Advance Care Planning in Canada:
Environmental Scan

Working Document
June, 2009

Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

SOINS CONTINUS Bruyère CONTINUING CARE

Acknowledgements

This Environmental Scan was researched and written by Gwen Barton.

Translation was provided by Raymond Arsenault Consultants Inc.

Formatting was provided by Abacus Services.

The research, writing and production of this Environmental Scan have been made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer.

The translation of this Environmental Scan was funded by the Palliative and End-of-Life Care Unit, Chronic and Continuing Care Division, Health Canada.

This Environmental Scan is a foundational document for *Advance Care Planning in Canada: A National Framework and Implementation* – a five-year project of the Canadian Hospice Palliative Care Association that is funded by The GlaxoSmithKline Foundation. It provided background information for the *Advance Care Planning in Canada: National Round Table*, which was funded by the Palliative and End-of-Life Care Unit, Chronic and Continuing Care Division, Health Canada.

Table of Contents

Advance Care Planning in Canada:

Environmental Scan

Preamble

This environmental scan has been developed as a foundation document to inform the participants attending the Advance Care Planning National Round Table and to support the Canadian Hospice Palliative Care Association's Advance Care Planning Task Group in their work to develop a national strategy for advance care planning. While efforts have been taken to identify all areas of advance care planning activity in Canada, it is possible that some initiatives may have been missed. It is important to remember that this document is a work in progress and is intended to serve as a starting point for the compilation of information which can be added to as new information surfaces to ensure a comprehensive summary.

Background

Advance care planning or ACP is a process whereby a capable (mentally competent) adult engages in a plan for making personal health care decisions in the event that this person becomes incapable (legally incompetent to personally direct) his or her own health care. ACP describes what kind of care the person would want (or not want) if he or she were unable to make health care decisions. It is the process of exploring questions that often go unasked, such as: What gives life meaning? Are there circumstances (loss of physical functioning or loss of mental awareness, for example) in which the person would not want their life prolonged by certain treatments, but rather would want nature to be allowed to take its course and they be allowed to die?[1]

As health care technologies and life saving interventions continue to improve and people live longer (many with complex medical conditions), advance care planning is becoming increasingly important. The ability to discuss and document one's wishes and concerns regarding end of life care, while often difficult, has the potential to significantly impact the quality of the end of life experience for both the patient and their family members.

[1] "Educating Future Physicians in Palliative and End-of-Life Care" (2007). *Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Material.*

In 2002, the Canadian Strategy on Palliative and End of Life Care of the Federal Government released their *National Action Plan*. As part of the Strategy, the Public Information and Awareness Working Group, one of several established to support the efforts of the plan, identified advance care planning (ACP) as a priority area. However, ACP in Canada remains in its early stage of development and is evolving with an inconsistent approach. There are some groups and jurisdictions that have established programs, whereas others are just beginning to understand the importance of ACP. This situation demonstrates the timely need for a systems-level approach to support and guide the advancement of ACP.

The Canadian Hospice Palliative Care Association has assumed a position of leadership in ACP in Canada. With funding support from The GlaxoSmithKline Foundation, Health Canada and the Canadian Partnership Against Cancer, the CHPCA has initiated a five-year project to develop a national framework for ACP in Canada. The key objective of the national framework is to provide a model that can be used to guide all related activity, program development and standards of practice.

To move this agenda forward, the CHPCA has established a Task Group charged with coordinating the process for the development of a *National Framework for Advance Care Planning*. The Task Group has organized a National Round Table to be held in March 2009, involving representatives from regional health authorities/integration networks, Federal/Provincial/Territorial governments, the academic community and key national organizations interested in this subject area. This meeting is to set the stage for the development of the Framework by identifying what is currently happening with respect to ACP across Canada and what components should be considered for inclusion in the model. The environmental scan, as presented in this report, will assist the Round Table participants in meeting these objectives by providing them with an overview of ACP activity across the country.

A list of the Advance Care Planning Task Group members can be found in Appendix A.

Approach

The methodology identified for the environmental scan review was designed to build on recent reports and other efforts to date in the area of ACP that have been initiated. Data collection focused on three main sources of information:

Document Review

The findings of several key reports recently been released related to ACP in Canada were reviewed and summarized.

Website Review

A review of provincial/territorial government, non-government and professional association websites was conducted to identify any new or emerging developments in the area of ACP. (The links are found in Appendix C.)

Key Informant Interviews

Interviews with key informants (identified by Task Group members and through the website review) were conducted to validate preliminary findings and further investigate areas of ACP activity. (The list of Key Informants is found in Appendix B.)

The following questions served as a framework for all three areas of data collection:

- What activities are underway at the national, provincial/territorial and regional (local) level regarding Advance Care Planning (including programs for the public, programs for professionals and general awareness-raising initiatives)?
- Are there jurisdictions that are in the planning phases/jurisdictions that have identified the importance of ACP, but have not yet initiated activities?
- What are the key elements of the programs/activities that are underway?
- Are there common guiding principles and/or values that have been identified in these programs/activities?
- Are there common competencies that have been identified for professionals engaging in ACP?
- Are there ACP tools available (for the public or professionals)?
- What are some of the enablers for advance care planning?
- What are the challenges to initiating and implementing activities/programs in advance care planning?

Document Review

A number of documents have been produced in recent years in an effort to increase awareness of ACP and its importance in the health care system. The purpose of this scan is not to 'reinvent the wheel', but to build on the findings of these reports and to highlight relevant information to support the Framework development.

Three key reports have been recommended by the Task Group to be included in the document review process. Each has been written from a Canadian frame of reference and will contribute significantly to the development of a National ACP Framework.

The *Glossary Project* (2006) was initiated in response to the inconsistency with respect to ACP terminology in Canada. The majority of health care service delivery and legislation is governed by the provincial and territorial governments. As a result, language to describe concepts integral to ACP varies among these jurisdictions. In addition to providing some clarification around terminology, the Project also examined current processes associated with ACP in the health, social (public) and legal arenas.

The second document, *Advance Care Planning: An implementation guide for health authorities in Canada* (2008) was developed as a guide to support the planning and implementation of ACP initiatives at the local/regional level. This report highlights the importance of engagement (organizational and community), education of those involved, system infrastructure and continuous quality improvement to support evaluation and outcome measurement.

Facilitating Advance Care Planning: An inter-professional education program (2007) puts forward a training module focusing on five key competency areas, each with an accompanying list of objectives.

The three reports described above have been reviewed in detail and summarized in the table below.

Document	Key Findings/Important Trends
Advance care planning: the Glossary Project, Final report (unpublished), by Janet Dunbrack for Health Canada, August 2006. **Description** The document presents an analysis of findings based on a literature/website review and key informant interviews with representatives from health, social (including clients) and legal sectors. The *Glossary Project* provides a detailed	▪ There are strong pockets of ACP expertise across Canada. ▪ Successful programs have effective systems that support the development of advance directives and ensure that all members of the health care team are aware of a patient's advance directive. ▪ Effective, ongoing communication among the patient, family and health care team is essential to effective ACP. ▪ Successful ACP often begins well in advance of serious illness. ▪ Raising the subject of ACP with patients can be difficult for health care providers and fearful for patients. However, many consumers are eager to discuss ACP if they are given the opportunity in a supportive environment.

Document	Key Findings/Important Trends
summary of how Canadians experience the process of ACP and how ACP is addressed in these three sectors (health, social/public and legal). The document also provides a detailed review and glossary of concepts and terms used with respect to ACP in Canada.	▪ Education, user-friendly tools and resources are needed by professionals in all sectors and by consumers. ▪ Key informants from all sectors stressed the importance of understanding the core concept of informed consent to treatment which underlies advance directives. ▪ Some family members recommended the development of creating advance directions that are disease/condition specific. ▪ Certain conditions lead to health professionals ignoring a patient's advance directions (limited staff time, ineffective communication, lack of awareness of advance directives). ▪ Informants in the health and legal sectors voiced strong opinions about the merits of proxy versus instructional directives. (Those in favour of proxy directives stressed their flexibility in response to changing circumstances; those in favour of instructional directives stressed the individual's right to autonomy, privacy and choice without reference to substitute decision-makers.) ▪ There is a need to foster ongoing dialogue about ACP among all sectors so that legislation, law and policy can be both legally and medically sound, as well as socially responsive. ▪ Research and evaluation are needed to increase the evidence base for ACP and to provide a foundation for evaluating processes and measuring outcomes.
Advance care planning: An implementation guide for health authorities in Canada. March 31, 2008. **Description** A guide to support health authorities in the planning and implementation of ACP initiatives.	The model is composed of four building blocks (necessary for ACP program implementation): **Engagement:** *Organizational engagement* consists of the support and involvement of senior management, health care providers and other staff within the health authority (demonstrating how the ACP initiative aligns with and supports existing organizational policies and priorities and how it can improve patient care). *Community engagement* involves outreach to the public in order to engage capable adults and their families in ACP

Document	Key Findings/Important Trends
	through raising awareness, initiating dialogue about ACP and connecting people to the means of engaging in ACP. **Education:** Education (for the entire health team) involves: engaging, training and supporting health care providers to facilitate ACP conversations and processes as part of their core skill set; information resources and tools such as workbooks, brochures and web-based resources for the public and health care providers; and tools for recording decisions about care wishes. **System Infrastructure:** System infrastructure to support ACP initiatives involves a variety of mechanisms to ensure that health care providers are aware of care preferences as the patient interfaces with different care settings. These systems can include: patient ownership of their ACP documents; highly visible documents in health care charts or in the home; mechanisms for ensuring that care wishes follow the patient through a variety of health care settings; electronic health care records; and consistent goals of care designations throughout the health care facility or region. **Continuous Quality Improvement** Continuous quality improvement elements include: a corporate culture that promotes quality improvement as a key component of evidence-based practice; development and testing of measurement and evaluation tools; development of performance indicators; mechanisms for sharing what is learned from evaluation; and incorporation of evaluation results into practice on an ongoing basis.
Facilitating Advance Care Planning: An Inter-professional Educational Program: Curriculum Material. 2007. Educating Future Physicians in Palliative and End-of-Life Care.	The educational module details the steps in the ACP process from the importance of determining capacity to initiating the conversations and building organizational capacity for ACP (including guidelines for policy development). The document identifies five key competency areas with related objectives: ▪ Defining ACP and its importance

Document	Key Findings/Important Trends
Description An educational program/module on ACP targeting inter-professional health care providers at all levels (undergraduate, postgraduate and continuing professional development) (2008)	▪ Initiating an ACP conversation and assist in the creation and/or documentation of an advance care plan ▪ Facilitating ongoing ACP conversations over the continuum of care ▪ Identifying potential conflicts in ACP and effectively manage conflicts ▪ Serve as an ACP resource in an organization. Health service provider 'self-care' is also recommended as a core competency in order to manage stress associated with the challenges of initiating ACP conversations.

Areas of Activities in ACP

The document and website review undertaken for this environmental scan provided a snapshot of activity related to ACP across Canada. Results found that most provincial and territorial governments have established legislation related to advance directives, but there are only a few areas in Canada that have established ACP programs within their organizations or jurisdictions.

The two most noted programs in Canada are the Alberta Health Services —Calgary and area (former Calgary Health Region) in Alberta and the Fraser Health Authority in British Columbia. Both health authorities have developed tools to increase public awareness and support clients as they explore ACP, as well as educational initiatives and tools to support health providers as they engage in conversations, document and evaluate the ACP process. The former Calgary Health Region has recently adopted an Advance *Care Planning: Goals of Care Designation (Adult)* policy. 80% of frontline staff received policy orientation and training. All "appropriate" clients (as defined for each health care sector) are to be engaged in a goals-of-care conversation which is communicated through a "Goals of Care Designation" physician order. These Goals of Care Designation Orders then travel with the client between health care sectors. Evaluation efforts related to the effectiveness of this policy are underway, but summative results are not yet available.

A number of other websites offered interesting information on ACP and tools to support the process. In addition to the description below, specific findings have been incorporated into other relevant sections of this report. (These areas of activity have been summarized in Appendix C.)

Provincial and Territorial Governments

All the provinces and territories (except for New Brunswick and Nunavut) have some form of advance directive legislation. Although the terminology differs among areas of jurisdiction, the essence of the legislation is the same in that it has provisions for an individual to document their care wishes and to identify a substitute decision-maker should they become incapable of doing so.

As noted in the chart below, all existing provincial/territorial legislation (except for Quebec and Nova Scotia) includes provisions for instructional and substitute decision maker (noted as proxy on the table below) directives.[2]

Province	Instruction	Proxy
Alberta	✓	✓
British Columbia	✓*	✓
Manitoba	✓	✓
New Brunswick	No legislation**	
Newfoundland	✓	✓
Northwest Territories	✓	✓
Nova Scotia	-	✓
Nunavut	No legislation	
Ontario	-	✓
Prince Edward Island	✓	✓
Quebec	-	✓
Saskatchewan	✓	✓
Yukon	-	✓

*The instructional legislation in BC is not yet in effect.
** New Brunswick may have proxy legislation, depending on how one interprets their act.

Several provinces, including British Columbia and Alberta, have recently participated in legislative reviews of advance directive legislation and are proposing amendments including the standardization of documentation for recording advance directives and support for the recognition of advance directives that originate out of the province, providing they meet the requirements of existing provincial legislation. New Brunswick is in the process of developing *Advanced Health-care Directives (Living Wills) Legislation*.

[2] *End of Life Project,* Health Law Institute, Dalhousie University, Advance Directives FAQs.

A number of provinces have developed public education and awareness tools highlighting the importance of ACP and steps that can be taken to initiate this level of planning.

- In Ontario, the Seniors' Secretariat has produced an awareness and education guide targeting families of individuals with Alzheimers that highlights the importance of ACP and steps that can be taken to initiate this level of planning.
- The Governments of Manitoba, Saskatchewan and the Northwest Territories have Q&A information sheets on their websites focusing on the role of advance directives.
- British Columbia Government has an advance directives fact sheet (2006) posted as well as links to Health Link B.C. (www.HealthLinkBC.ca) which provides a brief, descriptive overview of advance directives and substitute decision-making under the section related to hospice palliative care.
- Yukon Health and Social Services has produced a number of public education brochures and fact sheets related to the importance of planning for future health care choices and having documented advance directives. A separate brochure highlights the role of the substitute decision-maker.
- The Government of Alberta website has developed a brochure entitled "Choosing Now for the Future: Personal Directives" which includes questions and answers related to personal directives and sources for additional information. The website also highlights information sessions being held across the province related to how to write a personal directive and how to use the personal directive form.
- The Nova Scotia Government does not have a single approach to ACP, however, there are pockets of ACP incorporated into all aspects of palliative care, and educational initiatives (including lunch and learn sessions) are happening within the province.
- Nunavut is in the early stages of an initiative for palliative and advance care planning using resources available through the *Pallium Project*.

Professional Associations

Professional bodies across Canada have recognized the ethical obligation on the part of their members to honour a person's advance care choices wherever possible. They also

refer to the obligation of the professional to know the legal requirements for decisions about care of an incapable person.[3]

In 1999, the Boards of Directors of the Canadian Medical Association, the Canadian Nurses Association, the Canadian Healthcare Association and the Catholic Health Association approved a joint statement on *Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care*. The statement supports that the "needs, values and preferences of the person receiving care should be the primary consideration in the provision of quality care".[4]

Individual nursing and medical associations have included recognizing advance care choices in their *Codes of Ethics*. In the Canadian Medical Association's *Code of Ethics* (updated 2004), physicians are advised to "Ascertain wherever possible and recognize your patient's wishes about the initiation, continuation or cessation of life-sustaining treatment" (Section 27), and "Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent" (Section 28).

In 2008, the Canadian Nurses Association released a position statement on "Providing Nursing Care at the End of Life"—this includes a section on advance care planning recognizing the importance for individuals, healthy or ill, to make informed choice related to end of life care.

Non-Government Organizations

In addition to leading the development of a national ACP framework, the CHPCA has organized and participated in a number of other related initiatives. CHPCA is responsible for promoting *National Hospice Palliative Care Week* activities in Canada. The week is used as an opportunity to explore end of life care issues and for the palliative care community to share its knowledge and achievements with Canadians. For the past three years, ACP has been the focus of the week's events in an effort to raise awareness of the importance of ACP.

The ***Living Lessons***® campaign is a program developed by The GlaxoSmithKline Foundation in partnership with the CHPCA with a focus on improving quality, end-of-life care. As part of its public awareness initiative, *Living Lessons* has developed a *Bill of Rights* for the patient which highlights the importance of participation in decision-

---

[3] *Educating Future Physicians in Palliative and End of Life Care: Facilitating Advance Care Planning, An Interprofessional Educational Program* (2008).

[4] Canadian Healthcare Association, Canadian Medical Association, Canadian Nurses Association and Catholic Health Association of Canada, *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care* (1999).

making and the right to have their decisions and choices respected by others (see www.living-lessons.org/cando/patient.asp).

A number of other non-governmental organizations have initiated activity in the area of ACP. In 1999, the Government of Ontario announced a provincial strategy for *Alzheimer Disease and Related Dementias*. The Strategy outlines ten specific initiatives to address this illness including 'Advance Directives on Care Choices'. Since then, the Alzheimer Society of Canada has established ethical guidelines for decision-making. The document entitled *Decision-Making and Respecting Individual Choice* highlights the importance of planning ahead for individuals with Alzheimer Disease and provides strategies to facilitate decisions being made including taking an active role, having open discussions and exploring substitute decision-making and advance directives.

Also of interest is the fact that Accreditation Canada (formerly known as the Canadian Council on Health Services Accreditation) released hospice palliative and end-of-life care (HP/EOLC) standards in May 2006. Advance care planning has been incorporated into the standards among the core set of performance indicators. This has a significant impact on promoting nation-wide interest and attention on ACP development and implementation.

Advance Care Planning for Children and Youth

While this environmental scan focuses primarily on ACP as it relates to the general adult population, literature related to ACP for the paediatric population is also beginning to surface. A recent position statement from the Canadian Pediatric Society recognizes the importance of supporting health service providers in initiating ACP conversations with families and children dealing with life-threatening illness.[5]

As one can expect, there are unique aspects to ACP within the paediatric population. For example, the issue of 'consent' for children and youth can be categorized into three areas of decision-making capacity: incapable of consent; developing capacity for consent; and fully capable of consent. The last category defines the mature minor, who is legally not an adult according to chronological age criteria, yet has the cognitive ability to consider treatment choices and alternatives and weigh the consequences. Consent is further complicated when faced with a situation where the patient and family members do not share the same goals of care.[6]

Legislation that stipulates age for advance directives also varies among the provinces. Most jurisdictions in Canada do not have legislation granting legal validity to advance

---

[5] Canadian Pediatric Society (2008). "Advance care planning for paediatric patients". *Paediatric Child Health*, 13 (9), p. 791-796.
[6] *End of Life Project,* Health Law Institute, Dalhousie University, Advance Directives FAQs.

directives made by mature minors. However, the stipulated legal age for advance directives has been identified as 16 years in Saskatchewan, Ontario, New Brunswick, Prince Edward Island and Newfoundland.

Recent work by Weiner et al. (2008) used the basic concepts of the *Five Wishes*® initiative to explore whether adolescents and young adults living with a life-limiting illness find it acceptable and helpful to have a planning document to share their wishes and thoughts regarding end of life care. The *Five Wishes* initiative operating out of the *Aging With Dignity* organization in the United States expresses the role of advance care planning within five simple statements. *Five Wishes* encourages individuals to discuss their wishes with family and physician to ensure they know:

1. Which person you want to make health care decisions for you when you can't make them.
2. The kind of medical treatment you want or don't want.
3. How comfortable you want to be.
4. How you want people to treat you.
5. What you want your loved ones to know.

Results found that no patients found talking about the issues in *Five Wishes*® "stressful" or "very stressful." However, participants were more interested in items concerning how they wanted to be treated and remembered than items concerning medical decision-making. The article recommended that additional research be initiated to further explore whether an age-appropriate ACP document can improve communication with family and staff.

Alberta Health Services (Calgary and area) is waiting for approval to launch the Pediatric Goals of Care Designation Policy in late September 2009 - the paediatric equivalent of the "Advance Care Planning: Goals of Care Designation" policy implemented in the adult sector in late 2008.

The Pediatric Palliative Care and Grief Support Team at Alberta Children's Hospital in Calgary has just created an activity ("Hear My Voice") for families to encourage them to talk about their values and goals to guide decision-making during the illness experience.

Condition/Illness Specific Advance Care Planning

There is also recent support for a more tailored approach to ACP particularly for diseases with a high prevalence such as cancer or Alzheimer Disease. *Respecting Choices® Advance Care Planning*, a program of the Gundersen Lutheran Medical Foundation, states that "advance care planning is not a 'one size fits all' intervention. To be most effective, it should be individualized to the patient's diagnosis, understanding,

values, goals and beliefs and include a chosen surrogate decision maker."[7] The belief is that symptoms and treatment options associated with certain illnesses require extra assistance and skilled facilitation and need to be incorporated into the decision-making process. For example, individuals with end stage renal disease need to understand that they cannot be kept alive indefinitely on dialysis. Interestingly, research has shown that despite having a terminal illness, conversations related to death and dying are commonly avoided until late in the illness.[8]

A recent report from Cancer Care Ontario as part of its *Evidence-Based* series reviewed research that supported that ACP can affect patient outcomes such as the completion of advance directives (ADs) or powers of attorney for personal care, improvements in adherence to patient's wishes, and patient and substitute decision-maker satisfaction, understanding and comfort. Recommendations found in the report include that ACP should be conducted with cancer patients routinely, that education should be available for all patients and providers working in the cancer system and that ACP participants should include the patient, health service providers, family members and an ethics committee or advisor to consult with when there are differences of opinion between the patient and their family.

Another illustration examines the unique needs of individuals with ALS. Symptomatology associated with the disease recommends that decisions related to nutrition/feeding options, and ventilation be considered as soon as the individual feels prepared to have this discussion and revisited as the individual's condition deteriorates.[9]

Guiding Principles and Values

Guiding principles and values represent the broad philosophy that guide an organization or process. They are beliefs which the participants hold in common and endeavour to put into practice. The literature reviewed stresses the importance of assisting individuals in exploring their own value system as an important first step in the ACP process; however, there are few formal guiding principle or value statements specific to the ACP process.

The majority of palliative care programs have clearly articulated guiding principles and values—many largely based on those presented in the CHPCA palliative care

[7] www.respectingchoices.org
[8] Davison, S. (2006).
[9] ALS Integrated Care Pathway for the Champlain District (2008).

framework.[10] While some of these can be applied directly to ACP, there is a need for them to be reviewed using an ACP lens and edited accordingly.

Guiding Principles

The CHPCA *Model to Guide Hospice Palliative Care* identifies nine guiding principle statements. These are the major themes of the statements:

GP1. Patient/Family Focused

GP2. High Quality

GP3. Safe and Effective

GP4. Accessible

CP5. Adequately Resourced

GP6. Collaborative

GP7. Knowledge-based

GP8. Advocacy-based

GP9. Research-based

The four building blocks detailed in the *ACP Implementation guide for health authorities in Canada* also illustrate elements of guiding principles with a specific focus on ACP:

1. **Engagement: organizational and community**
   Advance care planning engages people at all levels in both the organization and the community.
2. **Education**
   Advance care planning consists of a process of reflection, decision and communication of choices or wishes. This requires education and support for health care providers and volunteers who engage and support individuals and families in ACP conversations as well as those involved in administration or records management.
3. **System Infrastructure**
   Systems are needed to ensure that the person's choices are acknowledged and acted on. These can include mechanisms for recording information in personal health records, visual identifiers in charts or in the home, and so on.

[10] Canadian Hospice Palliative Care Association (2002).

4. **Continuous Quality Improvement**
   Continuous quality improvement is essential to ensuring that interventions are appropriate, resources are invested effectively and for learning what works well and what could be done differently.

Values

The value statements as put forward in the CHPCA *Model to Guide Hospice Palliative Care* (below) reflect some of the underlying values within the ACP arena. Again, these need to be reviewed and modified from the frame of reference of ACP.

V1. The intrinsic value of each person as an autonomous and unique individual.

V2. The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.

V3. The need to address patients' and families' suffering, expectations, needs, hopes and fears.

V4. Care is only provided when the patient and/or family is prepared to accept it.

V5. Care is guided by quality of life as defined by the individual.

V6. Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.

V7. A unified response to suffering strengthens communities.

The Alzheimer Society of Canada has developed values and principles to guide decision-making for their client population. This has been done in recognition of the fact that a diagnosis of Alzheimer Disease, in itself, does not mean that a person is immediately incapable of making decisions. However, as the disease progresses, a person's decision-making abilities will change. Values identified focus on the relationship between the service provider and the client and include *respect, compassion, integrity and competency (*more detail on the Alzheimer Society's values and guiding principles can be found in Appendix C).

For ACP, there needs to be an emphasis on articulating value statements that reflect:

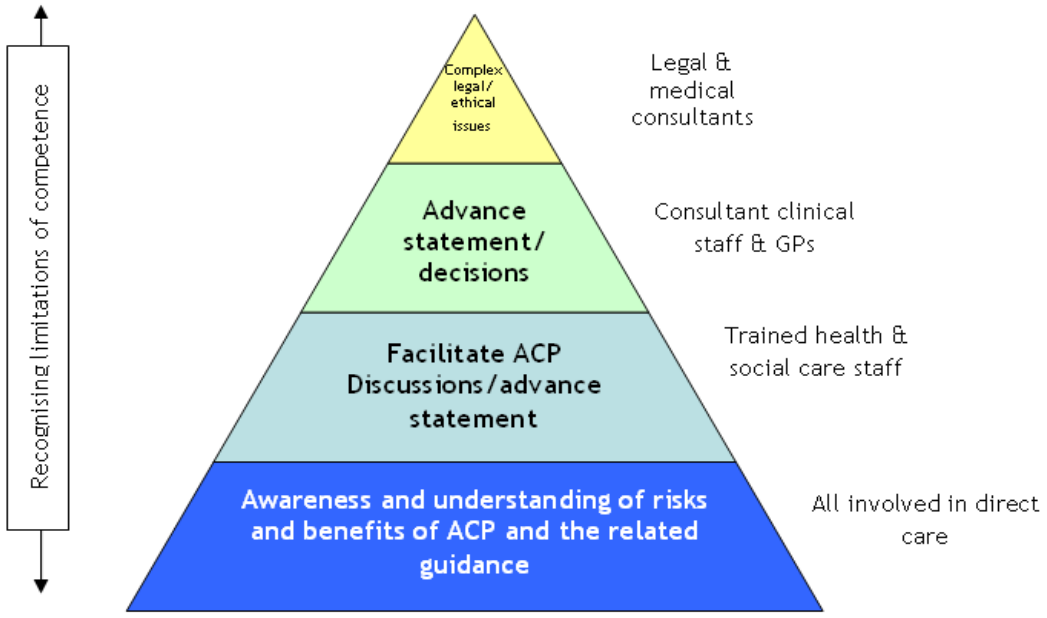
- 'honouring individual preferences based on their values and wishes in light of medically appropriate health care interventions
- 'informed-decision making' (clients must have access to current information, and receive coordinated care and support from knowledgeable, health-care professionals),
- 'respecting cultural values' (identify, acknowledge, and address differences in values and beliefs with care and sensitivity).

Common Competencies

Core competencies are the set of skills, knowledge and/or aptitudes/attitudes required for a specific job or task. In most cases, they also serve as a basis for professional development and to guide future training and curriculum development for specific disciplines.

The National Health Service in Great Britain has developed a framework depicting the different levels of competency for those involved in ACP. This framework (Figure 1) supports that client conversations require health care and legal professionals with differing areas of expertise and skill sets.

Figure 1: Competency Framework: End of Life Care Programme, National Health Service



Source: Henry, C. (2007).

The National Health Service model suggests different competency areas for different care providers. In Canada, there are a number of sources that have identified skill sets and knowledge areas that would be important to consider for inclusion in a national ACP framework. There are a number of commonalities, including a sound understanding of ACP and related concepts, skills related to initiating conversations, ongoing communication, documentation and recording of conversations as well as knowledge of ethical and legal issues related to ACP.

Source	Competencies
Fraser Health: Advance Care Planning --Assisting with the Process and Promoting the Concept Course Content	■ Describe the basic concepts of ACP ▪ Definition of ACP; legal, ethical and moral imperatives ▪ Who, why, and when should an individual make an advance care plan ■ Open and assist with an ACP conversation ■ Describe the fundamental legal aspects of ACP ▪ Overview of advance directives and the law ▪ Ethical and legal obligations of healthcare professionals with respect to advance directives ▪ Federal, provincial and common law ▪ Basic overview of consent and capacity ▪ Roles and responsibilities of substitute decision-makers ▪ Removal of barriers and resolution of concerns re: advance directives ■ Describe the challenges and opportunities involved with creating a personal advance care plan ■ Discuss the importance of developing and maintaining organizational systems and practices for ACP
Facilitating Advance Care Planning: An Inter-professional Educational Program: Curriculum Material (2007). Educating Future Physicians in Palliative and End-of-Life Care.	The document identifies five key competency areas with related objectives: ■ Define ACP and its importance ■ Initiate an ACP conversation and assist in the creation and/or documentation of an advance care plan ■ Facilitate ongoing ACP conversations over the continuum of care ■ Identify potential conflicts in ACP and effectively manage conflicts ■ Serve as an ACP resource in an organization
Advance care planning: Policy, legal and practical dimensions Janet Dunbrack, Joan Rush, Sue Grant	Available since January 2008 as a re-broadcast/archival podcast at http://www.pallium.ca/infoware/ACPPanel_May2006.pdf Suggested learning objectives for this session (content analyzed from original production):

Source	Competencies
Available at www.palliativeinsight.net and or Apple Canada iTunes Store under *Hospice Palliative Care Insights*	By the end of completing this self-study or small-group learning session, the learners should be able to discuss or refer back to the written material as required from time-to-time, to discuss: ■ The role and importance of Advance Care Planning (ACP), especially for progressive and life-limiting illness. ■ The two major approaches to Advance Care Planning in Canadian jurisdictions. ■ Recognition that roles and functions in Advance Care Planning have different labels in various jurisdictions. ■ The importance of supported dialogue and progressive conversation as a communication methodology for enabling Advance Care Planning within families. ■ The importance of having systems which support communication within the health care delivery team, particularly in multiple-shift environments and across settings of care (e.g., hospital, home, hospice, long-term/continuing care, etc.). ■ The importance of completing Advance Care Plans prior to life-threatening, crisis situations. ■ The health and wellness value of Advance Care Plans in supporting healthy bereavement processes for survivors.
Respecting Choices: Competencies that facilitate Advance Care Planning Discussions	■ Initiate the discussion ▪ Affirm relationship and assure patient you care about them, will not abandon them and will assist them in developing a plan for end-of-life when they are ready. ▪ Inform patient that these discussions are part of good care, that health professionals cannot respect choices if they are unknown. ▪ Provide support that making end-of-life decisions does not mean there is nothing more that can be done. Comfort care as desired by the patient will be provided. ▪ Schedule adequate time to begin these conversations and determines the type and number of follow-up meetings necessary.

Source	Competencies
	■ Assess the motivation, knowledge and beliefs of the person you are assisting. ▪ Allow them to tell their story of why they need assistance, what experiences they've had. ▪ Asks the patient if they have thought about how they want their care to go if their health condition got worse and they could no longer speak for themselves ■ Assess the patient's understanding of their health condition. ■ Provide education and clarification of their health condition as needed. ■ Explore and clarify patient statements and preferences. ■ Develop a plan of action to have further discussions and/or initiation of an advance directive to include: ▪ Provide written information, video's etc. ▪ Assist the patient in choosing an appropriate surrogate ■ Provide the surrogate with information, support and guidance to understand their role and promote optimal communication among all parties.
Competency Framework: End of Life Care Programme, National Heath Service (England)	■ Context awareness ■ Communication skills ■ Informed consent ■ Information giving ■ Legal and ethical issues ■ Technical skills and knowledge ■ Knowledge of local resources

Advance Care Planning Tools

Comprehensive, user-friendly ACP tools would benefit professionals in all sectors and by clients. The development and implementation of a standard set of tools can contribute significantly to the dissemination of consistent messages, collection of consistent data and ultimately, a program's successful implementation. A number of tools have been identified targeting the implementation needs of clinicians, educational needs of clients and the community at large as well as tools to support evaluation of ACP initiatives.

Clinical Tools

For the purpose of this report, clinical tools are defined as those that support the efforts of the health service provider. Tools identified as part of this environmental scan focus on quick reference guides, tools that support ACP conversations and tools that support the documentation of ACP outcomes. This allows for a consistent approach to engaging clients and consistent reporting of conversation and outcomes.

Since 2001, The Pallium Project has supported Hospice Palliative Care capacity development through a broad range of targeted initiatives using a Community of Practice (CoPs) model. The Pallium Project has supported the adoption and incorporation of advance care planning within professional practice using a workplace learning module approach. ACP is embedded within many of The Pallium Project's activities and initiatives. Examples include:

- *The Pallium palliative pocketbook: A peer-reviewed, referenced resource* (the PPP) where ACP is discussed as a generic cross-jurisdictional, pan-Canadian term in the *Language/construct conventions* section (p. xiv).

- *Retreat courses targeting primary care professionals* (explicitly covered in Module 5 (Communication) of the *Learning Essential Approaches to Palliative and End-of-Life (LEAP)* courseware package

- Curricular resource package associated with *Developing spiritual care capacity for Hospice Palliative Care* curricular resource package (2006).

The *Ian Anderson Program: A Continuing Education Program for End of Life Care* (University of Toronto) has developed a series of modules including one related to *End of Life Decision Making* (the Program is no longer offered, but resources continue to be available on-line).

The following list provides some examples of clinical tools that can be found on the Internet. *(N.B. This is not meant to be an exhaustive list.)*

Promoting Excellence in End Life Care: Steps in Advance Care Planning (2006), B. Stuart.	Promoting Excellence www.promotingexcellence.org
My Voice – Planning Ahead – Framework for Advance Care Planning Conversations Advance Care Planning Tracking Form Goals of Care Designation Order	Calgary Health Region http://www.calgaryhealthregion.ca/programs/advancecareplanning/index.htm
Abbreviated Advance Directive – Yukon Health and Social Services	Yukon Government www.hss.gov.yk.ca

Advance care planning: Policy, legal and practical implications (Pallium Project)	http://www.palliativeinsight.net/
Ian Anderson module on *End of Life Decision Making*	http://www.cmetoronto.ca/endoflife/Modules.htm

Public Education

For the general public, ACP is a relatively new concept. Over the last decade, Canadians have become more aware of the meaning of advance directives and living wills, but have had limited opportunities to consider and engage ACP as a broader process through which their care wishes can be expressed and honoured.

Several organizations in Canada have put significant effort into the development of brochures and related tools to strengthen clients understanding of ACP concepts and implications.

The following sample tools can be found on the Internet. *(N.B. This is not meant to be an exhaustive list.)*

My Voice: A workbook and personal directive for advance care planning Advance Care Planning Checklist and Wallet Card (Former Calgary Health Region)	Calgary Health Region http://www.calgaryhealthregion.ca/programs/advancecareplanning/index.htm
Information Booklet for Advance Care Planning	Fraser Health Authority www.fraserhealth.ca
A Guide to Advance Care Planning	Ontario Seniors Secretariat www.citizenship.gov.on.ca/seniors

Evaluation

One of the limitations in planning for ACP program development and implementation is the paucity of evaluation and clinical evidence that focuses on ACP outcomes. Evaluation is an important component of any program and needs to be incorporated into ACP initiatives. *Respecting Choices® Advance Care Planning* (Gundersen Lutheran Medical Foundation) has developed a quality improvement tool kit for ACP that includes:

- A *Chart Audit Form* (to evaluate the content of completed advance directives available in patient's medical records)
- *After Death Bereaved Family Interview* (to discover how effective advance care planning was in the eyes of a family member following the death of a loved-one including the types of conversations that occurred and if wishes were respected)

- *Process Measurement Systems* Tool (with a focus on continuous process improvement)
- *Community Pre and Post Presentation Tool* (to evaluate the impact of ACP education on the readiness of clients/community members).

The complete toolkit as found on the Respecting Choices® website can be found at www.respectingchoices.org/documents/QIToolkit_000.pdf.

Key Program Elements

One of the questions considered as part of the document/website review and key informant interviews focused on the identification of program elements that need to be incorporated into any ACP initiative. There was a great deal of consensus with respect to components noted when reviewing existing programs—these were also supported through conversations with key informants. A list and brief description of recommended program components includes:

Organizational Commitment

Senior administrators need to be supportive of ACP development and implementation within their organization. Organizational support can be demonstrated through the development and implementation of related policy and procedures, dedicated human and fiscal resources to support program development, and the identification of champions within the organization to take on leadership roles. For many health care providers, discussing issues associated with ACP can be very difficult and will require a definite shift in mindset. Change theories support the need for ongoing investment of time, energy and resources in order for program implementation to be successful.

Guiding Principles and Value Statements

Guiding principles and values are important statements describing the beliefs which the organization's members hold in common and endeavour to put into practice. While it was difficult to find guiding principles or value statements specifically for ACP programs in Canada, those developed for palliative care provide a sound base on which to begin to articulate these for ACP.

Public Awareness

One of the major barriers to ACP program implementation is the lack of understanding among the general public that ACP is a process and encompasses much more than the presence of advance directives or living wills. Individuals also need to be aware that ACP is not only a consideration for individuals who are very sick or terminally ill, but is something to be considered for a much broader sector of society.

In addition to the distribution of printed materials and resources, there needs to be a dedicated individual, organization and/or website that interested people can access to answer questions and obtain additional information. All awareness initiatives need to demonstrate a clear understanding of the target audience and consider the linguistic and cultural diversity of our society. Consideration also needs to be given to the generational influences of our society such as the growth of individual autonomy, the decrease in religious affiliation and the impact of social networking systems.

It is important to remember that public awareness does not necessarily result in public engagement. As described in the *ACP Implementation guide for health authorities in Canada* (2008), *c*ommunity engagement consists of not only outreach to individuals and groups and raising public awareness, but also fostering community involvement in the planning and implementation of advance care planning initiatives. Additionally, benefits of advance care planning efforts by members of the public are enhanced when health care systems are in place ensure that this work is honoured when these individuals interface with health care services.

Health Service Provider Education and Training

In order for an ACP initiative to be successful, health service providers must have the knowledge and skills required to ensure a consistent application of program elements. This begins with the identification of competency areas and the development of an education and training program to support knowledge transfer. The program needs to have adopted or developed relevant tools to support all aspects of ACP including how to initiate and structure conversations and to record and document conversation outcomes and decisions made. The process needs to be promoted through the presence of champions or role models and supported by ensuring continuing education initiatives are in place.

It is important to remember that although advance care planning is generally seen as a health care issue, it goes beyond health care to encompass the legal sector, social services and faith-based groups. Ideally, training in ACP should include all of these sectors.

System Infrastructure Support

Once an individual has engaged in ACP, it should be clear that the individual, not the facility or organization, is the owner of their advance care planning documents. There is a responsibility of the system to ensure that this information follows the individual through different care settings and that health service providers are aware of their clients' wishes.

Sector Integration

It is important for the different areas involved in ACP implementation to be aligned and integrated. One example of where challenges have occurred in the past, and continue to occur, is with respect to the legal and health service sectors. There is a need to ensure this positioning to avoid working at cross purposes.

Evaluation

As previously noted in this report, ACP programs in Canada are still in the early stages of development. There is very little evidence noted in the literature at this point in time with respect to its impact on patient and family outcomes. Programs must incorporate evaluation and continuous quality improvement components to evaluate client care preferences and the care received. With sensitivity to the controversy surrounding cost savings associated with ACP, evaluation measures must also take into consideration the impact of ACP on resource utilization. It can be suggested that ACP initiatives might decrease the overall health service utilization costs by reducing hospitalization and unnecessary medical procedures.

Challenges and Enablers

The literature identifies and supports a number of challenges and enablers with respect to initiating and implementing ACP. These issues have been summarized below and expanded based on conversations with key informants as part of the environmental scan investigation process:

Challenges:

- Modern society (in most cultures) has a general fear of dying. The topic of death is not a pleasant one and what is unknown is often feared and avoided. Many clinicians, who have traditionally focused their practice toward curing illness, experience discomfort when broaching the subject with a client and an individual's response is often avoidance.
- There is a widely held perception that **ACP is only associated with seriously ill or dying** patients, and as such, is perceived to be irrelevant. There is a dissonance between a deeply entrenched professional orientation to cure and the reality of serious illness and death.
- There is a definite **lack of awareness that ACP is a process** and involves a great deal more than simply the presence of advance directives.
- Increasing **public awareness does not necessarily result in *engagement*** of individuals in ACP. A range of public engagement strategies will need to be conceived, implemented and evaluated.
- There is a **need for further evidence regarding the impact of ACP**.

- Implementing ACP requires a **strategic investment of fiscal and human resources** as well as a high degree of inter-professional collaboration within an organization and across care settings.
- It is not uncommon for organizations to experience **resistance to change**. Initiating ACP requires a great deal of organizational commitment and champions from within to provide ongoing support and direction.
- The Glossary Project provides a detailed overview of terminology used within ACP. It illustrates that language used **across jurisdictions, provinces/territories and care settings continues to vary significantly**. This can cause confusion among the public and in the care setting.
- There are **significant legal implications** that need to be considered when planning for and implementing ACP. Although advance directive legislative frameworks vary across Canadian provinces and territories, frameworks generally follow a couple of major models. The issue of *consent*, particularly for vulnerable populations such as non-capable adults and children is particularly complicated.
- Health care legislation has historically evolved to-date as the constitutional responsibility of the provinces and territories. As a result, there are significant **barriers with respect to the portability of advance directives** among these jurisdictions.
- Challenges also arise around **incorporating language and cultural considerations** when developing ACP materials for multi-cultural communities.
- There is the potential for ACP to be **perceived by community predominately as 'way for the system to save money'** by avoiding costly medical intervention.
- **Current health care systems are not in place** to consistently communicate across sectors regarding health care decisions that have been made using an advance care planning process.

Enablers:

- An **increased public understanding of 'advance directives'** over the past couple of decades has opened the door to initiating dialogue with respect to ACP.
- Enhanced public awareness of the complexities of health care decision making.
- Accreditation Canada has included standards related to **ACP as part of the accreditation process** for long-term care and hospice palliative and end of life care programs resulting in increased nation-wide organizational interest and attention.

- **Planning initiatives through CHPCA** and the availability of a framework to support ACP have the potential to result in an increased organizational interest.
- The movement toward **integration among many health care systems** is an ACP enabler. For example, the concept of a single, electronic chart for all clients supports the documentation of ACP and the sharing of ACP status within and among care settings.
- **Disease specific ACP** has promoted ACP in these sectors (i.e., Alzheimer Disease, Cancer, Renal care programs).
- **Integration of applied ACP strategies and processes** within clinical tools and educational resources (e.g., Ian Anderson Program, The Pallium Project, etc).

Conclusions/Summary

Comprehensive ACP program planning and implementation in Canada remains in the early stages of development. While there is a growing understanding of the need to consider ACP in many health care settings, there is much work to be done, particularly in areas of increasing awareness, education and engagement of health care professionals, provincial and territorial governments and the general public, as well as evaluating outcomes.

This environmental scan provides an overview of ACP programs and activities across Canada based on a review of information available on websites, recently released publications and discussions with key informants. Its content will support the CHPCA and its partner agencies in identifying the critical elements of a *National Framework* and moving forward with this important project.

Bibliography

Bioethics Committee, Canadian Paediatric Society (2008). "Advance care planning for paediatric patients", *Paediatric Child Health*, 13 (9), p. 791-96.

Calgary Health Region and Fraser Health Authority (2008). *Advance care planning: An implementation guide for health authorities in Canada*.

Canadian Hospice Palliative Care Association (2002). *A Model to Guide Hospice Palliative Care*.

Canadian Medical Association (2002). *Code of Ethics*. Retrieved from: < http://www.cma.ca/index.cfm/ci_id/53556/la_id/1.htm >

Canadian Pediatric Society (2008). "Advance care planning for paediatric patients". *Paediatric Child Health*, 13 (9), p. 791-796.

Davison S. (2006). "Hope and advance care planning in patients with end stage renal disease: qualitative interview study", *British Medical Journal*, 333:886.

Dunbrack, J. (2006). *Advance care planning: the Glossary project, Final report* (unpublished), Health Canada, August. Retrieved from < http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/index-eng.php >

Dunbrack, J., Rush, J., & Grant, S. (2006). *Advance care planning: Policy, legal and practical dimensions.* Edmonton, Canada: The Pallium Project. Retrieved from http://www.pallium.ca/infoware/ACPPanel_May2006.pdf

End of Life Project, Health Law Institute, Dalhousie University. *A Summary of Canadian Legislation Concerning Advance Directives.* Retrieved from <http://as01.ucis.dal.ca/dhli/cmp_advdirectives>

Educating Future Physicians in Palliative and End-of-Life Care (2007). *Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Material.* Retrieved from <http://www.afmc.ca/efppec/docs/pdf_2008_advance_care_planning_curriculum_module_final.pdf>

Gundersen Lutheran Medical Foundation (2008). *Respecting Choices Disease-Specific Patient Centred Advance Care Planning.*

Harle, I., Johnston, J., Mackay, J., Mayer C., Russell, S. & C. Zwaal. (2008). "Advance Care Planning with Cancer Patients: Guideline Recommendations" (Report: *Evidence-Based Series #19-1: Section 1*). *A Quality Initiative of the Program in Evidence-Based Care: Cancer Care Ontario.*

Kryworuchko, J. (2008). *The Evidence Base for Advance Care Planning*.

Sudore, R. and Williams, B. (2009). "A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers", *Journal of the American Geriatrics Society*, 57 (1), p. 31-39.

Weiner, L. et al. (2008). "How I Wish to be Remembered: The Use of an Advance Care Planning Document in Adolescent and Young Adult Populations", *Journal of Palliative Medicine*, 11 (10).

Appendix A

Advance Care Planning Task Group Members

Appendix A

Advance Care Planning Task Group Members

Sharon Baxter	Canadian Hospice Palliative Care Association
Karen Chow	The GlaxoSmithKline Foundation
Bert Enns	Alberta Health Services
Darren Fisher	Canadian Lung Association
Daren Heyland	Queen's University
Debbie Gravelle	Elisabeth Bruyère Hospital
Melody Isinger	Canadian Medical Association
Leslie Greenberg	Canadian Partnership Against Cancer
Larry Librach	University of Toronto
Liliane Locke	Elisabeth Bruyère Hospital
Denise Page	Canadian Cancer Society
Lonny Rosen	Canadian Bar Association
Carolyn Tayler	Fraser Health Authority
Romayne Gallagher	Canadian Society of Palliative Care Physicians
Louise Hanvey	Canadian Hospice Palliative Care Association
Kristel Blais	Canadian Hospice Palliative Care Association

Appendix B

List of Key Informants

Appendix B

List of Key Informants

Michael Aherne, Chair, Education Committee, QELCCC, Pallium Project, Co-founder

Donna Allen, Government of the Northwest Territories

Kyle Anstey, Bioethicist, University Health Network

Pamela Bennet, Department of Health and Community Services, Government of Newfoundland

Jean Bustard, Government of New Brunswick

Jennifer Colepaugh, Government of Nunavut

Glenn Deics, Government of Saskatchewan

Bert Enns, Advance Care Planning Division, Alberta Health Services – Calgary and Area

Debbie Gravelle, Manager/APN, Regional Palliative Care Community Services, Bruyère Continuing Care

Erin Hnit, Government of Alberta

Cari Hoffman, ACP Implementation Coordinator, Fraser Health Authority

Pauline James, Government of British Columbia

Larry Librach, University of Toronto, Temmy Latner Centre for Palliative Care

Heather MacDonald, Government of Nova Scotia

Sharon Specht, Yukon Government

MK Sullivan, Government of Prince Edward Island

Carolyn Tayler, Director, Hospice Palliative Care Division, Fraser Health Authority

Appendix C

Web Site Review

Website Review

Organization/Website	Key Program Elements/New Initiatives
Alzheimer Society of Canada www.alzheimer.ca	In its report entitled, *Decision-making and Respecting Individual choice: Alzheimer Care Ethical Guidelines,* the Alzheimer Society has drafted values and guiding principles related to decision-making and the importance of respecting individual choice. **Values:** **Respect:** Show respect for the dignity of the person with Alzheimer's disease or a related dementia. **Compassion:** Show concern and understanding, and support the personhood of people with Alzheimer's disease. **Integrity:** Focus on trustworthiness, including honesty, reliability and loyalty, in an environment of total quality care. **Competency:** Focus on effective, appropriate, high-quality care and administration in programs and services for people with Alzheimer's disease and their families. **Guiding principles:** ▪ Alzheimer's disease is a progressive, degenerative disease of the brain that has profound impacts on people with the disease and their families. ▪ People with Alzheimer's disease need to be told their diagnosis and made aware of available treatment options. ▪ People with Alzheimer's disease must have access to current information, and receive co-ordinated care and support from knowledgeable, health-care professionals. ▪ People with Alzheimer's disease need to participate in decision-making regarding their daily lives and future care for as long as they are able. If unable to participate, the known values and wishes of the person with Alzheimer's disease must guide all decisions.

Website Review

Organization/Website	Key Program Elements/New Initiatives
	▪ People with Alzheimer's disease need a safe, restraint-free living environment, and protection from exploitation and abuse. ▪ Family and friends who care for people with Alzheimer's disease need to have their caregiving needs assessed and provided for. ▪ People with Alzheimer's disease and those who care for them need to take an active role in the planning and implementation of care. ▪ Adequate resources must be available to provide support to people with Alzheimer's disease and their caregivers throughout the course of the disease.
Alzheimer Knowledge Exchange Resource Centre https://akeontario.editme.com/	The Alzheimer Knowledge Exchange Resource Centre provides links to people, information and innovations related to the care of persons experiencing Alzheimer Disease and related dementia. The AKE has established a Health Care Consent and Advance Care Planning Community of Practice Core Working Group to leverage existing knowledge to develop, promote, implement, and evaluation, consistent lawful and evidence-based approaches to health care consent and advance care planning. The website has linkages to many related Ontario resources (most of which are mentioned in this environmental scan).
British Columbia Cancer Agency www.bccancer.bc.ca	The British Columbia Cancer Agency has released a report, *Cross Cultural Considerations in Promoting Advance Care Planning in Canada* (2007). Findings include: ▪ Culture is a critical issue in palliative and end-of-life (EOL) care, ▪ Stereotypes and assumptions are inaccurate. All cultures felt that if health care professionals could take the time to understand the individual, this would be the most respectful way to provide a dignified death. ▪ Beliefs, values and traditions are not necessarily shared by all in a specific cultural group.

Website Review

Organization/Website	Key Program Elements/New Initiatives
	▪ It is possible to deal with the language barrier but this costs increased time and human resources. Translating materials, providing interpreters and involving community leaders is one way to help break down the communication difficulties. ▪ ACP may be culturally incongruent for some patients; therefore, health care professionals should identify appropriate alternatives for health planning and decision-making.
Province of British Columbia Health Authorities of B.C. http://www.health.gov.bc.ca/hcc/endoflife.html http://www.healthlinkbc.ca/kbaltindex.asp www.fraserhealth.ca www.viha.ca	**Ministry of Health Services** The Ministry of Health Services' website on end of life and end-of-life care provides current information on the province's vision and approach to end-of-life care and services, and to advance care planning, with links to valuable resources and the health authorities. **HealthLink BC website** HealthLink BC provides access to a wide variety of health topics on care at the end of life and to decision-making tools called Decision Points, which help users to reflect on and plan for end-of-life care in a Canadian context. Users can learn about health topics and medications, check symptoms, and find local BC-specific hospice palliative end-of-life care services and resources. **Fraser Health Authority:** Fraser Health has a well developed advance care planning initiative entitled: *Lets Talk*. The program involves health service provider training, as well as client-focused information resources, for example, an e-booklet *Planning in Advance for Your Future Health Care Choices* (2007) and *Making Informed Decisions about CPR* (2007).

Website Review

Organization/Website	Key Program Elements/New Initiatives
	Vancouver Island Health Authority: In February 2009, a new interim advance health care planning information package and advance directive form was introduced. It is similar to the approach used by Fraser Health Authority, and can be seen at www.viha.ca/advance_directives.
Former Calgary Health Region http://www.calgaryhealthregion.ca/programs/advancecareplanning/index.htm	Calgary Health Region has a well developed ACP program entitled "My Voice – Planning Ahead" that includes training and tools for health care providers (physicians and other clinicians) and clients when considering ACP options. Calgary Health Region has recently adopted an "Advance Care Planning: Goals of Care (Adult) Designation" policy (Nov. 2008). 80% of staff participated in the policy training module. All "appropriate" clients (as defined for each health care sector) are to be engaged in a goals-of-care conversation which is communicated through a "Goals of Care Designation" order. Alberta Health Services (Calgary and area) is waiting for approval to launch the Pediatric Goals of Care Designation Policy in late September 2009, the paediatric equivalent of the "Advance Care Planning: Goals of Care Designation" policy implemented in the adult sector in late 2008. The Pediatric Palliative Care and Grief Support Team at Alberta Children's Hospital in Calgary has just created an activity ("Hear My Voice") for families to encourage them to talk about their values and goals to guide decision-making during the illness experience. This resource will be available on the web at http://www.calgaryhealthregion.ca/programs/advancecareplanning

Website Review

Organization/Website	Key Program Elements/New Initiatives
Canadian Hospice Palliative Care Association www.chpca.net	CHPCA is taking a major role in ACP in Canada and is leading the process to develop a *National Framework* for ACP. ACP has also been the focus for the CHPCA's *National Hospice Palliative Care Week* for 2006, 2007 and 2008 in an effort to raise awareness of the importance of Advance Care Planning.
Canadian Medical Association www.cma.ca	The CMA has two policies related to advance directives: "Advance Directives for Resuscitation and Other Life-Saving or Sustaining Measures", " Joint Statement on Resuscitative Interventions" (Update 1995)
Canadian Nurses Association www.cna-nurses.ca/cna	In 2008, the CNA released a position statement on "Providing Nursing Care at the End of Life"—this includes a section on advance care planning recognizing the importance for individuals, healthy or ill, to make informed choice related to end of life care.
Catholic Health Association of Canada www.chac.ca/resources/index.php	The CHAC has produced a public awareness pamphlet—*Advance Directives: Planning Ahead for End-of-Life Healthcare Decisions* (only cover page available on-line)
End of Life Project, Health Law Institute, Dalhousie University http://as01.ucis.dal.ca/dhli/cmp_advdirectives	The *End of Life Project* provides a summary of Canadian legislation concerning advance directives. The main objective of this project under the auspices of Dalhousie University was to facilitate informed public policy debate regarding the provision of potentially life-shortening palliative treatment and the withholding and withdrawal of potentially life-sustaining treatments. This objective was realized through the development of educational materials for policy decision-makers, the public, healthcare providers, and the media on the legal issues pertaining to end of life care to ensure that these stakeholders are better informed and better able to engage in discussions and debates about end of life policy and practice in Canada.

Website Review

Organization/Website	Key Program Elements/New Initiatives
Gundersen Lutheran – *Respecting Choices* www.respectingchoices.org	*Respecting Choices*, a department of Gundersen Lutheran Medical Foundation (Wisconsin), offers training opportunities and related materials in Advance Care Planning. Aspects of this program were used as a model for the development of ACP initiatives in Fraser Health and Calgary Health Authorities. The website allows access to the "Advance Care Planning Program Quality Improvement Tool Kit" which includes a chart audit form and questions/conditions for *After Death Bereaved Family Interview*.
The Ian Anderson Program www.cme.utoronto.ca/endoflife/	The *Ian Anderson Program*, a continuing education program for end of life care (University of Toronto) has developed a series of modules including one related to *End of Life Decision Making* (the Program is no longer offered, but resources continue to be available on-line)
The Pallium Project www.pallium.ca	Since 2001, The Pallium Project has supported Hospice Palliative Care capacity development through a broad range of targeted initiatives using a Community of Practice (CoPs) model. The Pallium Project has supported the adoption and incorporation of advance care planning within professional practice using a workplace learning module approach. Pallium Project resources integrate ACP learning opportunities, via explicit and transversal/longitudinal learning objectives. These learning objectives guide various curricular resources that support traditional classroom instruction and emergent models of just-in-time (JIT), competency-based workplace learning.
Regina Qu'Appelle Health Region www.rqhealth.ca	The Regina Qu'Appelle Health Region has established a plan for ACP for the RQHR with the initial focus on the general population. Planning has included extensive consultation with key stakeholders (internal and external) and a review of existing resources. A key feature of the RQHR's Advance Care Planning process is the implementation of a "person order" to guide the

Organization/Website	Key Program Elements/New Initiatives
	provision of care which will replace processes such as DNR. The RQHR is currently developing supporting policy and procedures for the Advance Care Planning process and developing a job description for Advance Care Planning Project staffing (a proposed 1.0 FTE permanent position and 2.0 FTE temporary positions to assist with implementation). The RQHR is currently in the process of developing supporting policy and procedures for the Advance Care Planning process and developing a job description for Advance Care Planning Project staffing (a proposed 1.0 FTE permanent position and 2.0 FTE temporary positions to assist with implementation). Activity is also taking place to develop a public education framework including associated resources. Future plans for RQHR include getting policies and procedures approved, developing a staff and public education program, establishing a related website, as well as a plan to target more specific populations (i.e., neonatal, mental health). The target date for implementation of educational initiatives for both the public and staff is Fall 2009. Implementation will include all RQHR portfolios (acute, community, long-term care, EMS, etc.) including affiliate organizations.
University Health Network www.uhn.ca	The University Health Network (UHN) is an acute-care teaching organization with approximately 1,000 beds, comprised of three hospitals located in downtown Toronto. The Bioethics program at UHN is helping to lead an initiative to promote the development and implementation of ACP within the organization. The initiative is piloting an ACP Toolkit that draws on other Canadian best practices. The toolkit provides an organizational process for obtaining, introducing, discussing, and documenting ACP. The pilots educate staff about these issues and provide documentation solutions supportive of

Website Review

Organization/Website	Key Program Elements/New Initiatives
	measurement and evaluation. The program is currently being piloted in different sites within the organization with the hope of rolling out organization-wide once evaluation outcomes and 'lessons learned' have been incorporated.

Website Review

Provincial and Territorial Government Initiatives	
Government of Newfoundland and Labrador http://www.gov.nl.ca	The Government of Newfoundland and Labrador established the *Advance Health Care Directives Act* in 1995. More recently (2006) an operational standards document for Long Term Care Facilities has established standards, including outcomes and performance measures for advance health care directives for both the 'cognitively well' and the 'cognitively impaired' resident. The Public Legal Information Association of Newfoundland has developed an *Advance Directive Fact Shee*t entitled, "What Are Your Wishes? Living Wills and Advance Health 2nd ed."
Prince Edward Island www.gov.pe.ca/law/statutes/pdf/c-17_2.pdf	PEI's *Consent to Treatment and Health Care Directives Act* was established in 1996.
Government of Nova Scotia www.gov.ns.ca	The Nova Scotia Government does not have a single approach to ACP, however, there are pockets of ACP incorporated into all aspects of palliative care, and educational initiatives (including lunch-and-learn sessions) are happening within the province. Nova Scotia Departments of Justice and Health have participated in a joint initiative to authorize the making of personal directives for personal care decisions. The *Planning for the Future: A Draft Personal Directives Legislation Discussion Paper* (April 2008) and *Draft Personal Directives Act* are written for individuals to prepare for the onset of incapacity to make personal care decisions.
Government of New Brunswick www.gnb.ca	The Government of New Brunswick is currently involved in advancing major initiatives within its *Provincial Health Plan* (2008-2012) including the development of *Advanced Health-care Directives (Living Wills) Legislation*.

Provincial and Territorial Government Initiatives	
	This legislation will enable New Brunswickers to set out in a living will their instructions regarding their health care and other matters, including the appointment of another person to make decisions on their behalf when they are no longer competent or able to make decisions themselves. In May 2008, the New Brunswick Government released a report entitled *The New Brunswick Extra-Mural Program Palliative Care Guidelines – Compassionate Home Care Services for End of Life.*
Government of Quebec www.gouv.qc.ca	The Government of Quebec has provisions for individuals to develop a "mandate in anticipation of incapacity". The website includes some questions and answers related to the concept of the mandate and what is involved. The mandate reflects proxy directives (not instructional directives).
Government of Ontario Ontario Seniors' Secretariat http://www.culture.gov.on.ca/seniors/english/programs/advancedcare/why.shtml	The Ontario Seniors Secretariat has developed an ACP awareness and education guide targeting the general public. The document entitled, "Guide to Advance Care Planning" focuses on the importance of ACP, steps to take in initiating ACP and where you can get additional information. The Prince Edward Family Health Team (PEFHT) is one of 150 Family Health Teams across Ontario, which opened as part of an Ontario Ministry of Health and Long Term Care initiative aimed at improving access to primary health care professionals in Ontario. The PEFHT's website allows access to the FHT's version of *My Voice* for advance care planning.
Government of Manitoba www.gov.mb.ca	The Government of Manitoba established the *Health Care Directives Act* in 1992. In 2004, The Manitoba Law Reform Commission recommended a legislative review of the *Health Care Directives Act* to implement measures that facilitate adults participating in ACP and documenting advance directives.

Provincial and Territorial Government Initiatives	
	The Manitoba Health web page also includes a question-and-answer guide as a public awareness tool for ACP with a link to a Health Directives pdf form.
Government of Saskatchewan www.gov.sk.ca	Saskatchewan implemented the *Health Care Directives and Substitute Health Care Decision Makers Act* in 1997. A question-and-answer information sheet on the topic of living wills/advance directives can be found on the Justice and Attorney General's web page.
Government of Alberta www.gov.ab.ca	The Government of Alberta has developed a brochure entitled "Choosing Now for the Future: Personal Directives". The brochure includes questions and answers related to personal directives and sources for additional information. The website also highlights information sessions being held across the province related to how to write a personal directive and how to use the personal directive form. In 2007, the Government released a report on the legislative review of the *Personal Directives Act*. Recommendations include the development of a standard form for documenting personal directives and provisions for recognizing advance directives originating outside of the province. The website also includes a report from the Office of the Public Guardian entitled "Understanding Personal Directives" (2008).
Government of British Columbia www.gov.bc.ca	In October 2007, the province of British Columbia passed new legislation on advance directives. The new legislation has not come into force. Currently, the legislated options available to British Columbians that support advance planning for heath care decisions are: 1. The *Representation Agreement Act:* enables individuals to appoint another person (a representative) to make decisions including health-care decisions on their behalf should they become incapable of making these decisions

Provincial and Territorial Government Initiatives	
	(may or may not be an execution requirement in the form of a certificate). 2. Since 2003, an adult may make an instruction or wish that must be followed (no forms or execution requirements): ▪ in an emergency by a physician or other health care provider when no family member is available to make decisions; and ▪ in a non-emergency by a temporary substitute decision-maker. These options are current until the changes passed in October 2007 come into force. Other initiatives underway to promote advance directives and advance care planning based on the proposed new legislation in BC include: ▪ Supporting primary health care providers to help patients prepare themselves, and their families, for death including guiding the appropriate use of advance directives and enabling advance care planning; ▪ Providing access through HealthLink BC's website at www.HealthLinkBC.ca to information on advance directives and advance care planning services in BC; ▪ Promoting reliable and quick identification of individuals (in-person) who have expressed their wishes for no cardiopulmonary circulation, in consultation with their physician and family, by the British Columbia Ambulance Service through their partnership with the Ministry of Health Services, the British Columbia Medical Association and MedicAlert Canada; ▪ Implementation of the *Provincial Framework for End of Life Care* (2006), which identifies the need for care planning once it is clear that a person's illness is likely to be terminal. It encourages individuals to explore their values and wishes and document them through the use of advance directives.

Provincial and Territorial Government Initiatives	
	Holding a consultation process in Fall 2008 to inform further implementation of the *Provincial Framework*. A recommendation was made that BC develop a common approach to advance directives and advance care planning across its health authorities.
Government of the Northwest Territories http://www.justice.gov.nt.ca/PDF/ACTS/Personal_Directives.pdf http://www.hlthss.gov.nt.ca/english/publications/pubresult.asp?ID=53	**The Northwest Territories passed its *Personal Directives Act* in 2006.** The purpose of the act is to allow adults (19 years of age or older) to arrange in advance how, when and by whom decisions about their health care and other personal matters will be made if they later lack the capacity to make those decisions themselves. The Government website has an online brochure entitled "Choosing Now for the Future" which discusses the importance of personal directives.
Yukon Government http://www.hss.gov.yk.ca/programs/decision_making/care_consent_act/advance_directives/	The Yukon Government *Care Consent Act* guides territorial efforts in ACP. Yukon Health and Social Services has produced a number of public education brochures and fact sheets related to the importance of planning for future health care choices and having documented advance directives(*Abbreviated Advance Directive, Planning for your Future Healthcare Choices, Making Health Care Decisions for a Loved One – the Role of the Substitute Decision-Maker*).
Government of Nunavut www.gov.nu.ca	Nunavut is currently in the initial stages of an initiative related to palliative care and advance care planning using the educational resources available through the *Pallium Project*.