

Advance Care Planning in Canada

A Pan-Canadian Framework

January 2020



Speak Up · Parlons-en



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Acknowledgements

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Executive Summary

THE EVIDENCE IS CLEAR. People who plan ahead for their health care — who think about the kind of care they want, share their wishes with the people around them and appoint a Substitute Decision Maker who understands their wishes and will speak for them if they cannot speak for themselves — experience less distress and anxiety when faced with a health crisis and are more satisfied with the care they receive.

We know that Advance Care Planning is part of a life well lived: 93% of people in Canada believe it's important to discuss their Advance Care Planning with family and friends. Yet only 17% of people in Canada have Advance Care Plans and more than 50% have not engaged at all in Advance Care Planning. Why? Because, in many people's minds, Advance Care Planning is associated with end of life.

Over the past seven years — since the first National Advance Care Planning Framework was introduced — attitudes towards Advance Care Planning have started to change. People in Canada are more aware of advance care planning and they see its benefits, yet they are not actively engaged.

With the 2019 Pan-Canadian Framework on Advance Care Planning, we set out a new strategy that will help people move from thinking that Advance Care Planning is a good idea to actually having those important conversations. To do that, we must make Advance Care Planning a normal part of the life journey and give all people in Canada regular opportunities throughout their lives to express their wishes for their future care.

The new framework recognizes the critical role that culture plays in how people view health care decisions — including the wide range of beliefs and practices related to life, health and well-being, individual and collective decision-making, and death and dying.^{1,2} It also strives to reach people at different ages and stages of life, and to engage a much wider range of players in promoting and supporting Advance Care Planning.

With the 2019 Pan-Canadian Framework on Advance Care Planning, we set out a new strategy that will help people move from thinking that Advance Care Planning is a good idea to actually having those important conversations.

The 2019 Pan-Canadian Framework on Advance Care Planning focuses on four interwoven activities:

1. **Extend the partnership network** — engage other sectors, such as law, life/financial planning and social services, and other people-centered health initiatives, in supporting and encouraging Advance Care Planning.
2. **Build supportive systems** — remove legal, health and other systemic barriers to Advance Care Planning, and develop effective ways for people to record and share their Advance Care Planning wishes and ensure the health care system respects those wishes.
3. **Engage and educate all stakeholders** — normalize Advance Care Planning and make it part of life planning, develop culturally respectful and safe strategies to reach underserved communities, and provide training and support for service providers and other champions of Advance Care Planning.
4. **Measure impact** — establish targets and key performance indicators for Advance Care Planning, track progress and use the results to drive change and quality improvement.

Our goals are clear and attainable. If we are successful, people in Canada will be better able to talk about their wishes for their care with their family, friends, Substitute Decision Makers, and care providers. They will be less anxious when health problems arise and more satisfied with the care they receive. Fewer people will receive unnecessary or unwanted medical interventions, and fewer health care providers will experience moral distress over care they believe is unnecessary or unwanted.

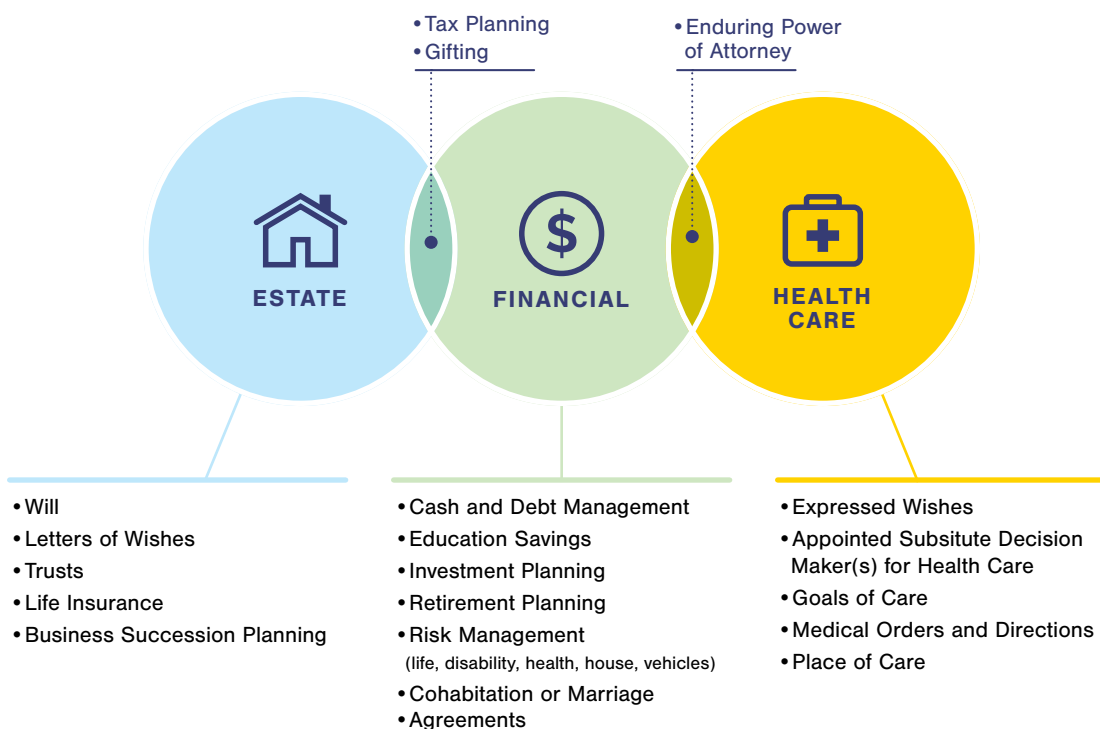
To reach those goals, we must work together. We must collaborate, integrate with other services, share resources and best practices, and build on our strengths and successes. In this way, we can make Advance Care Planning a life-long process that is a natural, integral part of a life well lived.

I. Advance Care Planning: Part of Life

LIFE IS A COMPLICATED JOURNEY full of both ups (e.g. graduations, new jobs, marriage, births, trips, retirement) and downs (e.g. financial setbacks, job losses, illnesses, deaths). To be able to handle both the good and the bad, most people engage in some form of life planning for themselves and their families. They plan for tomorrow so they can live for today. For example:

- **Financial planning:** They save money for school, major purchases and retirement. They buy insurance in case something happens to their house, car or themselves.
- **Estate planning:** At a certain stage in life, people make wills. They appoint guardians to look after their children in case something happens to them, and they set out what they want done with their assets.
- **Health care planning:** More people now also plan for their health care. They recognize that, at any stage in their lives, things can happen that make it difficult for them to speak for themselves. They plan where to receive care (e.g., home care, long-term care, etc.), what kinds of care they want or don't want, and who will speak for them if they cannot speak for themselves.

The Life Planning Model



The Life Planning Model shows how planning for future care, what we call Advance Care Planning, fits within different planning activities. The model is a general and flexible guide to life planning. Depending on your situation and where you live in Canada, these activities may overlap in different ways. For example:

- your Substitute Decision Makers' decisions about your care may be limited by your financial resources and insurance coverage
- in some provinces and territories, your Substitute Decision Makers for health care may also be able to make some decisions about:
 - » your legal and financial affairs
 - » your diet, exercise, and recreational activities
 - » where you live while you receive care.

Advance Care Planning

is a lifelong process of thinking and talking about the kind of health and/or personal care you would want if — at some point in your life — you cannot speak for yourself.

The process should include the people you have chosen to speak for you — your Substitute Decision Maker(s) — and may also include health care providers, lawyers, and/or other professionals helping you with your life and care planning.

During the conversations that are part of Advance Care Planning, you share your values, beliefs, and wishes, and make sure the people you've chosen to speak for you understand what matters most to you.

What is Advance Care Planning?

The Advance Care Planning process can involve:

- planning for a time when you cannot make your own health care decisions
- thinking about your values, beliefs and goals of care
- naming a Substitute Decision Maker
- talking to friends, family, significant others as well as health care and legal professionals about your values and goals of care
- recording or writing down your wishes.

Why is Advance Care Planning Important?

Advance Care Planning:^{3,4,5,6,7,8,9}

- reinforces the importance of tailoring care to each person's needs and wishes
- reduces some of the distress, anxiety and uncertainty that individuals, their loved ones, and their health care providers may experience during a serious health issue or crisis
- can lead to better communication and preparation when making health care decisions
- supports health system priorities of patient safety, quality improvement, and people-centered care
- recognizes that people's values and preferences can change over time and gives them the opportunity to continually revisit their planning.

The Pan-Canadian Framework: Our Approach

A National Advance Care Planning Framework was created in 2012, and it had an extremely positive impact. Policy makers and health care organizations and providers in all provinces and territories used the framework to raise awareness of the importance of ACP and make it an integral part of good quality care.

As a result of local, provincial/territorial and national initiatives, many of the National Framework actions have seen important developments (see Appendix A). As a result, attitudes towards ACP have changed significantly over the past seven years. CHPCA conducted a national poll of ACP attitudes and behaviours in 2013¹⁰ and again in 2019¹¹ (see Appendix B) and found some significant differences between them:

- 93% of people in Canada say it's important to talk about Advance Care Planning with family and friends (compared to 44% in 2013)
- 80% say it's important to talk to health care providers (compared to 51% in 2013) and 66% say it's important to talk to a lawyer (compared to 36% in 2019)
- 80% have given some thought to the care they would want at the end of their lives (compared to 74% in 2013)
- The 2019 poll asked additional questions to get insight into when people think it is appropriate in their life journeys to begin planning for their future care:
 - » 40% think people should plan for their future care when they are healthy and 30% think Advance Care Planning should be part of Will planning
 - » nearly 60% think people should start their planning when they are between the ages of 35 and 54

The 2019 Pan-Canadian Framework builds on the legacy of the 2012 National Framework and its influence on new developments and accomplishments. The new framework has been restructured to focus more on broadening partnerships, and promoting more collaboration among different jurisdictions (local, provincial/territorial, national) and among different systems (health, law, social services, life planning).

Why a Pan-Canadian Framework for Advance Care Planning?

Advance Care Planning in Canada is managed by different legal frameworks, systems, and processes from one region to another (see Appendix C). However, that does not mean these different bodies must operate in isolation. It is still helpful to situate the diversity of ACP under the broader umbrella of a Pan-Canadian Framework. There are common steps and principles to ACP that can guide programs and practices from coast to coast to coast (see Appendix D). It is possible to establish a common lexicon of definitions and terms that still recognize regional variations (see Appendix E).

Having a Pan-Canadian Framework for Advance Care Planning will:

- help bridge the differences between jurisdictions by identifying a common vision, goals, guiding principles and strategies
- promote the sharing of strategies, resources, and best practices in order to minimize duplication of work and the resources required to support ACP within each jurisdiction
- build on the foundational work and accomplishments of local, regional, and national leaders in Advance Care Planning
- make it easier for people in Canada to have their planning and wishes recognized and respected across the country
- lead to a common language, definitions and outcome/impact measures, which will make it easier to set ACP targets and measure progress across the country.

People in Canada say they would be more comfortable having ACP conversations if they had more support from health care providers and other professionals, and more personal time to think about their wishes.

Why Now?

While more people in Canada are thinking about Advance Care Planning and believe it's a good idea, very few have taken action. The change in attitudes towards ACP has not led to a change in behaviour. Only 17% of people in Canada have planned for their future care, and more than 50% have not engaged at all in Advance Care Planning.¹²

How can we close the gap between thinking and doing? According to the same poll cited above, people in Canada say they would be more comfortable having ACP conversations if they had more support from health care providers and other professionals, and more personal time to think about their wishes. They also said it would make a difference if they could afford a lawyer or other professional to help them. Many do not appear to be aware of the tools and resources that can help them with Advance Care Planning.

Professionals across Canada who actively promote ACP believe an updated Pan-Canadian Framework can help close the gap between thinking and doing. As a result of consultations with over 300 ACP stakeholders across the country — policy makers, health care providers and administrators, lawyers, financial advisers, community organizations, patient and caregiver advocates, and many others — this new framework:

- frames Advance Care Planning inclusively as everyone's right
- reflects the current landscape of Advance Care Planning in Canada and abroad
- respects the needs, preferences, and practices of diverse communities in Canada
- encourages better integration and coordination of activities while still ensuring the flexibility required to support Canada's diverse communities, jurisdictions, and legal frameworks.

II. Vision, Goals, Principles and Desired Outcomes

THE PAN-CANADIAN FRAMEWORK is based on a shared vision, goals, guiding principles and desired outcomes for Advance Care Planning across the country.

Our Vision: The Change We Want to See

Advance Care Planning is a normal part of the life journey. All people in Canada have regular opportunities to express their wishes for their future care, the care they receive reflects their wishes and, if they can't speak for themselves, their Substitute Decision Makers are ready to speak confidently on their behalf.

To achieve this vision, people in Canada must be able to have meaningful conversations throughout their lives with their families, friends, communities, and those who provide them with legal, health, financial, and life planning services. When they seek care, they must feel confident that they will be heard and receive care that respects and reflects their unique values, circumstances, and situations. When they have to rely on others to speak for them, they must be confident that their Substitute Decision Makers have a good understanding of their role and are well prepared to make decisions that reflect their values and wishes.

Our Goal: The Call to Action

To build a Pan-Canadian approach that **empowers, encourages and enables**:

- people in Canada to engage in Advance Care Planning throughout their lives
- health care systems, administrators, and providers to integrate Advance Care Planning into care
- legal, social services, and life/financial planning professionals to make Advance Care Planning a regular part of their scope of practice
- partnerships between these different stakeholders for an integrated approach to ACP.

Our Guiding Principles: The Touchstones for Our Work

The Pan-Canadian Framework recognizes that all provinces and territories have different populations, legislative frameworks, and health systems. It sets out the following common principles that all provinces and territories may share while respecting their differences:

Safe, integrated, people-centered care.^{13,14,15} All people in Canada should receive care that is safe, appropriate, and relevant based on their needs, values, wishes, and goals. Their care should also be coordinated across health and social services to ease the accessibility and transfer of information across settings.

Respect for diversity. Culture plays a strong role in how people view health care decisions, particularly those made near the end of life.^{16,17} Advance Care Planning is open to, respects, and supports the cultural, ethnic, sexual, gender, religious, socio-economic, geographic, and abilities diversity of Canada, including the wide range of beliefs and practices related to life, health and well-being, individual and collective decision-making, and death and dying.

Equity and human rights.¹⁸ People in Canada have rights enabling them to plan their future care, make their own health care decisions, and appoint Substitute Decision Makers to speak on their behalf. Through various legislations, they also have other cultural, religious, and political rights that apply to their health care planning and decision-making. Equity is attained by approaches that address systemic barriers and disadvantage, promote fairness, and reduce disparities in health and social outcomes.¹⁹

Reconciliation. First Nations, Inuit, and Métis peoples continue to experience colonization and its effects on their daily lives, including their health and well-being.²⁰ Health care is a core area in which to address systemic harms and to improve Indigenous lives.²¹ ACP is implicated within reconciliation efforts to assert Indigenous cultural, political, and health care rights; educate and train health care providers in cultural competency and safety; and support Indigenous traditions of healing and collective health care decision-making.

Normalization/de-stigmatization. Advance Care Planning is an essential part of a life well lived and planned. Like financial and estate planning, it begins long before someone is faced with a crisis or life-limiting illness, and continues throughout their lives. Normalizing ACP will help people feel more comfortable and confident talking about their values, wishes, and preferences for care.

Evidence-informed. The 2019 Framework priorities are informed by research and evidence, while also acknowledging and respecting stakeholders' capacity to build new evidence.

A culture of sharing. Advance Care Planning initiatives are more sustainable when jurisdictions share knowledge and resources — adapting them to meet local needs and each jurisdiction's unique circumstances.

Collaboration within and across sectors. The ACP process intersects with many sectors including health, law, social services, education, and financial and life planning. Advance Care Planning is more effective when these sectors work together to make ACP activities more accessible, transferable, and integrated.²²

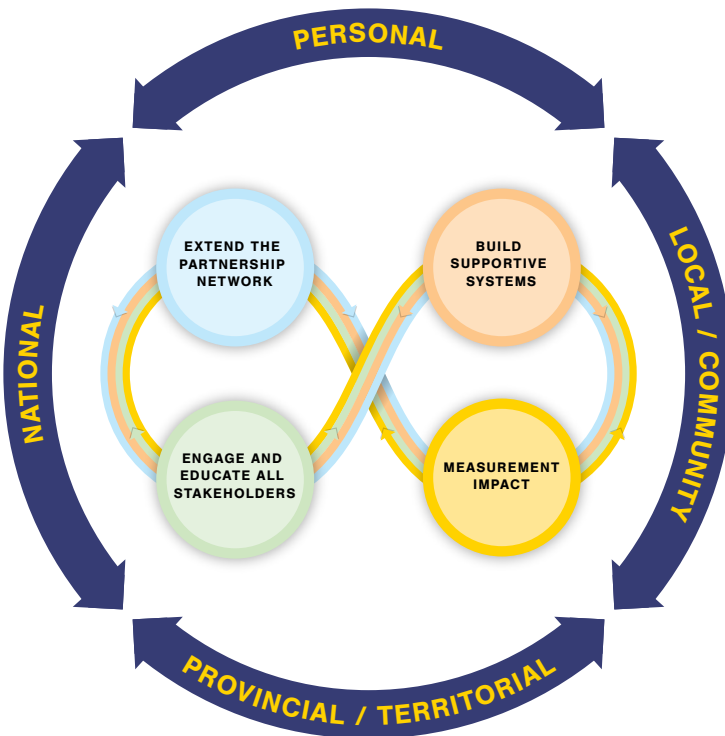
Quality improvement and accountability. ACP activities need to be tracked, evaluated, and modified to ensure programs are accessible, beneficial, and effective.²³

Our Framework: Where We Will Focus Our Efforts

The 2012 National Framework for Advance Care Planning established four separate action pillars: Engagement, Education, System Infrastructure and Continuous Quality Improvement. The 2019 Pan-Canadian Framework re-imagines and reframes those pillars as an interconnected web or strands of activities that — when braided together — have the potential to normalize, support and promote Advance Care Planning in Canada.

These interwoven ACP activities, in turn, can be integrated with the other life planning that people do, such as financial planning and estate planning, to create a kind of safety net for people throughout their lives, so they can plan for tomorrow and live for today.

Pan-Canadian Community ACP Framework Model



EXTEND THE PARTNERSHIP NETWORK

Key Priorities

- Identify potential partners with a shared purpose
- Integrate efforts to promote ACP

BUILD SUPPORTIVE SYSTEMS

Key Priorities

- Remove legal barriers to ACP engagement
- Identify ways to improve ACP processes within systems
- Invest in ACP
- Increase accountability for ACP

ENGAGE AND EDUCATE ALL STAKEHOLDERS

Key Priorities

- Normalize ACP conversations
- Reach out to underserved communities
- Support service providers and champions

MEASUREMENT IMPACT

Key Priorities

- Establish targets and key performance indicators
- Use data to drive change

The new framework has been restructured to focus more on broadening partnerships, and promoting more collaboration among different jurisdictions (local, provincial/territorial, national) and among different systems (health, law, social services, life planning).

Our Desired Outcomes: Where We Want to Be in Ten Years

If we are successful in implementing the Pan-Canadian Framework, in ten years' time:

- Extend the partnership network
 - » The health, law, life/financial planning, and social services sectors will collaborate more often and coordinate their efforts to support ACP.
 - » Legal, life/financial planning, and social services professionals will help more people in Canada plan for their future care earlier.
 - » More ACP programs and initiatives will be developed with and for Canada's diverse communities, using culturally appropriate and safe approaches that embrace communities' own ways of approaching health and wellness, care planning, death and dying, and decision-making.
- Build supportive systems
 - » Health systems will make ACP an integral part of improving the quality, safety, equity, and relevance of care.
 - » ACP will be integrated into related systems and sectors, such as law, financial/life planning, social services, education, and faith/spiritual communities.
 - » Jurisdictions will have mechanisms in place to record and share ACP conversations within and across health record systems.
 - » Structural barriers to ACP within health care and legal systems will have been removed.
- Engage and educate all stakeholders
 - » Growing numbers of people from across Canada's diverse communities will be engaged in Advance Care Planning.
 - » ACP knowledge and skills will be core competencies in health care providers' education and included in their curricula.
 - » People entering a health care setting will be asked more often about their values, wishes, and goals of care.
 - » Shared and supported decision-making will be the norm in health care practice.
 - » Local, provincial/territorial, and national ACP initiatives will coordinate their education, awareness campaigns, and promotion activities.
- Measure impact
 - » People with serious illnesses and their loved ones will report higher satisfaction with the communication, coordination, and experience of care.
 - » Fewer people will receive unnecessary or unwanted medical interventions.
 - » Fewer health care providers will experience moral distress over care they believe is unnecessary or unwanted.

To reinforce the importance of leadership and collaboration in achieving our common vision and goals, the 2019 Pan-Canadian Framework highlights the activities that would happen at all levels as those where one level would take the lead.

Our Relationships: How We Will Collaborate to Implement the Framework

Implementing a Pan-Canadian Framework will require coordinated leadership from:

- **The local community and organizational level** where much of the innovation happens and where providers are in a strong position to identify unmet needs, learn what works for their clients or patients, and use that information to inform ACP as well as how care is provided.
- **The jurisdictional systems or provincial/territorial level**, which develops legislation, policies, and standards to guide local programs and provides resources to support those programs.
- **The national or Pan-Canadian level** where jurisdictions and organizations come together to develop resources, identify scalable and cost-effective strategies, and undertake other tasks that promote a more consistent ACP approach across the country.

To reinforce the importance of leadership and collaboration in achieving our common vision and goals, the 2019 Pan-Canadian Framework highlights the activities that would happen at all levels as those where one level would take the lead.

III. The Roadmap

for Implementing the 2019 Pan-Canadian Framework for Advance Care Planning in Canada

A. Extend the Partnership Network

Priorities:

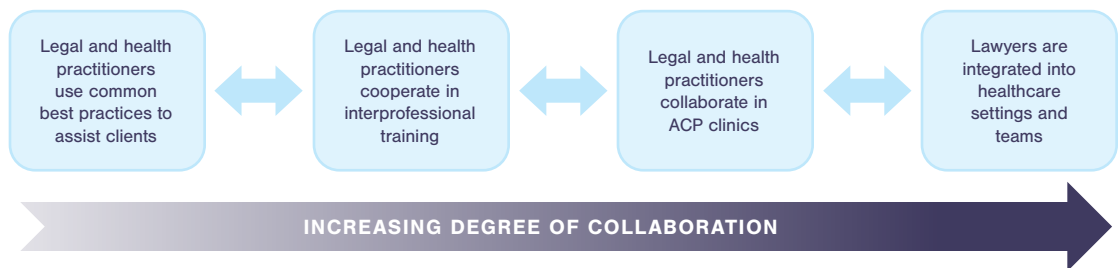
1. Identify potential partners with a shared purpose
2. Integrate efforts to promote ACP

Historically, ACP has been championed by palliative care specialists. It has focused mainly on engaging people who are at greatest risk of not being able to speak for themselves, particularly people diagnosed with a life-threatening illness and those nearing the end of life. As a result, many people in Canada think that ACP is only a priority for individuals who are very sick or terminally ill — not something for everyone to think about.^{24,25}

However, we know that the earlier people start having conversations about their wishes and preferences for their care, the less anxiety they experience when faced with a health crisis and the more prepared their Substitute Decision Makers feel when making decisions.^{26,27}

To reinforce that ACP is an essential part of a life well lived and is everybody's right, we need strong and effective partnerships among different groups involved in life planning. The 2012 National Framework focused on mobilizing and uniting the health and legal sectors. Since then, a framework for health-legal collaborations in ACP has been developed to support this inter-sectoral partnership:

Figure 1: Framework for health-legal collaboration



Used with permission by the author.²⁸


III. THE ROADMAP FOR IMPLEMENTING THE 2019 PAN-CANADIAN FRAMEWORK FOR ADVANCE CARE PLANNING IN CANADA

The 2019 Pan-Canadian Framework takes the next step, extending the ACP partnership network to include community partners and the life planning industries. A wide range of professionals and sectors could play key roles in promoting and supporting ACP. Leaders in implementing ACP should take a strategic approach to identifying and integrating new partners within the network, focusing on those who:


- are seen by the public as trusted advisors
- have contact with people at key life stages
- are able to reach populations that have had less access to ACP.

This extended partnership network will help normalize ACP conversations so they happen earlier, more often, and in the community as well as in the clinic. It will also give people across Canada access to a wider range of entry points into thinking about and planning for their future care.

Priority #1: Identify potential partners with a shared purpose

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|---|---|---|
| Identify potential allies within the health system | <p>ACP can help the health care system achieve many of the following priorities and may find allies within these areas:</p> <ul style="list-style-type: none"> • Patient-centered care/quality improvement – ACP helps providers have conversations with their patients about the care they want can lead to better satisfaction, quality of care, and care outcomes.²⁹ • Patient safety – ACP helps ensure care is appropriate, accessible, and people-centered by having a person’s wishes inform the care they receive and avoid unnecessary or unwanted interventions.³⁰ • Organ donation and chronic disease management programs – ACP conversations identify a person’s care preferences and illness management priorities. • Risk management – ACP helps to minimize unnecessary interventions and suffering; prevent errors, conflict and litigation³¹; and increase patient and family satisfaction with services. • Resource management and sustainability – ACP helps ensure people only receive care services that they want and need.³² | <p>NATIONAL</p>  |
| Identify potential allies in other government departments | <p>Departments such as education, justice, seniors’ services, veterans, and human rights, could be particularly strong ACP allies – however, a case can be made for most if not all government departments to play a role in supporting ACP (e.g., tourism services could provide information to travelers about preparing ACP/SDM documents that comply with the jurisdiction’s legal requirements).</p> | |

**III. THE ROADMAP FOR IMPLEMENTING THE 2019 PAN-CANADIAN FRAMEWORK
FOR ADVANCE CARE PLANNING IN CANADA**

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|--|--|---|
| Develop an integrated network of ACP champions across sectors that support future planning | <p>Many professions, organizations and agencies interact with people at key stages in their lives and already play a role in helping them think about their values and plan for the future. The following are key potential partners within an ACP partnership network:</p> <ul style="list-style-type: none"> • lawyers, life and financial planners, and funeral planners • faith-based and cultural organizations • parenting and family planning services • agencies that issue drivers' licenses, marriage licenses, birth certificates, and retirement benefits • financial planning, insurance, and mortgage companies • libraries, community centres, and adult education centres. |  <p align="center">REGIONAL</p> <p align="center">LOCAL</p> |
| Explore potential allies in the private sector | <p>The private sector can encourage innovation in ACP implementation. For example, corporate sponsors can support campaigns, events, and resource developments (e.g., digital technologies like mobile apps). Health and wellness industries, including pharmacies, health influencers, and health stores are also major sources for information about health planning.</p> | |
| Engage diverse communities and encourage public advocacy | <p>The public has significant power to make change. When people are more informed about their rights and start asking for ACP, sectors will be faster to respond. The network can identify and mentor ACP advocates and champions, and help them mobilize their different communities. The network also needs to work with community representatives and advisors to develop culturally safe and relevant messaging.</p> | |
| Include partners who support underserved communities | <p>Organizations that work with and understand the needs of underserved communities (e.g., Indigenous support centres, cultural organizations, community health clinics, social service agencies, shelters) are best positioned to identify and address issues of equitable access to ACP.</p> | |

Priority #2: Integrate efforts to promote ACP

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|--|---|--|
| Engage partners in an integrated approach to ACP | Members of the network need to coordinate their education and promotion efforts locally, regionally, and nationally. Ideally, partners and allies participate in cross-sector discussions, identify their strengths and opportunities, and share best practices and resources. ³³ | <p>NATIONAL</p> <p>REGIONAL</p> <p>LOCAL</p> |
| Integrate ACP into other relevant regional and national strategies | Strategies that support integrated, people-centered, and effective care at key life stages — such as strategies for seniors; dementia care; frailty; First Nations, Inuit, and Métis health; chronic disease management — are natural places to advocate for and integrate ACP. ^{34,35} | |
| Think strategically about how to leverage partnerships | Partnerships may take different forms depending on the buy-in, shared priorities, and leveraging necessary to deliver coordinated ACP programs. Within the health sector, for example, primary care providers can easily share take-home ACP resources and prompt patients to think about designating an SDM, home care providers may be uniquely positioned to start the ACP conversation, paramedics can be trained to always ask about ACP before providing care, and provincial health insurance programs can mail out information about ACP with health card renewals. Cross-sector partnerships may require more or less involvement of the health care sector. Some initiatives may be led by community leaders with health care providers playing a supportive role. | |
| Work together to develop/adapt relevant tools and resources | While network partners will benefit from an integrated approach to education, they will likely need tailored resources that address the specific needs of people within particular settings or at particular stages in their life and health ³⁶ . The ACP network should work with different partners to develop/adapt information and resources for their context rather than work independently — often at a much higher resource cost. | |

B. Build Supportive Systems

Key Priorities:

1. Remove legal barriers to ACP engagement
 2. Identify ways to improve ACP processes within systems
 3. Invest in ACP
 4. Increase accountability for Advance Care Planning
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It is not enough to ask people in Canada to have conversations about their wishes for their care. The systems in place must enable and be accountable to people's expression of wishes in order for organizations and service providers to do the same.^{37,38} Right now, in many places, there are gaps and "disconnects," particularly in the legal and health systems.

In terms of the **legal system**, Canadian common law recognizes that individuals have the right to consent to treatment and to plan for their future health and personal care. Health care professionals must always obtain consent to treatment from a person capable of the particular care or treatment decision. Legally, adults are presumed capable of giving or refusing consent unless it is determined that they are not capable of making a treatment decision.

Health care preferences and decisions are often informed by a person's social, cultural, and/or religious orientations, which are protected by a variety of other Canadian laws. For example:

- The Canadian Constitution recognizes a range of social, cultural, and political rights for First Nations, Inuit, and Métis peoples, which also apply to their health and well-being.
- The Canadian Charter of Rights and Freedoms states that people have the freedom to follow their conscience, religion, thoughts, and beliefs, including in situations of health and personal care.
- The Canadian Human Rights Act protects people from being discriminated against in the care they do or do not receive because of their age, ethnicity, race, religion, ability, marital or family status, sexuality, and/or gender.

Despite these legal supports, people's wishes are not always respected or followed. Some communities have unequitable access to their rights and, therefore, are less likely to engage in ACP.^{39,40}

Within the health care system, one of the greatest barriers to getting more health care providers involved in ACP is competing priorities.

Within the **health care system**, one of the greatest barriers to getting more health care providers involved in ACP is competing priorities.⁴¹ As someone said during the consultations on the 2019 Framework: “When health care providers spend only 15 minutes with a person, it’s hard to start the conversation.” Although ACP is a policy in most jurisdictions, there are few formal mechanisms to hold health care organizations or providers accountable for engaging people in ACP. In some situations, more explicit expectations, structures, and requirements would mean that more people are routinely engaged in ACP. In others, providers may need reassurance about some of the ethical issues associated with ACP, including concerns about liability, moral distress, and decisional conflict.⁴²

There is also an urgent need to ensure that health care providers are aware of people’s expressed wishes and respect their wishes. At the current time, the practice of recording wishes – or even noting that they have been expressed – is inconsistent. It is not uncommon for people to have gone through the ACP process only to learn that, when they seek care, their wishes are not part of their medical record and they do not get the type of care they want. Barriers exist when people move between health care settings within jurisdictions, and they become even more challenging when people move between jurisdictions.

Although provinces and territories are encouraging ACP and some have initiated province-wide ACP programs, they have not yet developed all the key system-wide infrastructure supports required, such as:

- a culture that recognizes and respects people’s rights to make informed decisions about their care
- adequate resources (i.e. funding, human resources)
- policies that integrate ACP into different programs, roles and job descriptions
- training for health care providers
- information and resources for staff as well as people who interact with the health system
- effective ways to document and transfer people’s wishes
- a system of accountability for ACP.

Priority #1: Remove legal barriers to ACP engagement

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|---|--|--|
| Conduct a national review of ACP, Health Care Consent, and Substitute Decision-Making legislation | Over the past few decades, almost all provinces and territories have enacted ACP legislation. However, these laws are not harmonized. ⁴³ Their definitions of capacity or competence differ as does the role of Substitute Decision Makers. Not all jurisdictions have consent to treatment legislation, and ACP documents created in one jurisdiction may not be valid in others. | <p>NATIONAL</p> <p>REGIONAL</p> <p>LOCAL</p> |
| Consider developing legislation to harmonize ACP and SDM processes across the country ⁴⁴ | The current differences in legislation can create barriers for people in Canada, who are fairly mobile and often have family members in other jurisdictions within Canada and abroad. | |
| Propose reforms to legislation that impedes access, transferability, or recognition of ACP | <p>Some legal requirements may not fully reflect the principles of freedom, fairness, and equity in Canadian law.⁴⁵ For example:</p> <ul style="list-style-type: none"> • Some wishes may be ignored or dismissed if they do not follow standard medical practice. • Once people are determined to have lost capacity, they can no longer give consent for their own care. • The default list of SDMs in each province/territory is usually close relatives. In some social and cultural contexts (e.g., when the person has no close or contactable relatives, is in conflict with family members, or has a family of choice), this list will not identify an appropriate person. • The legal norms of individual consent and decision-making do not always recognize or respect cultural practices of collective or deferred decision-making. <p>There may be grounds to challenge laws that limit people's rights unnecessarily. For example, Alberta has a specific process for Supported Decision-Making Authorization, designed for people with communication barriers and/or disabilities to access a supporter who can help them communicate, ask questions, and make decisions.⁴⁶</p> <p>Outside of the specific legislation for ACP and SDM, there may be other legal barriers that impede certain communities' equitable participation. First Nations, Inuit, and Métis communities have encountered particular barriers through legal regimes and principles that interfere with their cultural practices of healing, health governance and planning, and care decision-making.⁴⁷</p> | |

Priority #2: Identify ways to improve ACP processes within systems

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|--|---|---|
| <p>Establish standards for having ACP conversations, documenting and accessing them, and translating them into medical orders⁴⁸</p> | <p>Guiding documents help establish norms for implementing ACP. Standard-setting organizations, such as accreditation bodies, health authorities, professional associations, and regulators, can support the efforts of health organizations, administrators, and care providers to promote ACP by developing or adopting ACP standards, policies, and guiding principles. For example, Health Standards Organization (a branch of Accreditation Canada) has included ACP in their newest standards for primary care and palliative care. Related standards, policies, and aids for Supported and Shared Decision-Making practices may also enable more ACP engagement among people who may have wavering capacity or other barriers to full participation.⁴⁹</p> | <p>NATIONAL</p>  |
| <p>Establish professional cultures of Shared and Supported Decision-Making</p> | <p>Models of Shared and Supported Decision-Making include mechanisms that enable persons and their support networks to be better informed, more meaningfully engaged, and more involved in making decisions about their care^{50,51,52}. People with access to decision aids are more likely to be informed of their options, participate in decision-making, and achieve higher quality outcomes⁵³. Collaborative decision-making follows through on the promise of ACP—to ensure a person’s values and wishes will be respected and the people who will make decisions about their care are prepared and supported to act on their wishes.</p> | <p>REGIONAL</p>  |
| <p>Simplify the documenting and transferring of ACP conversations</p> | <p>People can move through many settings during their health care and too often previous conversations and planning are lost in the transition. Making the recording and transfer of ACP conversations easier will address a major issue in accessibility. Jurisdictions need to develop effective mechanisms and platforms for documenting ACP conversations that will address current barriers (e.g. different EMR platforms, no single location for documentation, systems that cannot share information). The transferability of ACP wishes may be improved significantly when the documentation is centralized in one, easy-to-find location, arranged chronologically, and accessible to staff across care settings. Documentation also needs to enable narratives that can include a person’s life circumstances, values, and other contextual factors involved in their choices. For example, Quebec has a provincial registry for documenting preferences,⁵⁴ but it is currently limited in offering different options and scenarios and in providing context to people’s choices.⁵⁵</p> | <p>LOCAL</p>  |

Priority #3: Invest in ACP

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|--|--|---------------------------|
| Make the case for an ACP program within organizations, communities and systems | To get buy-in for ACP, it is important to make the case for championing ACP. It is time to change the conversation from “what” ACP is to “why” we do it (its benefits) and “how” to do it. To make the case, it helps to share information about public attitudes from recent data ⁵⁶ , tell people’s stories, provide evidence of the benefits of ACP, set out the activities, objectives/goals, critical success factors, and reinforce the value of collaborating to develop an effective ACP program. | NATIONAL ↑ REGIONAL |
| Make funding and resources for ACP explicit | To fully implement ACP programs, organizations need adequate and dedicated resources and incentives. For example, to encourage physicians to engage their patients in ACP, jurisdictions could create a specific fee-for-service code. They could also require certain providers and practices to promote ACP as part of their funding. | REGIONAL ↑ LOCAL |
| Designate relevant departments and/or leads to champion ACP | Coordinating ACP programs and activities cannot be done off the side of someone’s desk. The responsibility for ACP should be championed by a relevant department, such as quality improvement, patient safety, or patient navigation services. ⁵⁷ | LOCAL |

Priority #4: Increase accountability for ACP

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|---|--|---------------------------|
| Integrate ACP standards into accreditation and funding | Standards are important but they are more likely to lead to operational change when they become part of the accreditation process. Identify situations where ACP should be mandatory and link to the accountability cycles of accreditation and funding. For example, as part of the funding for their units, providers in the Ontario Renal Network must talk to every patient who requires chronic dialysis about their goals of care and their Substitute Decision Maker, and to document the conversation in their medical record. | NATIONAL ↑ REGIONAL |
| Require organizations and professionals to account for how ACP is delivered | Most jurisdictions track the number of people who attend ACP education sessions as opposed to the number who actually engage in ACP and related outcomes. To ensure that organizations and practices help people fully engage in ACP, it’s important to tie performance indicators to competencies, practices and outcomes. | REGIONAL ↑ LOCAL |
| Develop a process for documenting non-compliance with expressed wishes | There can be many reasons why a person’s wishes were not followed. Tracking how care is delivered can provide concrete information about when and why wishes were not followed, as well as how to improve communication and compliance. | LOCAL |

C. Engage and Educate All Stakeholders

Key Priorities:

1. Normalize Advance Care Planning conversations
2. Reach out to underserved communities
3. Support service providers and champions

Though regional and national initiatives have made significant headway in educating the public and service providers about ACP, so far, that education hasn't led to enough concrete action. Misperceptions and uneasiness about Advance Care Planning continue to prevent people from starting the conversation. There are also many disparities in ACP engagement, with higher rates of ACP being associated with older age, higher education levels, and diagnosis of more severe health conditions.⁵⁸ Patients of ethnic minorities are also found to have lower rates of ACP which may reflect general disparities in their health care, distrust of health care systems, and cultural perspectives on end-of-life and decision-making.⁵⁹

Many people still associate Advance Care Planning only with the end of life — not as an ongoing part of the life journey. Because ACP is strongly associated with dying, many health care and other professionals do not have the confidence or skills to talk to patients about their values and wishes.⁶⁰ The task of talking to people about ACP often falls to a small number of care providers who, faced with other demands, sometimes find it difficult to find the time to have and to document these conversations.⁶¹




Research and experience has demonstrated that:^{62,63,64,65}

- Advance Care Planning is best facilitated by a combination of professionals initiating and having the discussions, combined with educational materials.
- The process may unfold over multiple sessions.
- Physician involvement is key.
- Advance Care Planning is dynamic, so health care professionals should be routinely reminded to offer ACP discussions at a time that is appropriate for their patients.

Fortunately, there are pockets of strength that we can build on to help people move from knowing ACP is a good thing to do and actually doing it. There is a growing appetite for conversations about life planning as well as new tools and opportunities (e.g. social media) to support an expanded ACP partnership network. Across Canada, there are a growing number of knowledgeable champions — particularly in the health care and legal professions — and many excellent programs, resources and platforms. More care providers are being trained in how to have conversations about serious illnesses. There are robust theories of change that could be applied to how jurisdictions approach education about ACP.

There are existing guidelines for engaging patients in initiatives meant to improve the quality and safety in their care.⁶⁶ There is also a wider range of ways to reach diverse communities, including the use of faith-based groups, seniors' and retirees' organizations, and cultural centres.




Priority #1: Normalize Advance Care Planning conversations

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|---|---|--|
| <p>Reframe Advance Care Planning as part of life planning</p> | <p>To reinforce that ACP is part of life planning, it's important to start earlier (e.g. high school) and build opportunities for ACP into key milestones in people's lives (e.g. getting a driver's or marriage license, having a child, retiring, and being diagnosed with a chronic condition). ACP is something everyone can and should consider doing, just as we go for check-ups, plan our finances and write wills. Given the concern that many people have about the cost of ACP (e.g. having to hire a lawyer), it will be important to support the DIY nature of ACP for people who are not in a crisis – many of whom are able to engage in ACP independently if they have access to the right tools.</p> | <p>NATIONAL</p>  |
| <p>Consult with different communities about what they value about ACP and engage them appropriately⁶⁷</p> | <p>Cultural orientations and values are diverse in Canada and abroad, and they can lead to diverse perspectives and practices of ACP and health decision-making.^{68,69,70} It's important to know what people value about ACP and identify and appeal to what is important within their particular orientations. Peer-to-peer education models for sharing knowledge, starting conversations, and supporting people's engagement within their communities may be effective.⁷¹</p> |  |
| <p>Develop clear, simple messages with and for target audiences</p> | <p>ACP messaging and resources are most effective when they resonate with the audience's own orientations. ACP is a predominantly English, Western concept that is foreign to many people outside of its development within health and legal systems. The concept itself does not always make sense to communities unfamiliar with the term. While some more general forms of messaging may resonate across audiences, it is important to work with different communities to determine how ACP might be reframed even further to reflect their own cultural orientations.</p> | <p>REGIONAL</p>  |

III. THE ROADMAP FOR IMPLEMENTING THE 2019 PAN-CANADIAN FRAMEWORK FOR ADVANCE CARE PLANNING IN CANADA

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|--|--|--|
| <p>Improve ACP literacy</p> | <p>For the general public:</p> <ul style="list-style-type: none"> • Start gradually by sharing stories, having informal conversations, or having group discussions. • As people get more comfortable, start to prompt them about expressing and recording their wishes. • Walk them, step by step, through the ACP process. • Inform them of the rights and how to access them. • Equip them with questions they can ask their health care provider when making a decision about different treatment options. <p>For service providers:</p> <ul style="list-style-type: none"> • Include them in some of the public conversations and education sessions, so that they may learn from stories too. • Help them understand people’s rights and the legal requirements for ACP within their jurisdiction.⁷² • Situate training within professional responsibilities and concerns. • Train them to identify and address conflict, elder abuse, liability issues, and other violations of rights and responsibilities. • Have regular opportunities for professional development and training, including the ability to ask questions before a crisis situation or conflict happens.⁷³ | |
| <p>Engage communities using a wide variety of strategies</p> | <p>Learn from the successes of other social marketing campaigns (e.g. mental health) that have moved people from awareness to action. The following strategies have potential to increase public awareness of ACP:^{74,75,76,77}</p> <ul style="list-style-type: none"> • Disseminate printed materials and resources in different sectors and community settings. • Establish a dedicated organization and web presence with accessible, easy-to-navigate content. • Use social media, including campaigns, interactive content, and dissemination of news, research, and resources, to engage people. • Engage health influencers, public figures, and people with large online following. • Use creative methods to start conversations, including intergenerational conversations about living well and life planning, storytelling, online modules, games, comics, and fortune cookies. • Contact media (local to national) and capitalize on multimedia coverage in television, radio, podcasts, blogs, video, and print. • Implement community development strategies through local trusted agencies, centres, and organizations. | <p style="text-align: center;">↓</p> <p>LOCAL</p> |

Priority #2: Reach out to underserved communities

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|---|--|---|
| <p>Identify and address systemic biases (e.g. racism, sexism, ablism, gender discrimination, ethnocentrism, colonization)</p> | <p>A number of communities and populations — such as Indigenous communities, racialized communities, people with disabilities, newcomers, members of some cultural groups and vulnerable populations that are homeless or unstably housed — have historically not participated in ACP. In some cases, they face specific barriers. In others, they have a history of being exploited or having been denied access to services, and they may perceive ACP as another way to deny them services. To ensure everyone has equitable access to ACP, it's important to understand and respect different cultural values and perspectives on both care and dying. To engage underserved people in ACP, it's important to identify and address underlying issues or systemic biases that may limit their access and participation in ACP.</p> | <p>NATIONAL</p>  |
| <p>Provide cultural safety and humility training as a way to support culturally diverse forms of ACP⁷⁸</p> | <p>First Nations, Inuit, and Métis communities have prioritized culturally appropriate care that is Peoples-specific, self-determined, closer to home, and respecting of Indigenous laws and protocols.^{79,80} Cultural safety training is available in several provinces and resources have been designed to support a culturally relevant shared decision-making process.⁸¹</p> | |
| <p>Develop trusting and respectful relationships with underserved and disadvantaged communities</p> | <p>To improve the equity of ACP engagement, service providers must develop trusting relationships with underserved communities and populations, and understand their needs. There are helpful recommendations for health care providers to better respect and engage end-of-life issues affected by culture, including care inequities, communication barriers, truth telling, and family decision-making.⁸²</p> <p>It is also important to determine how to better support people with physical and/or cognitive disabilities who may experience challenges giving consent. Internationally, there is a shift from guardianship and substitute decision-making models to supported decision-making models that better respect and support the right of people with disabilities, although there is still some support for the latter.^{83,84} Supported decision-making can be fostered using communications bridging technologies and support persons (i.e., translators, aid workers) that can make ACP more accessible to more people.</p> <p>Decisions can be a challenge when there are differing interests and preferences between patients, SDMs, and health care providers.⁸⁵ While consensus might not always be attained in decision-making, many of the emerging models to build trust with historically disadvantaged communities reflect more collaborative and less unilateral approaches to decision-making.</p> | <p>REGIONAL</p>   |

III. THE ROADMAP FOR IMPLEMENTING THE 2019 PAN-CANADIAN FRAMEWORK FOR ADVANCE CARE PLANNING IN CANADA

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|---|--|--|
| Tailor tools, education and language to different underserved groups. | <p>Different communities may need unique information and resources, tailored to their needs including:</p> <p>Developing a communications plan for each ACP initiative that identifies both partners and target audiences as well as how to frame messages respectfully and reach/engage people in a meaningful way.</p> <p>Developing guides and tools to help people of different cultures choose effective Substitute Decision Makers. Choosing a Substitute Decision Maker is one of the most critical parts of Advance Care Planning and cultural traditions vary widely in terms of how decisions are made and who makes them.</p> | <p style="text-align: center;">↓</p> <p style="text-align: center;">LOCAL</p> |

Priority #3: Support service providers and champions

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|--|--|---|
| Define core ACP competencies and integrate them into the scope of practice and both initial and ongoing training for all health care providers | <p>Provider education should include: the importance of ACP, how to start the conversation, how to normalize ACP, how to have conversations about serious illness, and how to advocate on their patients' behalf. The training should also include critical self-awareness of their attitudes and perceptions about ACP as well as the importance of listening to and respecting patients' cultural perspectives.</p> <p>Incentives, such as MAIN-PRO credits (as has been done in British Columbia), may encourage more providers currently in practice to take ACP training.</p> | <p style="text-align: center;">↑</p> <p style="text-align: center;">NATIONAL</p> |
| Ensure all health care providers understand how ACP and GOC is part of the decision-making process. | <p>Most models present ACP as a continuum, starting upstream and moving into more specific Goals of Care conversations and, finally, to in-the-moment decision-making. Health care providers could benefit from a better understanding of this progressive process from upstream conversations to informed consent and decision-making.</p> | |
| Provide training to use evidence-based tools that can help facilitate ACP and GOC conversations | <p>A number of ACP, GOC, and end-of-life conversation tools and strategies have been reviewed and tested in recent years.^{86,87,88,89} While there may be a need for new resources, many of the existing tools have not yet entered into standard practice. Initiatives that train people to use these tools support accessibility and implementation.⁹⁰</p> | |

**III. THE ROADMAP FOR IMPLEMENTING THE 2019 PAN-CANADIAN FRAMEWORK
FOR ADVANCE CARE PLANNING IN CANADA**

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|--|--|---|
| <p>Develop and support ACP communities of practice that build skills and strengths⁹¹</p> | <p>To reinforce that ACP is part of the life journey, it's critical to identify a range of providers and professionals – in primary, home, long term, hospice and acute care as well as legal aid, financial planning, funeral planning, etc. – who can champion ACP. To support them:</p> <ul style="list-style-type: none"> • Connect with or initiate a community of practice where people can share tools, resources and experience. • Break ACP down into smaller doable steps by, for example, encouraging primary care providers to focus on helping patients choose a Substitute Decision Maker. • Provide practical education strategies and resources within a sharing environment. • Provide skill building opportunities during working hours for professionals currently in practice. | <p align="center">↓ REGIONAL</p> |
| <p>Identify champions who can be mobilized to promote ACP awareness and education</p> | <p>Many individuals and groups are providing highly effective ACP education that leads to action. The ACP network can learn from them, share the strategies they use, and support them to be ACP champions by:</p> <ul style="list-style-type: none"> • Educating providers and partners from other sectors together. • Giving them the opportunity to share what works and learn from one another. • Empowering them to recognize barriers in their sectors and advocate for change. • Developing mentorship programs for health care providers and other professionals. | <p align="center">↑ LOCAL</p> |

D. Measure Impact

Key Priorities:


1. Establish targets and key performance indicators
2. Use data to drive change

Like all health initiatives, Advance Care Planning is expected to be able to track its progress, measure its impact, and use data to improve both the quality of its programs (i.e. continuous quality improvement) and their effectiveness.

The fourth pillar of the 2012 ACP framework — continuous quality improvement (CQI) pillar — was the least developed because the concept was relatively new and the sector had not yet developed an evaluation or CQI framework. Over the past seven years, the field has developed a growing body of evidence about both quality and best practices in ACP, while the health system as a whole has more experience establishing targets and indicators, and measuring success and impact on health outcomes.

The 2019 Pan-Canadian Framework recognizes the need to track and measure progress within each of its activities and priorities. To achieve our common goals, it is not enough to document whether people across Canada have engaged in ACP. We must also start to measure whether their planning affects the care they receive and is translated into health practices and medical directives. A Pan-Canadian approach to both targets and indicators is needed in order to be able to measure progress across the country, identify gaps (e.g. underserved populations), and determine which initiatives (i.e. best practices) have the greatest impact.

Priority #1: Establish targets and key performance indicators

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|--|---|---|
| Establish a small Pan-Canadian group to identify a discreet number of targets and key performance indicators | Targets and indicators should be developed for each Framework strand that can be used to track progress in ACP across the country. It will be important to address the need for metrics beyond the health system (e.g. to measure the impact of other ministries, non-health interventions). The ACP network should encourage a multi-disciplinary approach that can measure, for example, whether ACP facilitated by legal or life planning professionals can be translated into health practices. | NATIONAL  |

**III. THE ROADMAP FOR IMPLEMENTING THE 2019 PAN-CANADIAN FRAMEWORK
FOR ADVANCE CARE PLANNING IN CANADA**

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|---|---|--|
| Adapt existing QI frameworks and education competencies to engage health care providers in CQI | <p>To enhance capacity to continuously measure and improve services, health care providers must be actively engaged in the process of collecting data and assessing the impact of their practices.</p> <p>A number of organizations and committees have helped develop key performance/quality indicators, standards, and/or core competency frameworks that include ACP, GOC, and SDM.^{92,93,94,95,96,97,98,99}</p> <p>While they may focus on particular care settings, professions, or jurisdictions, it is important to leverage the work of these organizations rather than creating something new.</p> | <p align="center">REGIONAL</p> <p align="center">LOCAL</p> |
| Determine how to roll up data to report on progress by organization, by jurisdiction and at a Pan-Canadian level. | <p>ACP targets and indicators must be able to be used and rolled up across organizations and jurisdictions so the ACP network can measure and compare the impact of programs within a province/territory and across the country. Data sources such as InterRAI¹⁰⁰ may offer a minimum data set, assessment protocols, and status and outcome measures that could be used to evaluate ACP programs.</p> | |

Priority #2: Use data to drive change

| PRIORITY ACTIONS | RATIONALE | SCOPE |
|---|---|---|
| Invest in research and integrated knowledge translation on effective ACP programs and practices | <p>ACP practice and research within Canada and in other jurisdictions should be closely monitored to identify best practices. ACP research has boomed in recent years, but that evidence has not consistently been used to inform policies and practices. New models of integrated knowledge translation and exchange provide frameworks to close the knowledge-to-action gap.¹⁰¹ For ACP research to have an impact, the questions, process, results, and recommendations must be developed in partnership with relevant stakeholders.</p> | <p align="center">NATIONAL</p> <p align="center">REGIONAL</p> |
| Collect data on meaningful outcomes for ACP | <p>A systematic review identified documentation as the most common measure of the success of ACP, but this does not reflect the quality of ACP or care received.¹⁰² An organization framework for ACP was developed by an international Delphi process, including process (e.g., behavior change), actions (e.g., communication), quality of care (e.g., care satisfaction, care consistent with goals), and health care outcomes (e.g., care utilization).¹⁰³ Outcome measures specifically for health care providers (e.g., moral distress, comfort and confidence) are also needed to demonstrate the impact of ACP on the health care system.</p> | |
| Leverage data to make the case for ongoing investments in ACP. | <p>The transparent tracking and reporting of indicators should lead to a sustainability plan for ACP. Use the indicators to advocate for funding/dedicated resources for ACP.</p> | <p align="center">REGIONAL</p> <p align="center">LOCAL</p> |
| Explore the potential to build ACP questions into existing patient-reported outcomes tools. | <p>Patient-reported outcome tools are one mechanism to measure satisfaction and influence care. Some of these tools already include questions relevant to ACP, and they could be expanded to provide a way to collect ongoing measures of both ACP engagement and patient satisfaction.</p> | |

IV Appendices

APPENDIX A:

History and Development of ACP Framework

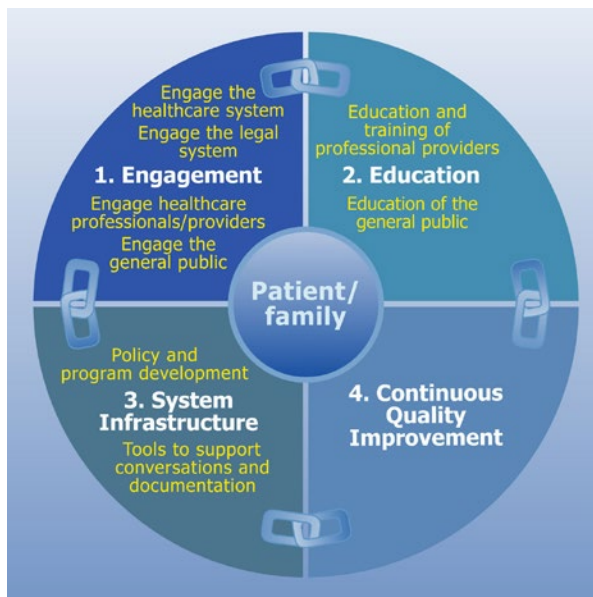
ACP National Framework, 2012

The original National Framework for Advance Care Planning was launched in 2012. The goal of the Framework was to provide a model for Advance Care Planning that can be used to guide all related activity, program development, and standards of practice in Canada.

This first iterative of the Framework was developed by the Advance Care Planning in Canada Project Task Group—a currently existing body who, along with being experts in the field, represents national professional organizations and non-governmental groups concerned with Advance Care Planning. The National Framework was developed over a multi-year national consultative process engaging stakeholders from across the sectors of health, law, and life planning services.

The National Framework built on foundational work at the time that had been done in the former Calgary Health Region (now Alberta Health Services) and Fraser Health Authority. With financial support from Health Canada, these two health authorities led the development of a guide for other authorities to implement Advance Care Planning. A working group established this model in March 2008. They proposed a model with patients and families featured at the centre and four basic building blocks—engagement; education; system infrastructure; and continuous quality improvement. The National Framework followed this basic model and its four core elements.

National Framework for Advance Care Planning in Canada (2012)



Adapted with permission from Health Canada.
Implementation Guide to Advance Care Planning
in Canada: A Case Study of two Health Authorities.
March, 2008.
www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf

The ACP Landscape and Accomplishments, 2012-2019

The National Framework has been the leading model for Advance Care Planning implementation since its launch in 2012. It has driven the development of programs, resources, communities of practice, and public awareness campaigns throughout the last seven years. It has even influenced ACP initiatives abroad, for example, being the basis for the national ACP initiative and implementation plan of the Health Quality and Safety Commission in New Zealand.

There have been incredible successes and achievements in Advance Care Planning since the Framework's release. Over the last seven years, the landscape of Advance Care Planning in Canada has evolved dramatically. New laws have been introduced, new programs have been developed and spread, and new players have joined the field. People found creative ways to engage the public in ACP conversations, educate and support professionals to facilitate these conversations with their patients, and change systems to improve the quality and transferability of conversations across care settings. Research in Canada and abroad has evaluated and identified best practices, quality indicators, sustainability drivers, and effective resources and strategies for supporting Advance Care Planning.

Many of these new developments were indicated as priorities within the 2012 National Framework, including:

Engagement

- Develop and disseminate resources materials that assist health care professionals in understanding the benefits of ACP and in recognizing their role.¹⁰⁴
- Develop and disseminate ACP resources that assist legal professionals in their role.¹⁰⁵
- Conduct a comparative review of the provincial/territorial legislations and develop resources that provide an easy-to-use summary of the legal requirements for ACP.¹⁰⁶
- Develop and disseminate free and available resources to support public engagement in ACP.
- Coordinate a national, multi-media public awareness campaign about the importance of ACP.¹⁰⁷
- Develop and disseminate regionally adaptable resources that assist provincial, territorial, and regional organizations with engaging their local communities.

Education

- Create an online, free repository of ACP resources for different stakeholders and include relevant resources from professional groups and organizations, as well as different jurisdictions.¹⁰⁸
- Invite professional groups and organizations to post their existing tools on the Web so that they can be easily accessed by others.
- Develop online continuing professional education modules for professionals in Advance Care Planning.¹⁰⁹
- Identify education initiatives and resources that are already underway and promote their use.¹¹⁰
- Develop/adapt public education materials regarding ACP for the general public and disseminate them in a wide variety of media.
- Ensure that resources, tools and materials are innovative and are created in plain language.
- Develop standard toolkits that can be shared across Canada and adapted locally.¹¹¹

System Infrastructure

- Accreditation Canada and relevant funding and regulatory authorities in the provinces and territories be engaged to set requirements for policies and practices for Advance Care Planning.^{112,113}
- Local/regional health authorities and their institutions and agencies develop ACP policies and/or programs.
- Ensure that tools are innovative and in plain language.
- Encourage the sharing of tools across jurisdictions and agencies.
- Encourage/support research activities that demonstrate the effectiveness of tools.
- Establish a repository of published research findings and current research activities.¹¹⁴

Measure Impact

- Develop a research agenda that identifies the priorities for research in ACP in Canada.¹¹⁵
- Develop/adapt a continuous quality improvement framework for jurisdictions to use when implementing Advance Care Planning programs in Canada.¹¹⁶

ACP Pan-Canadian Framework, 2019

In early March 2019, nearly 50 Advance Care Planning experts and champions from across Canada met to answer key questions about the National Framework for Advance Care Planning in Canada:

- Is the Framework still relevant seven years in? Does the basic model still stand?
- Which recommendations have been met or are no longer relevant?
- What has changed in the ACP environment that needs to be integrated into the Framework?
- Does anything need to change to ensure more people in Canada — individuals, families, care providers and other professionals — benefit from Advance Care Planning?

A meeting report was crafted and reviewed by the meeting participants (including those invited but unable to attend). Meeting participants agreed that the National Framework has been a valuable, effective tool. Its focus on engagement, education, system infrastructure and continuous quality improvement (i.e. the four pillars) still resonates. The Framework has sparked activity across the country and has helped facilitate, stimulate and catalyze ACP.

The basic take-away from the meeting was that the National Framework is still very much relevant to the current ACP landscape and is still used to inform resource and program development; however, meeting participants indicated that updates were needed to the Framework's guiding principles, mission or call to action, and specific recommendations within the pillars. Furthermore, they identified six key aspects of ACP needing to be addressed in the updated Framework:

1. **Broaden the scope of ACP beyond just end-of-life planning.** It is about planning for when a person is unable to make their wishes known and is an essential part of a life well lived/ planned. ACP should begin much earlier — long before someone is faced with a crisis or life-limiting illness — and continue throughout people's lives.
2. **Integrate ACP into the other future planning conversations.** People plan for their futures throughout their lives (e.g. wills, financial powers of attorney, organ donation). ACP is part of this broader matrix of life planning.
3. **Normalize ACP.** Make it clear that ACP applies to everyone and help people feel more comfortable and confident in having conversations about their future care and how they want to live and die.
4. **Recognize that culture plays a strong role** in how people view decision making, future planning, care at the end of their lives, and death. Ensure approaches to ACP respect cultural diversity and foster equitable participation.
5. **Make ACP simpler and easier to do.** Keep messaging in plain language and close gaps in the accessibility of resources.
6. **Make quality improvement a higher priority.** Ensure health systems are accountable for being aware of people's wishes, transferring them across settings, and providing care that is concordant with their wishes to the fullest extent possible.

The next step in the consultative process was to consult with a broader audience to further refine the report, which was to inform this new Pan-Canadian ACP Framework. This process ran from April to June 2019, involving a series of webinar-style consultation meetings with various stakeholders. There were webinars specifically addressing each of the four pillars and specifically engaging stakeholders from three different jurisdictions—national, provincial/territorial, and community-level.

In total, there were 9 consultative events over 4 months, engaging over 300 stakeholders involved in Advance Care Planning. The new Pan-Canadian ACP Framework synthesizes the comments, resources, and perspectives shared over the consultation process.

APPENDIX B:

National Poll Results Infographic

ADVANCE CARE PLANNING

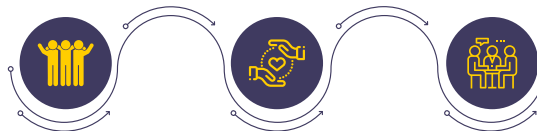


by 2020, over 330,000 people in Canada will die each year

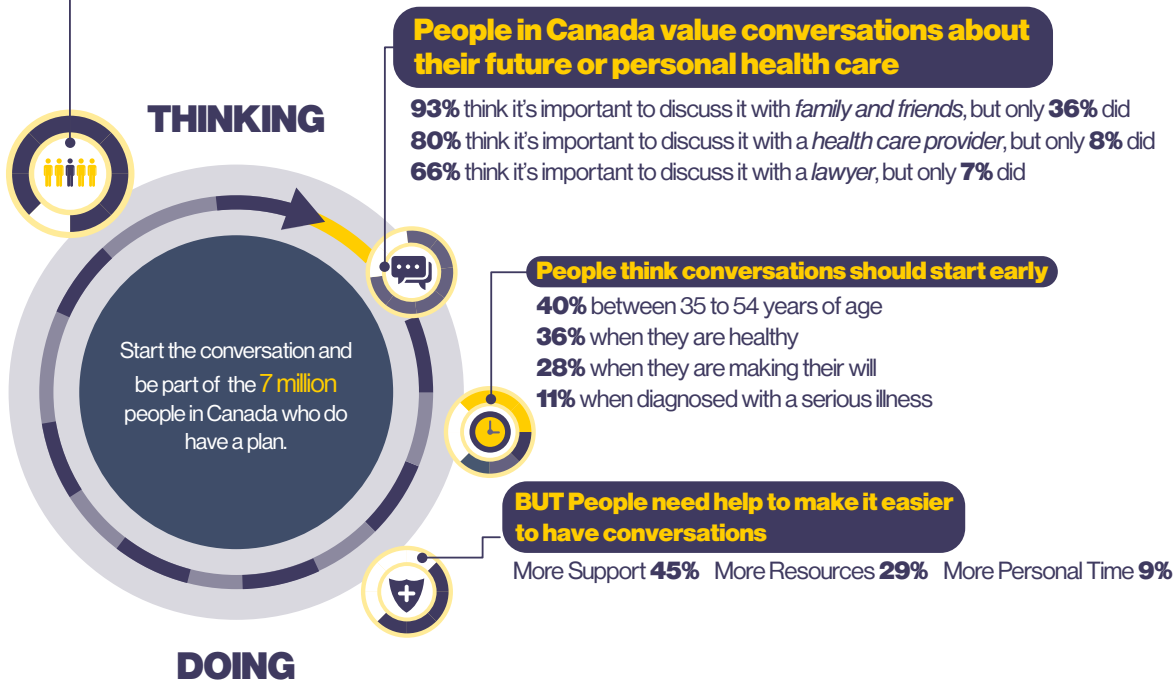
Advance Care Planning is about thinking and sharing wishes for future health and personal care.

It allows you to tell others what would be important if you were unable to communicate due to illness or an unexpected crisis.

It involves conversations with your family and friends, substitute decision-makers, health care providers, legal and life planning service providers.



80% of people in Canada think it is important to do Advance Care Planning
Yet less than 1 in 5 people in Canada have an Advance Care Plan



www.advancecareplanning.ca
 This poll was conducted by Nanos, February 2019, with nearly 3000 people across Canada

APPENDIX C:

Assumptions

In Canada, we have a number of different systems and jurisdictions that are responsible for health, justice, and social services. Therefore, there is a need for a Framework to recognize, adapt to, and synergize with these different structures.

Every province and territory in Canada has laws that govern the process of Advance Care Planning. For the most part, these laws all outline:

1. When and how a person can plan for their future care.
2. When and how a person can choose Substitute Decision Makers.
3. What kinds of care can be included in Advance Care Planning and what powers Substitute Decision Makers have.
4. Who is responsible for assessing a person's capacity and how assessments are to be made.
5. How Advance Care Planning may be applied once a person's has lost capacity.

One of the challenges faced by people in Canada is that the laws around Advance Care Planning, Substitute Decision Making, and Health Care Consent vary from jurisdiction to jurisdiction. This results in complex and sometimes unclear differences under the various provincial/territorial statutes as, for example:

- The legal status and validity requirements of Advance Directives
- The validity requirements for choosing Substitute Decision Makers
- The hierarchy of potential Statutory or Specific Decision Makers (in the event no Substitute Decision Maker has been chosen or is available)
- Legal recognition of Advance Care Planning or Substitute Decision Making documents from outside the province/territory.

Since laws differ across the country, the general public and professionals must know what the law says in their own province/territory. Health care professionals, in particular, need to be able to answer such questions as:

- What form of Advance Care Planning or expressed wish is recognized?
- What does it mean to be capable/competent? How is it determined?
- At what age is a person able to make an Advance Directive?
- Does the law enable a person to appoint a Substitute Decision Maker?
- Does the law allow a health care provider to take instructions from an Advance Directive or must they get consent from a Substitute Decision Maker first?
- If there is no Substitute Decision Maker appointed, to whom does a health care provider turn?

Despite these differences, there are several common guiding principles, many of which are enshrined in law, that can inform Advance Care Planning, Substitute Decision Making, and Health Care Consent practices across the country (Appendix C). It is the position of this Framework that health care decision making must be in keeping with a person's expressed wishes and must meaningfully involve the person and/or their Substitute Decision Makers to the fullest extent possible. This recommendation is based on the Framework's prioritizing of equity, collaboration, accountability, and cultural safety.

APPENDIX D:

Common Steps and Principles to Advance Care Planning

Canada is a diverse place and the structures, language, and protocols for Advance Care Planning differ greatly across the country. However, no matter what the system or jurisdiction, there are common steps and principles that people may follow as they prepare for their future care.

The following steps may guide the personal process of Advance Care Planning:

Step 1: Think about your values, wishes, beliefs and understanding about your life, death, and future care.

Step 2: Learn about different medical procedures and care options, including what they can and can't do.

Step 3: Decide who will be your Substitute Decision Maker(s) to speak on your behalf if you cannot.

Step 4: Talk about your wishes with your Substitute Decision Maker(s), important people in your life, your health care providers, and legal and life planning professionals.

Step 5: Record your wishes verbally or in writing. You may wish to share your recorded wishes with those who might be involved in your future care. You should also review your recorded wishes at regular intervals (e.g., yearly), or whenever there is a change in your health or life circumstances.

The following principles may guide all aspects of Advance Care Planning:

Individual respect

1. Each person is intrinsically valuable, unique, and has the moral right to autonomous decision making.
2. Advance Care Planning is guided by the quality of life people perceive as acceptable for themselves.
3. Health care professionals enter into a therapeutic relationship with patients and families based on mutual respect for the inherent dignity and integrity of all parties.
4. Advance Care Planning must occur within the context of, and with respect for, a person and their loved ones' social, cultural, and religious values, their beliefs and practices regarding the quality of life and dying, their situation and place within the life journey, and their readiness to talk about difficult topics.

Cultural safety and humility

1. Respect for diversity and equity in Advance Care Planning is supported by self-reflection and awareness of how some communities are systematically disadvantaged, as well as practices of respectful and meaningful engagement with those communities.
2. Facilitating ACP with these communities requires culturally relevant and strengths-based approaches.
3. Cultural safety and humility are particularly relevant for supporting First Nations, Inuit, and Métis engagement in ACP.

Relational autonomy^{117,118}

1. Autonomy emerges within and because of relationships; in situations of care, a person is able to plan and/or make care decisions through their interdependence on loved ones, families, communities, care providers, institutions, and systems.
2. Advance Care Planning focuses not only on *what* possible decisions might be made but also *who* will be making decisions and *how* they will be made.
3. Conversations address people's relational concerns about ACP, for example, burdening their Substitute Decision Makers to follow their wishes; balancing control over future decisions with trust in their Substitute Decision Makers; or disrupting customary patterns of decision making within their family or community.
4. A relational approach to ACP and Goals of Care conversations is fostered within health care settings by patient-and-family-centered care, Supported and Shared Decision Making, patient advocates and navigators, and other collaboration-based practices.

Presumption of capacity

1. Enshrined in law is the presumption that all people in Canada above the age of majority have capacity unless there is clear evidence to suggest otherwise.
2. A person's level of capacity is complex; it depends on the situation and the decisions to be made, and can also change significantly over a short or long period of time.
3. If there is reason to doubt a person's capacity, it is the responsibility of health care providers or the courts (depending on the jurisdiction) to conduct an assessment of their capacity.
4. For people under the age of majority, their level of capacity is assessed and applied to the degree to which they participate in Advance Care Planning. Consideration is given to the impacts of their involvement in decision making on their transition into adult care.
5. People with limited capacity are involved in decisions about their care to whatever extent is possible and appropriate for them. They are provided with all available opportunities for Supported Decision Making through the use of friends, family or community members, caregivers, technologies and tools (e.g., communication aids, decision aids), and/or professionals (e.g., translators, language pathologists, mental health professionals) to enable their participation.

Informed consent

1. Health care providers are responsible for meeting the legal requirements for informed consent, including the core elements of:
 - » Reference to the particular treatment and administrator of the treatment
 - » Full information about the risks, benefits and side effects of the particular treatment; the alternatives to the particular treatment, including not having treatment, and the risks and benefits of these alternatives
 - » Voluntariness (e.g. lack of coercion) in decision making
 - » Consent given by the patient or, if the patient lacks capacity, the legally authorized Substitute Decision Maker.

Access

1. All persons have the opportunity to engage in and access support for Advance Care Planning, in a manner that is personally and culturally meaningful.
2. All persons have access to accurate and relevant information regarding their options for Advance Care Planning and health care decision making.
3. All reasonable efforts are made to maintain a person's meaningful involvement in current and future health decision-making.

Beneficial and effective

1. There are benefits from Advance Care Planning for the person involved, their Substitute Decision Makers and loved ones, the health care team, and the health care system. These may include improved satisfaction with care, quality of life, and/or readiness and preparation for health care decision-making; as well as a reduction in moral distress, decisional conflicts, and/or unnecessary and potentially harmful interventions.
2. ACP conversations are not lost in transitions between care settings. Mechanisms are in place to share conversations during transfers.
3. Conversations are revisited regularly (e.g., during annual exams) and during significant changes in a person's life (e.g., marriage, childbirth, relocation, diagnosis or health crisis, etc.)

Quality of Advance Care Planning activities

1. All Advance Care Planning activities are guided by the following:
 - » The ethical principles of equity, justice, relational autonomy, beneficence, accessibility, fidelity, and privacy/confidentiality;
 - » Standards of practice that are based on generally accepted principles and norms of practice across the country, and standards of professional conduct for each discipline;
 - » Policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines; and
 - » Data collection/documentation guidelines that are based on validated measurement tools.
2. Health care, legal, and other professionals involved in Advance Care Planning have a responsibility to follow:
 - » The ethical frameworks of their professions
 - » The policies/guidelines of their organizations and regulatory bodies
 - » The legal requirements of their jurisdictions for Advance Care Planning, Substitute Decision Making, and Health Care Consent.
3. Advance Care Planning programs and tools are informed by the highest quality of available evidence. Ongoing evolution of Advance Care Planning programs are guided by emerging research in this area.
4. Introductory and ongoing education of the public, patients and caregivers, professionals, and related stakeholders is integral to the continuing provision and progression of quality Advance Care Planning.

APPENDIX E:

Definitions and Terms

1. **Advance Care Planning:** A lifelong process of reflection and communication in which people express their wishes for their future health and/or personal care if they could not speak for themselves. It also involves choosing who you would like to make decisions about your care if you could not (your Substitute Decision Makers). Advance Care Planning should involve the person's Substitute Decision Maker(s), important people in the person's life, and may involve health care providers, lawyers, and/or others involved in life planning.
2. **Advance Care Plan / Advance Directive:** A verbal or written summary of a person's wishes or instructions about the kinds of care they want or do not want in their future care. An Advance Care Plan can be written down or simply told to someone who is authorized to make care decisions on their behalf, such as a Substitute Decision Maker. Documentation is an important but specific part of Advance Care Planning, which more broadly includes reflecting on, discussing, and revisiting what's most important in life as circumstances evolve and priorities change.
3. **Cultural Safety:** An outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care. While cultural safety approaches often refer to providing care to First Nations, Inuit, and Métis communities, it can have broad application a number of communities that have experienced systemic discrimination or disadvantage.
4. **Cultural Humility:** A practice of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience. While cultural humility approaches often refer to providing care to First Nations, Inuit, and Métis communities, it can have broad application a number of communities that have experienced systemic discrimination or disadvantage.
5. **Goals of Care Conversations:** Discussions about values, beliefs, and wishes as they apply to current clinical situations, sometimes resulting in medical orders for the use or non-use of life-sustaining treatments. If Advance Care Planning has not previously occurred, conversations about a person's values, beliefs, and wishes are still needed in order to develop goals of care that are consistent with them.
6. **Health Care Decision Making:** A situation in which immediate decisions about care need to be made. Informed consent to proceed with the decision is often required from either the person or their Substitute Decision Maker, although there are some exceptions (e.g., emergency treatment by first responders). Ideally, decisions are informed by prior Advance Care Planning and Goals of Care conversations and are consistent with the person's wishes.

7. **(In)Capacity:** A person is capable of giving or refusing consent to care or medical treatment if they are able to understand the information relevant to making a decision about their care (which may include the withdrawal of treatment) and are able to appreciate the likely consequences of that decision. A person may lose capacity when they can no longer understand the information needed to make an informed decision. Capacity is often assessed by the health care provider who is proposing the course of care.
8. **Informed Consent:** The permission a person gives to health care providers to follow a course of care or treatment. Health care providers are responsible for providing the adequate information needed to give informed consent. The component elements of consent include:
 - » voluntariness (e.g. lack of coercion)
 - » the requirement that consent be given by the person or, if they lack capacity, their legally authorized Substitute Decision Maker
 - » reference to the particular treatment and administrator of the treatment
 - » full information about the risks, benefits and side effects of the particular treatment
 - » full information about the alternatives to the particular treatment, including not having treatment, and the risks and benefits of these alternatives.
9. **Palliative Care:** Care provided for people who have a life-limiting illness that focuses on providing good quality of life — in other words, keeping the person as comfortable and free of pain as possible. Palliative care may involve medicines, treatments, physical care, psychological/social services and spiritual support, both for the person and for those who are helping to care for them. Palliative care can be complementary to treatments focused on control or cure of disease.
10. **Public Guardian and Trustee/Québec Public Curator:** The decision maker of last resort in some jurisdictions, who will make decisions for a person who has lost capacity and has no other Substitute Decision Maker, or where equally ranking Substitute Decision Makers disagree about a treatment decision.
11. **Shared Decision Making:** A process that promotes collaboration between health care providers and the recipients of care in health care decisions. This process involves providing medical information, eliciting patient values and preferences, exploring preferred roles in decision-making, and deliberating on options.¹¹⁹ Shared Decision Making also supports open and unencumbered access to information about the benefits and harms of different care options.

12. **Supported Decision Making:** When a person who has limited capacity, or may need assistance in making decisions, uses friends, family or community members, and/or professionals to help them understand their situation and their choices. This support can enable people with wavering capacity or other barriers to giving consent to make care decisions rather than a Substitute Decision Maker or Guardian.
13. **Substitute Decision Makers (SDMs):** Before a person loses capacity, they may choose one or more persons to make decisions about their care when they are no longer able to do so. Terms differ across the provinces/territories; depending on the jurisdiction, this person might also be known as a Proxy, Mandatary, Health Representative, Agent, or a Power of Attorney for Personal Care. When possible, use the appropriate terms for your jurisdiction.
14. **Statutory or Specific Decision Makers:** If a person has not chosen a Substitute Decision Maker before they lose capacity, a Statutory or Specific Decision Maker will be chosen for them (by their health care provider or by the courts, depending on the jurisdiction). The person is chosen based on a hierarchy of possible decision makers outlined in the jurisdiction's laws. The possible decision makers are for the most part a person's nearest relatives (e.g., spouse, children, parents, siblings, etc.), but depending on the region they may also include close friends, health care providers, another interested party, or the provincial/territorial Public Guardian (Le Curateur public in Québec).

APPENDIX F:

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