



BETTER TOGETHER:

Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19



#MoreThanAVisitor

Canadian Foundation for **Healthcare Improvement**

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Rapid Response Expert Advisory Group

To develop this report and the next steps for hospitals to re-integrate family caregivers as essential partners in care, the Canadian Foundation for Healthcare Improvement (CFHI) convened a Rapid Response Expert Advisory Group. This report has been contributed to, reviewed and is supported by the members of [the advisory group](#).

About The Canadian Foundation for Healthcare Improvement

CFHI works shoulder-to-shoulder with partners to accelerate the identification, spread and scale of proven healthcare innovations. Together, we are delivering lasting improvement in patient experience, work life of healthcare providers, value for money and the health of everyone in Canada.

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HOW TO MOVE AHEAD

1

Ensure a foundation of patient- and family-partnered care

2

Revisit policies on family presence with patient, family and caregiver partners at the table

3

Distinguish between family caregivers who are essential partners in care and visitors

4

Consider the needs of people who face specific risks without the presence of family caregivers as essential partners in care

5

Take a comprehensive, balanced approach to assessing risk

6

Establish a rapid appeal process

7

Increase the evidence to guide decisions regarding family caregiver presence

Step 1: Ensure a foundation of patient- and family-partnered care

Next Steps:

- 1.1. Ensure the philosophy of patient- and family-centred and partnered care are foundational to practice, policy development and decision-making within a hospital, even in times of crisis.

Step 2: Revisit policies on family presence with patient, family and caregiver partners at the table

Next Steps:

- 2.1. Review policies to support the reintegration of family caregiver presence in hospitals in collaboration with patient, family and caregiver partners.
- 2.2. Consider the regional/local/hospital pandemic status when supporting the reintegration essential partners in care.
- 2.3. Support hospital staff to understand, value and support the role essential partners in care.

Step 3: Distinguish between family caregivers who are essential partners in care and visitors

Next Steps:

- 3.1. Clearly and consistently distinguish between “visitors” and “family caregivers” who patients designate as active and essential partners in care.
- 3.2. Ensure a clear understanding of whose authority determines the interpretation of provincial/territorial guidance and directives, particularly as to who are considered “essential” partners in care. Address inconsistencies in the application of guidance and directives.
- 3.3. Support increased awareness of the distinction between “essential care partners” and “visitors”.

Step 4: Consider the needs of people who face specific risks without the presence of family caregivers as essential partners in care

Next Steps:

- 4.1. Consider inequities in the care of some populations where the absence of family caregivers as essential partners in care may result in additional risk and unintended harm. This includes, but not limited to people with physical disability, intellectual disability, impaired cognitive functioning, medical complexity, social anxiety, depression, specific cultural needs, comprehensive discharge planning and people who have recently transitioned from pediatric to adult care.

Step 5: Take a comprehensive, balanced approach to assessing risks

Next Steps:

- 5.1. Introduce a comprehensive and collaborative approach to harm reduction for the reintegration of essential partners in care that includes expertise from multiple perspectives including public health, health professionals, ethicists, healthcare administrators and people with lived experience.
- 5.2. Consider local/regional circumstances and pandemic status when developing family caregiver presence guidance.
- 5.3. Outline a comprehensive harm reduction approach that takes into account practical implementation considerations such as screening essential care partners for COVID-19 (like staff screening), infection control training and staff education.

Step 6: Establish a rapid appeal process

Next Steps:

- 6.1. Ensure broad communication of the hospital’s policies regarding essential care partners, how decisions are made and the appeal process.
- 6.2. Consider COVID-19 specific appeals processes where existing structures do not enable timely decisions.

Step 7: Increase the evidence to guide decisions regarding family caregiver presence

Next Steps:

- 7.1. Continue to review relevant literature and synthesize the existing evidence base to support comprehensive risk-tailored assessments regarding essential partners in care.
- 7.2. Examine existing models for infection prevention and control, as well as best practices to support harm reduction approaches, in the context of the re-integration of essential care partners during outbreaks.
- 7.3. Prioritize research into the impact (including patient safety implications) of initial and evolving “visitor restriction” guidance and the restriction essential care partners.



BETTER TOGETHER: Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19

THE CONTEXT

Over the last five years, open family presence policies had become common in Canada's hospitals. As reported in *Much More Than Just A Visitor* ([Appendix B: Supporting Documents](#)), by winter 2020, 73 percent of hospitals across Canada had adopted accommodating visiting policies, up from about 32 percent in 2015. This change demonstrated a commitment to creating environments supportive of patient and family partnership in care, and an appreciation of the partnership role of family caregivers.

The situation changed dramatically in mid-March 2020 in response to the COVID-19 pandemic. Highly restrictive hospital access policies (including blanket "visitor restrictions") were implemented across Canada in an effort to reduce transmission of the virus, as well as protect the hospital environment and limited supply of personal protective equipment (PPE). By March and April 2020, none of the hospitals included in a follow-up study had accommodating visiting policies. While these restrictive policies were introduced with best intent, it has become apparent that extended blanket visitor restrictions have risks for patient care, safety, experience and outcomes, as well as causing moral distress for patients, family caregivers and healthcare providers.

To develop this report on "Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19," the Canadian Foundation for Healthcare Improvement surveyed current provincial/territorial, regional and hospital policies, reviewed the literature, conducted key informant interviews and convened a Rapid Response Expert Advisory Group (advisory group). [This advisory group](#) is composed of clinicians, healthcare system leaders, hospital CEOs, legal/bioethics experts, public health experts, and patient, family, and caregiver partners with lived experience. They reviewed the evidence, familiarized themselves with the current provincial/territorial "visitor restriction" guidance, and provided expert advice about balancing potential benefits and harm for patients, families and caregivers, and the healthcare system as a whole. They also came to consensus on wise counsel about how to reintegrate family caregivers as essential partners in care.

CFHI and the advisory group share this report to inform and support those who are looking to reintegrate family caregivers as essential partners in hospitals in the time of COVID-19. We hope it will serve as a resource to support provinces/territories, regions and hospitals to adjust their blanket visitor restriction guidance/policies.

This report is intended to be helpful to provincial/territorial health authorities and medical officers of health who are developing and implementing guidance regarding family caregivers as essential partners in care. To ensure a comprehensive risk-tailored approach, discussions to update guidance should include collaboration with patients, families and caregivers with lived experience.



In recent weeks, several jurisdictions including British Columbia, Alberta, Saskatchewan, Manitoba, Ontario and Quebec have updated guidance regarding visitor restrictions ([Appendix B: Supporting Documents #1](#)). These guidance updates are examples of the evolving COVID-19 situation that is highly provincial/territorial, regional and local in nature. They are examples of what is possible and underpin the necessity of regularly examining and re-considering restrictive guidelines to ensure a comprehensive approach that takes into account the full range of risks from a patient and societal perspective, including infection control but also well-being, experience and safety.

The report is also intended to be a resource for hospital administrators and staff who are applying provincial/territorial guidance to their hospital and determining the best, most compassionate policy for family caregiver presence as essential partners in care.

Finally, we hope the report will be an important source of information and consideration for patients, family and caregivers who are seeking to partner in care in a time of COVID-19. They must remain partners in care. This partnership may look different depending on the provincial/territorial, regional and specific hospital circumstances during these challenging times, however there should be a focused effort to support the essential role of family caregivers and embed this partnership role within and across hospitals.

Family Caregiver Presence and Partnership in Long-Term Care Settings

The original work of CFHI's Better Together programming focused on hospital settings, as the initial evidence base for family caregiver presence emerged from hospital-based settings. During this time of COVID-19, issues emerging from the long-term care sector are notable, including the role of family caregiver presence as essential partners in care. Recognizing that long-term care is not part of the Canada Health Act and the jurisdiction and regulation for long-term care and other settings (including home care) is determined by a different set of provincial/territorial legislation and regulation, the work of the advisory group focused on hospital settings. A separate stream of work at CFHI is being developed that will focus on family caregiver presence as essential partners in care in long-term care settings. We hope this report and the work of this advisory group will provide guidance to current "visitor restrictions" for family caregivers who are essential partners in care in long-term care and congregate resident settings, and will serve as a basis of evidence for future work in long-term care.



HOW TO MOVE AHEAD

The advisory group identified key next steps to move forward and reintegrate family caregivers as essential partners in care. The audience for the next steps includes: provincial/territorial health authorities, regional health authorities, medical officers of health, hospital senior leadership, boards of directors, clinical staff, patient relations and patient engagement teams, and research and academia. Across the healthcare system, a considered approach of the required actions for each step will be important.

1. ENSURE A FOUNDATION OF PATIENT- AND FAMILY-PARTNERED CARE

The advisory group emphasized the importance of embedding an underlying philosophy of person-centred and patient-partnered care, as well as the role of the family caregiver as an essential partner in care across the health system.¹ In times of crisis, this philosophy may look different but should remain foundational to how hospitals organize and provide care, for instance:

- Patient, family and caregiver partnership is a strategic focus, foundational principle and guiding value for the hospital.
- Patient, family and caregiver lived experience informs and is part of hospital policy, program and practice.
- Staff are prepared, trained and supported to partner with patients, family and caregivers.
- Family caregivers are recognized and supported as essential partners in care using a consistent approach and formalized role.
- Patient, family and caregiver lived experience and partnership is core to quality improvement.
- Leaders model behaviours and practices that support a culture of partnership in care.

Patient engagement is the involvement of patients and/or family members in decision-making and active participation in a range of activities (e.g. planning, evaluation, care, research, training and recruitment). Starting from the premise of expertise by experience, patient engagement involves collaboration and partnership with professionals.²

NEXT STEPS

1.1. Ensure the philosophy of patient- and family-centred and partnered care are foundational to practice, policy development and decision-making within a hospital, even in times of crisis.

RESOURCES

- [Better Together Change Package](#)
- [The Institute for Patient-and Family-Centered Care](#)
- [10 Lessons Learned from Patient and Family Advisors](#)
- [10 Insights from Healthcare Providers and Leaders](#)



2. REVISIT POLICIES ON FAMILY PRESENCE WITH PATIENT, FAMILY AND CAREGIVER PARTNERS AT THE TABLE

While a heavy focus on infectious disease risk management related to COVID-19 was understandable at the outset of the pandemic, concerns have emerged related to patient safety and well-being from extended blanket “visitor restrictions.” As we learn more about COVID-19 and the pandemic status unique to each province/territory, region and hospital, the advisory group noted the importance of taking into account benefits and harms of blanket “visitor restrictions” when considering go-forward policies.

Consistent with a commitment to patient- and family-partnered care, when the re-integration of family caregivers as essential partners in care is considered by a hospital, the advisory group indicated that changes and updates to guidelines and policies should be revisited in collaboration with patient, family and caregiver partners. Doing so helps ensure patient and community values, experiences and knowledge are incorporated into care discussions at a policy level and in patient care.

NEXT STEPS

- 2.1. Review policies to support the re-integration of family caregiver presence in hospitals in collaboration with patient, family and caregiver partners.
- 2.2. Consider the regional/local/hospital pandemic status when supporting the re-integration family caregiver presence as essential partners in care.
- 2.3. Support hospital staff (administrative and clinical) to understand, value and support the role of family caregivers as essential partners in care. Offer them guidance and tools to ensure family caregivers can continue to partner in care during the pandemic.

RESOURCES

- [Better Together Change Package](#)
- [Planetree: Person-Centered Guidelines for Preserving Family Presence in Challenging Times](#)
- [Report of the Diversity in Patient Engagement Learning Exchange](#)
- [Diversity in Patient Learning Exchange Case Studies and Framework](#)



3. DISTINGUISH BETWEEN FAMILY CAREGIVERS WHO ARE ESSENTIAL PARTNERS IN CARE AND VISITORS

Family caregivers who serve as essential partners in care are different than general visitors. Most broad-based policies introduced in the context of the pandemic did not distinguish between the two, although many hospitals' pre-pandemic policies did. ([Appendix B: Supporting Documents #1](#)).

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A clear distinction must be made between “visitors” who are non-essential and not directly partnering in the care of the patient and 1-2 “family caregivers” as designated by the patient should be considered active and essential partners in care.

The important role of family caregivers as partners in care is grounded in the growing evidence that demonstrates their presence has a range of benefits to care, experience, safety and outcomes.^{3,4} This includes decreased patient anxiety during procedures,^{5,6} improved medication adherence, maintained cognitive function in older adults and prevention of falls,^{7,8,9,10} improved accuracy and quality of shared information,¹¹ improved transitions and understanding of discharge instructions,¹² and lower readmission rates.^{13,14} Visiting policies that are not accommodating and do not involve essential partners in a patient's care can increase anxiety and dissatisfaction in both critically ill patients and their families,¹⁵ increase risk for medication errors and falls and can result in inconsistent patient care or withholding of needed treatment¹⁶ while in hospital.

Advisory group members pointed out that patients' rights under the Canadian Charter of Rights and Freedoms and provincial human rights law are at stake. They noted the right to security of the person (section 7 of the Charter), and the right to be free from discrimination (section 15 of the Charter and discrimination provisions in provincial human rights codes). Blanket restrictions on access to hospitals may affect the ability to obtain consent for treatment and the effective articulation of the patient's interests and personal health needs. Designated family caregivers become the voice of the vulnerable patients who cannot speak for themselves. They can be essential to enable patients to obtain equal access to health care.

Evidence is emerging both anecdotally and in the research literature of psychological trauma, post-traumatic stress and moral distress expressed by healthcare providers who seek to provide patient- and family-partnered care, and the trauma experienced by patients and families as they are isolated from trusted family caregivers.^{1,2,17}

Directives and guidance regarding “visitor restriction” policies have been provided at the provincial/territorial and regional/local levels across the country. The advisory group noted these directives have been applied inconsistently in several jurisdictions. For instance, the advisory group cited where restrictions to visitation were introduced through a public health order which did not align with the family presence philosophy of the provincial health authority. It was highlighted that authority and accountability to restrict or permit family caregivers as essential partners in care remains unclear in some jurisdictions as there are variations in provincial/territorial healthcare structures and overlapping or unclear authority regarding public health decision-making and hospital leadership authority and/or accountability.



The advisory group felt that, in many hospitals, the interpretation of the provincial/territorial directives and guidance has been stricter than possibly intended. There are several questions about authority and accountability when it comes to the interpretation of directives and guidance for “visitor restrictions,” and there is a lack of clarity surrounding whose authority it is to determine what an “essential visitor” means (as referenced in some provincial, regional and hospital guidance). In a person-centred and patient-partnered healthcare system, patients would also have authority/autonomy to determine who is essential to support them in their care.

Family Caregivers are those people who are designated by the patient to partner in their care and may include: family caregivers, non-family caregivers, support people, power of attorney or substitute decision makers.

NEXT STEPS

3.1. Clearly distinguish between “visitors” and “family caregivers” who patients designate as active and essential partners in care. This distinction in language should be used consistently and at all levels of guidance, including provincial/territorial, regional, organizational and hospital (administrative and clinical).

3.2. Ensure a clear understanding of whose authority determines the interpretation of provincial/territorial guidance and directives, particularly as to who are considered “essential” partners in care. Address inconsistencies in the application of guidance and directives.

3.3. Support increased awareness among patients, communities, and hospital teams of the distinction between family caregivers as essential partners in care and how this differs from “visitors.”

RESOURCES

- [Better Together Change Package](#)
- [The Change Foundation/Ontario Hospital Association Summary Report: Family Presence and Open Visiting Policies in Ontario Hospitals](#)
- [The Caregiver Identification \(ID\) Program and Family Presence Policy](#)



4. CONSIDER THE NEEDS OF PEOPLE WHO FACE SPECIFIC RISKS WITHOUT THE PRESENCE OF FAMILY CAREGIVERS AS ESSENTIAL PARTNERS IN CARE

All patients can benefit from the support of designated family caregivers as essential partners in care, but a lack of this support can accentuate inequities that already exist in the care of some populations. These populations may be at particular risk without this support.

Some early guidance and recommendations allowed for specific people to have “essential visitors.” Examples often included pediatric patients, mothers giving birth and individuals at end-of-life. The advisory group highlighted gaps in these lists that have become apparent. They also noted that the reliance on individual providers or organizations to interpret what is meant as “essential” has proven challenging and has led to inconsistencies.

More recent guidance has addressed this issue. For instance, the COVID-19 Disability Advisory Group to the Minister of Employment, Workforce Development and Disability Inclusion indicate that, “the Government of Canada is committed to ensuring that it considers, respects and incorporates the interests and needs of persons with disabilities into its decision-making and pandemic response.”¹⁸ Several jurisdictions, both provincial/territorial and regional, have also developed ethical frameworks for pandemic response ([Appendix C: Provincial Resources](#)). These frameworks outline the guiding principles to justify and support public health policies, goals of the pandemic response specific to a jurisdiction, and justification for easing public health restrictions. They may be guides in the context of a comprehensive risk-tailored approach to the re-integration of family caregiver presence as partners in care.

NEXT STEPS

4.1. Consider inequities in the care of some populations where the absence of family caregivers as essential partners in care may result in additional risk and unintended harm. Examples include, but are not limited to:

- People with an intellectual disability who require decision-making and/or communication support
- People with a physical disability who require physical and/or communication support
- People with medical complexity and multi-systemic conditions
- People with impaired cognitive functioning (e.g. global developmental delay or dementia) who require decision-making and/or communication support
- People who are experiencing social anxiety, depression and/or requiring mental health support
- People with specific linguistic and/or cultural needs
- People for whom the patient and clinical care team have concluded that a family caregiver as an essential partner in care is required
- People who have recently transitioned (< 1 year) from pediatric to adult care
- People who will require comprehensive discharge planning where a family caregiver presence/role will be imperative to implement.



5. TAKE A COMPREHENSIVE, BALANCED APPROACH TO ASSESSING RISKS

A comprehensive risk-based (also known as risk-tailored) approach is about managing the risk from many perspectives. The adoption of blanket “visitor restriction” policies has been a blunt instrument to curtail the infectious disease risk of COVID-19 within hospitals, in an effort to minimize risk to patients and providers alike. Restricting the number of potential contacts and contact intensity (through physical distancing and PPE use) has been the primary focus of these policies.

Recognizing COVID-19 will be present for some time and other infectious disease outbreaks may bring similar issues, the advisory group noted the importance of also weighing other risks that these policies have unintentionally introduced, as outlined in several of the previously stated next steps. This process needs to be dynamic, taking into account the status of the pandemic, response capacity and knowledge about risks will continue to evolve. Harm reduction principles can be helpful in this regard.

NEXT STEPS

5.1. Introduce a comprehensive and collaborative approach to harm reduction for the re-integration of family caregivers as essential partners in care that includes expertise from multiple perspectives including public health, health professionals, ethicists, healthcare administrators and people with lived experience (patients, families and caregivers).

5.2. Consider local/regional circumstances and pandemic status, including advice from public health authorities, in developing guidance for applying family caregiver presence policies.

5.3. Outline a comprehensive harm reduction approach that takes into account practical implementation considerations such as:

- Making a clear statement, readily available to patients, families and caregivers via the hospital’s website and other communications media regarding both “visitor restrictions” and guidance on family caregiver presence as essential partners in care. This should include information on how decisions about family caregiver presence will be made.
- Screening family caregivers for exposure to COVID-19 (similar to staff screening procedures) and logging their presence to support contact tracing if required
- Providing information and training on infection control protocol, physical distancing and isolation (while in hospital) for family caregivers
- Supporting the effective use of PPE where/when available and appropriate
- Ensuring designated family caregivers are identified to the healthcare team so staff understand who they are, why they are at the bedside and that they have been informed of their role and responsibility as an essential partner in care (for instance, through “family caregiver” ID and being identified in the patient health record)
- Educating staff on the value and importance of family caregiver presence
- Where physical presence of family caregivers is not possible, ensure virtual partnership in care is effectively supported (for instance, active participation in shared decision-making, bedside rounds, daily updates and contact with the patient).



RESOURCES

- [TOH Education - Personal Protective Equipment for Family Caregivers \(Donning/Doffing PPE: COVID-19 Simulations from the Ottawa Hospital\)](#)
- [The Change Foundation/Ontario Hospital Association Summary Report: Family Presence and Open Visiting Policies in Ontario Hospitals](#)
- [The Caregiver Identification \(ID\) Program and Family Presence Policy](#)



6. ESTABLISH A RAPID APPEAL PROCESS

Ethical decision-making frameworks developed for the pandemic include principles and values such as: respect, the Harm Principle, fairness, proportionality, partnership, flexibility, least coercive and restrictive means, working together, reciprocity and procedural justice (which includes the principles of openness and transparency, inclusiveness, accountability, reasonableness). Examples can be found in this document under Provincial Resources.

The advisory group noted there have been inconsistent interpretations of “visitor restriction” guidance or recommendations. They advised that patients and family caregivers need access to a rapid appeal process because how to appeal a decision is not always clear and/or existing processes have been overwhelmed with the volume of requests made during the pandemic. Timely access is critical when considering the role of an essential partner in care, given the potential implications for continuity of care, patient well-being and safety, patient experience and other outcomes when they are not present. The advisory group noted that clarity regarding appeals processes is important to increase fairness and transparency.

NEXT STEPS

6.1. Ensure broad communication of the hospital’s policies regarding family caregivers as essential partners in care, how decisions about family caregiver presence will be made and the appeal process.

6.2. Consider COVID-19 specific appeals processes at the provincial/territorial, regional, and/or hospital level where existing structures do not enable timely decisions. Such an appeals process should be rapid and transparent, be aligned with federal/provincial/territorial/regional ethical decision-making frameworks (where available), ensure a trauma-informed approach, be inclusive of the patient and designated family caregiver perspective, and be able to be accessed by a clinical team on behalf of a patient and/or family caregiver.



7. INCREASE THE EVIDENCE TO GUIDE DECISIONS REGARDING FAMILY CAREGIVER PRESENCE

There is much we do not know about family caregivers' presence as essential partners in care, associated effects on patient experience and quality of care, as well as implications for safety and infection control during a pandemic. This makes weighing the benefits and harms of potential policies on family caregivers as essential partners in care in this context challenging. The absence of evidence is not evidence against. Examples of potential research questions include:

- How do different policies on family caregivers as essential partners in care – including access to PPE, training in infection prevention and control and testing – change the risk of nosocomial infection?
- How do they influence other dimensions of safety and quality including medication safety, mental health, continuity of care and patient experience?
- What are the short- and long-term implications of such policies on patient, family caregiver and clinician health and well-being?
- How do policies affect patient care and clinical human resource capacity (for instance, when essential partners in care who have been providing substantial amount of personal care are stopped from doing so)?

NEXT STEPS

7.1. Continue to review relevant literature and synthesize the existing evidence base to support comprehensive risk-tailored assessments regarding family caregiver presence as essential partners in care.

7.2. Examine existing models for infection prevention and control, as well as best practices to support harm reduction approaches in the context of the re-integration of family caregivers as essential partners in care during outbreaks, including the current pandemic but also other infectious disease outbreaks.

7.3. Prioritize research into the impact (including patient safety implications) of initial and evolving “visitor restriction” guidance and the restriction of family caregivers as partners in care.



APPENDIX A: RAPID RESPONSE EXPERT ADVISORY GROUP MEMBERS

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APPENDIX B: SUPPORTING DOCUMENTS

1. [Much More Than Just A Visitor: An Executive Summary of Policies in Canadian Acute Care Hospitals](#)
2. COVID-19 Government Policy Guidance Scan
3. CFHI Family Presence Evidence Brief and Literature Search

APPENDIX C: PROVINCIAL RESOURCES

1. [Ottawa Public Health Ethical Framework for Pandemic Response](#)
2. [Coronavirus COVID-19 – BC Centre for Disease Control & BC Ministry of Health: COVID-19 Ethical Decision-Making Framework](#)
3. [Shared Health Manitoba: COVID-19 Ethics Framework Information for Providers](#)
4. [Saskatchewan Health Authority Framework](#)
5. [Access to Hospitals for Essential Visitors Guidance for Toronto Regional Hospitals](#)



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