POLICY GUIDANCE: ESSENTIAL TOGETHER

Recognition of Essential Care Partners as Members of the Care Team

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Healthcare Excellence Canada works with partners to spread innovation, build capability and catalyze policy change so that everyone in Canada has safe and high-quality healthcare. Through collaboration with patients, caregivers and people working in healthcare, we turn proven innovations into lasting improvements in all dimensions of healthcare excellence. Launched in 2021, HEC brings together the Canadian Patient Safety Institute and Canadian Foundation for Healthcare Improvement.

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Executive summary

This policy guidance to integrate the role of essential care partners (ECPs) as members of the care team is for healthcare decision-makers — notably system-level policy-makers — and health system leaders. The policy guidance was co-developed as part of a 2022 collaborative policy lab process that included policy/decision-makers, health system leaders who implement policy and the people impacted by policy decisions: providers, patients,* families and caregivers. This policy guidance may be applied in all settings where people receive care, including hospitals, long-term care, congregate care facilities, primary care, home care and elsewhere in the community. It further builds on Healthcare Excellence Canada's earlier Policy Guidance for the Reintegration of Caregivers as Essential Care Partners. ECPs play a key role across the continuum of care to support quality and safety of care of their loved ones.

Background/Context

The benefits of the caregiving provided by family and other informal caregivers are well recognized. Each year, ECPs account for $97.1 billion in unpaid resources for the healthcare system across Canada,[1] improve patient outcomes and well-being and help reduce pressures on over-burdened care facilities. The recognition of ECPs as key members of a person's healthcare team is a foundational element of person-centred care.

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* For the purposes of this report, "patient" also includes clients and people living in long-term care/nursing homes/advanced care homes, other congregate care facilities and in their own homes.

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The essential nature of these care partners was brought into stark relief during the blanket visitor restrictions imposed by care facilities in the first year of the COVID-19 pandemic. The absence of ECPs resulted in a range of unintended harms that impacted not only patients, but also caregivers and healthcare professionals. For patients, these harms included more falls, issues with medication reconciliation and deteriorated physical and mental health.[2] ECPs experienced increased psychological and emotional distress and increased social isolation resulting from reductions in family support as well as disruptions to care in the home.[3] Staff saw increased workloads, moral distress and burnout.[4]

Lessons learned throughout the pandemic point to the need to crisis-proof policies and practices that fully embed and integrate ECPs across the continuum of care. As a starting point, it is important to differentiate between "visitors" and "ECPs". Clearly defining, recognizing and valuing the role of ECP will ensure that their presence is not unduly limited in the future. This requires equitable policies and practices that provide flexibility to address patient needs; clear, respectful communication with patients and their care partners; and accountability that characterizes person-centred care. ECP policies are grounded in a philosophy of person-centred care, which is critical to ensure a more resilient health system in the face of future crises.
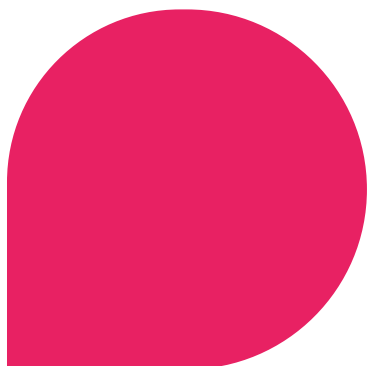
Definitions

Blanket visitor restrictions refer to restrictions that extend to all "visitors" entering a facility, often without exceptions, including ECPs.[5, 6]

Essential care partners (ECPs) are caregivers who provide physical, psychological, spiritual and emotional support, as deemed important by the patient. This care can include support in decision-making, care coordination and continuity of care. ECPs can include family members, close friends or other caregivers, and are identified by the patient or substitute decision-maker as ECPs.[7]

Health and care organizations refer to any setting where a person receives healthcare or care, including hospitals, long-term care/nursing homes/advanced care homes and other congregate care settings.

Health and care teams refers to health professionals and paid care providers who provide health and care services.

Patient refers to anyone receiving healthcare or care in any setting. This can include patients, clients, healthcare users and those living in congregate care/long-term care/nursing homes/advanced care homes.[8]

Person-centred care is a holistic approach that includes family, significant others, context, prevention, promotion and preferences. It builds on the concept of patient- and family-centred care that includes compassion, empathy, respect and responsiveness to the needs, values and expressed desires of each individual patient. Person-centred care is personalized, coordinated and enabling.

Visitors play an important social role for patients; however, they do not engage as active partners in care.[9, 10]

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Guiding Principles

Policy lab participants identified two guiding principles as foundational to integrate the role of ECP as a member of the care team:

1. **Value and recognize the role of ECP throughout the journey of care**

   ECPs bring unique knowledge and experience of supporting their loved ones throughout the journey of care in all care settings. They know their loved ones best and can often provide necessary information and act as essential communicators with health providers. Evidence shows ECPs (often family or other informal caregivers) provide over $97.1 billion worth of care annually in Canada. The active involvement of ECPs improves patient outcomes, increases patient safety, improves psychological and mental well-being, and improves quality of life.[11] During care transitions that are often fraught with uncertainty, anxiety and stress, the role of care partners becomes even more critical to ensure safe transitions within the system and to/from home, community and healthcare settings. ECPs help to ensure better continuity of care.

2. **ECPs are partners in care, not replacements for other healthcare team members**

   ECPs are not a replacement for paid or professional members of the care team. Education is needed for healthcare providers across the health system and in the community to understand the value of the ECP role and how this role can support their work and augment existing care roles. Patients and caregivers who assume the role of ECP also need to understand the ECP function, the expectations regarding how to provide safe, appropriate care and how to access support. As is inherent to person-centred care, the roles that ECPs play are determined by patients and caregivers in discussion with members of the healthcare team.

Policy Guidance

This policy guidance for the recognition of ECPs as members of the care team is fundamental to the practice of person-centred care, and focuses on three key elements:

1. Create the foundation to welcome the role of ECP.

2. Establish the role of ECP and take accountability to integrate the role.

3. Support the role.

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Table 1: Policy guidance for integration of ECPs as members of the care team

I. Create the foundation to welcome the role of ECP.	
Take a person-centred care approach to care.	• Make a person-centred approach to care the basis for ECP policies and practices.
Use the evidence base to demonstrate the value of ECPs.	• Ground person-centred practices by using and expanding the evidence base for the value of ECPs.

II. Establish the role of ECP and take accountability to integrate the role.	
Establish a standard definition for the ECP role.	• Develop a nationally (provincially and territorially) accepted document that defines the role and value of ECPs.
Provide education regarding the ECP role.	• Develop educational tools and opportunities for patients and caregivers about the ECP role and the value for caregivers to be designated as an ECP. • Offer education and training to those providing and leading care efforts (e.g. healthcare providers, leaders, policy makers) about the role and value of ECPs. • Establish clear communication regarding the role and value of ECPs to patients and others involved in care.
Create accountability to integrate the role.	• Establish an accountability framework/ pathway for each care team to clarify roles and responsibilities and ensure effective communication about and with ECPs.

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III. Support the role.

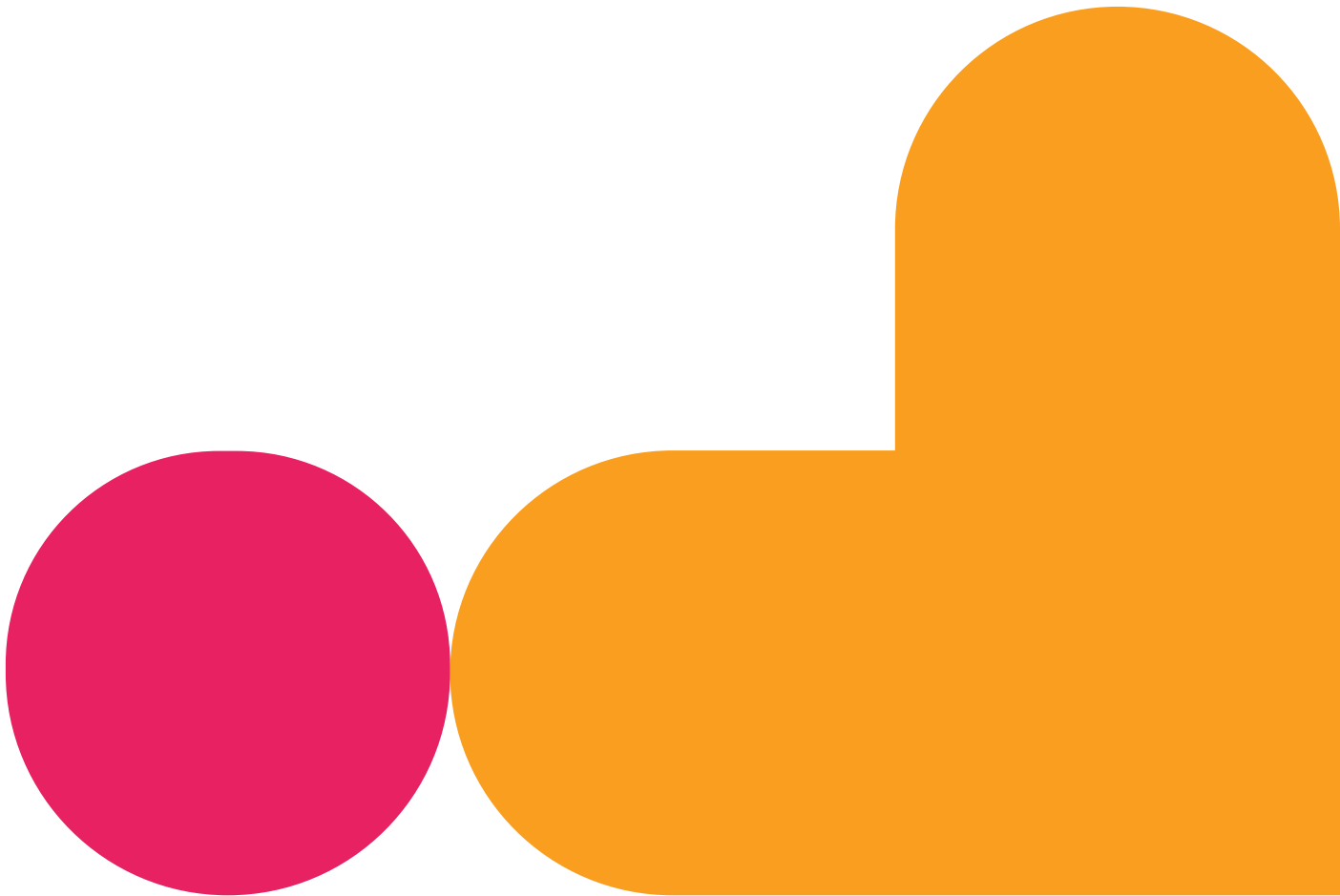|	
Provide training/educational supports and resources to increase the skills and confidence of ECPs and to orient healthcare teams and other staff toward the role and value of the ECP.	• Ensure training/education supports and tools are developed and available for ECPs, as well as orienting healthcare teams and other staff members in collaborating with ECPs.
Provide opportunities for peer-to-peer support.	• Create and/or promote venues for peer-to-peer learning and support, and provide information about external peer support resources.
Develop a system navigator role.	• Establish a system navigator role to act as a health system guide, and support patients and ECPs through the care journey.

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Policy guidance for recognition of essential care partners as members of the healthcare team

Overview

The essential nature of care partners and their importance in supporting the care of their loved ones is evident. Essential care partners (ECPs) bring unique knowledge and experience to the care of a patient throughout the journey of care – in the home and community, within health and care institutions, and through transitions in care. As we have learned throughout the COVID-19 pandemic, the absence of ECPs during times of strict lockdowns in health and care facilities was notable. Their absence negatively affected patient safety and the experiences and outcomes of patients, residents, and care partners, as well as for health and care staff. Now is the time to build resiliency into the system, and to crisis-proof person-centred policies and practices that recognize and support the presence of ECPs by fully integrating them as members of the healthcare team.

This report offers policy guidance to support a consistent and effective approach for recognizing the role of family and other caregivers as ECPs and as vital and active members of the care team across the care journey, in health and care facilities,[1] and in the home and the community. This guidance aims to inform and support those who are developing and implementing policy regarding the recognition and presence of ECPs, including health ministries, regional health authorities, and healthcare system and long-term care administrators and leaders. This policy guidance offers a holistic approach to the integration of ECPs in care teams that embody the principles of person-centred care.

Healthcare Excellence Canada (HEC) developed and revised Policy Guidance for the Reintegration of Caregivers as Essential Care Partners during early phases of the pandemic when blanket visitor restrictions were introduced. The guidance focused on the co-development and implementation of person-centred policies that enabled the safe re-entry of ECPs into health and care facilities. The policy lab and report you are reading seeks to further embed the essential role of care partners as members of the care team, recognizing this role as one that spans across the continuum of care, including care that is provided at home and in the community, as well as in institutional care and care in congregate settings. In effect, ECPs accompany and care for patients from home to health and care facilities and back to home, and continue providing that care even when formal healthcare resources end.

Context

ECPs across Canada provide care estimated at over $97.1 billion annually.[12] The benefits that ECPs bring are well known, with clear evidence that demonstrates improvements to patient safety, patient experience, patient outcomes and patient care across a range of institutional care settings.[13] Throughout the COVID-19 pandemic, the importance of their role became more evident as ECPs continued to care for their loved ones at home and in the community when services were being drastically reduced or altered. When the presence of ECPs was restricted in health and care facilities, significant unintended harms resulted,[14, 15, 16, 17, 18, 19] including increased fall incidents, medication errors and exacerbation of mental health issues and dementia.[6] ECPs experienced significant moral distress and anxiety in not being able to care for their loved ones.

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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.

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Staff noted increased workloads, concerns for their own safety and that of patients, and some expressed moral distress from having to abide by restrictions that separated patients/residents and their care partners.[6, 20, 21, 22]

As the pandemic continued through subsequent waves, our ongoing policy scans revealed that provincial and territorial directives shifted to become less restrictive. There is growing understanding about the difference between "visitors" and "ECPs" for public health protocols intended to keep patients, caregivers and providers safe. In addition, the harms that have resulted when blanket restrictions are enforced are becoming more widely recognized. Despite the changing policy context, implementation of such policies at the facility level has not been consistent[23] and anecdotal reports of ECPs being denied access to their loved ones persist across the country. We need to incorporate the lessons learned from this pandemic and build resilience into the healthcare system to ensure that the presence of ECPs is an embedded, person-centred practice at all times going forward — and not an exception.

HEC conducted a policy lab in summer 2020 that co-developed policy guidance to support a safe and consistent approach for reintegrating ECPs back into healthcare facilities, long-term care and congregate care settings during the pandemic. This co-designed policy process brought together people with a diverse range of expertise and COVID-19-related experience — including policy-makers, healthcare administrators, providers, patients, families and caregivers. Together, they detailed an "ideal journey map" for the caregiver experience, which formed the foundation of the co-developed policy guidance. The policy guidance was updated during the summer of 2021 as the COVID-19 pandemic continued to evolve and planning for recovery and resiliency began.

Building on this earlier work, a subsequent policy lab was held in the summer of 2022 to focus on how to further embed and integrate ECPs as vital and active members of the care team throughout the care journey. A journey map of the ECP role was updated during the 2022 policy lab to create a visual representation of the key actions critical to identifying, establishing and supporting ECPs as members of the healthcare team throughout the care journey. (See Figure 1 for the map and Appendix C for the map-development process.) The policy guidance in the 2022 lab focused on the third and fourth elements of the journey map — Caregiving and Transitions.
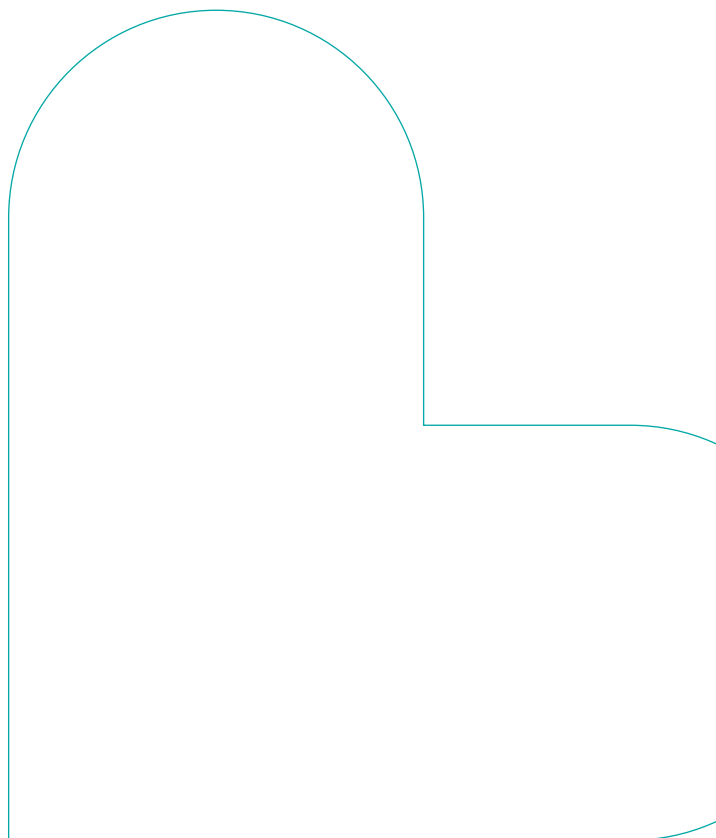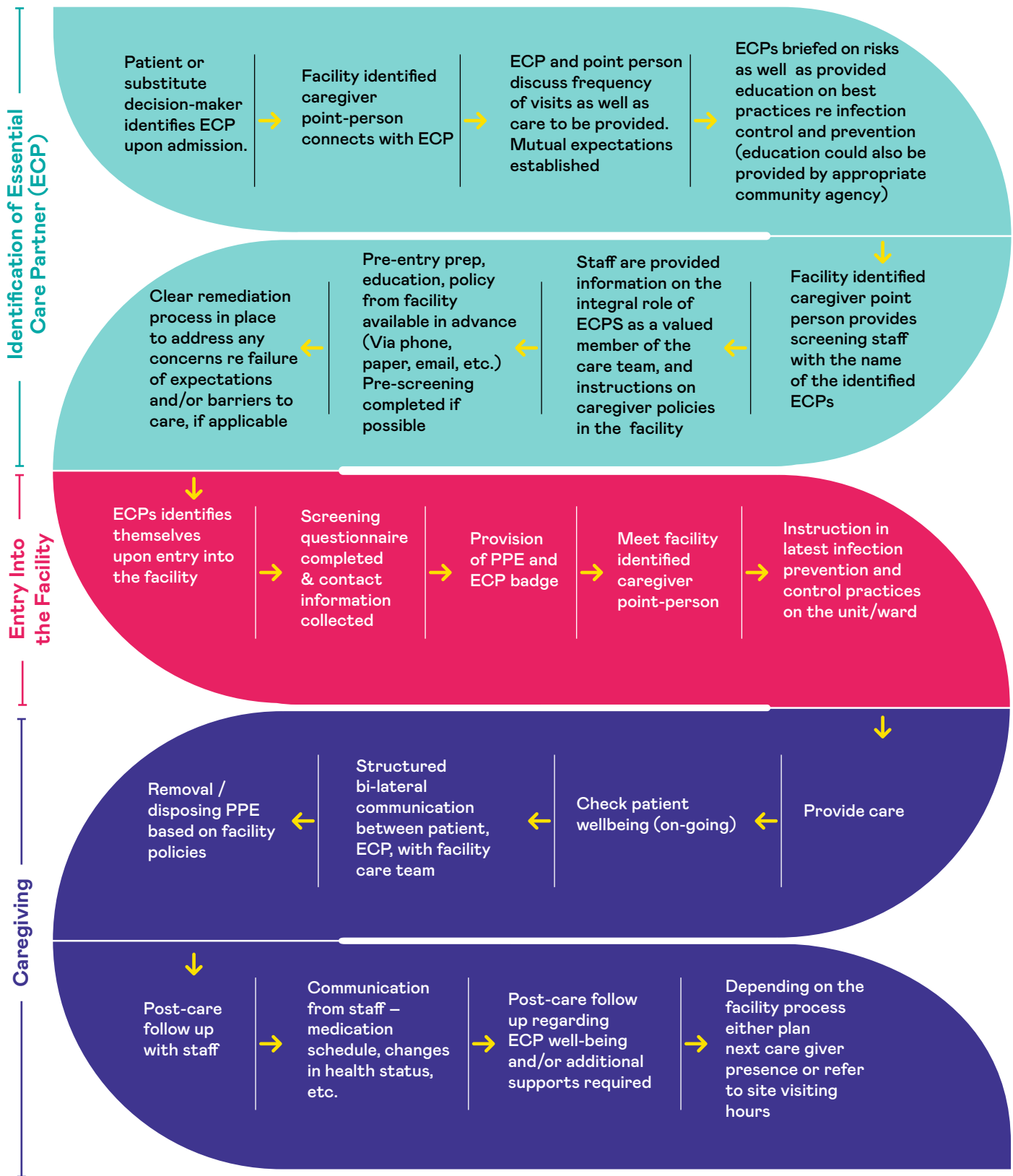
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Figure 1: Essential Care Partner Map

ESSENTIAL CARE PARTNER MAP

Identification of Essential Care Partner (ECP)

Patient or substitute decision-maker identifies ECP upon admission. → Facility identified caregiver point-person connects with ECP → ECP and point person discuss frequency of visits as well as care to be provided. Mutual expectations established → ECPs briefed on risks as well as provided education on best practices re infection control and prevention (education could also be provided by appropriate community agency)

↓

Clear remediation process in place to address any concerns re failure of expectations and/or barriers to care, if applicable ← Pre-entry prep, education, policy from facility available in advance (Via phone, paper, email, etc.) Pre-screening completed if possible ← Staff are provided information on the integral role of ECPS as a valued member of the care team, and instructions on caregiver policies in the facility ← Facility identified caregiver point person provides screening staff with the name of the identified ECPs

Entry Into the Facility

ECPs identifies themselves upon entry into the facility → Screening questionnaire completed & contact information collected → Provision of PPE and ECP badge → Meet facility identified caregiver point-person → Instruction in latest infection prevention and control practices on the unit/ward

Caregiving

Removal / disposing PPE based on facility policies ← Structured bi-lateral communication between patient, ECP, with facility care team ← Check patient wellbeing (on-going) ← Provide care

↓

Post-care follow up with staff → Communication from staff – medication schedule, changes in health status, etc. → Post-care follow up regarding ECP well-being and/or additional supports required → Depending on the facility process either plan next care giver presence or refer to site visiting hours

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Policy lab approach

Healthcare Excellence Canada conducted a policy lab series to create policy guidance for recognizing ECPs as members of the care team. Through multiple virtual sessions, guidance was developed with the expertise and experience of four user groups:

1. patients and ECPs

2. direct care staff and managers

3. health system leaders

4. provincial and territorial decision-makers

The methodology of the policy lab is detailed in Appendix B.

This policy lab builds on longstanding work that HEC has done related to family presence and the essential role of care partners, including:

- the Better Together campaign and programming

- a webinar and subsequent series on family and caregiver presence during COVID-19

- an expert advisory group that co-developed the report Reintegration of Family Caregivers as Essential Partners in Care

- an initial policy lab in advance of the Reintegration of Families and Caregivers as Essential Partners in Care report[7]

- Essential Together programming to implement policy guidance for the safe reintegration of essential care partners
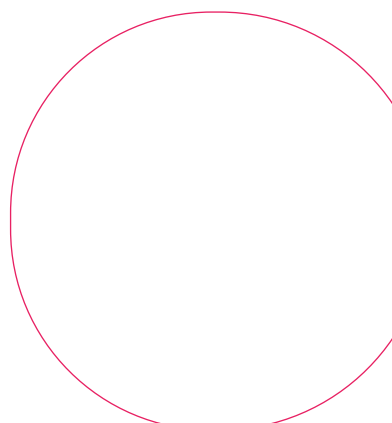
Guiding Principles

Policy lab participants identified two key principles that are foundational to enable the full integration of ECPs as members of the care team. These principles are fundamental to establishing a model of care that increases the resilience of health systems by recognizing the necessary partnership with patients and their ECPs.

Value and recognize the role of ECP throughout the journey of care

ECPs bring unique knowledge and experience of supporting their loved ones throughout the journey of care. This is true in institutional care settings and residential or congregate care, for outpatients in community settings and in the home. ECPs know their loved ones best, and can often provide necessary information and act as essential communicators with health providers.

Caregivers provide support equivalent to 2.8 million full-time paid care providers each year, as well as providing three hours of care for every one hour in healthcare and social support systems.[24] The active involvement of ECPs has demonstrated improvements in patient outcomes, increased patient safety, increased psychological and mental well-being and improved quality of life.[25] In particular, during times of care transitions that are often fraught with uncertainty, anxiety and stress, the role of care partners becomes even more critical to ensure safe transitions within the system and to or from home and community and healthcare settings.

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ECPs are partners in care, not replacements for other team members

While ECPs have unique roles as members of their care teams, they do not replace healthcare team members and are not considered to be paid or professional healthcare workers.

Currently, challenges exist in establishing and maintaining partnerships with ECPs, especially where clarity is lacking about the role and how it might differ across care settings. In long-term care, where ECPs may be a more constant presence and involved for a longer period, it may be easier to build trust and partnership than in an acute care setting, where the patient may have a much shorter stay.

Education is needed for healthcare providers across the health system and in community to understand the value of the ECP role and how this role can support and augment their work. Furthermore, as ECPs provide the vast majority of care in home and community, education opportunities can help ECPs learn how their unique role fits into the care team across the journey of care, including how to deliver safe, appropriate care and how to access support when needed. Proper communication and tools to help build trust will be essential.

The COVID-19 pandemic has greatly exacerbated existing health human resources shortages in many settings. These shortages will continue for some time, so it is critical to increase partnership and role clarity within the care team. From the ECP perspective, transparency is often lacking from staff and institutions about shortages and other challenges that might impact care. It is critical for ECPs to be part of conversations and solutions to improve care and outcomes for patients and providers. At the same time, ECPs cannot be viewed as a solution for shortfalls in professional healthcare staffing.

Detailed Policy Guidance

The ECP journey map, updated in this policy lab, provides a visual representation of the key actions critical to identifying, establishing and supporting ECPs as part of the care team throughout the care journey. (See Appendix C for the map development process and Figure 1 for the map.) The policy guidance in this recent lab focused on the third and fourth elements of the journey map: Caregiving and Transitions.

Importantly, a philosophy that values partnering with patients and their caregivers throughout the care journey creates the foundation to welcome ECPs and to develop the role. This role may be clarified by establishing a standard definition and terminology for ECPs. (See p. 8 of this national scan of hospitals and long-term care facilities for terminology used in lieu of "essential care partner".) Education in the form of training, resources and support systems is needed for healthcare professionals as well as for patients and ECPs to help firmly establish this role. Accountability mechanisms are also needed.

> Patient engagement and partnership approaches to care have demonstrated improved organizational culture, improved care, experiences and outcomes for patients, caregivers and providers, better adherence to treatment regimes and lower healthcare costs.[26, 27] **The presence and involvement of essential care partners as active members of the care team is an explicit expression of a person-centred philosophy in practice.**

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I. Create the Foundation to Welcome the Role of ECP

1. **Take a person-centred care approach**
   Policy guidance:

   - Make a person-centred approach to care the basis for ECP policies and practices.

   A collaborative environment in which the patient's and care partners' values, needs and perspectives are respected should be the basis for ECP policies and practices. Taking a person-centred approach can increase the consistency and coordination of care that builds in ECP practices across all stages of the care journey and supports equitable health outcomes. Building on concepts of patient- and family-centred care — which emphasizes respect and dignity, information sharing, participation and collaboration — policy lab participants elaborated on this concept of person-centred care by reinforcing many elements:

   - **Engagement and partnership** — Ensure all partners, including patients, families and caregivers, are not only involved in care and shared decision-making, but also engaged in meaningful and intentional ways to co-develop processes and systems of care, including policy, to ensure a more comprehensive approach that balances the many perspectives of risks and harms that need to be considered within a person-centred healthcare system.

   - **Accountability** — Person-centred structures and frameworks are needed to ensure clarity and accountability regarding the value of and approaches to support person-centred care, including a better understanding of the ECP role and the roles of other team members, as well as a commitment to living the values of person-centred care.

   - **Flexibility** — The health system, and the people working within it, need to be flexible to meet the needs of patients and care partners and accommodate their individual circumstances, including the need for multiple care partners to support patient care.

   - **Apply an equity lens** — Policies and practices must be appropriate for patients, families and ECPs from all communities and cultures. Policies and practices should be culturally safe and appropriate and, where possible, eliminate barriers to caregiving.

   - **Compassion and respect** — Employing a compassionate and respectful approach that includes being attentive to both patient and ECP's well-being is essential for effectively integrating the ECP role within the care team.

2. **Use the evidence base to demonstrate the need for and value of ECPs**
   Policy guidance:

   - Ground person-centred practices by using and expanding the evidence base regarding the need for and value of ECPs.

   Families and informal caregivers contribute nearly $100 billion worth of unpaid caregiving to the healthcare system annually, helping keep patients out of hospitals, long-term care and care institutions.[28] The participation of ECPs in care teams has been shown to improve patient outcomes and quality of life and reduce the stress and workload pressures of healthcare providers.[29]

   This evidence, and the contribution of new and emerging evidence, help clarify the contributions and benefits of care partner presence throughout the care journey. Such evidence can also be used to support associated policy development and establish accountability for its implementation at both the jurisdictional and institutional levels. Importantly, such evidence needs to be grounded in the lived experience of patients and their caregivers, and brings together both qualitative and quantitative forms of evidence.

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How to Take Action

Table 2 provides examples of possible policy solutions for creating the foundation to welcome the role of ECP. The policy solutions are not intended to be prescriptive, but instead outline some potential implementation ideas.

Table 2: Examples of policy solutions for creating the foundation to welcome the role of ECP

Related policy guidance	Examples of how to take action on policy guidance
Take a person-centred care approach.	• Create a framework/declaration of values/mission statement founded on person-centered approaches at the organization and system levels. • Design structures and processes to ensure effective and sustained partnerships with patients and care partners that are grounded in respect, compassion and equity. • Support collaborative efforts by removing barriers to accessibility, and address systemic barriers to enable cultural safety and anti-oppression practices. • Create communication mechanisms that are consistent, clear and easy to understand. • Develop accountability frameworks to ensure person-centred philosophy of care is supported in practice and policy.
Use and expand the evidence to support the role of ECPs	• Disseminate evidence that creates understanding of the essential nature of care partners and how they support improved patient care, outcomes and well-being of patients and residents in all settings throughout the care journey, including home and community. • Identify and implement the best practices for effective ECP involvement in care teams in various care settings (e.g. role definition, staff and ECP training, peer support). • Use evidence to support policies that enable care partner presence within health and care facilities, and to integrate their role in healthcare teams across all settings, including home and community and through transitions in care. • Ensure experiences of patients and their care partners provide on-the-ground insights and culturally appropriate perspectives as part of the evidence base. • Include caregivers in workforce surveys and statistics. • Support research and evaluation that contributes to this evidence base.

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II. Establish the Role of ECP and Take Accountability to Integrate this Role

1. **Establish a standard definition for the ECP role**
   Policy guidance:

   - Develop a nationally (or provincially/territorially) accepted document that defines the ECP role.

   The COVID-19 pandemic highlighted the importance of ECPs as well as the negative impacts that blanket visitor restrictions have had on the quality of life and quality of care of patients. To avoid confusion regarding the place of ECPs on the care team, a standard, nationally accepted definition for the ECP role is needed. This will distinguish ECPs from visitors. The definition should specify that the ECP is identified and designated by the patient based on their care needs. Clearly recognizing the distinct roles of ECPs and the value they bring creates conditions that enable person-centred policies to be put into practice. Informal caregivers who act as ECPs may use different language to express their roles; therefore, these persons, as well as the patients they care for, must be made aware of the ECP role and the opportunity for caregivers to be designated as ECPs. Flexibility is key, as patients and their ECPs need to define what the ECP role looks like for them. This may be particularly relevant in a culturally diverse society like Canada.

   More broadly, the ECP role needs to be normalized across healthcare with facilities and professionals, as well as with patients, caregivers and the general public. The role is not widely recognized or understood by those outside the healthcare sector. The ability to designate an ECP, and the advantages of doing so, must be communicated to patients and families upon accessing the system — and they must be welcomed to do so.

2. **Provide education regarding the ECP role**
   Policy guidance:

   - Establish education and clear communication for patients, ECPs and staff regarding the role and value of ECPs.

   Consistent with a jurisdictional, regional and/or organizational philosophy that embraces the principles of person-centred care, it is important for healthcare leaders and staff to recognize the widely accepted role and benefits of caregiver presence and welcome caregivers' physical presence as ECPs. Many organizations use caregiver ID or other processes to identify caregivers who are supporting their loved ones, and link this with standard training for ECPs regarding organizational safety protocols, infection and prevention control practices, and other public health measures.[30]

   Policy lab participants highlighted the need for broad education to alleviate staff concerns and create greater clarity for the role of care partners. Education and training for all members of a patient's care team — healthcare staff and ECPs — are critical for recognizing the mutual value each role brings to the care journey, clarifying expectations for roles to ensure the safety of patients and care team members, and gaining a better understanding of person-centred policies. Shared learning underscores how healthcare teams, patients and ECPs have much to learn from each other. Staff training may be encompassed in broader education related to person-centred philosophy of care. Former patients, ECPs or patient and family advisory council members could serve as co-educators for ECPs and staff, given the shortage of nurses, or use a train-the-trainer model within the healthcare team.

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3. Create accountability to integrate the role

Accountability is essential for ensuring that policies are in place for integrating ECPs in the care team, and that the ECP role is recognized across care setting, into home and community and through transitions in care. Having appropriate structures and processes in place will enable healthcare staff to implement policies and be accountable for person-centred practices within their organizations. New accreditation standards that support people-centred policies and practices also support the accountability of organizations.

Policy guidance:

• Establish an accountability framework/ pathway for each care team to clarify roles and responsibilities and ensure effective communication about and with ECPs.

To support person-centred care within the care team, it is important to establish clear lines of communication, build trust and ensure shared decision-making. An accountability framework/pathway associated with each patient identifies key individuals and points of contact, and ensures regular communication and access to information. Having such a standard tool in place can improve relationships with staff, patients and ECPs, and help ensure the entire care team is kept informed on all matters impacting patient care and well-being.

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How to Take Action

Table 3 provides examples of possible policy solutions for clarifying the ECP role. The policy solutions are not intended to be prescriptive, but instead outline some potential implementation ideas. What works best will depend on the local context of the organization implementing the guidance.

Table 3: Examples of policy solutions for establishing the role of ECP

Related policy guidance	Examples of how to take action on policy guidance

Establish a standard definition for the ECP role.	The definition of the ECP role should broadly encompass the essence of the role and allow for customization that takes into account different care settings and the needs of the individual patient.
	
	• The ECP document should specify:
	   The requirements, responsibilities and rights of the ECP
	
	   That the ECP is chosen and designated by the patient, and the role to be played by an ECP is determined by the patient and their ECP in discussion with the healthcare team
	
	   That multiple ECPs (an ECP team) may be designated, and that ECPs may change over time and as the needs of the patient change
	
	Additionally, the document should acknowledge the importance of a person-centred approach to care and the need to accommodate for cultural differences.

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Related policy guidance	Examples of how to take action on policy guidance
Provide education regarding the ECP role.	• Provide education for patients, ECPs and staff, leaders and policy-makers on partnering in care to ensure mutual respect and facilitate communication and information sharing. • Develop educational tools and opportunities for patients and caregivers about the ECP role and the value for caregivers to be designated as an ECP. • Establish protocols that welcome patients to identify their ECPs as early as possible in the care journey. • Create a shared understanding and expectation that ECPs are integral to the care team, and clearly communicate this understanding to patients, ECPs and all members of the care team. • Ensure ECPs receive training on their role and responsibilities, and how the role functions in various settings, as well as on relevant facility/unit-specific safety protocols, infection control and public health measures. • Offer education and training to healthcare teams about the role and value of ECPs, and ensure they are aware of training provided to ECPs.

Create accountability to integrate the role.	• The accountability framework/pathway should specify:
	
	  How patients are welcomed to designate an ECP
	
	  That ECP(s) are identified by the patient, and their role determined by the patient and ECP in consultation with healthcare staff
	
	  Key individuals on the care team and their responsibilities
	
	  Primary points of contact
	
	  Channels for ongoing and urgent communication, such as how ECPs can access patient information (e.g. EMR, test results)
	
	• The accountability framework should also benchmark and measure success by establishing and auditing standard performance indicators of ECP involvement in patient care.

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III. Support the ECP Role

Participants in the policy lab noted the need to support ECPs in their role, enable them to be recognized and welcomed, and receive support from providers, from peers and through other means within the system. Recognizing the impact of caregiving on care partners is a first step toward putting supports in place to maintain their wellness and avoid burnout.

Many participants in the policy lab spoke about the role that ECPs take on and how this role may be stressful and emotionally demanding. Health human resources shortages and other systemic shortcomings compounded by the pandemic have exacerbated the strain and demands placed on caregivers, increasing their risk of burnout. Healthcare-recognized assessment tools to evaluate caregiver wellness will help identify when further supports are required for both the patient and caregiver. This may include providing respite care and mental health supports, and developing other policy levers such as income supports (e.g. paid caregiving leaves, tax credits).

In particular, transitions from health and care facilities to home and community can be difficult and emotionally draining. ECPs are often expected to carry out various care tasks that may also be technical in nature and for which they may have received minimal training. Often during transitions, there is much information for ECPs to absorb and act on, and the information may change frequently. It can be hard to keep up, and cultural and language barriers can make this even more challenging. Additionally, poor communication protocols can leave ECPs out of the loop and uninformed about key aspects of a transition in care. ECPs need ongoing support to ensure they can provide appropriate care that keeps the patient safely in the home.

Patients and care partners have also expressed frustration at not knowing who is leading or coordinating the patient's care, and whom to go to with questions post-discharge. Often, there are challenges in accessing supports and understanding what resources are available.

The healthcare system is complicated to navigate. Improved access to information and integration with other community services, such as housing and income supports, is needed.

Outlined below are a number of supports highlighted by policy lab participants that may enhance the well-being of caregivers, as well as their ability to carry out their roles as care partners.

1. **Develop and provide training/educational supports and resources to increase the skills and confidence of ECPs, and ensure supports are available to them**

   ECPs take on many roles to support the physical, psychological, spiritual and emotional well-being of their loved ones, and may also take on specific care tasks. Proper training and access to educational resources can make ECPs feel better prepared, and more confident and effective in their role, and can reduce stress and anxiety. Creating more comprehensive lists of supports for ECPs at local, regional, provincial and national levels would help care partners know where to access training, resources and supports when needed. Additional recognition and understanding of caregivers as "both co-provider and co-recipient of care" will foster resilience among ECPs.[31]

2. **Provide peer-to-peer support by creating and/or promoting venues to access peer support services**

   Caregivers, especially those new to the role, can feel alone and overwhelmed by the demands of caring for a loved one. Having a place where ECPs can feel safe to share their experiences with their peers, and receive support by learning with and from peers who have had similar experiences, can help to enhance caregiver wellness, increase their confidence and create a sense of community. Support groups can help new care partners deal with the complexities of caregiving, and those who are more experienced can provide valuable insights and play a mentoring role for others. Peer support is also an opportunity for

experienced caregivers to assist with system navigation.[32] Using a train-the-trainer model, peer workers, former ECPs and members of patient and family advisory councils are excellent candidates for training as peer educators. Peer support programs, including online support groups in Ontario and Alberta, provide evidence of the benefits of this approach.[33, 34]

3. **Develop role for a system navigator who acts as a health system guide and supports ECPs at all stages of the care journey**

    Many ECPs act as advocates for patients and support coordination and continuity of care. Recognizing the complexities and fragmentation of the healthcare system, and the steep learning curve for those not familiar with it, a system navigator can support ECPs as they interact with the various elements and levels of the system. A system navigator can also ensure regular communication and provide an autonomous interface with health providers.

While not a substitute for achieving better integration of services and resources in a fragmented system, system navigators do offer much needed guidance for patients, families and ECPs accessing healthcare services. System navigators also orient them to available resources and programs, and support continuity of care during transitions from one setting or stage of care to another in a way that is culturally appropriate to the patient and their care partner. Having a system navigator available can increase the confidence of ECPs and improve communication with the rest of the care team. System navigator support can also help alleviate stress and burnout among ECPs and make them more confident in their role.[35]

Recent research on caregivers in Canada notes that while system navigators are increasingly available across Canada, the "development of these roles could be expanded to transform system navigation and care co-ordination into a public responsibility, rather than obligation downloaded onto caregivers and care recipients."[32]

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How to Take Action

Table 4 provides examples of possible policy solutions for supporting ECPs. The policy solutions are not intended to be prescriptive, but instead outline some potential implementation ideas.

Through Essential Together, we will continue to develop and share information and examples of practical solutions implemented by organizations and health regions across Canada.

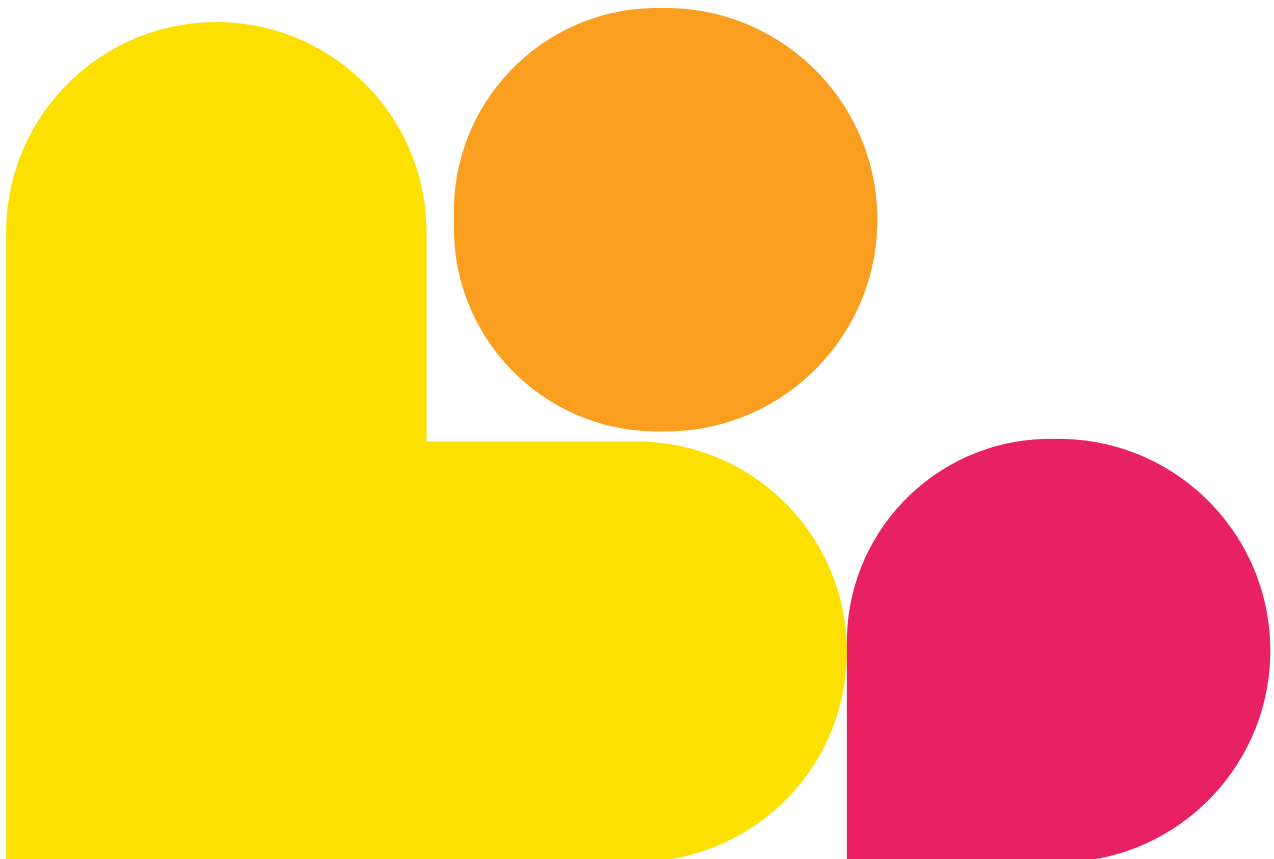*Table 4: Examples of policy solutions for supporting ECPs*

Related policy guidance	Examples of how to take action on policy guidance

Provide training/educational supports and resources to increase skills and confidence of ECPs.	• Learning opportunities:
	
	  Develop based on needs of ECPs.
	
	  Co-design with patients and ECPs.
	
	  Encompass preparation for the ECP role as well as specific skills for common caregiving tasks.
	
	  Address caregiver burnout and self-care.
	
	  Acknowledge that learning is two-way and that staff can learn from patients and ECPs as well.
	
	  Have multiple formats available for ECPs to access.
	
	  Create resource library that is openly accessible to ECPs and that covers a wide range of caregiving tasks and issues.

Provide peer support.	• Ensure ECPs are aware of the many family and caregiver peer support networks available across the country. • Ensure recognized caregiver peer support resources are available on an ongoing basis across care settings and throughout the care journey; these peer supports are based on relationships and foster a peer community. • Where demand is sufficient, offer onsite or online peer support groups with a thematic focus (e.g. long-term care, cancer care, etc.). • Create a community of practice model for both in-person and virtual ECP communities.

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Related policy guidance	Examples of how to take action on policy guidance
Develop system navigator role.	• System navigators can provide information and guidance related to health settings, available resources and services in the community and how to access them. • System navigators support ECPs throughout transitions in care. • Staffing system navigators with a team of personnel with healthcare systems experience will help provide reliable access to different system resources, as well as help troubleshoot problems related to care as they arise. • If a dedicated system navigator is not available, ECPs need contact information for someone who can answer questions or concerns.

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Conclusion

The unique value that ECPs bring to healthcare systems is well documented in health and related literature. We know from evidence that their value benefits patients, healthcare providers and the system overall. The absence of ECPs during the COVID-19 pandemic lockdowns clearly illustrated the harms that result when their involvement in patient care is interrupted or disallowed. Fully integrating the role of ECP into healthcare teams helps build health and care systems that are more resilient and advance the delivery of person-centred care.
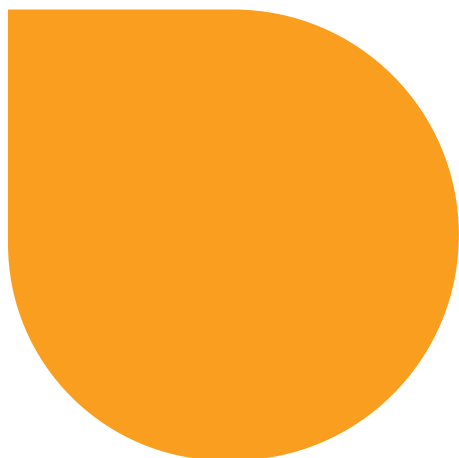
This policy guidance, co-developed with participants in a collaborative policy lab process, provides a roadmap for fully integrating the role of ECP across the continuum of care. The policy solutions presented in this report are intended as concrete examples that health system policy-makers and leaders can draw on when developing and implementing policy to create the foundation to welcome the ECP role, establish that role in any given care setting, take accountability for its integration and support ECPs as valued members of the care team.

When healthcare organizations develop their own ECP policies it will be important to do this in partnership with patients, caregivers and front line staff. Healthcare Excellence Canada will continue to build on its work through the Essential Together initiative to support the full integration of the care partner(s) as an essential member of the care team across the continuum of care.

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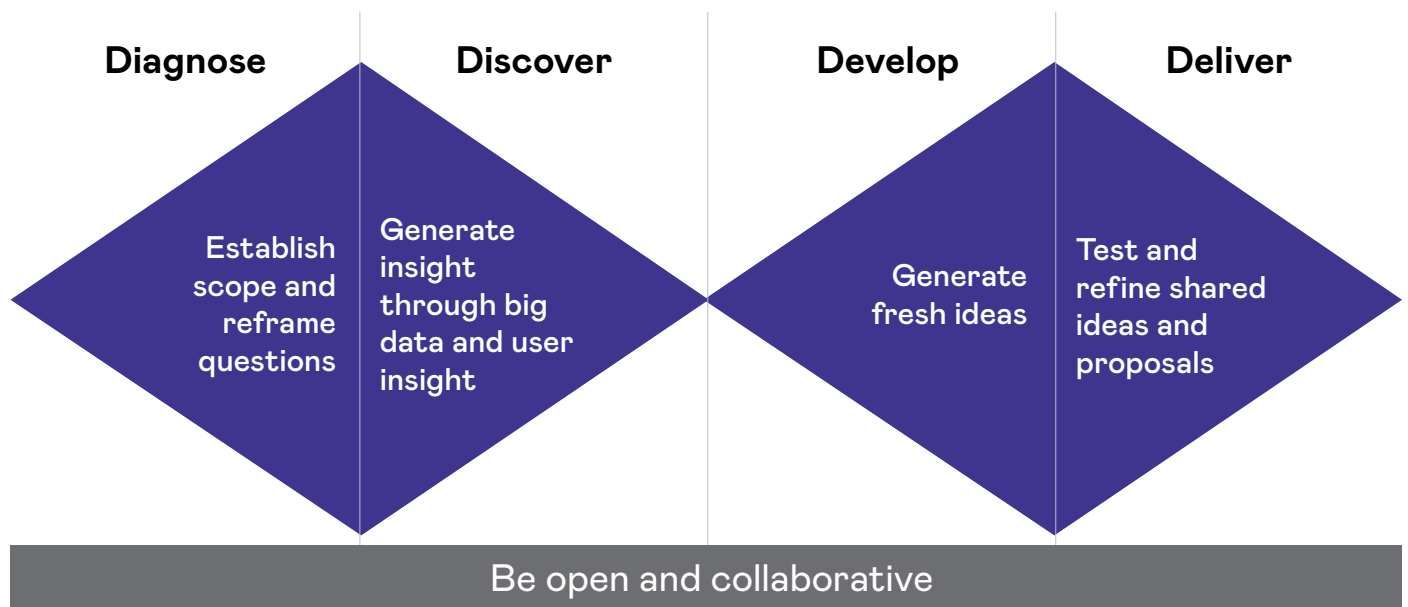
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Appendix B: Policy lab methodology

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

Diagnose	Discover	Develop	Deliver
Establish scope and reframe questions	Generate insight through big data and user insight	Generate fresh ideas	Test and refine shared ideas and proposals

Be open and collaborative

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:

1. 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.

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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 Map for the Reintegration of Essential Care Partners 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.

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