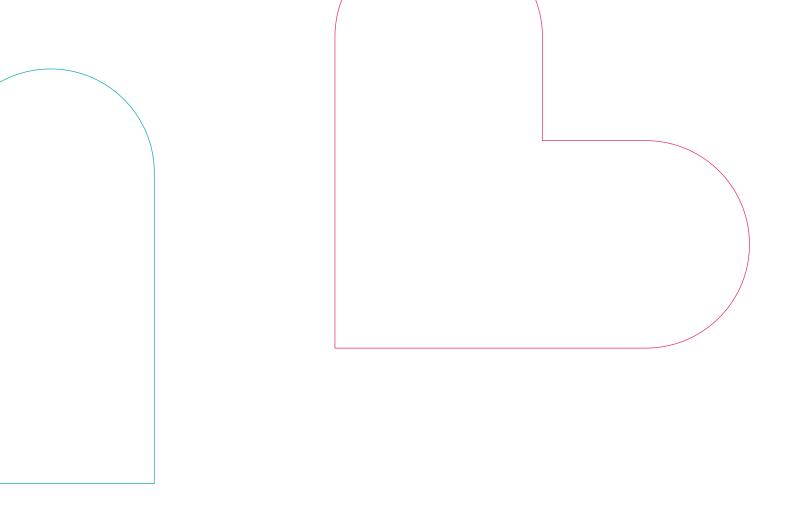


Executive Summary and Report

Updated in September 2021





About Healthcare Excellence Canada

Healthcare Excellence Canada (HEC) is an organization with a relentless focus on improving healthcare, with — and for — everyone in Canada. Launched in March 2021 from the amalgamation of the Canadian Patient Safety Institute and the Canadian Foundation for Healthcare Improvement, Healthcare Excellence Canada has greater capacity to support partners to turn proven innovations into widespread and lasting improvement in patient safety and all the dimensions of healthcare excellence. We believe in the power of people and evidence and know that by connecting them, we can achieve the best healthcare in the world. HEC is an independent, not-for-profit charity funded primarily by Health Canada.

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EXECUTIVE SUMMARY

This policy guidance is for healthcare decision makers, notably system level policy makers and system leaders. The policy guidance was co-developed as part of a 2020 collaborative policy lab process that included policy decision-makers, health system leaders who implement policy, and the people who are impacted by policy decisions — providers, administrators, patients,* families and caregivers. This policy guidance has been updated based on evidence emerging through COVID-19 as the context of the pandemic continues to change, with the adoption of vaccinations and broad availability of rapid testing, and plans to move into recovery and resiliency phases.

Lessons emerging throughout this pandemic tell us that we must act now to 'crisis-proof' person- and family-centred policies and practices. The COVID-19 pandemic created major changes throughout the world, including substantial shifts in healthcare policy and practice in Canada. Fear regarding transmission of COVID-19, particularly in the initial stages of the pandemic, resulted in significant changes to visitor policies in many care facilities. Many policies did not differentiate visitors from essential care partners, prohibiting essential care partners from having access to patients. Prior to COVID-19, family presence policies were embedded in the majority of hospitals across Canada, with a Canadian Foundation for Healthcare Improvement study showing 73 percent of surveyed hospitals in January 2020 had accommodating policies. This openness to caregiver presence dropped dramatically in wave one of COVID-19 and none of the hospitals surveyed again in March 2020 had accommodating policies.1

As we have moved through subsequent waves of the pandemic, we have seen shifting provincial and territorial directives as community transmission rates have varied and with the rollout of vaccines. In general, there has been loosening of restrictions reflected in the directives over time but applied and interpreted inconsistently across jurisdictions.

What we understand through subsequent waves of COVID-19 is that these restrictive policies did not balance all the potential risks, and what has emerged in the literature and through media accounts are numerous instances of unintended harm to patients across multi-jurisdictional health and care facilities, including issues of patient safety and quality of care, quality of life, continuity of care, outcomes, and emotional and psychological distress for patients, family and staff.^{2,3,4,5,6}

Blanket visitor restrictions refer to restrictions that extend to all "visitors" entering a facility, often without exceptions, including essential care partners.

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. Essential care partners can include family members, close friends or other caregivers and are identified by the patient or substitute decision maker.

Family caregivers/care partner may include relatives and non-relatives as defined by the patient.

Open family presence policies support the presence of family caregivers to be at the patient bedside at any time, i.e. not restricted by "visiting hours."

Patient- and family-centred/partnered care is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, families and caregivers.

^{*} This document is meant to reflect many settings where people receive healthcare and care, including hospitals, long-term care and congregate care facilities. For the purposes of this report, "patient" also includes clients and people living in long term care/nursing homes/advanced care homes and other congregate care facilities.

What has become abundantly clear through this pandemic is the essential nature of care partners and their importance in patient care. Although provincial directives have provided some guidance to enable the physical presence of essential care partners, the implementation of these policy directives at the facility level has not been consistent. Additionally, there is the need to consider the post-pandemic reality and build policies together with patients and essential care partners that are crisis-proof to ensure the presence of essential care partners is an embedded person and family-centred practice and not an exception.

The issue of family caregiver presence as essential care partners is multi-jurisdictional and there are similar concerns, challenges and opportunities for policy conversation across the hospital sector, long-term care and other congregate care settings. The policy lab participants were largely from the hospital sector, however the evidence, research and insights that were drawn on to establish this policy guidance indicates that the essential care partner role is a foundational principle across all settings where care is provided. 37,8 As such, this report is intended for healthcare leaders across healthcare systems in all settings and facilities in Canada.

Guiding Principles

In this updated policy guidance, the three key principles remain foundational for the successful reintegration of essential care partners:

Differentiate between visitors and family caregivers as essential care partners

In an effort to reduce COVID-19 transmission, particularly in the early days of the pandemic, restrictions were placed on all "visitors" entering health and care facilities and continued through subsequent waves. These restrictions failed to differentiate between the role of visitors and essential care partners.

Visitors have an important social role but do not participate as active partners in care.

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. Essential care partners can include family members, close friends or other caregivers and are identified by the patient or substitute decision marker.

2. Recognize the value of caregivers as essential care partners

Essential care partners provide critical services to Canada's healthcare system, contributing up to \$66.5 billion annually in unpaid care to patients in hospital, long-term care, congregate care facilities and home care. There is clear evidence that the presence and engagement of patients in their care, and partnership with essential care partners, improves patient and staff experience, safety and outcomes. 6,10,11,12,13,14

Ensure patients, families and caregivers have a voice in the development of policies related to visitors and essential care partners

A fundamental premise of a healthcare system that values person- and family-centred care is the engagement and partnership with patients, families and caregivers in the design of programs, practices, and policies. Authentic engagement that includes all partners at the table is essential for a comprehensive, fair, and balanced approach to policy development going forward.

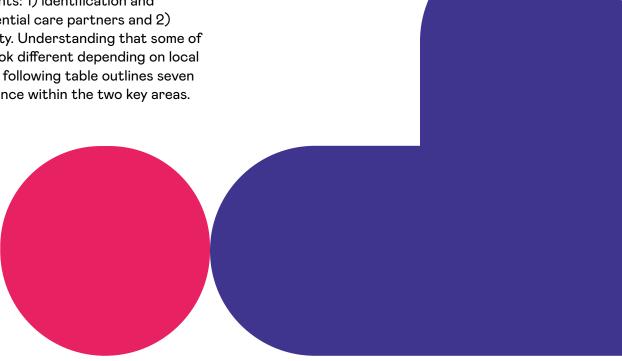
What we have seen through this pandemic is that organizations that were committed to these three key principles enabled the physical presence of essential care partners throughout subsequent waves of the pandemic and worked together with patient and caregiver partners and staff to co-develop polices, processes, and practices that ensured safe and compassionate care.

Policy Guidance

The original policy guidance outlined a 'how-to' operationalize policy into practice, and it remains relevant through ongoing waves of the pandemic and into planning for recovery and resilience. As noted above in the three key principles, person-centred policies that recognize the valuable role of essential care partners and differentiate this role from that of a visitor create the conditions that underlie balanced policies that promote family presence and person- and family-centred care and partnership in practice.

Different contexts exist for the various healthcare, long-term care and congregate care facilities, including the local contexts of community spread. Access for essential care partners to be physically present with patients should be the baseline for policy and practice across all settings. The impact of blanket restrictions that emerged through the pandemic point us to the need to safely welcome essential care partners as part of the care team at all times, whether in times of crisis or not.

This policy guidance for the reintegration of essential care partners focuses on two key areas where barriers to consistent and supportive access of caregivers have been noted by the policy lab participants: 1) identification and preparation of essential care partners and 2) entry into the facility. Understanding that some of the guidance will look different depending on local circumstances, the following table outlines seven categories of guidance within the two key areas.



I. Identification and preparation of essential care partners (ECPs)

Develop mutual expectations of	
responsibilities	

- Ensure patients understand what an ECP is and are welcomed to identify their own ECPs
- Establish process and roles to connect ECPs with a staff point-person for consistent coordination

Establish pre-entry preparation for ECPs

 Ensure consistent and ongoing information and education for ECPs regarding safety protocols required for entry (including public health measures and infection control and prevention practices such as hand hygiene, vaccinations, and personal protective equipment [PPE], as required)

Establish staff education to understand roles and safety protocols for ECPs

 Ensure there is education and clear communication for staff regarding the role and value of ECPs and their safe re-entry

Establish a rapid appeals process

 Communicate a clear and transparent appeals process to patients and ECPs so concerns can be raised and addressed quickly.

II. Entry into facility

Establish a clearly communicated screening process

- Implement a consistent screening process with relevant, evidence-informed protocols and questions that will continue to evolve with the changing context
- Ensure clear communication regarding what is expected at screening
- Create an opportunity for different methods of pre-entry screening (for example online in advance) and provide information on expected safety protocols

Establish caregiver IDs for ECPs

- Institute processes that clearly identifies ECPs
- Connect these processes with supportive education for safety protocols and PPE processes

Ensure ECPs are informed about existing and updated infection prevention and control protocols

 Provide an opportunity for ongoing updates to ensure ECPs are aware of recent safety protocols and processes. Examples of policy solutions to put this guidance into action are outlined in <u>Table 2</u> and <u>Table 3</u> in this report. <u>Appendix A</u> includes resources that support implementation of this policy guidance. Changes made to, and communication of, processes and policies should be co-developed with patients, families, essential care partners and staff to ensure their efficiency and effectiveness to support practices in care that are person- and family-centred, compassionate, and safe for all.



POLICY GUIDANCE FOR THE REINTEGRATION OF CAREGIVERS AS ESSENTIAL CARE **PARTNERS**

Overview

Throughout the pandemic, it has become increasingly evident care partners play an essential role as part of the care team to support safe, high quality and compassionate care of patients. There is an urgent need to fully embed personcentred principles into policies and practices in health and care systems, whether in times of crisis or not. This report offers policy guidance to support a safe and consistent approach for the reintegration of family caregivers as essential care partners across multi-jurisdictional health and care facilities. This guidance aims to inform and support those who are developing and implementing policy regarding the presence of essential care partners, including health ministries, regional health authorities, healthcare system and long-term care administrators and leaders. This policy guidance offers a balanced approach to the reintegration of essential care partners in a way that embodies the principles of person- and family-centred and partnered care with infection prevention and control considerations.15

While the original content of this report was developed between waves one and two of the current COVID-19 pandemic, the co-developed guidance continues to be relevant as we move into the recovery phase, to create a resilient and person-centred health system. Updates to this report reflect emerging evidence through the pandemic. We will continue to update this guidance as new evidence continues to emerge to reflect the changing context of COVID-19, and into recovery and resilience mode. This policy guidance forms the foundation for the Essential Together program that supports health and care facilities to safely welcome essential care partners, at all times.

Context

The COVID-19 pandemic created major changes throughout the world, including substantial shifts in healthcare policy and practice in Canada. Considerable fear regarding transmission of COVID-19, particularly in the initial stages of the pandemic, resulted in significant changes in visitor policies in many care facilities that largely prohibited essential care partners from having access to their loved ones. A Canadian Foundation for Healthcare Improvement study showed in January 2020, 73 percent of surveyed hospitals had open family presence policies. By mid-March, the situation changed dramatically due to COVID-19. While there were some specific patient exceptions, none of the hospitals in a follow-up study had open family presence policies.1 Healthcare facilities previously restricted visitors during respiratory outbreaks, such as Severe Acute Respiratory Syndrome (SARS). 6,16 However, the blanket visitor restrictions that occurred at the beginning of the COVID-19 pandemic were largely unprecedented.

In an environmental scan conducted in May 2020 of publicly available provincial and territorial directives released through ministries and/or medical officers of health, it was evident that guidance had been led by provincial/territorial pandemic task forces and command tables. It appeared the intent by government was to ensure tight control of potential COVID-19 transmission and consistency through provincial level directives. However, the resultant blanket visitor restrictions failed to distinguish between a visitor and a family member and/or caregiver who actively participates and partners in patient care - an essential care partner.

¹ Health and care facilities refers to hospitals, long-term care/residential care/nursing homes and other congregate care settings as well as primary care and outpatient care settings.

Most directives were highly restrictive, with a few notable exceptions in paediatrics, birthing mothers, and end-of-life care.

By the Fall of 2020, there began to be public calls for a more balanced approach and the safe re-integration of essential care partners. 3,17,18 In most cases visits by essential care partners were still allowed in a very limited capacity during wave two and the definition of what was essential was mostly left up to the organizations to define. creating inconsistencies in how provincial/ territorial policy directives were operationalized. During wave three, in spring 2021, a policy scan showed many provinces moving to a regional approach. Colours or levels were assigned to areas and regions based on COVID-19 prevalence taking into account regional variations of community transmission. Policies on essential care partners varied depending on the assigned level/colour.

Inconsistency of the application of provincial/ territorial directives continues, with variation within and across regions. A recent environmental scan of policies was conducted in July 2021 and showed minimal changes to policies in hospitals, where limited numbers of essential care partner visits are permitted. However, there has been a large shift in policies allowing both essential care partners and general visitors into long-term care. The high rates of vaccination of people living in long-term care homes and their essential care partners has reduced the risks of transmission and has been a key enabler to support family presence and remove restrictions. In general, COVID-19 vaccines have been shown to be effective against transmission and reducing the acuity of illness. 19,20,21 As such, provincial/territorial vaccination mandates are beginning to emerge across the country for entry into some areas of the public sphere. Including how these mandates apply to staff in health and care settings and for essential care partners and visitors.

The emerging evidence throughout the pandemic has highlighted significant unintended consequences as a result of these restrictive policies, including issues related to patient safety, quality of care and emotional and psychological distress for patients, caregivers and staff. 3,4,5,6,14 Among other consequences, restrictive policies have increased falls, have negative impacts on medication reconciliation and decision making, and have exacerbated.14 Anecdotally, some patients reported avoiding emergency departments or hospital admissions due to blanket visitor restrictions. Staff noted increased workload and patient/family complaints. Some staff experienced moral distress from having to abide by restrictions that separate patients and loved ones.^{2,7,14,22}

There is clear evidence that the role of essential care partners is important to the physical care needs and the psycho-social wellbeing of people living in in long-term care and congregate care facilities. 8,18 Fear of transmission has not borne out as we see in the literature, with evidence showing that essential care partners can safely be present if infection prevention and control protocols such as masking and screening are in place.14 Vaccines now add an additional layer of protection, as they have rolled out across the country. A more balanced approach that considers the many risks and harms needs to be considered, with many negative impacts on those receiving care as well as their caregivers and healthcare providers. We must act on the lessons from this pandemic as we plan for recovery and build resilience into the system that enables person- and family-centred policies to become common practice, and not the exception.

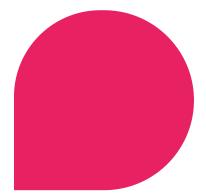
We have synthesized evidence that demonstrates the change in open family presence and person and family- centred and partnered policies over the past few years. We have added an addendum to this evidence brief of emerging literature through COVID-19 related to transmission risk and family caregiver presence, and recent studies that have shed lighton the impact of blanket visiting policies on patients, families, caregivers and providers. 14,23

Policy Lab Approach

The Canadian Foundation for Healthcare Improvement and Canadian Patient Safety Institute (now amalgamated as Healthcare Excellence Canada) conducted a policy lab to create policy guidance for the safe reintegration of essential care partners into health and care facilities. Through multiple virtual sessions of the policy lab, we co-developed guidance with a range of people with expertise and COVID-19 experience - including policy makers, hospital administrators and leaders, providers, patients and essential care partners - who provided insights and input to form the foundation of this policy guidance. The methodology of the policy lab is detailed in Appendix B.

The policy lab builds on longstanding work in family presence including the Better Together campaign and programming, a webinar and subsequent series on family and caregiver presence during COVID-19, and work with an expert advisory group to co-develop the report Reintegration of Family Caregivers as Essential Partners in Care.

Note: The participants in this policy lab were largely experienced in the hospital sector, however through our collaborative work in long-term care it has become clear the issues, priorities and guidance relate to a broad range of healthcare settings where presence of essential care partners is important.



Guiding Principles

Three foundational principles were identified when developing the policy guidance to reintegrate essential care partners: the differentiation between visitors and essential care partners; recognition of the value of essential care partners; and ensuring that patients, families, caregivers have a voice in the development of policies related to visitors and essential care partners. These guiding principles are fundamental to enact a person and family-centred philosophy into practice and remain constant through this ever-evolving pandemic to create resilient health and care systems that partner with patients and their care partners.

1. Differentiate between visitors and caregivers as essential partners in care

In the early weeks of the COVID-19, guidance from medical officers of health, provincial and territorial ministries of health, and regional health authorities recommended that, with some specific exceptions (e.g., mothers giving birth, persons at the end of life, and pediatric patients), all 'visitors' be restricted from entering hospitals and congregate care facilities. While directives have continued to shift over time, many directives and policies developed through subsequent waves continue to fail in their lack of clarity to differentiate between the role of visitors and essential care partners. Using language that clearly recognizes the essential role of care partners creates conditions that enable person-centred policies into practice. During the pandemic, organizations that made the distinction early on were able to find ways that supported essential care partners to be physically present to support the care of patients without disruption.

Visitors have an important social role but do not participate as active partners in care.

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. Essential care partners can include family members, close friends or other caregivers and are identified by the patient or substitute decision marker.

2. Recognize the value of caregivers as essential care partners

The literature is clear and supports the important role of essential care partners. Caregiver presence directly impacts the physical, psychological, emotional wellbeing and safety of patients. 6,15,16 Essential care partners provide critical services to Canada's healthcare system across many jurisdictions (including hospitals, long-term care, other congregate care facilities and in home care), contributing up to \$66.5 billion annually in unpaid care to patients in hospital, long-term care and home care.8 Caregiver presence improves patient safety, reduces harm, and improves patient outcomes and care experience.24 The presence of essential care partners also contributes to better staff morale and well-being, and communication between healthcare teams and patients.3,7

Throughout the pandemic, the risks and harm resulting from restrictions have become evident. 14 Restrictive policies have resulted in negative impacts to patients' physical and mental health, experience of care, and safety. In addition, restrictive policies have also negatively impacted caregiver and staff well-being and experiences of care. The restrictive policies that were created and refined over

the course of the pandemic have not fully appreciated the impact and value of essential care partners and did not fully account for the evidence supporting caregiver presence. Compounding these decisions in the early weeks of the pandemic was the uncertainty of the epidemiology, perceived risk of COVID-19 transmission and concerns regarding facility resource availability (including personal protective equipment). When properly supported, essential care partners can successfully follow infection prevention and control processes and that these processes, such as masking and screening, ensures that patients, essential care partners, and staff can stay safe.14 As the evidence clearly indicates, essential care partners are 'more than a visitor'.

Ensure patients, families and caregivers have a voice in the development of policies related to visitors and essential care partners

A fundamental premise of a healthcare system that values person- and family-centred care is the engagement and partnership with patients and caregivers in the design of programs, practices, and policies. It has been noted that early policy guidance that led to rapid restrictions of visitors was developed in the absence of collaboration with patients and caregivers. Organizations that have continued to work with patients and caregivers during the pandemic have been able to implement policies that took a more balanced approach and enabled the presence of essential care partners, even in the early days of the pandemic.

The growing body of literature related to patient engagement and partnership at all levels across the health system demonstrates its many impacts including: improved organizational culture, improved care, improved experiences and outcomes for patients, caregivers and providers, better adherence to treatment regimes and lower healthcare costs. 13,25 Ensuring all partners, including patients, families and caregivers, are involved in meaningful and intentional ways to co-develop policy moving forward will ensure a more comprehensive approach that balances the many risks and harms that need to be considered within a person- and familycentred and partnered healthcare system.

Detailed Policy Guidance

During the policy lab in the summer of 2020, participants began by co-developing a map for reintegration of essential care partners to help them understand what an ideal journey would look like. The map is based on a range of organizational and lived experience and provides a visual construction of the key actions deemed critical to enable essential care partners to be safely welcomed back into health and care facilities. (See Appendix C for the process of the map development and Figure 1 for the map). The policy guidance is based on this map.

The map is divided into three main phases:

- Identification of caregivers as essential care partners
- Entry into the facility
- Caregiving

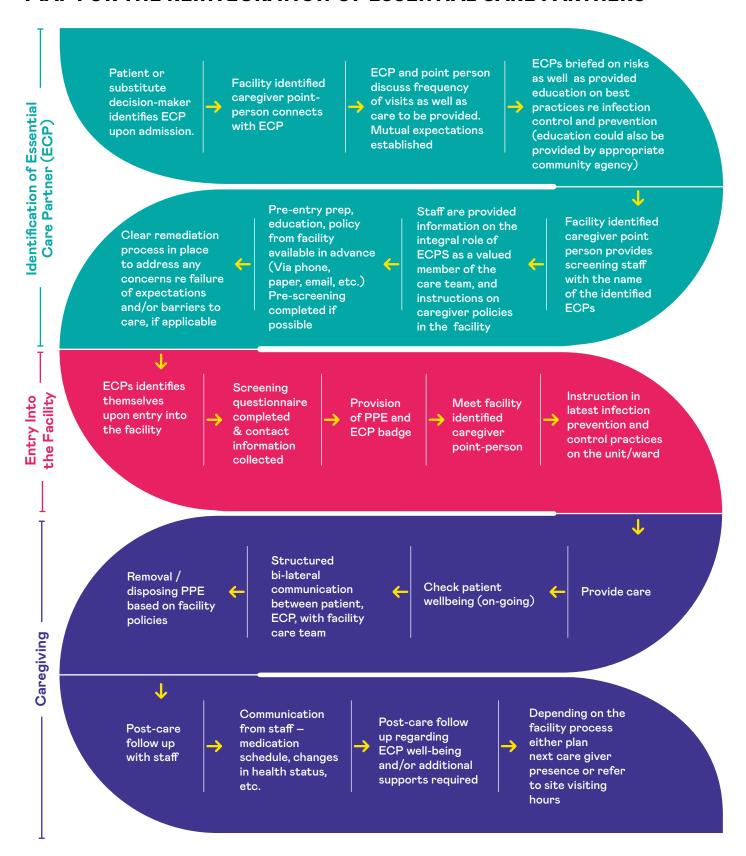
While the map was developed at a time when visitor restrictions were commonplace through the initial wave of the pandemic, the key actions remain relevant when considering the entry of care partners at any time, whether in times of crisis or not. The policy guidance focuses on the first two

phases of the map. Best practices and protocols for caregiving itself are well established and have not significantly changed with COVID-19 and hence are not a part of the this policy guidance.

A philosophy that values patient and family partnerships and is supportive of the role of essential care partners is fundamental to healthcare delivery at all times, including when times are challenging. First and foremost, the default policy and practice should enable essential care partners to be physically present, and their presence should not be the exception. As we have seen through this pandemic, there have been significant consequences when essential care partners have been restricted. Where this is not possible (for example if there is an active COVID-19 outbreak on the unit and a temporary lack of personal protective equipment or the essential care partner has acquired COVID-19) the health or care facility should establish a clear protocol for safety where the essential care partner is supported to actively participate with the care team. This participation may occur through virtual means such as phone, video conference or email and should be considered a short term or interim measure. Using virtual means is also a way to bring in other partners that cannot physically be present, but provide important support for the patient (e.g. if geographically they live at a distance).

Changes made to processes and policies, and the communication of these policies, need to be co-developed with patients, families, caregivers and providers in order to meet everyone's collective needs. Patient and family advisory councils and institutional networks of patient and caregiver partners are good starting points for this design process in times of crisis.

MAP FOR THE REINTEGRATION OF ESSENTIAL CARE PARTNERS



I. Identification and Preparation of the Essential Care Partner

The first phase outlines key steps to create a positive caregiver experience and corresponds with policy guidance to identify and prepare essential care partners to safely welcome them into the health or care facility.

 Develop mutual expectations: identify essential care partner(s) and establish a point of contact

Policy guidance:

- Ensure patients understand what an essential care partner is and are welcomed to designate their own essential care partners.
- Establish processes and roles to connect essential care partners with a staff point-person for consistent coordination of responsibilities and expectations.

Patients should be encouraged to identify their essential care partners. As we have seen emerge through the pandemic, it is useful to have a staff person (or people) designated as a point person for essential care partners to ensure smooth and effective coordination of the essential care partner responsibilities, provide supportive education with information regarding infection prevention and control measures, and offer clear and consistent communication. In addition, the point person could liaise with staff to ensure they are aware of who the essential care partners are, highlight relevant policies and provide guidance in the case of any conflicts. Currently there is often no single source of information for essential care partner policies and practices, causing unnecessary confusion for patients, essential care partners and staff. In some cases, this may be a point person for each unit, or may be someone who coordinates organization wide. Consistency of application of policy guidance is key across the organization.

2. Pre-entry Preparation of Essential Care Partners

Policy guidance:

 Establish consistent and ongoing mechanisms for essential care partner education regarding safety protocols required for entry (including but not limited to infection control and prevention practices, hand hygiene, use of personal protective equipment and facility and unit-specific safety and/or vaccination protocols).

Supportive information and education for essential care partners related to public health measures and infection control practices is needed. This may include the provision and use of personal protective equipment, vaccinations, hand hygiene, and facility/unit-specific protocols and processes. While safety education became paramount through COVID-19, these practices remain relevant to support infection prevention and control practices at all times. This education needs to be flexible and respond to the differing levels of health literacy, cultural and language needs of caregivers as well as differing risk profiles of patients. It should be offered in various formats, times and frequency. An effective education program will reduce fear for both staff and caregivers and provide a balanced approach for the safe re-entry of essential care partners.

3. Staff education to understand roles and safety protocols for essential care partners Policy guidance:

 Establish education and clear communication for staff regarding the role and value of essential care partners and their safe re-entry.

As we had seen throughout COVID-19, many staff made attempts to take on roles that care partners had assumed, adding to their workload. It became apparent throughout the pandemic the valuable role of essential care partners and the impacts that blanket restrictions had to the quality of life and quality of care received by patients. Consistent with an organizational philosophy that embraces principles of person- and family-centred and partnered care, it is important for leaders and staff to continue to recognize the widely accepted role and benefits of caregiver presence and welcome their physical presence as essential care partners. Staff concerns or fears may be alleviated through appropriate education and communication strategies to ensure that essential care partners are properly and methodically identified, screened, educated in facility/unit-specific infection prevention and control practices other safety protocols and public health measures (e.g. vaccination, rapid testing).

4. Establish a rapid appeals processPolicy guidance:

 Establish and communicate a clear and transparent appeals process for patients and essential care partners so concerns can be raised and addressed quickly.

Health and care facilities should ensure patients and essential care partners have access to a transparent and timely appeal or dispute resolution process to resolve disagreements about essential care partner access, weather in times of crisis or not. This process needs to allow for regional flexibility as needed based on risk. The appeals process should be lean and publicly available so patients and essential care partners can understand the decisions related to access. A clear and transparent process will help reduce potential conflicts and avoid putting essential care partners or staff in untenable positions.

How to Take Action: Examples of Policy Solutions for the Identification and Preparation of Essential Care Partners

Table 2 provides examples of possible policy solutions addressing different phases of the map for reintegration related to the identification and preparation of essential care partners. The policy solutions are not intended to be prescriptive, but instead outline some potential implementation ideas. Many innovative examples have emerged throughout COVID-19, and will continue to be relevant in the recovery and resiliency phases so that we are able to crisis-proof policies and practices to ensure that essential care partners may be present as needed to support the care of patients, whether in times of crisis or not. What works best will depend on the local context of the organization implementing the guidance. The Essential Together Learning Bundles has more information and examples for how health and care facilities across Canada implemented elements of the policy guidance. As the pandemic continues to evolve and public health measures continue to change, we will continue to update and share these learning bundles to provide practical solutions implemented by organizations and health regions across Canada that address the ever-changing landscape.

Table 2: Examples of Policy Solutions for the Identification and Preparation of Essential Care Partners

Examples of how to take action on policy guidance

Identification of essential care partner(s)

 Develop mutual expectations: identify essential care partner(s) and establish a point of contact:

Ensure patients understand what an essential care partner is and are welcomed to designate their own essential care partners.

Establish processes and roles to connect essential care partners with a staff point- person for consistent coordination of responsibilities and expectations.

• Establish a rapid appeals process:

Establish and communicate a clear and transparent appeals process for patients and essential care partners so concerns can be raised and addressed quickly.

 Develop an essential care partner guidance framework that provides clarity for decision making. Key principles can include the following:

Caregivers are identified as essential care partners by the patient or substitute decision maker

Default is that essential care partners should have unrestricted access (framework determines what is possible based on risk)

Framework must be clear, transparent and accessible to all patients, essential care partners and staff

There must be a clear appeals and dispute resolution process associated with the framework

Allow for regional flexibility based on risk (for example the current context of community spread)

Identify a process for monitoring and education/reenforcement of mutual obligations

Identify a staff member(s) to coordinate the essential care partner identification process. This role may be taken on by screeners, ward clerks, patient relations staff or others already involved in coordinating activities within the hospital/faculty.

Develop a mutual obligations charter:

Provide guidance on how the health or care facility will support essential care partners: clarifying roles and responsibilities, required personal protective equipment and safety processes/protocols specific for the facility/unit, make every effort to ensure that caregiver presence is established practice, and not the exception

Charter may be used as a supportive educational tool for staff and essential care partners.

Examples of how to take action on policy guidance

 Pre-entry preparation of essential care partners:

Establish consistent and ongoing mechanisms for essential care partner education regarding safety protocols (including infection control and prevention practices, hand hygiene, use of personal protective equipment, facility and unit-specific safety processes).

 Provide supportive education for essential care partners regarding safety protocols/processes so they can feel prepared for entry, and provide content in different formats (for example via online caregiver portal, written, video or in- person):

Allow essential care partners to schedule their time

Provide access to required resources and education

Enable essential care partners access to staff pointperson for any questions or concerns

Use similar education content for essential care partners as for staff to align infection control and prevention practices and use of personal protective equipment

Co-develop education with patient partners/Patient and Family Advisory Councils so it is relevant and clear to all involved

Align with the risk level on the specific unit (such as face- to-face education and training where COVID-19 is present or where people are immunocompromised).

Essential care partner education may contain:

Basics of safely moving around the facility and physical distancing

Specific personal protective equipment requirements

Facility layout

Expectations regarding role and number of essential care partners

Facility/unit-specific safety protocols

Hand hygiene protocols

Procedures based on types of care provided.

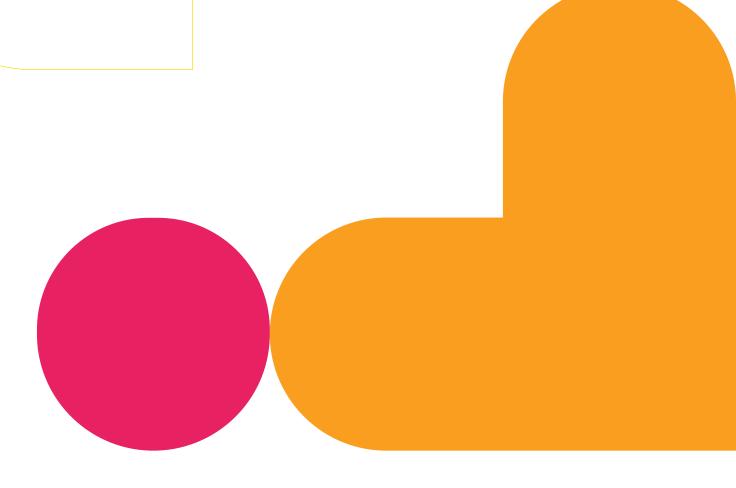
Supportive education regarding vaccines as an additional public health measure as needed

 Staff education to understand roles and safety protocols for essential care partners:

Establish education and clear communication for staff regarding the role and value of essential care partners and their safe re-entry.

Examples of how to take action on policy guidance

- Shared education with patients, essential care partners and staff on partnering in care can ensure mutual respect concerning the value of family presence in patient care and impact on health outcomes (rather than risks)
- Create a shared understanding and expectation that family caregivers are part of care team — and that they should remain so, 'formalizing' their role and support through the education.
- Ensure understanding of staff regarding the education and training provided to essential care partners related to public health measures and safety protocols to enable their safe re-entry.



II. Entry into the Facility

Policy guidance related to the second stage of the map for reintegration of essential care partners focuses on the point of entry into the facility (see Figure 1). Like the identification process, the entry process needs to be clear, accessible and respectful.

1. Screening process

Policy guidance:

- Implement a consistent screening process
 with relevant and evidence-informed
 screening protocols and questions. While
 the most recent screening protocols were
 specific to COVID-19, various types of
 screening protocols remain relevant as part
 of general public health measures.
- Provide clear communication regarding what to expect at screening.
- Create an opportunity for different methods of pre-entry screening (such as online and in advance) and provide information on expected safety protocols.

It is paramount to reduce vectors of transmission when entering an environment with medically vulnerable people, especially during a pandemic. Screening processes ensure everyone — including healthcare providers, administrators, staff and essential care partners — entering a health and care facility is symptom free. Contact information needs to be collected for tracing purposes as per public health guidelines.

Screening processes need to be clearly communicated to everyone entering the facility so expectations are known. This includes the key screening protocols and questions, which should be evidence-informed based on the most recent literature and best practices. There should also be clarity in the different ways screening may be done, such as self-screening prior to arriving at the facility and/or in person at the time of entry.

Consistency is important so screeners at the facility are methodical with everyone entering. Screening provides an opportunity for essential care partners to identify themselves, which in some cases can be with the patient as they are enter the facility. Screening questions and methods may change as the pandemic changes and may reflect public health measures that are in place in other public spaces (For example, including screening questions about vaccination status).

2. Essential care partner identification processes

Policy guidance:

- Institute processes that clearly identify essential care partners.
- Link identification processes with supportive essential care partner education and ensure appropriate personal protective equipment has been provided.

Before COVID-19, some facilities had already instituted formal caregiver identification (ID) programs. ID processes remain relevant during the pandemic so staff can identify who is in the facility/on the unit and part of the care team. The provision of an ID badge or another visible icon can be linked to other processes, such as the designation of essential care partner(s) by the patient, cleared pre-entry screening and essential care partner education and other requirements for entry. This process may promote the normalization of the role of essential care partners and alleviate staff fears as they can be confident essential care partners have been designated by patients, understand the safety protocols and are prepared to be on the unit as part of the care team.

3. Review of updated safety protocols and processes

Policy guidance:

 Provide an opportunity for ongoing updates to ensure essential care partners are aware of recent safety protocols and processes. Connecting essential care partners with a staff point-person as they enter a facility provides an opportunity for essential care partners to receive updates on relevant infection control and prevention practices and ask questions or clarify details on protocols. This additional touchpoint contributes to ensuring safety protocols are understood and applied.

Currently, masking remains a common practice indoors or when physical distancing is not possible and in particular, within health and care facilities, which is consistent with the requirements of most provinces and territories.

In a red zone where many COVID-19 cases are present, or on a ward with immunocompromised patients, there may be requirements for additional personal protective equipment. Additionally, vaccine mandates are beginning to emerge across the country, which may be inclusive of essential care partners. Organizations need to consider how to continue to support the physical presence of essential care partners as the rule, rather than the exception.. Access to necessary protective equipment and vaccination should be provided by the healthcare facility. In the case of increased personal protective equipment needs, safety education would ensure appropriate use of equipment

How to Take Action: Examples of Policy Solutions to Support Entry Into the Facility

Table 3 provides some examples of the policy solutions to support the entry to the facility phase of the essential care partner journey. These policy solutions are not intended to be prescriptive and outline some potential implementation ideas. What works best will depend on the local facility specific context. The Essential Together Learning Bundles has more information and examples for how health and care facilities across Canada implemented elements of the policy guidance.



Table 3: Examples of policy solutions to support entry into the facility

Examples of how to take action on policy guidance

Screening process:

Implement a consistent screening process with relevant, evidence-informed screening protocols and questions

Provide clear communication regarding what to expect at screening

Create an opportunity for different methods of preentry screening (e.g. online and in advance) and provide information on expected safety protocols. Create consistent screening communications specifically for essential care partners:

Co-develop communication tools with patient partners/ Patient and Family Advisory Council to outline relevant information regarding safety protocols and policies

Ensure communication is accessible to everyone, recognizing differing levels of health literacy and cultural/linguistic needs

Screening processes need to be clear and consistent, with opportunities to complete screening in different formats (for example pre-entry)

Screening processes should be reflective of current public health recommendations

Contact information may be required for tracing purpose.

• Essential care partner ID process:

Institute processes that clearly identify essential care partners

Link identification processes with supportive education and ensure appropriate personal protective equipment has been provided.

 Provide an ID badge to clearly identify essential care partners:

Where possible, integrate the ID card system into an electronic system similar to staff processes

The ID card would contain contact information and enable after-hours access to the building as needed.

Examples of how to take action on policy guidance

 Review updated safety protocols and processes:

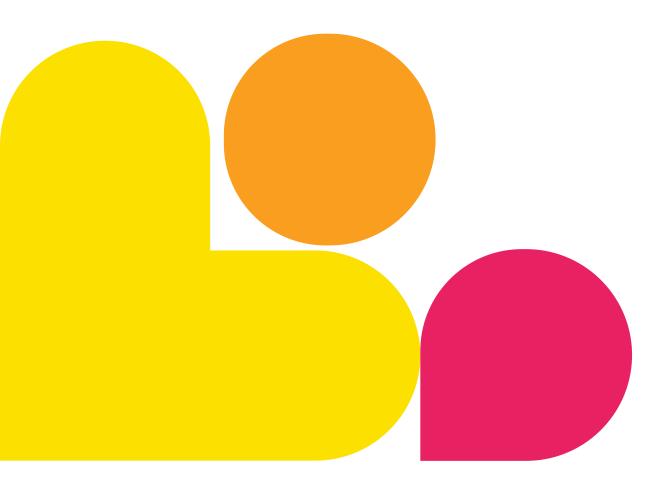
Provide an opportunity for ongoing updates to ensure essential care partners are aware of recent safety protocols and processes.

 Essential care partners should have the opportunity to meet with the staff point-person as they enter the facility:

Develop consistent communication for essential care partners when they enter the facility/unit including wayfinding and any current recommendations or requirements for entry (e.g. masking, vaccination, rapid testing)

Co-develop communication approaches with patient partners/Patient and Family Advisory Council to ensure clear, relevant, accessible and culturally appropriate communication

Use quality improvement techniques to evaluate and improve the process.



REFERENCES

- Canadian Foundation for Healthcare Improvement. "Much More Than Just a Visit: An Executive Summary of Policies in Select Canadian Acute Care Hospitals." Canadian Foundation for Healthcare Improvement (2020), https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/better_together_executive-summary_en.pdf.
- 2. Goldman, Brian. "No Visitors Please: Families grapple with new COVID-19 policies that leave them cut off from vulnerable loved ones in hospital." CBC LISTEN. Audio file. (April 18, 2020). https://www.cbc.ca/listen/live-radio/1-75-white-coat-black-art/clip/15771656-no-visitors-please-families-grapple.
- Stall, Nathan M., Jennie Johnstone, Allison J. McGeer, Misha Dhuper, Julie Dunning, and Samir K. Sinha. "Finding the Right Balance: An Evidence-Informed Guidance Document to Support the Re-Opening of Canadian Nursing Homes to Family Caregivers and Visitors during the Coronavirus Disease 2019 Pandemic." Journal of the American Medical Directors Association 21, no. 10 (2020): 1365-1370.
- 4. Comas-Herrera Adelina, Salcher-Konrad Maximillan, Baumbusch Jennifer, Farina Nicolas, Goodman Claire, Lorenz-Dant Klara, Low Lee-Fay. "Rapid review of the evidence on impacts of visiting policies in care homes during the COVID-19 pandemic." Pre-print published in LTCcovid.org. (2020) https://ltccovid.org/2020/11/01/pre-print-rapid-review-of-the-evidence-on-impacts-of-visiting-policies-in-care-homes-during-the-covid-19-pandemic/.
- 5. Hwang, Tzung-Jeng, Kiran Rabheru, Carmelle Peisah, William Reichman, and Manabu Ikeda. "Loneliness and Social Isolation during the COVID-19 Pandemic." International Psychogeriatrics (2020): 1-15.
- 6. Bélanger, Lynda, Sylvain Bussières, François Rainville, Martin Coulombe, and Marie Desmartis. "Hospital visiting policiesimpacts on patients, families and staff: A review of the literature to inform decision making." J Hosp Adm 6, no. 6 (2017): 51-62.
- Canadian Agency for Drugs and Technologies in Health. "COVID-19 Infection Risk Related to Visitors in Long-Term Care." (2020). Internal document.
- Ontario's Long-Term Care COVID-19 Commission. (2020), http://www.ltccommission-commissionsld.ca/ir/pdf/20201023_ First%20Interim%20Letter_English.pdf.
- 9. Fast, J. (2018). Unpublished analysis of Statistics Canada 2012 General Social Survey on Caregiving and Care Receiving Department of Human Ecology, University of Alberta Edmonton.
- 10. Institute for Patient and Family Centered Care. "Facts and Figures About Family Presence and Participation. "(n.d.). Retrieved July 14, 2015, http://www.ipfcc.org/advance/topics/BetterTogether-Facts-and-Figures.pdf.
- 11. U.S. Department of Health and Human Services. (2014). New HHS data shows major strides made in patient safety. Washington, DC: Author. Retrieved from http://innovation.cms.gov/Files/ reports/patient-safety- results.pdf.
- 12. Davidson, Judy E., Karen Powers, Kamyar M. Hedayat, Mark Tieszen, Alexander A. Kon, Eric Shepard, Vicki Spuhler et al. "Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005." Critical care medicine 35, no. 2 (2007): 605-622.
- 13. Institute for Patient- and Family-Centered Care. "Changing Hospital "Visiting" Policies and Practices: Supporting Family Presence and Participation." (n.d.), https://www.ipfcc.org/resources/visiting.pdf.
- 14. Healthcare Excellence Canada. Evidence Brief Addendum: Essential Care Partners Emerging Evidence. 2021.
- 15. Institute for Patient- and Family-Centered Care. "Patient-and Family-Centered Care." (2010), https://www.ipfcc.org/about/pfcc.html.
- 16. Bell, L. "Family presence: visitation in the adult ICU." American Association of Critical Care Nurses 32, no. 4 (2011): 76-78.
- 17. Healthcare Excellence Canada. Policy Guidance for the Reintegration of Caregivers as Essential Care Partners. November 2020 Policy Guidance for the Reintegration of Caregivers as Essential Care Partners (cfhi-fcass.ca)
- 18. Toronto Region COVID-19 Hospital Operations Table. "Access to Hospitals for Visitors (Essential Care Partners): Guidance for Toronto Region Hospitals (Acute, Rehab, CCC) During the COVID-19 Pandemic.' October 2020. https://www.oha.com/Documents/Access%20to%20Hospitals%20for%20Visitors%20-%20Oct%206.pdf.
- 19. National Institute on Ageing. 2021. After the Shot: Guidance Supporting the Re-Opening of Canada's LTC Home Following COVID-19 Vaccination. AftertheShot_0704+(1).pdf (squarespace.com)

- 20. Hart and Taylor. 2021. Family presence for critically ill patients during a pandemic. Chest. Family Presence for Critically Ill Patients During a Pandemic ScienceDirect
- 21. Van Veenendaal et al 2021. Supporting parents as essential care partners in neonatal usits during the SARS-CoV-2 pandemic.

 Acta Paediatrica. Supporting parents as essential care partners in neonatal units during the SARS-CoV-2 pandemic
 Veenendaal - Acta Paediatrica Wiley Online Library
- 22. Reinhard, Susan., Drenkard, Karen., Choula, Rita., Curtis, Alyson. "Alone and Confused: The Effects of Visitor Restrictions on Older Patients and Families." (July 2020), https://blog.aarp.org/thinking-policy/alone-and-confused-the-effects-of-visitor-restrictions-on-older-patients-and-families.
- 23. Canadian Foundation for Healthcare Improvement. Evidence Brief: Caregivers as Essential Care Partners. 2020. Evidence Brief: Caregivers as Essential Care Partners (cfhi-fcass.ca)
- 24. Canadian Foundation for Healthcare Improvement. "Better Together Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19." (2020), https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/bt-re-integration-of-family-caregivers-as-essential-partners-covid-19-e.pdf.
- 25. Frampton, Susan B., Sara Guastello, Libby Hoy, Mary Naylor, Sue Sheridan, and Michelle Johnston-Fleece. "Harnessing evidence and experience to change culture: a guiding framework for patient and family engaged care." NAM Perspectives (2017).



APPENDIX A: KEY RESOURCES TO TAKE ACTION ON POLICY GUIDANCE

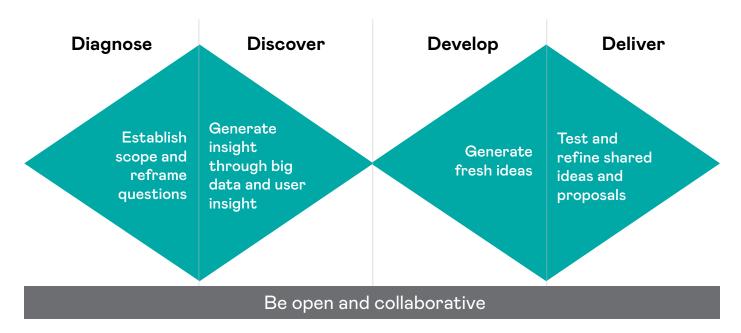
- 1. Better Together Change Package
- Care Partner Presence Policies During COVID-19: Considerations for Hospitals in Anticipation of Changes to Temporary Restrictions for Care Partner Presence During COVID-19. Ontario Hospital Association
- 3. CFHI Provincial and Territorial Guidance and Directives Scan
- 4. CFHI Federal, Provincial and Territorial Guidance on Family Presences and Visitation Scan
- 5. <u>Coronavirus COVID-19 BC Centre for Disease Control BC Ministry of Health: COVID-19 Ethical</u>
 Decision- Making Framework
- 6. <u>Hotel Dieu Grace Healthcare HDGH Patient Visitation Plan: Phased Approach to Reintroduction of Visitation</u>
- 7. Finding the Right Balance: An Evidence-Informed Guidance Document to Support the Re-Opening of Canadian Nursing Homes to Family Caregivers and Visitors during the Coronavirus Disease 2019 Pandemic
- 8. <u>Huron Perth Health Alliance Family and Caregiver Presence Guidelines</u>
- 9. McMaster University Continuing Education: Caregiving Essentials
- 10. Patient Ombudsman Special Report October 2020. Honoring the voices and experiences of Long-Term Care Home residents, caregivers and staff during the first wave of COVID-19 in Ontario.
- 11. Planetree: Person Centred Guidelines for Preserving Family Presence During Challenging Times
- 12. Saskatchewan Health Authority Framework
- 13. Shared Health Manitoba COVID-19 Ethics Framework. Information for Providers
- 14. The Caregiver Identification (ID) Program and Family Presence Policy. The Change Foundation (Ontario)
- 15. The Ottawa Hospital Education Personal Protective Equipment for Family Caregivers (Donning/Dofng PPE: COVID-19 Simulations from the Ottawa Hospital)
- 16. <u>Institute for Patient and Family Centred Care Family Presence During a Pandemic Guidance and Tools for Decision Making</u>
- 17. Safely Re-entering Long-Term Care Homes During COVID-19 (healthcare excellence.ca)
- 18. Essential Together Program Website

APPENDIX B: POLICY LAB METHODOLOGY

Twenty-nine participants from across Canada (4 participants from Atlantic Provinces, 10 Central Canada, 11 Prairie Provinces, 3 West Coast, and 1 Northern Territories) and one participant from the United States of America, collaborated to co-develop policy guidance for the reintegration of caregivers as essential partners in care.

The policy lab process adopted a Double-Diamond style methodology to collaboratively create policy tools. This process puts the people using and applying policies in the centre of the design. It involves using creative approaches (including adapted Liberating Structures techniques) to explore the issues more widely (also called divergent thinking) and then focusing on potential solutions (convergent thinking). The virtual policy lab used a systemic design approach to policy development that enabled participants to fully understand the system and leverage points in order to develop policy which works for those who make, implement and experience policy.

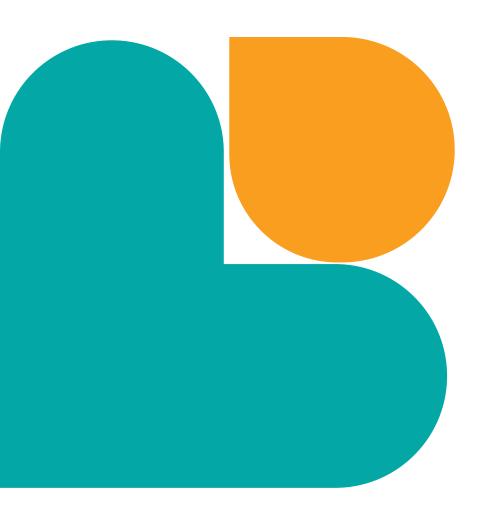
Figure 2 A visual of the Double-Diamond methodology which has been adapted and popularized by the UK Design Council



A range of facilitation tools and techniques were used over five sessions to develop better policy together with patients, caregivers, healthcare providers, policy makers and healthcare leaders. Leaning on the design thinking way of solving problems, the following steps were taken:

- Key informant interviews: We conducted interviews with 12 people including patients with lived experience of COVID-19, caregivers, providers and decision-makers from across Canada to learn what they do and need in relation to the role of essential care partners and further our understanding of the impact of blanket visitor restrictions in hospitals.
- 2. Mapping the journey of an essential care partner: We applied interview insights and research data to map the journey of an essential care partner entering a hospital amidst the pandemic. Specifically, the needs and pain points noted at every point of the journey.

- 3. Identification of 'pain points:' looking at the whole mapped experience, key pain points were identified to be addressed with the reintegration of a family presence policy.
- 4. Development of policy options: multiple policy options were developed using a policy canvas for each identified pain point. A policy canvas is a template that brings the needs and pains in the system, options and implications/results of a policy in one place, helping inspire and align policy needs with outcomes.
- 5. Simulation testing of policy options: Potential options were tested through simulations of what the essential care partner journey would look like if such policy options were implemented. This helped to iron out inconsistencies and identify blind spots and made the policy guidance more rigorous and responsive to on-the- ground realities.



APPENDIX C: KEY STEPS TO DEVELOP THE MAP FOR REINTEGRATION OF ESSENTIAL CARE PARTNERS

A key component of the policy lab was the development of a multi-layered map of what reintegration of essential care partners looks like. This exercise considered the perspectives and experiences of policy makers, policy implementers and those impacted by policies. This approach provided an understanding of the 'user experience' in parallel with the experience of policy makers, healthcare system leadership and healthcare providers.

The <u>Map for the Reintegration of Essential Care Partners</u> offers a visual construction of the key actions and policy guidance that policy lab participants deemed necessary to reintegrating essential care partners (see Figure 1).

- 1. Describe family caregiver/care partner experience. Identify key points in the story of caregiver access.
- 2. Describe key points of the family caregiver/care partner experience in more detail. Focus on emotion and feelings that parallel the journey.
- 3. Highlight where experiences were good or poor, and what might have been different.
- 4. Describe the decisions, policies, practices and actions that policy makers and implementers may have made or put in place at different key points of the experience map.
- 5. Reflect. Review. Ask questions for clarification. Describe what might have been different.
- 6. Celebrate the development of the map and thank all who participated for their insights.
- 7. Develop the experience-based map based on the conversations. Review with the people who provided input.
- 8. Validate the map with organizations, healthcare system leaders, patient/family/caregivers outside of the participant group.
- 9. Identify the policy guidance opportunities.