief is another valuable resource: <u>Evidence Brief: Caregivers as Essential Care</u> <u>Partners</u> (healthcareexcellence.ca)

I am interested in the differentiation by the team and patient and family of a visitor versus a care partner, how is it done, who decides?

Essential care partners provide physical, psychological and emotional support, as deemed important by the patient. This care can include support in decision making, care coordination and continuity of care. They are also key holders and conveyors of information including health information. Essential care partners are identified by the patient (or substitute decision maker) and can include family members, close friends or other caregivers. It is recommended that patients be encouraged to identify who their essential care partners are and to have this information recorded in medical records.

Recommended resource: The Essential Together learning bundles include curated resources related to develop mutual expectations to help in the identification of essential care partners and to develop and implement caregiver ID programs to support the identification of essential care partners while they are on site: <u>Essential Together Learning Bundles (healthcareexcellence.ca)</u>

I wonder what the panel would say being welcomed to a site looks like. How do we describe the difference to staff between welcomed and allowed?

Essential care partners should be welcomed and included as part of the care team. Practices that promote respect and value include welcoming patients/residents to identify their essential care partner(s), using visual ways in which caregivers are identified (e.g., provided with an ID badge), where there is clarity in their role(s), where they are included in care discussions, and where their presence is expected and not seen as the exception. Welcoming an essential care partner also entails equipping them to carry out their role, which includes providing them with the education and information they require. Resources to support these practices can be found in the Essential Together Learning Bundles: <u>Essential Together Learning Bundles</u> (healthcareexcellence.ca)

Recommended resource: Having essential care partner presence policies that are created in partnership with essential care partners is a tangible step organizations can take to welcome essential care partners as part of the care team. Take the Essential Together pledge and use the change package: <u>The Essential Together Pledge (healthcareexcellence.ca)</u>

I love that tag line, " we are your eyes ears voice and hands." It makes me curious how areas are integrating essential caregiver documentation into the charts?

While participants noted that integrating family/caregiver documentation could be hugely valuable for clinicians, this is rarely if ever current practice. Participants who self-identified as essential care partners commented on how difficult it can be to correct errors in the chart. We know that essential care partner policies are a tangible action toward person- and family-centred care. Other tangible practices include welcoming essential care partners at bedside rounds, including care partners in care transitions discussions and education, and allowing access to and documentation into patient charts.

Recommended resource: Open Notes is a movement towards transparent communication in healthcare with patients and essential care partners through sharing of documentation: <u>OpenNotes – Patients and clinicians on the same page</u>

Did the essential care partners on the panel get any pushback from the healthcare team and if so, how did they deal with it? What empowered them and made them feel they had a right to be there and stand up for that right?

Linda - "Yes my sisters and I got pushback from the beginning but to be honest we felt we had every right to be there. We taught them that we are just as essential, and we are also participating in our dad's care. They eventually thanked us and loved it when we came in because that gave them time to breathe and focus on other patients that needed them more. "We got you"

Recommended resource: Healthcare Excellence Canada has a variety of tools to help healthcare providers deliver safer care and support members of the public to partner with their providers to create safer care. The 'CUS' tool may be used by patients, families and caregivers to communicate their concerns to the healthcare team: <u>Tools for Advocacy & Assertion</u> (patientsafetyinstitute.ca)

What are your views on dealing with caregivers who do not promote the best outcome for the patient, such as deviating from best practices in a way that is not beneficial for the patient?

Education and training for both care partners and for staff can support care that is in the best interests of the patient/resident. Many organizations have developed training modules for caregivers to support them in their role as care partners. There is also training available for staff to support how they can effectively partner with patients and their caregivers. Having clear, mutually defined expectations, roles and responsibilities is important so that everyone on the team can see how they may be most supportive in the care of the patient.

Recommended resources: The Ontario Caregiver Organization has many tools and resources, as well as courses, for essential care partners, providers, and employers: <u>Ontario</u> <u>Caregivers Organization (ontariocaregiver.ca)</u>

This tool for essential care partners visiting LTC homes can be found here: <u>Safely Re-entering</u> Long-Term Care Homes During COVID-19 (healthcareexcellence.ca)

More potential resources can be found in the staff training learning bundle, part of the Essential Together program: <u>Essential Together Learning Bundles Staff</u> <u>Education</u> (healthcareexcellence.ca)

Are there any recommendations as to how healthcare providers can be advocates for this change? I would love ideas to pass along in our clinic and expand into our health care program.

Healthcare providers can encourage their organizations to take the Essential Together pledge, to demonstrate a commitment to essential care partners, and a way to recognize the role they play in the care of their loved ones. Healthcare providers can demonstrate the value they hold for ECPs by including them as part of the care team, involving them in care discussions, and to welcome essential care partners within their organizations. It is important that providers know and understand the evidence that supports the physical presence of essential care partners. It can be helpful to share evidence as the literature is clear – essential care partners do not drive transmission of COVID-19 in health and care settings and the harms from restricting their access is clear and impacts patient outcomes as well as negatively impacting caregivers, providers, and the system as a whole. Healthcare providers can also use and share with colleagues, the various tools/resources of Essential Together.

Recommended resources: As mentioned during the webinar, welcoming essential care partners at all times creates a culture that values patient and caregiver partnership in care. The Essential Together program has collected the evidence and packaged it as a brief and addendum that can be shared with your organizations: Evidence Brief: Caregivers as Essential Care Partners (healthcareexcellence.ca)

Other helpful resources are the learning bundles and <u>Essential Together Pledge</u> that can be found on the Essential Together site: <u>Essential Together</u> (healthcareexcellence.ca)