

Advance care planning: the Glossary project

Final report

August 22, 2006

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For Health Canada

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Table of contents

EXECUTIVE SUMMARY.....	1
INTRODUCTION.....	3
MAIN CONCEPTS AND TERMS USED IN ADVANCE CARE PLANNING IN CANADA.....	4
UNDERSTANDING OF ADVANCE CARE TERMINOLOGY.....	5
EXPERIENCE OF ADVANCE CARE PLANNING IN CANADA	8
Health care sector.....	8
Implications – health care sector.....	15
Social sector.....	15
Implications: social sector.....	18
Legal sector.....	18
Implications: legal sector.....	21
SUCCESSES AND CHALLENGES IN ADVANCE CARE PLANNING.....	21
Successes in advance care planning: key factors	21
Challenges in advance care planning	22
OPTIONS FOR FURTHER WORK.....	23
APPENDICES.....	25
Appendix 1: Advance Care Planning Glossary of concepts and terms	25
Appendix 2: Brief overview of legislation and practice in Canadian provinces and territories:.....	33
Appendix 3: Key informants interviewed.....	42
Appendix 4: Questionnaire for key informant interviews	44
Appendix 5: Resources.....	45

Executive Summary

This report seeks to bring clarity to the concepts and terms used in advance care planning in Canadian provinces and territories and in the health, social and legal sectors in order to facilitate pan-Canadian dialogue about advance care planning. The report examines commonly-used concepts and terms and the ways in which they are understood by professionals and consumers. The report also provides an overview of experience with advance care planning in Canada and identifies factors which contribute to successes and challenges in advance care planning. It presents options for further work by the Public Information and Awareness Working Group. Appendices to the report contain a glossary of advance care planning concepts and terms and a brief overview of legislation and practice in Canadian provinces and territories.

Information for the report was gathered from literature and web-based research and from interviews with 56 key informants representing the health, legal and social sectors, including consumers.

In general, key informants thought that the concepts of advance care planning are easy to understand but that the terminology can be confusing. Key informants in the health sector who are experienced in advance care planning have a good understanding of terminology and can translate terminology into accessible language when communicating with patients and clients. Those with less experience report more confusion over terminology. Informants who work at the pan-Canadian level expressed the need to understand the varied terminology used in all jurisdictions to mean similar things.

The informal term *living will* is instantly recognized by all, but is passing out of use in favour of *advance directive* or the exact terminology used in provincial/territorial legislation. Key informants in the social sector tend to be less familiar with advance care planning terminology because they have less direct experience. Consumers report confusion over terminology and tend to use the terms used by their lawyer or physician. Those in the legal sector tend to be familiar with the terminology used in legislation in their jurisdiction. Key informants from all sectors thought that confusing terminology presented a barrier to consumers which could discourage them from engaging in advance care planning, although many thought that this barrier might be a rationalization used to avoid dealing with an uncomfortable subject.

The rich collective experience of key informants indicates some important trends with respect to advance care planning:

- There are pockets of strong expertise across Canada and other areas with little knowledge. Information sharing could be helpful to those in all jurisdictions.
- 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 throughout the continuum of care.
- Effective, ongoing communication is essential to effective advance care planning: between the patient and family; between the patient/family and the health care team; and among the members of the health care team.
- Successful advance care planning often begins well in advance of serious illness.
- Raising the subject of advance care planning with patients can be difficult for health care providers and fearful for patients. Nevertheless, there is evidence to

suggest that many consumers are eager to discuss advance care planning if they are given the opportunity in a supportive environment.

- Education, user-friendly tools and resources are needed by professionals in all sectors and by consumers. Some suggested that a web-based national information resource centre or clearinghouse could meet this need.
- Key informants from all sectors stressed the importance of understanding the core concept of informed consent to treatment which underlies advance directives. Many spoke of the challenges in determining a patient's capacity to give informed consent, particularly because consent must be based on the immediate treatment proposed. The patient's capacity must be frequently assessed because it can vary and may be adequate for consent in one area and not in another. Family caregivers and health care providers mentioned the difficulty of determining cognitive impairment when dealing with particular diseases. Some suggested that advance directive guidelines could be created for specific health or disease conditions.
- Limited staff time and ineffective systems of communication and awareness of advance directives can lead to ignoring the provisions of a patient's advance directive.
- 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 advance care planning among the legal sector (including those who develop legislation), policy makers, health care providers and consumers so that legislation, law and policy can be both legally and medically sound and socially responsive.
- Research and evaluation are needed to increase the evidence base for advance care planning and to provide a foundation for evaluating processes and measuring outcomes.

Options for further work by the Public Information and Awareness Working Group are suggested, focusing on: knowledge-sharing; best practices identification and dissemination; education; developing user-friendly tools and resources; research and evaluation; and national awareness-raising campaigns targeted at the public and professionals.

Introduction

Background

This report arose from the need to bring clarity to the concepts and terms used in advance care planning in the various Canadian jurisdictions and in the health, social and legal sectors in order to facilitate pan-Canadian dialogue about advance care planning

Advance care planning has been identified as a priority issue by the Public Information and Awareness Working Group of the Canadian Strategy on Palliative and End-of-Life Care. As Canada's population ages, more Canadians will require end-of-life care. Each year more than 248,000 Canadians die; by the year 2020, there will be an estimated 330,000 annual deaths.¹ Increasingly, Canadians will be pondering how they want to be cared for during chronic and terminal illness and whether they will prepare advance directives. Most Canadians still do not discuss their wishes for end-of-life care with their families or their family physician. A survey conducted in 2003 revealed that 40% of Canadians talk to their family members about their last wishes and 10% discuss their wishes with their family physician.²

There is a growing awareness of the need to consider advance care planning. Several high-profile cases in recent years have raised public awareness of advance directives and their role in withdrawal of treatment. Since the mid-1990s, all Canadian provinces and territories, with the exception of Nunavut, have enacted legislation concerning advance directives for health and personal care.

In March 2005, the Secretariat on Palliative and End-of-Life Care, Health Canada, hosted an invitational forum on advance care planning. It became evident at that meeting that there are regional, provincial, sectoral and cultural differences³ with respect to terminology, definitions and interpretation of most aspects of advance care planning. Accordingly, this report was commissioned to develop a cross-sectoral glossary of terms and definitions that comprise advance care planning concepts, tools, instruments and dialogue across Canada. It was anticipated that the report would help to provide a common ground for communication and understanding that would contribute to the development of an effective action plan for cross-sectoral collaboration to encourage the integration of advance care dialogue and instruments for end-of-life care into health care delivery and practice models.

After the report was commissioned, further discussion by the Public Information and Awareness Working Group led to a broadening of the objectives for the report to include the perspectives of those working in the health, social and legal sectors with respect to their approaches to advance care planning and their experience in dealing with advance directives.

The report is intended to provide a clearer picture of what is happening in the various jurisdictions and sectors and to shed light on successes and challenges in advance care planning. It also suggests options for further work by the Public Information and Awareness Working Group. The report includes a glossary of commonly used concepts

¹ Statistics Canada. *Population Projections for Canada, Provinces and Territories –2000-2006*. Catalogue #91-520, page 124.

² Ipsos-Reid. 2003. Telephone survey conducted for the Canadian Hospice Palliative Care Association and GlaxoSmithKline Inc.

³ The ethnocultural dimensions of advance care planning will be addressed in a separate report commissioned by Health Canada.

and terms (Appendix 1) and a brief overview of legislation and practice in Canadian provinces and territories (Appendix 2).

Methodology

Information for this report was gathered from:

- Interviews with 56 key informants in the health, social and legal sectors, including consumers and volunteers (see Appendix 3 for a list of key informants). In the body of the report, the persons interviewed are referred to as *key informants* or *informants*.
- Literature and web-based research (see Appendix 5 for a list of primary resources).

The information-gathering process focused on obtaining a reasonable depth and diversity of perspectives within the health, social and legal sectors. The key informants were drawn from those with experience in end-of-life care, chronic and long-term care and disability issues. Some key informants work in health care management, policy development, the legal profession or research. An exhaustive in-depth survey of each sector and profession was beyond the scope of this report, as were a detailed analysis of the many legal questions associated with advance care planning and advance directives and the situation of dependent adults and guardianship, which is a large field that has implications for advance care planning. There were enough interviews, however, to verify and confirm major trends that were repeatedly stated by key informants.

Acknowledgements

Sincere thanks are extended to all those who supported the development of this report: Health Canada staff; members of the Public Information and Awareness Working Group and its Advance Care Planning Task Group; and especially to the 56 key informants who contributed their time, expertise, insights and follow-up resources. Special thanks to Karen McEwen, Joan Rush, Ann Soden and Judith Wahl who gave feedback on legal questions at various stages in the development of the report.

Main concepts and terms used in advance care planning in Canada

According to the information gathered from key informants and the literature, the most commonly used concepts and terms are:

- Advance care planning
- Living will
- Advance directive
- Advance care plan
- Personal wishes for care
- Substitute decision maker
- Power of Attorney for personal or health care
- Capacity (to make decisions about treatment or other health care matters)
- Do Not Resuscitate or No Code orders
- Levels of Care forms (usually signed on admission to long-term care facilities or hospitals at the request of the facility)

Less frequently used terms include:

- Proxy

- Facilitator
- Terms used in provincial legislation to indicate advance directives such as Mandate, Representation Agreement, Authorization, and so on.

Understanding of advance care terminology

Key informants from all sectors agreed by a margin of more than 3:1 that confusing terminology can create barriers to effective advance care planning. There is general agreement that the concepts are simple and easily understood, but that the terminology can be confusing for both consumers and professionals. One key informant stated that, “If professionals don’t understand the terminology, how can we expect the public to?” There was general agreement that the barriers created by confusing terminology tend to disappear when there is adequate time for dialogue by all parties involved; in these cases, professionals use everyday language to explain the concepts well before a written advance directive is created by the consumer.

The following summary of understandings in the various sectors is derived from the key informant interviews. The glossary of concepts and terms in Appendix 1 and the brief overview of legislation and practice in the provinces and territories in Appendix 2 are based on broader research.

Healthcare sector: understanding of terminology

The key informants interviewed for this report are involved in providing health care either directly to patients or indirectly (e.g. in management or policy development). They include physicians, nurses, social workers and chaplains.

Health care providers who have experience with advance care planning have a good understanding of terminology and can offer equivalent terms in lay language to facilitate communication. Health care providers with little experience with advance care planning report more confusion over terminology. The term *Living Will* is the most frequently recognized term, especially by those with little experience of advance care planning, including physicians. Some health care providers report frustration when the members of the health care team use different terminology to mean the same thing.

Health care providers report that terminology can create barriers for patients and families who feel confused by it and therefore avoid engaging in advance care planning discussions. Many informants stated that this may be a rationalization of the fear of broaching the fearful subjects of illness and possible death. Most health care providers thought that terminology may be confusing but the concepts can be easily understood if they are explained in everyday language. This underlines the importance of having a skilled facilitator, who could be one of the existing care team or a volunteer, to support the process, and the importance of education for all those involved.

Some informants suggested that a national advance care planning website with a glossary, guides, workbooks, personal experiences and other user-friendly resources for both consumers and professionals would be a great help to them. Some health care providers and consumers are using web-based resources from other provinces because they have been unable to find user-friendly resources in their own jurisdiction.

These are the various understandings of terminology in the health care sector:

- **Advance care planning**
 - Almost unanimously understood as a *process of communication* that may take place over a long or short period of time and may be initiated while a person is healthy or when they are facing a serious illness
 - Most respondents understand advance care planning to involve the patient, family, physician and possibly other members of the health care team.
 - Several informants stressed that this is not necessarily a process involving the creation of a document prepared by a lawyer or notary.
- **Living Will**
 - The term instantly recognized by all informants.
 - There is a common perception that a living will states what the patient does not want and usually results in a DNR order
 - Some informants equate a living will with an expression of a patient's wishes of any kind
 - Others assume that the living will is equivalent to a legal proxy directive.
- **Advance directive.** This is variously understood to mean:
 - An expression of the patient's wishes for care when he/she is unable to communicate in any form or not capable of giving informed consent to treatment. The wishes can be expressed verbally, as long as they have been understood by the family and health care providers, and as long as the patient trusts that his/her wishes will be respected to the extent that this is possible. The wishes may also be in writing.
 - A document prepared by a lawyer which names proxy
 - A document prepared by the patient which names a proxy and has the same legal status as a document prepared by a lawyer
 - A Do Not Resuscitate order or No Code order on a patient's health care chart.
- **Advance care plan.** Depending on the informant, this is understood to mean:
 - A verbal or written expression by the patient of wishes for care; this can include the legal designation of a proxy
 - A comprehensive approach to care by all family members and all members of the health care team that is focused on respecting the patient's wishes to the extent that this is possible
 - Most health care providers prefer the term *advance directive* to *advance care plan*.
- **Personal wishes for care**
 - Usually understood to mean a person's wishes for care expressed orally or in writing when they are capable of doing so; the wishes state preferences for care when the person can no longer communicate or is not capable of giving informed consent to treatment.
- **Substitute decision maker.** There are various understandings:
 - Most commonly understood to mean anyone who makes care decisions for another person when that person is unable or unwilling to make their own decisions about care and treatment
 - A family member chosen from the hierarchical list in most provincial legislation (spouse, etc) when a proxy has not been named by the patient or when there is no advance directive of any kind

- The legally designated proxy in an advance directive (proxy directive)
- **Power of Attorney for personal or health care**
 - Usually understood to mean a legal document naming a proxy
 - Sometimes understood to mean the person (e.g. *She is my power of attorney*) who is named as proxy in a proxy directive prepared by a lawyer.
- **Capacity to give informed consent to care and treatment** (referring to the patient)
 - Often understood to mean the ability to understand information, to grasp the implications of the information and to make decisions based on these implications
 - Persons may be capable of decision making in some parts of their lives or with respect to some types of treatment, but not others. In some cases, therefore, capacity to give informed consent to treatment must be frequently re-assessed.
- **Do Not Resuscitate (DNR) or No Code orders**
 - Orders that can be placed on a patient's chart by a physician in any health care setting, including the home
 - Usually refer to a witnessed sudden death (cardiac or respiratory arrest)
 - No Code orders can be specific to cardiac or respiratory or other conditions; No Code orders could state no intubation only, for example, and not deal with cardiac arrest, in which case attempts would be made to restart the heart but not to intubate.
- **Levels of Care forms**
 - These are forms asking a person to choose a level of care. The levels offered typically range from providing comfort care with no attempt to reverse a worsening of the illness to full intervention to prolong life as long as possible. Levels of care forms are mentioned by informants most often as being required on admission by long-term care facilities and sometimes by hospitals. Their legal status is dubious.
- **Facilitator**
 - A person trained to help initiate and support discussions about advance care planning among patients, families and the health care team. The facilitator can be any member of the health care team, a volunteer or someone from outside the immediate care team. The facilitator is a required part of the Respecting Choices® program that is being adopted in some regions.

Social sector: understanding of terminology

Key informants in the social sector are representatives of voluntary sector organizations and consumers. In cases where health care providers spoke as consumers, their observations are included in this section.

In general, key informants in the social sector have less experience than those in the health care sector in using the terminology of advance care planning. The most commonly used term is *Living Will*, but many admit that they do not really understand clearly what it means and are unsure of its legal status. There is a tendency to assume that it is equivalent to requesting a Do Not Resuscitate order. Some consumers report confusion between an advance directive and a will; others believe that a Power of Attorney for financial matters also covers personal care.

Legal sector: understanding of terminology

The lawyers interviewed for this report have a good understanding of the terminology used in provincial legislation in their provinces. Three of the key informants have done extensive study of legislation in other provinces and are familiar with terminology used across Canada. Those who work closely with health care providers and consumers involved in advance care planning have an appreciation of the confusion that terminology can create on the front line.

Informants who are lawyers stressed the importance of the need for the public and health care providers to understand the concept of capacity/incapacity and its relation to the ability to give informed consent.

Many stressed that members of the legal profession need education and training with respect to the concepts and requirements of advance care planning and their role in helping clients prepare advance directives.

Some informants expressed scepticism that it would be possible to achieve consensus on commonly -accepted terminology or legislation across Canada because each jurisdiction jealously guards its powers and uniqueness with respect to health care and legislation.

Experience of advance care planning in Canada

An objective of this report is to go beyond terminology to begin a discovery of how Canadians in the health, social and legal sectors experience the process of advance care planning and of acting on advance directives. This section is based on information gathered from interviews with key informants in all three sectors.

Health care sector

Observations by key informants from the health sector cluster around nine main topics:

1. Developing advance directives: working with clients, patients and their families
2. Acting on advance directives in care and treatment: working with patients and their families
3. Challenges in assessing the capacity of the patient to give informed consent to treatment
4. Roles of members of the health care team
5. Levels of Care forms
6. The need for systems that support advance care planning and following advance directives
7. Paediatric advance care planning
8. The need for education and resources
9. Research and evaluation

Key informant observations on each of these topics are briefly summarized below.

1. Developing advance directives: working with clients, patients and their families

- Several informants stated that medical technology has outrun ethical decision making. We can now keep people alive longer and have raised expectations that medicine can “keep us alive forever – a miracle that just isn’t there”. This discourages some people from engaging in advance care planning which they may see as unnecessary because they do not expect to die.

- Some key informants thought that a barrier to discussion of advance care planning was the perception that many consumers not only fear illness and death, but that they may see death as a personal failure in a society and medical culture that emphasize “fighting” and “surviving” disease.
- Many informants stated that a written document is not the focus or the goal of advance care planning. They stressed the importance of the dialogue between the patient and family and, secondarily, among the patient, family and health care providers.
- Many health care providers state that they would choose a proxy directive for themselves but that they recognize the need of many patients without close family ties to have an instructional directive.
- Many informants stressed the need to include advance care planning as part of the continuum of care: “Introduce the topic of advance directives early in the disease trajectory so you don’t end up later in the emergency room with nothing said or planned for.”
- Some informants suggested that the family physician could raise the topic of advance care planning with relatively healthy adults during the annual physical examination as a way of normalizing the discussion.
- Several health care teams that have engaged in formal advance care planning programs report that patients and families are usually eager to engage in discussions about advance care planning if they have the support of a facilitator (nurse, social worker, volunteer – anyone with training) who can demystify terminology and help people begin to engage in reflection and discussion. One program reported that it took an average of 2.5 meetings of the patient and family with a facilitator in order for advance care planning to be successfully initiated.
- Some informants see a trend toward more patients coming into care who have advance directives but who have not had conversations with their family or physician about their wishes or values.
- Informants working in palliative care report a higher number of patients with advance directives than those in other types of care.
- Informants working in renal care tend to have extensive experience with advance care planning because of the need to discuss decisions with patients about initiation and discontinuation of dialysis (i.e. withholding and withdrawing treatment).
- Some informants spoke about advance care planning programs based on the Respecting Choices® program developed in Wisconsin. This program emphasizes the naming of a proxy and the expression of wishes; it is being piloted in British Columbia, Alberta and possibly other provinces.
- Desire for no resuscitation:
 - Some informants observed that there may be a self-selection among those preparing an advance directive: they may be largely those who do not wish resuscitation in the event of heart or respiratory failure.
 - Informants stated that there are few good educational resources about resuscitation and intubation to help consumers make an informed choice about stating a desire for resuscitation or not in their advance directive. Some informants thought that educational resources should inform without terrifying. They also thought that euphemisms such as “breathing

machine” blurred reality and that communication should be more forthright and realistic.

- A health care provider observed that patients of low socioeconomic status tend to choose all measures to prolong life whereas the more affluent tend to choose not to be resuscitated. The informant thought that this was because the life experience of people of lower social and economic status makes them more likely to feel that others want to take advantage of them or do away with them.
- Family dynamics:
 - Informants working in rural areas and in Atlantic Canada spoke about the situation of the elderly who have no immediate family who live in the province. The elderly may have had the expectation that their children would look after them, but the children are not available except during vacations and by telephone. In these cases, the proxies and other substitute decision makers must function at a distance.
 - A patient may refuse to name a proxy for fear of causing family conflict if one child or family member is chosen instead of another. Some persons choose multiple proxies in their advance directive in order to avoid hard feelings. In these cases, it is important to specify the roles of multiple proxies and to include a dispute resolution mechanism in the advance directive; if this is not done, the provisions in provincial/territorial legislation apply with respect to multiple proxies.

2. Acting on advance directives in care and treatment: working with patients and their families

- An informant stated the need for clear ethical guidelines in health care institutions because decisions to withhold or withdraw treatment involve judgements about standards of care, professional judgement and values. Without clear ethical guidelines, scarce resources could lead to pressure to withhold or withdraw treatment.
- Many informants stressed the importance of knowing the patient’s goals when interpreting their wishes. For example, a patient may not want to be kept alive indefinitely by artificial means but they many want to live long enough for their children to arrive from other provinces.
- Informants with extensive experience with advance care planning have worked out ways to deal with conflict between any or all of the parties engaged in advance care planning. Informants report that in almost all cases where there is good will by all parties, conflicts can be resolved.
- Helping a patient to define their wishes involves an ongoing process of negotiation. This was emphasized by informants working in renal care. They stressed that there is not just one decision point as there may be in intensive care.
- Most informants thought that the gradual shift in health care toward a more patient-centered model of care has the support of most health care providers. Most felt that, where possible, the health care team did their best to respect patients’ wishes where these were realistic. Several people gave the example of the patient having expressed the wish to die at home but the family admitting that they could not cope with providing this level of care at home, in which case the patient was kept in the hospital or long-term care facility.

- Concerns about people being coerced into choosing no resuscitation were not widespread. Practice appears to vary widely: while some informants noted that Do Not Resuscitate orders might be placed on an elderly patient's chart by a physician, other informants stated that the default decision in a health care facility could be resuscitation even if the patient is elderly and frail.
- Some informants noted that, in their experience, the wishes of the family may sometimes prevail over the patient's wishes with the result that the patient's life is prolonged for the benefit of the family. Some informants observed that health care staff may tend to "forget" a patient's wishes if the family speaks more strongly than the patient. As one informant said, "The patient dies but the family survives and we have to deal with the family."

3. Challenges in assessing the capacity of the patient to give informed consent to treatment

- Some informants stressed the need to assess capacity to give informed consent on an almost daily basis because of the changing health condition of the patient.
- One informant reported having to remind her staff often that the patient is capable of informed consent to treatment until proven otherwise.
- Some informants reported that families may assume that the patient is incapable in all areas of decision making whereas consent must be incident-based.
- Some informants expressed concern about whether consent was truly informed because, in their experience, the patient may not absorb information even when they seem to understand. Similarly, informants dealing with diseases such as ALS stated that new research shows that there may be cognitive impairment even though behaviour may appear normal; in these cases, determining if the patient is capable of informed consent can be difficult and emotionally fraught for health care providers and families.

4. Roles of members of the health care team

- Several health care providers noted that physicians often do not know how to initiate what may be an uncomfortable discussion about advance care planning or they may not have time for dialogue; nurses have a heavy work load and may not have time to talk with patients or may feel they will be out of their depth if the patient asks detailed medical questions. Many agreed that social workers have a privileged position because they are already engaged in discussion with patients about other matters and can start conversations about advance care planning. Others saw volunteers as playing an important role in initiating or supporting the dialogue because of their training in listening and communication.
- Many informants noted a reluctance by physicians to initiate discussions about advance care planning with their patients based on the concern that the patient may assume that the discussion means that their diagnosis or prognosis is worse than they have been told. The patient may fear that the discussion signals that death is approaching.
- Some informants thought that physicians were pushing for advance directives "because it makes it easier for them in the end".
- Several informants noted that physicians who have come to Canada from other countries may have more paternalistic or authoritarian attitudes toward

patients than Canadian-trained doctors who have been exposed to the philosophy of patient-centered care and self-determination for patients. Informants noted that foreign-trained physicians often do not believe in advance directives and think that only the physician should decide. Informants noted, however, that these physicians are aware of the law concerning advance directives and consent to health care and will obey the law.

- The importance of communication within the interdisciplinary team came up often in the interviews as crucial to awareness of the patient's wishes and of their changing health status and to the mutual support and sharing of expertise within the team.
- Some informants pointed out the challenge for other staff and families when staff members in the same facility have different opinions on whether or not to respect the wishes of the patient and family. In these cases, the family finds itself in constant negotiation with staff members.
- Several informants commented on the role of paramedic personnel with respect to instructional directives requesting no resuscitation and Do Not Resuscitate orders signed by physicians. When paramedic personnel are called on to transport patients to hospital from home or long-term care facilities, in most cases they are legally obligated to attempt resuscitation except when they are shown appropriate documentation (a Do Not Resuscitate order signed by a physician or an instructional directive in jurisdictions where it is recognized in legislation). Informants emphasized the need to ensure that the advance directive or DNR order is easily found so that paramedic personnel can consult it.

5. Levels of Care forms

Levels of Care forms are used especially by long-term care facilities and some hospitals when a person is admitted. The person is asked to choose among three or four levels of care, typically including: no resuscitation; comfort measures only; specified treatments; or all necessary interventions to prolong life. Some long-term care facilities require that these forms be completed as a condition of admission. The legal status of these forms is dubious.

- Informants from several provinces mentioned Levels of Care forms as being required by most long-term care facilities. Some thought that they were first developed by physicians who were concerned about lawsuits and legal liability for their treatment decisions. Most informants cautioned that there is a distinction between a Levels of Care form and an advance directive and that the danger exists that facilities and patients will mistakenly assume that completion of a Levels of Care form is equivalent to having a valid proxy and/or instructional directive.
- According to informants, Levels of Care forms are often not reviewed and revisited on a regular basis except if the resident's or patient's family applies pressure to do this.
- One informant cited research showing that most residents in long-term care do not remember signing a Level of Care form and do not remember their choice of care level.
- Some informants stated that, regardless of the uncertain legal status of these forms, most people will sign them if they are required by the long-term care facility because they fear having no other place to live.

- Some informants pointed out a source of confusion regarding levels of care designation when patients are transferred between facilities because a Level One in a hospital may be equivalent to a Level Three at a long-term care facility in the same city.

6. The need for systems that support advance care planning and following advance directives

- Many informants stated the vital importance of systems that support patients, families and health care providers to engage in dialogue about advance care planning and to ensure that advance directives are consulted. Based on their experience, informants suggested that the health care and social service systems need to devote financial resources and staff/volunteer time to advance care planning dialogue with patients and families. They also pointed out that effective mechanisms must be in place such as workbooks for patients and families interested in preparing advance directives, periodic reviews of the advance care plan with all concerned, easily visible ways of attaching advance directives to a patient's chart, and so on. Many informants stated that systems must be established so that preparation of advance directives and consulting them become part of normal health care practice.
- Several informants stated that systemic challenges present the biggest barriers to staff awareness of a patient's advance directive. Many informants observed that advance directive or care wishes are often not seen by staff for a variety of reasons, including lack of staff time to consult the patient's record.
- Some informants pointed out the importance of mechanisms to ensure that an advance directive follows the patient. If the family physician has the advance directive on file in his/her office, it is unlikely to be seen when the patient is admitted to hospital. In most urban areas in Canada, the family physician will not necessarily see the patient in hospital.
- In general, informants noted a lack of effective documentation processes across the continuum of care with respect to advance directives. According to many informants, there are serious problems with transfer of information and awareness of an advance directive when a patient is transferred from home to a care facility, between care facilities, or to a different unit within the same facility. The different centres of responsibility often do not communicate with each other.
- Several informants spoke about systems that are used, or could be used, to ensure that health care providers are aware of a patient's advance directive, including:
 - electronic health records and smart cards
 - colour-coded medic-alert type of bracelet (These have been tried in the United States. There is some evidence that they may lead to stigmatization of patients with respect to their care choices)
 - a colour-coded transparent document holder prominently displayed in the patient's home and on the front of their medical record in hospital (e.g. the Greensleeves folder used by British Columbia's Fraser Health Authority).
 - hospital admission procedure that requires asking all patients if they have an advance directive. If so, a copy of the advance directive is placed on their chart and its presence is flagged by a visual reminder. Informants

observed that physicians may have to be reminded to look for the advance directive in the chart.

7. Paediatric advance care planning

In Canadian jurisdictions, the minimum age for making an advance directive ranges from 16 to 19, although younger minors can give informed consent to treatment in some jurisdictions. Most children in care, including paediatric palliative care, cannot make an advance directive but informants pointed out that they can participate in planning and decision making. Close to 6000 children die each year in Canada, mostly in intensive care. The informants who contributed the following observations have experience in paediatric palliative care.

- Informants stated that the child or adolescent should have the same rights as adults to information and involvement in discussions about their care; the informants emphasized that the information must be suited to the child's stage of development and expression.
- Continuous communication and decision making involving the child and family are crucial. In paediatric palliative care, there is time for this communication to take place because death is rarely sudden.
- Palliative care staff talk to children of all ages about their illness and treatment, about "what we can do and what we can't do".
- Parents often try to protect their children from knowledge of the severity of their illness, but children usually know and want to communicate about it.
- Children are often more ready to talk about death than their parents. Staff observe that children are often wiser than adults and more able to face the truth about illness and death. The child may have to guide the parents through the process. As one informant said, "The illness has fast-tracked learning that it takes adults years to achieve because the children have to learn about things that most of us don't".
- An informant stated that she could not think of a single case where a child did not want to understand what was happening to them.
- Paediatric palliative care facilities use a variety of therapies to help children express their feelings and desires, including play, music and art therapy.
- Some families agree to a Do Not Resuscitate order for their child near the end of life.
- Informants stated the need for a paediatric advance care planning program for children and families.

8. The need for education and resources

Informants stated that there is widespread interest among both the public and health care professionals in learning more about advance care planning and for resources and programs to support both consumers and health care providers.

9. Research and evaluation

- Informants expressed the need for research and evaluation in advance care planning, particularly with respect to:
 - Evaluation of processes of transfer of information across the continuum of care and between care facilities: how well do advance directives follow the patient throughout the system?

- Evaluation tools for performance measures: How closely does the care received match the patient's wishes expressed in an advance directive or by other means. Are end-of-life care choices respected?

Implications – health care sector

- Across Canada, there are pockets of strong expertise and experience in advance care planning and other areas with weak knowledge. Ways of sharing experience and knowledge could be helpful to those in all jurisdictions.
- In order for advance care planning to be initiated and acted on, systems must be in place to support and sustain the process.
 - Patients, families and health care providers need encouragement, support and tools to help them engage in discussion and preparation of advance directives. Trained facilitators and user-friendly resources have proved valuable.
 - The onus for making health care providers aware of an advance directive still rests largely with the patient, family or proxy, although some jurisdictions have provisions in legislation for registering advance directives or having them attached to the patient's medical record. Systems are needed to ensure that all health care providers are aware of advance directives and that the advance directive follows the patient between care settings.
- There is a need for advance care planning education and training for health professionals, especially focusing on interdisciplinary practice and education because of the team nature of health care. Advance care planning might be an appropriate case study for education aimed at training health care providers to work in interdisciplinary teams.
- More research is needed into the use of Levels of Care forms in long-term care facilities and hospitals, particularly because their legal status is doubtful and because many consumers and health care providers mistakenly assume that the Levels of Care form constitutes a valid advance directive.
- Worthwhile research could be conducted into the influence of social determinants of health on advance care planning.⁴
- Consideration should be given to developing a program for advance care planning for paediatric care.

Social sector

Information gathered from social workers was included in the previous section because the social workers interviewed all work in front-line health care settings. The information in this section is based on interviews with voluntary sector organizations advocating for or supporting those with specific diseases and interviews with family caregivers and volunteers. When key informants from the health sector spoke as consumers about their own advance care planning, their observations were included in this section. To a large extent, the distinction between the health and social sectors is

⁴ The Public Health Agency of Canada (www.phac-aspc.gc.ca) lists the determinants of health as: income and social status; social support networks; education; employment and working conditions; social environments; physical environments; biology and genetic endowment; personal health practices and coping skills; health child development; health services; gender; and culture. This list may evolve as population health research progresses.

arbitrary because advance care planning (in the context of this report) usually concerns health care.

Observations by key informants in the social sector cluster around five main topics:

1. Preparing and acting on an advance directive: consumer perspectives
2. Capacity to give informed consent to treatment
3. The influence of religion on advance care planning
4. Special concerns of the disability community
5. Resources, education and public awareness

Key informant observations on each of these topics are briefly summarized below.

1. Preparing and acting on an advance directive: consumer perspectives

- Family caregiver informants reported that their experience in caring for a critically ill patient made them more likely to do their own advance directive. Some reported that they now encourage their children to start talking about advance care planning while they are healthy, instead of waiting for a stroke or an accident, when it may be too late to communicate about wishes.
- Family caregivers stressed the need for ongoing discussion and revision of care goals as the disease progresses.
- Several respondents noted the beneficial effect on family bereavement of a positive experience with advance directives and the relieving of guilt because “We respected his/her wishes and we did all we could”.
- Consumers who had prepared their advance directives well in advance of severe illness and who had discussed their wishes often with their families reported a good experience with having the advance directive respected by family members and health care providers.
- Some informants noted that it can be fairly simple to record specific instructions in an advance directive if you are living with a specific disease process and you know the outcomes of treatment; otherwise it can be difficult.
- Families who have not been able to discuss wishes with the patient can have difficulty in acting as proxies or substitute decision makers and can feel that the burden of choice about treatment is too heavy. In these cases, they may devolve entire responsibility for decision making to the health care provider (usually the physician).
- A health care provider commented on consumer perceptions that advance care planning is something they can put off thinking about. This informant stated that the slogan *Talk to your doctor* could be used to raise public awareness: “We don’t all need Viagra, but we will all need an advance directive. Think about it while you’re healthy.”
- Informants reported that generational and gender factors influence advance care planning: older people are often not accustomed to talking about care or asking questions when they don’t understand things. This can make it difficult to initiate a conversation about advance care planning. Women reported that men are not prone to open up the subject of advance care planning. The attitude they perceived was *we don’t talk about that*.
- The growing role of the funeral industry in advance care planning was noted by several informants. They reported that funeral directors increasingly encourage people to prepare advance directives and wills when they do their funeral

planning. One senior, however, stated that all of her friends had pre-planned and paid for their funerals but that none had an advance directive.

- The cost of a lawyer's services to prepare an advance directive is prohibitive for many consumers. Many informants thought that the services of a lawyer are often not needed in advance care planning and that a facilitator of some kind would be more helpful but they cautioned that most people do not have access to programs that offer the services of a facilitator.
- Speaking as consumers, many health care professionals said they would not choose cardiopulmonary resuscitation for themselves when expressing their wishes in an advance directive. A frequent joke was the possibility of having **DNR** tattooed on their chest.

2. Capacity to give informed consent to treatment

Some family caregivers spoke of the difficulty of determining the capacity of the patient to make informed decisions about care and treatment. A disease may involve cognitive impairment which is not obvious, leaving the patient capable in some areas of daily living, but unable to give informed consent to treatment based on understanding of information. This leaves family members, and sometimes health care providers, with often agonizing decisions and uncertainties about communicating with the patient and feeling sure that the patient's consent is truly informed. Family members reported walking a fine line between respecting the autonomy of the patient and acting in his/her best interests.

3. The influence of religion on advance care planning

- Several informants reported that religious officials of some faiths and denominations insist that members of their faith community ask for all measures to prolong life. A few informants said that their conversations with patients indicated that the patient may go along with something that is sanctioned by their faith community even though it may not be in line with their personal beliefs.
- Some informants mentioned a statement by Pope John Paul II about the need to offer feeding tubes, following his experience of treatment when critically ill. These informants reported that the Pope's statement sometimes influenced the treatment wishes of patients despite the advice or professional judgement of their physician.

4. Special concerns of the disability community

The disability community has strong concerns about advance care planning and advance directives because of the episodic nature of severe health crises and the danger that the person may not be resuscitated when they are capable of recovery. They are concerned about being assessed as incapable of giving informed consent to treatment because they cannot always communicate easily with health care providers.

Those living with disabilities continually fight against stigma and discrimination based on the judgments of non-disabled people (and care providers) that the lives of the disabled may not be worth living. As a result, those living with disabilities are advocates of documents that state *I want to be kept alive and helped to recover*. There is a fear, based on some experience, of having a Do Not Resuscitate order placed on their chart without their knowledge or consent (as is a physician's legal right, although the Canadian Medical Association *Code of Ethics* advises physicians to *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.)*⁵

5. Resources, education and public awareness

Key informants seldom mentioned the many Canadian websites that offer reliable processes and forms for advance care planning (e.g. provincial consumer guides). Many informants said that people often do not know where to find a user-friendly, affordable way to engage in advance care planning. Several informants spoke of the need for simple tools to help people prepare an advance directive and some suggested that a national website or information clearinghouse be established for consumers and health care providers.

Implications: social sector

- Disease-specific voluntary organizations could develop advance directive tools and resources specific to their diseases and situations because the trajectories of chronic and/or terminal illnesses vary. This would help patients to express care wishes in their advance directive which are tailored to their needs.
- The advance care planning needs of the disability community and of those living with chronic, long-term conditions are different from the needs of those living with critical or terminal illness. The diversity of needs is a possible subject area for further research.
- There is a need to raise consumer and professional awareness of advance care planning in a way that normalizes the process as part of health care and personal planning.
- A national website with user-friendly resources for consumers and professionals or an information clearinghouse would be valuable resources for advance care planning.

Legal sector

This section is based on interviews with lawyers and those in the health and social sectors who commented on advance care planning legislation or the law. Observations by key informants in the legal sector cluster around seven main topics:

1. The difficulty of obtaining pan-Canadian consensus on advance care planning terminology or standardized legislation
2. The central issue of informed consent to treatment
3. The debate over proxy versus instructional directives
4. Legal practice and consumer access to legal advice
5. Legislation
6. The need for dialogue involving the health, legal and social sectors, including consumers
7. The need to educate lawyers about advance care planning

Key informant observations on each of these topics are briefly summarized below.

1. The difficulty of obtaining pan-Canadian consensus on advance care planning terminology or standardized legislation

Some key informants expressed scepticism that it would be possible to achieve pan-Canadian consensus on terminology or legislative provisions because health care falls

⁵ Canadian Medical Association. *CMA Code of Ethics* section 28. 2004.

under provincial/territorial jurisdiction and current political trends favour more, rather than less, divergence.

2. The central issue of informed consent to treatment

There is concern by lawyers that those involved in advance care planning, particularly in the health and social sectors, fail to grasp the importance of the central issue of informed consent to treatment, which is the ultimate purpose of an advance directive, whether the consent is given by a proxy or via the person's wishes expressed in an instructional directive.

3. The debate over proxy versus instructional directives

An important difference of opinion exists within the legal and health sectors in particular over whether provincial/territorial legislation should allow proxy directives only or both instructional and proxy directives. It should be noted that even in jurisdictions where only proxy directives are recognized in legislation, the patient's wishes must still be taken into account if they are known.

Resolving the debate over proxy versus instructional directives is beyond the scope of this report. The main arguments put forward by key informants are summarized below.

In favour of proxy directives only:

- A proxy directive is flexible and responsive to actual reality because your proxy knows your values. It is almost impossible to create an effective instructional directive because you would have to predict the future and know what your wishes would be if you became critically ill. Your wishes would probably change as your health condition changed. What would happen if you forgot to update your wishes? Your intimate others and health care providers might be legally bound by outdated wishes. In any case, your values and recent wishes can be expressed to your proxy who will use them as guidance in giving consent to treatment.
- Proxy directives encourage meaningful dialogue with your proxy and family.
- Some physicians find it easier to deal with a written instructional directive instead of dealing with a real person (your proxy). A proxy directive will ensure that your next of kin are consulted by the physician if you lose capacity to give informed consent.
- Instructional directives are hard to interpret and follow. They may use vague terms such as "no heroic measures" or the wishes expressed may be unrealistic.
- People who do not have good relations with their family can appoint a proxy who can stand up to the family; otherwise, the family may take over as substitute decision makers.
- Many health care providers may be treating you. They may all have different interpretations of your instructional directive. Your proxy is the only constant in your care; your proxy can be the advocate who asks that your values and wishes be respected.
- An instructional directive is weaker than a proxy directive or a combination of instructional and proxy directive (where both are recognized in legislation). Without a proxy, you are at the mercy of the system or a conflicted family.

In favour of recognizing instructional directives in legislation:

- Some persons have no family, or no family whom they want to involve in their care. The person may want privacy with respect to their wishes. An

instructional directive allows them to have their wishes respected without reference to a substitute decision maker.

- Persons are entitled to choice, autonomy and self-determination. This is a Charter right. Persons should be able to have their wishes respected without the intervention of a proxy or substitute decision maker.
- Seniors want the right to make their own choices and therefore should be able to express their wishes, including wishes that may request no resuscitation in the event of witnessed sudden death (cardiac or respiratory arrest).

Another comment on instructional directives from a key informant:

The informant thought that a statement of values would be more useful as an instructional directive than a prescriptive list of dos and don'ts with respect to treatment choices because wishes can change as a person's health status changes. If the written instructional directive no longer reflect the patient's wishes, the patient may no longer be capable of changing the directive. A statement of values, however, should stand the test of time and changed circumstances.

4. Legal practice and consumer access to legal advice

- Key informants from the health and social sectors have de-emphasized the development of legal documents involving the services of a lawyer. Some informants have stated that it is preferable not to have a legal document because this may be constraining in some cases.
- Key informants who are lawyers have mostly stressed that the process of reflection and communication between the patient and family is as important as the production of a document.
- Lawyers who work in health law observe that physicians may not seek out the proxy named in an advance directive and may instead talk to whichever family member is present.
- Many informants reported that lawyers routinely ask clients about preparing an advance health care directive (usually a proxy directive) when they prepare a will or a power of attorney for financial matters.
- Access to legal services for preparing an advance directive:
 - Some informants consider that many consumers cannot afford legal fees
 - Low literacy or language difficulties experienced by consumers may make it difficult for them to understand what the lawyer is saying
 - People living in rural and remote areas have difficulty in getting access to a lawyer.

5. Legislation

A few key informants expressed the need for provincial/territorial legislation that is specific to advance care planning, in addition to existing legislation governing proxy directives which may have been put in place to protect the rights of those living with long-term disabilities.

6. The need for dialogue involving the health, legal and social sectors, including consumers

While some informants stated that the most important key to understanding advance directives is the legislation and the law, other informants stressed the need for understanding advance directives as the result of a dialogue involving the health, legal and social sectors, including consumers, because legislation and the law are developed

and evolve as a result of social consensus. These informants saw the evolution of legislation and the law about advance care planning as a long-term interactive process involving all of society.

7. The need to educate lawyers about advance care planning

- Many key informants from the health sector stressed the need for education about advance care planning for lawyers. The informants stated that lawyers often give their clients inappropriate advice when preparing an advance directive that contains wishes for treatment, often based on the lawyer's own perception of what he/she would want in terms of treatment. These informants considered that lawyers do not know enough about medical treatment to advise clients about treatment wishes and one stated that *lawyers shouldn't try to be doctors*. Many informants suggested that a lawyer should advise the client to talk to their family physician before defining treatment wishes.
- Examples given by key informants of the lack of expertise or sensitivity on the part of some lawyers included:
 - A husband and wife asked their lawyer to draw up their instructional directives. The wife wanted to be kept alive by all possible means and the husband wanted no resuscitation. The lawyer chastised the wife for her selfishness.
 - An elderly patient was admitted to intensive care with an advance directive prepared by his lawyer stating that he did not wish a brain transplant, among other things.
 - A patient came into care with three documents prepared by his lawyer: an instructional directive, a proxy directive and an application for guardianship. The patient's legal bill was close to \$5,000.

Implications: legal sector

- Mechanisms are needed to foster ongoing dialogue about advance care planning among lawyers (legislators), policy makers, health care providers and consumers.
- Education and training in advance care planning are needed for legal professionals.

Successes and challenges in advance care planning

Successes in advance care planning: key factors

A number of informants reported experience with successful advance care planning. Based on the research and interviews, the following are key factors in success:

- Open communication over a period of time between:
 - patient and family members
 - physician and family
 - members of the care team
- Initiating the advance care planning dialogue while the patient is capable of making decisions and is relatively healthy, rather than trying to do advance care planning in a health crisis.
- The presence of a trained facilitator during at least 2-3 meetings with the patient and family to support opening and sustaining the conversation

- Congruence of values between patient/family and the physician/health care team
- Trusting relationships between the patient/family and the care team
- Systems and structures that support advance care planning, including time and resources devoted to it and procedures that ensure that the patient's wishes are known and followed to the extent possible
- Mechanisms for ensuring that the advance directive is readily available to all health care providers (including paramedics called to the home) in all settings: the advance directive follows the patient throughout the continuum of care.

Challenges in advance care planning

The following factors were consistently identified as challenges or barriers to effective advance care planning:

- The inability to talk about it by all concerned
- Fear of facing the thought of illness and death – confusing terminology may present an additional barrier
- The near impossibility of anticipating future wishes
- Conflict of values within a family
- Insufficient communication skills and conflict resolution skills by all members of the care team
- The advance care planning needs of the disability community and of those living with chronic long-term conditions can be different from the needs of persons receiving end-of-life care. Blanket legislation or generic resources and tools may not be responsive to these differences.
- Lack of systems to support advance care planning and health care providers' awareness of the advance directive when it is needed
- Absence of any means of knowing the incapable patient's wishes
- Difficulties in getting the care desired regardless of the patient's wishes, because of scarce resources in the health care system. This can be especially difficult in home care.
- Generational (elder) reluctance to talk about death or lack of a sense of entitlement to express personal wishes about care
- Consumers sometimes give up on advance care planning if they cannot find user-friendly, affordable help and resources
- A lack of research and evaluation hampers work in the field of advance care planning.

Options for further work

The Public Information and Awareness Working Group requested that this report identify options for further work that the Working Group might consider. The following 14 options are based on the research done for the report.

In many cases, these options are closely aligned with the short-term options and long-term possibilities that were identified by participants at the March 2006 Advance Care Planning Forum.

- [Where this occurs, the options identified at the March 2006 Forum are indicated in bulleted paragraphs within brackets.]

Options:

1. Facilitate the exchange of knowledge and expertise that exists in pockets across Canada through meetings or information resources (this links to options 2 and 6 below).
2. Identify best practices (factors for success) and disseminate the findings. This could be a subject for collaboration with the Best Practices and Quality Care Working Group.
 - [Literature review of best practices; Get all the good work on ACP to frontline health care workers; To know and share best practices.]
3. Collaborate with the Best Practices and Quality Care Working Group to ensure that accreditation standards and guidelines of health care facilities and hospices continue to include advance care planning.
4. Dialogue with national associations representing the professions involved in health care and those representing the hospital and long-term care sectors (e.g. Canadian Healthcare Association and the Canadian Association for Community Care) to discuss ways of ensuring that all staff become aware of advance directives at every stage of the continuum of care. There may be a possibility for collaboration with the Best Practices and Quality Care Working Group.
 - [Research on why health care professionals are not getting the proper consent from patients; Find ways to ensure that the expressed wishes of people are honoured.]
5. Support disease-specific organizations to develop advance care planning resources tailored to the specific needs of their clients.
6. Create a clearinghouse for advance care planning information coupled with a user-friendly website and resources for consumers and professionals. This could include a plain-language guide to the differences among provinces in their practices (including legislation) and use of terms.
 - [Plain-language document on differences among provinces in their use of terms and in their practices; Clearinghouse of information for all professionals; Inventory of discussion tools and ways of helping people; Find a way to leverage the transfer of knowledge]
7. Develop educational modules, focusing on interdisciplinary education for professionals. Tap the expertise of those with experience, such as social workers

- and other health care providers in renal care. This could involve collaboration with the Working Group on Education for Formal Caregivers.
- [Educational modules for each profession on consent, which includes advance care planning; Inter-professional and interdisciplinary education modules; Education in communication skills; Help non-palliative care physicians learn to share power in decision-making; Train medical students to share power; Moving away from the medical model towards integration of various disciplines with the patient at the centre]
8. Work with the legal profession to develop education and training programs. Because legal and ethical (both bioethics and legal ethics) principles underlie and inform advance directives and health care consent as well as interrelated capacity issues, include the legal profession in the development of interdisciplinary educational modules described in option 7.
 9. Work with national stakeholder organizations representing the long-term care sector to do further study of Levels of Care forms and the need to engage in true advance care planning.
 - [Need to clarify the purpose of levels of care as guidelines rather than consents, orders or true advance directives.]
 10. Support research and evaluation initiatives in advance care planning.
 - [Research on why it is so hard for professionals in the system and for the systems themselves to do advance care planning well.]
 11. Develop and/or support a national public awareness campaign about advance care planning
 - [National social marketing campaign like Participaction, anti-smoking, etc.; Public awareness for patients and proxies, including awareness of their rights; People would realize that they have rights and responsibilities and would know what they are]
 12. Develop and/or support a national awareness campaign for professionals. The Canadian Nurses Association indicated in an interview for this report that it would be willing to assist by getting nurses involved through its 33 nursing interest groups. Their individual newsletters can raise awareness among nurses by covering advance care planning topics and soliciting feedback from members which could be incorporated into broader awareness-raising initiatives.
 13. Support the development of advance care planning in paediatric end-of-life care by connecting with working groups working on paediatric palliative care issues.
 - [A collaborative process in the best interests of the child in a family-centered approach]
 14. Facilitate dialogue among the health, social, legal sectors and consumers, including those involved in developing provincial legislation and policy.

Appendices

Appendix 1: Advance Care Planning Glossary of concepts and terms

This glossary provides definitions and explanations of terms used frequently in advance care planning. The glossary is meant to be understood by the average reader and does not attempt to provide exact legal definitions. The concepts and terms generally apply to advance care planning by capable adults for health and/or personal care, rather than advance planning for financial and property matters. Terms that are defined elsewhere in the glossary are underlined in the text. The glossary is derived from a study of several resources and information gathered from interviews with key informants in the health, social and legal sectors. Major resources consulted in the development of the glossary are listed at the end of the glossary.

Advance care plan is a term sometimes used to describe an advance directive. The term *advance directive* is generally preferred in the health and legal sectors.

Advance care planning is a process of reflection and communication in which a capable person makes decisions with respect to future health and/or personal care in the event that they become incapable of giving informed consent. The process may involve discussions with health care providers and significant others with whom the person has a relationship. Advance care planning may result in the creation of an advance directive.⁶

Advance directive for health or personal care consists of instructions given by a capable person, often in written form, about their wishes for health care (treatment) and/or personal care in the event that they become incapable of giving informed consent. The advance directive may appoint a proxy who will assume responsibility for ensuring that the person's wishes are respected. In all Canadian provinces, the Yukon and the Northwest Territories, an advance directive can name a proxy. In five provinces and the Northwest Territories, an advance directive may contain health or personal care wishes that must be followed by health care providers to the extent that the wishes are reasonable, possible and legal (Newfoundland and Labrador, Prince Edward Island, Manitoba, Saskatchewan, Alberta and the Northwest Territories; in these jurisdictions, the law does not require that an advance directive name a proxy).

An advance directive that names a proxy is called a proxy directive. An advance directive that expresses wishes for health or personal care is called an instructional directive. In the five provinces which recognize instructional directives and in the Northwest Territories, an advance directive may be either a proxy directive or an instructional directive or both.

The following are the legal terms used to describe advance directives in Canadian jurisdictions:

⁶ Note: Some consumer guides refer to *Advanced* care planning. The word *advanced* means "greatly developed" or "being beyond others in progress" whereas *advance* (as an adjective) means "made ahead of time"; therefore the term *advance care planning* is more accurate than *advanced care planning*.

- Advance Directive: Yukon (proxy directive)
- Advance Health Care Directive: Newfoundland and Labrador; Prince Edward Island (instructional and proxy)
- Authorization: Nova Scotia (proxy directive)
- Health Care Directive: Manitoba and Saskatchewan (instructional and proxy)
- Mandate: Quebec (proxy directive)
- Personal Directive: Alberta and Northwest Territories (instructional and proxy)
- Power of Attorney for Personal Care: New Brunswick and Ontario (proxy directive)
- Representation Agreement: British Columbia (proxy directive).

Advance Health Care Directive is the legal term used to designate an advance directive in the provinces of Newfoundland and Labrador and Prince Edward Island. The advance health care directive in both of these provinces can be either instructional or proxy or both.

Agent is the legal term used in Alberta and the Northwest Territories to designate a proxy named in an advance directive.

Allow natural death means that no treatments will be used to delay death where death is about to happen from natural causes. Some health care providers prefer Do Not Resuscitate as being clearer and less euphemistic.

Attorney for Personal Care is the legal term used in New Brunswick and Ontario to designate a proxy named in an advance directive.

Authorization is the legal term used in Nova Scotia for an advance directive. The Authorization is a proxy directive only.

Best interests of the patient (in the context of health care decision-making) are used to guide decision making where there is no knowledge of the patient's wishes. In determining best interests, the following are usually taken into account: whether the treatment will improve the person's condition, prevent it from deteriorating or reduce the rate of deterioration; whether the benefits of the treatment outweigh the risks; and whether a less intrusive intervention would be as beneficial.

Capacity is the ability to understand the nature and consequences of the decision to be made and the ability to communicate this decision in any understandable manner. In Canadian law, an adult is presumed to be capable unless determined otherwise. A person must be capable in order to make an advance directive. A person may have cognitive deficits in some areas and still may be capable of making an advance directive or giving a simple direction or expression of wishes about care.

When capacity with respect to informed consent to treatment is in doubt, a determination of capacity may be made by a qualified professional, usually a physician or other health care provider who is offering the treatment. An advance directive only becomes active if the person who made the advance directive is deemed incapable of making an informed decision about the matter in question.

Cardiopulmonary Resuscitation or CPR is a treatment intervention for cases of sudden unexpected cardiac or respiratory arrest. CPR may include mouth-to-mouth resuscitation, chest compression, ventilation, intubation and defibrillation.

Continuing or enduring Power Of Attorney is a Power of Attorney that continues to be valid after the person who made the Power of Attorney becomes incapable of making their own decisions. A proxy directive for health care is sometimes referred to in the legal sector as a durable Power of Attorney for health care.

Dispute resolution is sometimes needed when a person names more than one proxy in their advance directive or when more than one substitute decision maker is involved in making decisions on behalf of an incapable person. A person making an advance directive may specify how the proxies are to act (e.g. jointly or separately), whether the proxies have different or overlapping areas of responsibility, and how disputes should be resolved in cases of disagreement among the proxies. If this is not specified in the advance directive, the process provided for in legislation is used (this varies somewhat depending on the jurisdiction).

Do Not Resuscitate order or DNR order is an order placed by a physician on a person's health record which instructs health care personnel not to attempt resuscitation in the event of heart or respiratory arrest. A physician can place a DNR order on a person's health record in response to an instructional directive or instructions made the patient or on the basis of a judgement that resuscitation would be futile or of no benefit.

Extraordinary measures or *heroic measures* are vague terms sometimes used in informal language to mean a variety of life-sustaining procedures. Health care providers advise that more precise terms should be used in instructional directives or expressions of wishes, such as cardiopulmonary resuscitation, mechanical ventilation, and so on.

Facilitator in advance care planning is a person trained to help initiate and support communication among patients, families and health care providers about advance care planning. Certified facilitators are an integral component of the Respecting Choices[®] advance care planning initiatives in development in some provincial health care regions.

Guardian is the legal term used to designate a proxy named in an advance directive in Nova Scotia.

Health Care Directive is the legal term used to designate an advance directive in the provinces of Manitoba and Saskatchewan. The advance health care directive in both of these provinces can be either instructional or proxy or both.

Health care provider or service provider in advance directive or health care consent legislation is a professional who is a member of a professional college or association recognized in that jurisdiction. The professions recognized for the purposes of advance directive legislation may vary from one jurisdiction to another but usually include physicians, nurses and social workers, among others.

Incapacity is the mental inability to understand the nature and consequences of the decision to be made or the physical inability to communicate this decision in any understandable manner, for example, in the event of a severe stroke or coma.

Informed consent is agreement to a health care treatment given by a capable person who is able to understand and appreciate the nature and consequences of the proposed treatment. If a person is incapable of giving consent, a proxy or substitute decision maker may give consent in their place. Unless there is an emergency such that informed consent cannot be obtained, full and informed consent is the standard required for any health care treatment. The option of no treatment is specified as a possibility for informed consent in some legislation.

Instructional directive is an advance directive that states wishes for health care and/or personal care in the event that the person making the directive is unable to give informed consent to such decisions. In jurisdictions where an instructional directive is provided for in legislation (NL, PEI, MB, SK, AB, NT), the instructional directive is designated by the same name as the proxy directive (e.g. in Alberta and the Northwest Territories, both the instructional and proxy types of directive are called Personal Directives). An instructional directive serves as the voice of the person and can be followed by health care providers without reference to a substitute decision maker.

Levels of Care forms are used especially by long-term care facilities and some hospitals when a person is admitted. The person is asked to choose among three or four levels of care, typically including: no resuscitation in the event of heart or respiratory failure; comfort measures only; specified treatments; or all necessary interventions to prolong life. Some long-term care facilities require that a level of care form be completed as a condition of admission to the facility.

The legal status of these forms is dubious, according to several key informants, although there have been no legal challenges to them as yet. Long-term care facilities justify their use to help in decisions about emergency treatment and the possible need to transfer an incapable person to hospital. Critics of the use of these forms state that not only are they illegal, but also that the decision about treatment should be made when the need arises, rather than several months or years in advance. Most health care professionals and patients are not aware that these forms do not have legal status and that persons cannot be compelled to complete them as a condition of admission to a facility. Given the shortage of spaces in facilities, most people are unlikely to raise objections to the forms for fear of being denied admission.

Some health care providers are concerned that Levels of Care forms may be seen as substitutes for true advance care planning.

Living will is an informal term not used in any legislation in Canadian jurisdictions. The term *living will* originated in the United States in the 1990s and was largely popularized by the media. The definition of *living will* varies with the source consulted. Most key informants understand it to mean an expression of wishes for treatment in the event of incapacity to give informed consent in the nature of an instructional directive. Because the term is widely recognized by the public, health care providers and lawyers often use it to start conversations about advance care planning. Most professionals prefer to use the term advance directive.

Mandate in anticipation of incapacity is the legal term used to designate an advance directive in Quebec.

Mandatary is the legal term used in Quebec to designate a proxy named in an advance directive (Mandate) .

Mandator is the term used in Quebec legislation to designate the person creating a mandate in anticipation of incapacity.

Mature minors are persons younger than the legal age of majority who may be able to give informed consent if they are judged by health care providers to be capable of doing so. There is no consistent fixed age at which a person is considered able to make an informed decision and each case is judged on its merits. Assent to treatment for children is usually given by their parents or guardians who must decide in the child's best interests, not necessarily as the child would decide. A substitute decision maker, in contrast, decides as the person would if they were capable.

In some jurisdictions, persons as young as 16 can make advance directives.

Next of kin, family members, or relatives are usually defined in legislation dealing with advance directives or substitute decision making as being legal or blood relatives (see spouse). Some legislation includes friends or "persons with a special interest" in the hierarchical list of substitute decision makers.

No Code is an expression used by health care providers to indicate that no action will be taken in the event of a sudden event such as heart failure. Since specific codes refer to responses to specific situations, *No Code* can pertain to one event and not another. When *No Code* refers to cardiopulmonary resuscitation, a No Code order is equivalent to a Do Not Resuscitate order.

Palliative care or hospice palliative care is care aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or who are bereaved.

Paramedics, also known as Emergency Medical Responders, are professionals trained in emergency patient care and transportation. They are normally the first responders to emergency health care calls to 911.

Patient or client-centered care is health care based on the principle of self-determination for the patient or client and respect for the patient's or client's wishes to the extent that is possible in the circumstances.

Person making the advance directive is referred to in legislation by various terms, including: adult, director (Northwest Territories), donor (New Brunswick), grantor (Ontario), maker, mandator (Quebec) or person.

Personal care may be considered to include health care and also assistance with daily living and decisions about where a person will live and with whom. It may include decisions about admission to care facilities.

Personal Directive is the legal term used in Alberta and the Northwest Territories for an advance directive, which may be either an instructional or proxy directive, or both.

Power of Attorney is a written instrument authorizing a person to act as agent on behalf of another person to the extent indicated in the instrument. The most common types of Power of Attorney are for property and financial management and, in advance care planning, for health and personal care.

Power of Attorney for Personal Care is the legal term used to designate an advance directive in the provinces of New Brunswick and Ontario. The Power of Attorney for Personal Care in both of these provinces is a proxy directive only.

Proxy is a person named in an advance directive to make health and/or personal care decisions on behalf of the maker of the advance directive when that person becomes incapable of giving informed consent; sometimes referred to as a *health care proxy*. Most jurisdictions allow for the naming of more than one proxy in an advance directive.

The following are the legal terms used to describe a proxy in Canadian jurisdictions:

- Agent: Alberta and Northwest Territories
- Attorney for Personal Care: New Brunswick and Ontario
- Guardian: Nova Scotia
- Mandatary: Quebec
- Proxy: Prince Edward Island; Manitoba; Saskatchewan; Yukon
- Representative: British Columbia
- Substitute Decision Maker: Newfoundland and Labrador.

Proxy directive is an advance directive that names a person (proxy) or persons (proxies) who will make decisions in place of the person making the advance directive if that person becomes incapable of making their own informed decisions about health and/or personal care. The proxy is obligated to be guided by any instructions or wishes made by the person while they were capable and/or by the proxy's knowledge of the person's values and beliefs.

Reciprocity is the legal recognition of an advance directive created in another jurisdiction, usually on the condition that the advance directive complies with the law in the jurisdiction where it will be used and was valid at the time and according to the laws of the jurisdiction where it was made.

Representation Agreement is the legal term used to designate an advance directive in British Columbia. The Representation Agreement is a proxy directive only.

Representative is the legal term used in British Columbia to designate a proxy named in an advance directive.

Revising or revoking an advance directive is provided for in legislation governing advance directives. The most recent version of the advance directive is considered to be authoritative. A verbal expression of more current wishes of the patient on the same issue covered by an earlier advance directive can supersede an earlier written version of the advance directive. The changing of a proxy requires a new or revised written advance directive. Alberta is the only jurisdiction that allows a person to have more than one personal directive in effect at a time, provided that the versions are not in conflict.

Spouse in legislation dealing with advance directives or substitute decision making usually means a legally married partner or one in a relationship of cohabitation or other recognized form of intimate relationship. In all jurisdictions that have legislation dealing with advance directives or substitute decision-making, a spouse cannot act as proxy or substitute decision maker after a divorce or annulment. In some jurisdictions, a legal separation disqualifies a spouse from acting as a proxy or substitute decision maker. A

former spouse, however, may qualify as a friend of the interested party under relevant legislation.

Substitute decision maker is the general term used to designate a person who is appointed to make health and/or personal care decisions on behalf of a person who is incapable of giving informed consent. A proxy is a substitute decision maker appointed in an advance directive. If there is no advance directive naming a proxy, then next of kin or other substitute decision makers (e.g. friends or health care providers) will usually be named in legislation to act in a hierarchical order, beginning with the spouse. New Brunswick, Manitoba, Alberta and Nunavut do not have a default hierarchical list of substitute decision makers provided for in legislation. In practice, next of kin would be consulted where possible.

Substitute Decision Maker is the legal term used in Newfoundland and Labrador to designate a proxy named in an advance directive.

Treatment in most legislation means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment or plan of treatment.

Wishes, preferences, values, or beliefs are recorded or communicated by a capable person with the intention of guiding a proxy or other substitute decision makers in their advocacy of what the person would have decided in the event that the person becomes incapable of informed consent with respect to treatment and/or personal care. The wishes may be recorded in an instructional directive, which has legal status in six jurisdictions (NL, PEI, MB, SK, AB, NT), or they may be expressed separately in any form: in writing, audio or videotape, in conversation with health care providers or potential substitute decision makers, or by any other means. In other provinces and the Yukon, where instructional directives are not recognized in legislation, the person's wishes must still be taken into account by proxies or other substitute decision makers and health care providers as long as the wishes are reasonable, possible and legal.

Withdrawing and withholding treatment are considered to be treatment options requiring informed consent. A physician, however, may not be obligated to offer treatment that he or she judges to be futile or non-beneficial (e.g. Cardiopulmonary resuscitation) but should discuss this with the patient or proxy, as the case may be, as part of full and informed disclosure in keeping with the principles of the Canadian Medical Association's *Code of Ethics*.⁷

Major sources for the Glossary:

- Canadian Council on Health Services Accreditation. *CCHSA's Accreditation Program Glossary*. 2006.
- Canadian Healthcare Association, Canadian Medical Association, Canadian Nurses Association and Catholic Health Association of Canada. *Joint Statement on Resuscitative Interventions (Update 1995); Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care*, 1999.

⁷ Canadian Medical Association. *CMA Code of Ethics*. 2004.

- Canadian Hospice Palliative Care Association definitions. www.chpca.net
- Canadian Medical Association. *CMA Code of Ethics (Update 2004)*.
- Canadian Nurses Association. *Joint Statement on Advance Directives*.1994; *Position Statement on End-of-Life Issues*. 2000.; *Code of Ethics for Registered Nurses*. 2002.
- Dalhousie University Health Law Institute End of Life Project Glossary and Advance Directives brochure. <http://as01.ucis.dal.ca/dhli/cmp>
- Fraser Health Authority (BC). *Advance Care Planning: Let's Talk*. Glossary.
- Interviews with key informants in the health, legal and social sectors.
- Manitoba Law Reform Commission. *Substitute Consent to Health Care*. Report #110. 2004.
- Merriam-Webster's Collegiate Dictionary, 10th edition. 2001.
- Provincial and territorial legislation and consumer guides dealing with advance directives and health care consent (see Appendix 5 - Resources)
- University of Toronto: Ian Anderson Program in End-of-Life Care. *Module 4: End-of-Life Decision-Making*. 2000.

Appendix 2: Brief overview of legislation and practice in Canadian provinces and territories:⁸

Common or similar provisions in provincial/territorial legislation

All Canadian provinces and territories have legislation dealing with advance health care directives except Nunavut, which provides for powers of attorney for property and financial matters only. There is no federal legislation dealing with advance care planning.

In jurisdictions where an instructional directive is recognized in legislation (Newfoundland and Labrador, Prince Edward Island, Manitoba, Saskatchewan, Alberta and the Northwest Territories), there is no requirement to appoint a proxy. The wishes expressed in the instructional directive must be followed where they are reasonable, possible and legal. In these jurisdictions, a person may create either an instructional directive or a proxy directive or both (often in the same document).

Most advance directives cover health and personal care, such as hygiene, nutrition and where the person will live or receive treatment. In some jurisdictions, (e.g. Ontario under a Power of Attorney for Personal Care) the maker of an advance directive can restrict the areas in which a proxy can make decisions.

Onus on maker of advance directive or proxy to bring advance directive to the attention of health care providers

In all jurisdictions, the onus for bringing the advance directive to the attention of health care providers rests largely with the maker of the advance directive, the proxy or other substitute decision maker. In some jurisdictions, the maker of an advance directive is required to inform their physician or health care system of the existence of the advance directive. In some jurisdictions (e.g. Quebec), an advance directive can be registered with provincial authorities so that it is easily located when required. Legislation varies according to jurisdiction with respect to the duty of the health care provider to become aware of a patient's advance directive.

Expression of wishes for care and treatment

In all jurisdictions, whether or not an instructional directive is recognized in legislation, the wishes of the patient which were expressed when he or she was capable must be taken into account by the proxy or other substitute decision maker and the health care provider, if these wishes are known. The wishes may be expressed in writing, orally or in any other form. Government-issued guidelines in the Yukon, for example, recommend expression of wishes in writing, orally, on audiotape, videotape or by any other means. Provincial/territorial guidelines for consumers who are developing advance health care directives usually include advice about communicating treatment wishes to proxies or other substitute decision makers and to the personal physician or other health care providers. The legislation in Newfoundland and Labrador requires makers of advance health care directives to communicate the contents of their directive to a health care

⁸ A quick reference table for terms used in provincial/territorial legislation concerning advance directives is provided at the end of this appendix. Web links to provincial/territorial legislation and to consumer guides for advance care planning are provided both at the end of this appendix and in Appendix 5: Resources.

professional. Yukon guidelines advise makers of directives to register them with the territorial health care plan and with their local hospital.

Informed consent

Canadian law presumes that persons 16 years of age and older have the capacity to consent to or refuse care. All jurisdictions recognize the right of patients to give informed consent to treatment decisions provided the patient is capable of giving such consent. In general terms, informed consent to treatment requires that the person understand the information given and appreciate the probable risks and benefits of consenting to or refusing the treatment. The option of no treatment is included as a possibility for informed consent in some legislation. Some legislation requires that alternative treatments or courses of action be explained where relevant. Treatment is usually understood to mean any examination, procedure, service or treatment done for a therapeutic, preventive, palliative, diagnostic or other health-related purpose.

Presumption of capacity

All jurisdictions presume that an adult is capable of making informed decisions, including the development of advance directives or consenting to treatment or admission or discharge from a health care facility, unless they are judged to be incapable. A general determination of capacity is usually made by a health care provider, which in many jurisdictions includes physicians, nurses social workers and psychologists. A determination of capacity to make an informed decision about a specific health care treatment is usually made by the health care professional providing the treatment. In some cases, this determination must be verified by a second health care professional. In Quebec, the determination of incapacity must be confirmed by court order before the advance directive (Mandate) can take effect.

Most legislation recognizes that capacity may vary from time to time or with respect to consent to some care and treatment options and not others. In these cases, the advance directive would govern only the areas in which the person is incapable of giving informed consent. Some legislation requires that assessments of incapacity be reviewed regularly.

If a person who has been deemed incapable of making treatment decisions is later deemed to have regained capacity, the person can then give informed consent to treatment decisions and the advance directive is not in effect unless the person is again deemed incapable.

Some jurisdictions recognize that the patient's inability to communicate, even though they may possibly be mentally capable, requires that consent to treatment be given by a proxy or other substitute decision maker.

Persons who are younger than the age of majority may be considered mature minors who are capable of giving informed consent to treatment. Each case is usually assessed according to the person and the circumstances. Mature minors usually do not make advance directives because the minimum age for making an advance directive ranges from 16 to 19, depending on the jurisdiction. If a minor is deemed incapable of giving consent to treatment, the parent or guardian is their surrogate decision maker.

Guidance in decision making

Most legislation includes guidelines for decision making by proxies or other substitute decision makers and health care providers, whether or not instructional directives are recognized in that province or territory. These apply when the patient is deemed incapable of giving informed consent.

The usual guidelines in legislation for decision-making by proxies or other substitute decision makers and health care providers are:

- Follow the patient's instructions in an advance directive or other document or form of record. The most recent version of the patient's wishes must be followed. If verbal wishes have been expressed more recently than the written instructions, the more recent verbal wishes prevail.
- If there are no known instructions, the decision must be guided by knowledge of the patient's values, principles or beliefs. This information can be inferred from knowledge of their life, actions and statements.
- If there is no way of knowing what the patient's values, principles or beliefs are, the decision is guided by the best interests of the patient, taking into consideration:
 - the extent to which the proposed treatment or no treatment would cause the patient's condition to improve, or prevent or reduce deterioration of the patient's condition.
 - consideration of the risks and benefits of treatment or no treatment
 - whether a less intrusive treatment would be as beneficial as the proposed treatment.

Multiple proxies

All jurisdictions (except New Brunswick, which does not specify this in legislation) allow for the naming of more than one proxy in a proxy advance directive.

Provincial/territorial legislation usually allows the maker of the advance directive to choose how the proxies will act, either jointly or separately, how agreement will be reached among the proxies and how decisions will be reached when the proxies cannot agree.

If the maker of the advance directive does not specify how the proxies should act, legislation usually provides a process for acting and for dispute resolution. Since the legal process for dispute resolution may not correspond to the maker's wishes, it is important for persons to consider including some guidance in their advance directive about the roles of multiple proxies and dispute resolution.

Substitute decision makers

The term *substitute decision maker* includes proxies and other persons who may be asked to give consent to treatment when a patient is deemed incapable. In Newfoundland and Labrador, the term *Substitute Decision Maker* is used to indicate a proxy in the legislation governing advance directives. The other jurisdictions use a variety of terms to indicate the proxy named in the advance directive: *Agent* (Alberta and Northwest Territories), *Attorney for Personal Care* (New Brunswick and Ontario); *Guardian* (Nova Scotia); *Mandatary* (Quebec); *Proxy* (Prince Edward Island, Manitoba, Saskatchewan and Yukon); and *Representative* (British Columbia). When there is no advance directive, health care providers will ask next of kin to act as substitute decision makers.

In most legislation, substitute decision makers are named in a hierarchical list in the order in which they would be asked to give substitute consent to treatment. The list usually includes:

- legal guardian or some other court-appointed tutor or trustee
- proxy named in an advance directive

- Next of kin:⁹
 - spouse (usually unless separated or divorced; *spouse* in most jurisdictions includes those legally married, co-habiting or in a recognized intimate relationship who may not be legally married)
 - adult children
 - parents
 - other relatives
 - friend
 - person who shows a special interest in the mandator (Quebec)
- If there are no next of kin:
 - health care provider (Newfoundland and Labrador; Yukon)
 - health care provider may provide treatment (Saskatchewan)
 - the relevant provincial/territorial body or official may make decisions or appoint someone to make decisions.

Emergency health care

Most jurisdictions allow for treatment decisions to be made by health care providers in emergency situations if the patient is not capable of giving consent. In these cases, where time is of the essence and a quick decision must be made by the health care provider, there is no requirement for the advance directive to be consulted or followed. If an advance directive exists, if the health care provider is aware of it and if the wishes expressed in it are clear and legal (e.g. a request that no resuscitation be performed in the event of heart or lung failure), then the health care provider may follow the wishes in the advance directive in an emergency situation.

Paramedic personnel and calls to 911¹⁰

The situation with respect to resuscitation after emergency calls from home or long-term care facilities to 911 involving the services of paramedic personnel varies somewhat according to the jurisdiction involved. In the absence of appropriate documentation, paramedic personnel are legally obligated to attempt resuscitation. Appropriate documentation would consist of a Do Not Resuscitate order signed by a physician which must be shown to paramedic personnel or, in jurisdictions where an instructional directive is recognized, a valid copy of the instructional directive stating that the patient does not wish resuscitation. A Do Not Resuscitate order can be a standing order and does not have to be rewritten each time a call is placed to 911.

In the absence of appropriate documentation, paramedic personnel must start resuscitation efforts based on the presentation of the patient. If resuscitation efforts have no effect, paramedic personnel will call the physician to request the right to discontinue resuscitation.

Contrary to the belief of some key informants, a body does not necessarily have to be transported to hospital in order for death to be certified. A coroner or their agent (sometimes a police officer) can certify death in the home or long-term care facility.

⁹ New Brunswick, Manitoba, Alberta and Nunavut do not have a default hierarchical list of substitute decision makers in legislation. In practice, next of kin would be consulted where possible. Source: Manitoba Law Reform Commission. *Substitute Consent to Health Care*. Report #110. 2004.

¹⁰ Source of information: Paramedic Association of Canada

Paramedic personnel will usually call the coroner and wait with the body until the coroner or the coroner's agent arrives.

Given the statement by some informants that physicians sometimes advise against calling 911 if the patient does not wish resuscitation, this situation needs further study and clarification.

Conflict of interest: witnesses

In order to avoid conflict of interest and potential abuse of power, most jurisdictions exclude as witnesses to an advance directive any proxy named in the advance directive or their spouse. Some jurisdictions also exclude as witnesses the child or parent of anyone named in the advance directive, the employee or agent of anyone named in the directive, anyone under legal age or anyone unable to understand the type of communication used by the person making the advance directive.

Revising or revoking an advance directive

All jurisdictions with advance directive legislation have provisions in their legislation for a capable adult to revise or revoke an advance directive. The most recently dated advance directive is valid and makers of advance directives are usually advised to recall and destroy copies of previous advance directives. Alberta is the only province that allows a person to have more than one advance directive at a time; in this case, the different versions of the advance directive must deal with different matters and cannot be contradictory. (e.g. A person may want to change their proxy (Agent) without rewriting the instructional portion of their personal directive. In this case they would have two personal directives.)

Protection from liability

All jurisdictions with advance directive legislation except Nova Scotia, New Brunswick and Quebec include in the legislation protection from liability for health care providers and substitute decision makers for actions taken (or not taken) with respect to treatment decisions as long as actions were taken in good faith and in accordance with the law. British Columbia does not offer protection from liability to health care providers under the *Representation Agreement Act*, but does under the *Health Care (Consent) and Care Facility (Admission) Act*. Protection from liability in provincial/territorial legislation covers civil matters which are within provincial/territorial jurisdiction. Criminal matters are governed by the Criminal Code of Canada, which does not contain specific protection from liability for health care providers or substitute decision makers who are acting according to advance directives.

No standard form

Most jurisdictions offer a standard form for making an advance directive but this form does not have to be used as long as the advance directive conforms to the law. Most provide consumer-friendly guides online. The services of a lawyer may be required in New Brunswick because of the requirement that a power of attorney for personal care be created under seal. In Quebec, a notary or lawyer is usually required to create and register a mandate. A Section 9 Representation Agreement in British Columbia must be witnessed by a lawyer who must also complete a certificate (Section 9 refers to the relevant section in the British Columbia *Representation Agreement Act*).

Quick reference: Terms used in provincial/territorial legislation

Jurisdiction	Type of advance directive provided for in legislation	Instructional directive	Proxy directive	Proxy
Newfoundland and Labrador	Instructional and proxy	Advance Health Care Directive	Advance Health Care Directive	Substitute decision maker
Nova Scotia	Proxy directive	-----	Authorization	Guardian
Prince Edward Island	Instructional and proxy	Advance Health Care Directive	Advance Health Care Directive	Proxy
New Brunswick	Proxy directive	-----	Power of Attorney for Personal Care	Attorney for personal care
Quebec	Proxy directive	-----	Mandate	Mandatar [the maker of a Mandate is called the Mandator]
Ontario	Proxy directive	-----	Power of Attorney for Personal Care	Attorney for personal care
Manitoba	Instructional and proxy	Health Care Directive	Health Care Directive	Proxy
Saskatchewan	Instructional and proxy	Health Care Directive	Health Care Directive	Proxy
Alberta	Instructional and proxy	Personal Directive	Personal Directive	Agent
British Columbia	Proxy directive	-----	Representation Agreement	Representative
Yukon	Proxy directive	-----	Advance Directive	Proxy
Northwest Territories	Instructional and proxy	Personal directive	Personal directive	Agent

Web links: provincial and territorial legislation and consumer guides to advance care planning:

Alberta:

- *Personal Directives Act*, 2000 and Regulation: www.canlii.org/ab/laws/sta/p-6/20060310/whole.html
- Consumer guide: Government of Alberta, Seniors and Community Supports; Office of the Public Guardian.: *Understanding Personal Directives*: 2005: www.seniors.gov.ab.ca/services_resources/opg/persdir/publications/pdf/ISB_N0778533158.pdf

British Columbia:

- *Representation Agreement Act*, 1996: www.qp.gov.bc.ca/statreg/stat/R/96405_01.htm
- Supplement to *Representation Agreement Act*: www.qp.gov.bc.ca/statreg/stat/sup/sup40500.htm
- Representation Agreement Regulation, 2001: <http://www.qp.gov.bc.ca/statreg/stat/sup/sup40500.htm>
- *Health Care (Consent) and Care Facility (Admission) Act*, 1996: www.qp.gov.bc.ca/statreg/stat/H/96181_01.htm#section1
- Health Care Consent Regulation, 2000: www.qp.gov.bc.ca/statreg/reg/H/20_2000.htm
- Consumer guide: Government of British Columbia, Ministry of Health and Ministry Responsible for Seniors. *A Primer to British Columbia's New Health Care Consent Legislation*. 2000: www.healthservices.gov.bc.ca/cpa/publications/hc-primer.pdf
- Public Guardian and Trustee of British Columbia. *B.C's Adult Guardianship Laws: Supporting Self-Determination for Adults in British Columbia*. 2005: www.trustee.bc.ca/pdfs/STA/Consent_Health_Care_March_2005.pdf
- Representation Agreement Resource Centre. www.rarc.ca

Manitoba:

- *The Health Care Directives Act*, 1992: <http://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php>
- Consumer guide and forms: www.gov.mb.ca/health/livingwill.html
- Manitoba Law Reform Commission. *Substitute Consent to Health Care*. Report #110. 2004. www.gov.mb.ca/justice/mlrc/reports/110.pdf

New Brunswick:

- *Infirm Persons Act*, amended in 2000 (sections 40-44): <http://www.gnb.ca/0062/acts/acts/i-08.htm>
- Consumer guide: www.legal-info-legale.nb.ca/showpub.asp?id=35&langid=1#poa%20for%20personal%20care

Newfoundland and Labrador:

- *An Act Respecting Advance Health Care Directives and the Appointment of Substitute Health Care Decision Makers*, 1995. www.hoa.gov.nl.ca/hoa/chapters/1995/A04-1.c95.htm
- Consumer information: www.publiclegalinfo.com/publications/living_will.html

Northwest Territories:

- *Personal Directives Act*, 2005:
www.canlii.org/nt/laws/sta/2005c.16/20060718/whole.html
- Consumer guides:
 - Northwest Territories Health and Social Services:
www.hlthss.gov.nt.ca/content/Publications/pubresult.asp?ID=61
 - *Personal Directives: Choosing Now for the Future*:
 - *Examples of Personal Directives*
 - Audio explanation of Personal Directives

Nova Scotia:

- *Medical Consent Act*, 1999:
www.gov.ns.ca/legislature/legc/statutes/medcons.htm
- *Hospitals Act*, 1989:
www.canlii.org/ns/laws/sta/r1989c.208/20060310/whole.html

Nunavut:

- *Powers of Attorney Act*, 2005: http://action.attavik.ca/home/justice-gn/attach-en_sourcelaw/e2005snc91.pdf

Ontario:

- *Substitute Decisions Act*, 1992 and Regulations:
www.canlii.org/on/laws/sta/1992c.30/20060314/whole.html
- *Health Care Consent Act*, 1996 and Regulations:
www.canlii.org/on/laws/sta/1996c.2sch.a/index.html
- Consumer guides:
 - Government of Ontario. *A Guide to Advance Care Planning*.
www.citizenship.gov.on.ca/seniors/english/advancecareguide.pdf
 - Government of Ontario, Ministry of the Attorney General. Power of Attorney Kit:
www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp

Prince Edward Island:

- *Consent to Treatment and Health Care Directives Act*, 1996:
www.gov.pe.ca/law/statutes/pdf/c-17_2.pdf

Quebec:

- *Civil Code* of Quebec, 1991 (Articles 10-25; 2166-2185):
www.canlii.org/qc/laws/sta/ccq/20060310/whole.html
- *An Act Respecting Health Services and Social Services* (2003) R.S.Q.D-4.2:
www.canlii.org/qc/laws/sta/s-4.2/20060310/whole.html
- Consumer guide: Government of Quebec, Curateur public du Québec. 2006. *My Mandate in Case of Incapacity*. Available at:
www.curateur.gouv.qc.ca/cura/publications/mandatE.pdf

Saskatchewan:

- *The Health Care Directives and Substitute Health Care Decision Makers Act*, 1997: www.qp.gov.sk.ca/documents/English/Statutes/Statutes/H0-001.pdf
- Consumer guides:
 - Government of Saskatchewan:
www.saskjustice.gov.sk.ca/learning_centre/healthdirectives.shtml

- Public Legal Education Association of Saskatchewan:
www.plea.org/freepubs/hcd/health.htm

Yukon:

- *Care Consent Act, 2003 and Regulations:*
www.hss.gov.yk.ca/programs/decision_making/care_consent_act
- Consumer guides, Government of Yukon:
 - *Planning for Your Future Healthcare Choices: Advance Directives in the Yukon (20-page booklet):*
www.hss.gov.yk.ca/downloads/adv_directive_booklet.pdf
 - *Planning for Your Future Healthcare Choices: Advance Directives in the Yukon (brochure):*
http://199.247.156.231/downloads/adv_directive_brochure.pdf
 - *Making a Health Care Decision for a Loved One: The Role of a Substitute Decision-Maker:*
www.hss.gov.yk.ca/downloads/substitute_dm_brochure.pdf
 - *Notes for Completing An Advance Directive (includes forms):*
www.hss.gov.yk.ca/downloads/adv_directive_form.pdf

Appendix 3: Key informants interviewed

1. Janet Arnold, Project Leader for the Calgary Health Region for the Respecting Choices® advance care planning initiative (AB).
2. Sharon Baxter, Executive Director, Canadian Hospice Palliative Care Association
3. Jeff Blackmer, Executive Director, Office of Ethics, Canadian Medical Association
4. Carmelina Cimaglia, Psychogeriatric Resource Consultant, Royal Ottawa Hospital (ON)
5. Judy Cutler, Co-Director of Government and Media Relations, Canadian Association of Retired Persons
6. Dorothy Dawson, nurse and Board member, Saint John Regional Hospital (NB)
7. Richard Elliott, Deputy Director, Canadian HIV/AIDS Legal Network (e-mail exchange)
8. Louis-Marie Gagnon, Executive Director, Maison Plein Coeur, Montreal (QC)
9. Leslie Gaudette, family caregiver and member of Surveillance Working Group, Canadian Strategy on Palliative and End-of-Life Care (BC)
10. Thomas Gibson, family caregiver (ON)
11. Bill Gleberon, Co-Director of Government and Media Relations, Canadian Association of Retired Persons
12. Susan Graham-Walker, Executive Director, ALS Society of Ontario
13. Sue Grant, Project Leader, Advance Care Planning, Fraser Health Authority (BC)
14. Karen Henderson, Founder and President, Caregiver Network (ON)
15. Marion Hall, Director, ALS Society of Ottawa-Carleton (ON)
16. Nora Hammell, Director of Nursing Policy, Canadian Nurses Association
17. Laura Hawryluck, Physician Leader, Ian Anderson Continuing Education Program in End-of-Life Care, Toronto (ON)
18. David Henderson, palliative care physician, Colchester East Hants Hospice Palliative Care Program (NS)
19. Sandy Johnson, Executive Director, Hospice Saint John and Sussex (NB)
20. Sylvia Jurgutis, Renal Social Worker, Ottawa Hospital (ON)
21. Suzanne Kendall, family caregiver, BC
22. Nuala Kenny, Professor, Departments of Bioethics and Pediatrics, Dalhousie University, Halifax (NS) [the consultant attended two of Dr. Kenny's workshops on advance care planning during the course of research for this report]
23. Heather Lambert, Occupational Therapist, Centre for Health Services and Policy Research, Queen's University, Kingston (ON)
24. Joan Lesmond, Chief Operating Officer and Director of Professional Practice, Casey House Hospice, Toronto (ON)
25. Linda Lysne, Executive Director, Canadian Caregiver Coalition
26. Joan MacDonald, National Clinical Consultant, VON Canada
27. Karen McEwen, Director of Professional Practice, Policy and Education, Pembroke Regional Hospital (ON)
28. Beverlee McIntosh, Social Worker, Ottawa Rehabilitation Centre, ALS (ON)

29. Sylvia McNeil, family caregiver (BC) -by e-mail
30. Ken Monteith, lawyer and Executive Director, AIDS Community Care Montreal (QC)
31. Cathy Mosher, Nephrology social worker, QEII Hospital, Halifax (NS)
32. Paul Muirhead, lawyer, Williams McEnergy, Ottawa (ON)
33. Filomena Nalewajek, Executive Director, Canuck Place Children's Hospice, Vancouver (BC)
34. Barbara O'Connor, Executive Director, The Hospice at Maycourt, Ottawa (ON)
35. Marie-Josée Paquin, Provincial Coordinator, Hospice Palliative Care Network and Project Manager, Medical Affairs and Community Oncology, Alberta Cancer Board (AB)
36. Pierre Poirier, Executive Director, Paramedic Association of Canada
37. Anita Pudlik, renal social worker, Credit Valley Hospital, Mississauga (ON)
38. Shirley Pulkkinen, Renal social worker, Sault Area Hospital, Sault Ste Marie (ON)
39. Michele Rigby, Social worker, Colchester East Hants Hospice Palliative Care Program (NS)
40. Monique Rigole, Personal Directives specialist, Government of Alberta (AB)
41. Esther Roberts, family caregiver (ON)
42. Jerry Rothstein, Chair, Task Group on Volunteer Best Practices and Quality (preliminary discussion about volunteer role)
43. Maria Rugg, Clinical Nurse Specialist, Palliative and Bereavement Care Program, Hospital for Sick Children, Toronto (ON)
44. Joan Rush, lawyer, Vancouver (BC)
45. Bonnie Schroeder, Project Manager, National Programs, VON Canada
46. Lily Shatsky, Chair, Clinical Ethics Committee and Board member, Maimonides Hospital Geriatric Centre, Montreal (QC)
47. Cathy Simpson, healthcare chaplain, Halifax (NS)
48. Cheryl Smith, Palliative Care Coordinator, North Eastman Regional Health Authority (MB)
49. Ann Soden, Lawyer, National Elder Law Section, Canadian Bar Association (overview discussion)
50. Lorraine St Martin, Vancouver General Hospital, CKD Clinic (BC)
51. Sarah Taber, Specialist, Canadian Council on Health Services Accreditation
52. Judith Wahl, lawyer and Executive Director, Advocacy Centre for the Elderly, Toronto (ON)
53. Linda Watts, Supervisor, renal social work, Sault Ste Marie Hospital (ON)
54. Bev Weeks, Board member, Canadian Association for Community Care; Director, Harvey Outreach for Seniors Incorporated (NB)
55. Rhonda Wiebe, Researcher, Vulnerable Persons New Emerging Team, and Representative, Council of Canadians with Disabilities (MB)
56. Bonnie Wood, Patient and Family Counsellor, Royal Columbian Hospital, New Westminster (BC)

Appendix 4: Questionnaire for key informant interviews

1. There is often confusion about the terminology used in advance care planning. In your experience, what you understand these terms to mean:

- a. Advance care planning
- b. Advance directive
- c. Living will (Testament biologique in Quebec)
- d. Substitute decision-maker or proxy
- e. Power of attorney for personal (or health) care
- f. Competence/incompetence or capacity/incapacity (i.e. to give consent to treatment)

2. What terminology do you use most often?

3. Does confusing terminology create barriers to effective advance care planning? How? Can you give examples?

4. More generally, in your experience what are the challenges that care providers and consumers (clients, patients, families) face with respect to advance care planning?

5. What successful experiences with advance care planning can you tell me about?

6. To your knowledge, how often does the treatment or care actually received correspond to:

- the patient's wishes?
- the family's wishes?
- the health care providers' professional judgement?
- the needs of the health care facility?

7. What other important points do you wish to raise that the questions may not have covered?

8. Who else would you recommend to be a key informant?

Appendix 5: Resources

1. Advocacy Centre for the Elderly. www.advocacycentreelderly.org.
2. ALS Society of Canada. *A Guide to ALS Patient Care for Primary Care Physicians*. CD available from the ALS Society of Canada at www.als.ca.
3. Ashpole, Barry and Associates Inc. *Advance Care Planning – An Environmental Scan*. Prepared for the Secretariat on Palliative and End-of-Life Care, Health Canada. 2005.
4. Canadian Broadcasting Corporation. *Living Wills: FAQs*. 2005: www.cbc.ca/news/background/wills/
5. Canadian Council on Health Services Accreditation. CCHSA's Accreditation Program: *Glossary and Hospice Palliative and End-of-Life Care Standards*. 2006. www.cchsa.ca
6. Canadian Healthcare Association, Canadian Medical Association, Canadian Nurses Association and Catholic Health Association of Canada.
 - a. *Joint Statement on Preventing and Resolving Ethical Conflicts Involving Health Care Providers and Persons Receiving Care*. 1999. www.cma.ca
 - a. *Joint Statement on Resuscitative Interventions (Update 1995)* www.cma.ca
7. Canadian Hospice Palliative Care Association:
 - a. News releases and fact sheets for National Hospice Palliative Care Week. Issued May 6, 2006. www.chpca.net/events/nhpc_week/2006/nhpcw_resources.htm
 - b. Definition of hospice palliative care: www.chpca.net/menu_items/faqs.htm#faq_def
8. Canadian Medical Association. *CMA Code of Ethics*. 2004. <http://policybase.cma.ca/PolicyPDF/PD04-06.pdf>
9. Canadian Nurses Association. www.cna-aicc.ca
 - a. Policy Statement: Joint Statement on Advance Directives. 1994.
 - b. Position Statement: End-of-Life Issues. 2000.
 - c. Position Statement: *Code of Ethics for Registered Nurses*. 2002.
10. Chambers-Evans J and Carnevale FA. The Dawning of Awareness: The Experience of Surrogate Decision Making at the End of Life. *Journal of Clinical Ethics* 2005; 16 (1): 28-45.
11. Dalhousie University Health Law Institute – End-of-Life Project Advance Directives resources. http://as01.ucis.dal.ca/dhli/cmp_advdirectives
12. Fraser Health Authority (BC):
 - a. *Let's Talk*. Resources for advance care planning. 2006. www.fraserhealth.ca/healthinfo/advancecareplanning
 - b. *Adult Guardianship and Personal Planning Instruments Legislative Review*. Brief submitted to the British Columbia Ministry of the Attorney General. 2006.
13. Gunderson Lutheran Medical Centre, La Crosse, Wisconsin, USA. Resources for the Respecting Choices® advance care planning program: www.gundluth.org/eolprograms

14. Health Canada. Canadian Strategy on Palliative and End-of-Life Care. Reports of the March 2005 and March 2006 Advance care planning Forums.
15. Heyland, DK et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* February 28, 2006; 174(5): .
16. Ipsos-Reid. 2003. Telephone survey conducted for the Canadian Hospice Palliative Care Association and GlaxoSmithKline Inc.
17. Lambert, HC et al. *Advance Directive Use in Ontario Long-Term Care Facilities: A Policy Study*. Centre for Health Services and Policy Research, Queen's University. Poster presentation. 2005.
18. Ottawa Hospital (Ontario) Nephrology Advance Directives Work Group. *Guide: Advance Care Planning*. 2005.
19. Paramedic Association of Canada. www.paramedic.ca
20. Rush, Joan R. *Stillborn Autonomy: Why the Representation Agreement Act of British Columbia Fails as Advance Directive Legislation*. Unpublished thesis for Master of Laws Degree, University of British Columbia. 2005. 262 pages.
21. Statistics Canada. *Population Projections for Canada, Provinces and Territories –2000-2006*. Catalogue #91-520, page 124
22. University of Manitoba Department of Continuing Medical Education. *Rural Physician's Orientation Guide for Practice in Manitoba*. 4th edition, 2005: www.ornh.mb.ca/docs/RPGuide_4thedition.pdf
23. University of Toronto. Ian Anderson Program in End-of-Life Care. *Module 4: End-of-Life Decision-Making*. 2000. www.cme.utoronto.ca/endoflife/Modules/End-of-Life%20Decision-Making%20Module.pdf
24. University of Toronto Joint Centre for Bioethics. Living Will: www.utoronto.ca/jcb/outreach/living_wills.htm
25. Yarborough M. Deciding for Others at the End of Life: Storytelling and Moral Agency. *Journal of Clinical Ethics* 2006; 16 (2): 127-143.

26. Provincial and territorial resources:

Alberta:

- *Personal Directives Act*, 2000 and Regulation: www.canlii.org/ab/laws/sta/p-6/20060310/whole.html
- Consumer guide: Government of Alberta, Seniors and Community Supports; Office of the Public Guardian.: *Understanding Personal Directives*: 2005: www.seniors.gov.ab.ca/services_resources/opg/persdir/publications/pdf/ISB N0778533158.pdf

British Columbia:

- *Representation Agreement Act*, 1996: www.qp.gov.bc.ca/statreg/stat/R/96405_01.htm
- Supplement to *Representation Agreement Act*: www.qp.gov.bc.ca/statreg/stat/sup/sup40500.htm
- *Representation Agreement Regulation*, 2001: <http://www.qp.gov.bc.ca/statreg/stat/sup/sup40500.htm>
- *Health Care (Consent) and Care Facility (Admission) Act*, 1996: www.qp.gov.bc.ca/statreg/stat/H/96181_01.htm#section1

- Health Care Consent Regulation, 2000: www.qp.gov.bc.ca/statreg/reg/H/20_2000.htm
- Consumer guide: Government of British Columbia, Ministry of Health and Ministry Responsible for Seniors. *A Primer to British Columbia's New Health Care Consent Legislation*. 2000: www.healthservices.gov.bc.ca/cpa/publications/hc-primer.pdf
- Public Guardian and Trustee of British Columbia. *B.C's Adult Guardianship Laws: Supporting Self-Determination for Adults in British Columbia*. 2005: www.trustee.bc.ca/pdfs/STA/Consent_Health_Care_March_2005.pdf
- Representation Agreement Resource Centre. www.rarc.ca

Manitoba:

- *The Health Care Directives Act*, 1992: <http://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php>
- Consumer guide and forms: www.gov.mb.ca/health/livingwill.html
- Manitoba Law Reform Commission. *Substitute Consent to Health Care*. Report #110. 2004. www.gov.mb.ca/justice/mlrc/reports/110.pdf

New Brunswick:

- *Infirm Persons Act*, amended in 2000 (sections 40-44): <http://www.gnb.ca/0062/acts/acts/i-08.htm>
- Consumer guide: www.legal-info- legale.nb.ca/showpub.asp?id=35&langid=1#poa%20for%20personal%20care

Newfoundland and Labrador:

- *An Act Respecting Advance Health Care Directives and the Appointment of Substitute Health Care Decision Makers*, 1995. www.hoa.gov.nl.ca/hoa/chapters/1995/A04-1.c95.htm
- Consumer information: www.publiclegalinfo.com/publications/living_will.html

Northwest Territories:

- *Personal Directives Act*. 2005: www.canlii.org/nt/laws/sta/2005c.16/20060718/whole.html
- Consumer guides:
 - Northwest Territories Health and Social Services: www.hlthss.gov.nt.ca/content/Publications/pubresult.asp?ID=61
 - *Personal Directives: Choosing Now for the Future*:
 - *Examples of Personal Directives*
 - Audio explanation of Personal Directives

Nova Scotia:

- *Medical Consent Act*, 1999: www.gov.ns.ca/legislature/legc/statutes/medcons.htm
- *Hospitals Act*, 1989: www.canlii.org/ns/laws/sta/r1989c.208/20060310/whole.html

Nunavut:

- *Powers of Attorney Act*. 2005: http://action.attavik.ca/home/justice-gn/attach-en_sourcelaw/e2005snc91.pdf

Ontario:

- *Substitute Decisions Act*, 1992 and Regulations:
www.canlii.org/on/laws/sta/1992c.30/20060314/whole.html
- *Health Care Consent Act*, 1996 and Regulations:
www.canlii.org/on/laws/sta/1996c.2sch.a/index.html
- Consumer guides:
 - Government of Ontario. *A Guide to Advance Care Planning*.
www.citizenship.gov.on.ca/seniors/english/advancecareguide.pdf
 - Government of Ontario, Ministry of the Attorney General. Power of Attorney Kit:
www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp

Prince Edward Island:

- *Consent to Treatment and Health Care Directives Act*, 1996:
www.gov.pe.ca/law/statutes/pdf/c-17_2.pdf

Quebec:

- *Civil Code* of Quebec, 1991 (Articles 10-25; 2166-2185):
www.canlii.org/qc/laws/sta/ccq/20060310/whole.html
- *An Act Respecting Health Services and Social Services* (2003) R.S.Q.D-4.2:
www.canlii.org/qc/laws/sta/s-4.2/20060310/whole.html
- Consumer guide: Government of Quebec, Curateur public du Québec. 2006. *My Mandate in Case of Incapacity*. Available at:
www.curateur.gouv.qc.ca/cura/publications/mandatE.pdf

Saskatchewan:

- *The Health Care Directives and Substitute Health Care Decision Makers Act*, 1997: www.qp.gov.sk.ca/documents/English/Statutes/Statutes/H0-001.pdf
- Consumer guides:
 - Government of Saskatchewan:
www.saskjustice.gov.sk.ca/learning_centre/healthdirectives.shtml
 - Public Legal Education Association of Saskatchewan:
www.plea.org/freepubs/hcd/health.htm

Yukon:

- *Care Consent Act*, 2003 and Regulations:
www.hss.gov.yk.ca/programs/decision_making/care_consent_act
- Consumer guides, Government of Yukon:
 - *Planning for Your Future Healthcare Choices: Advance Directives in the Yukon* (20-page booklet):
www.hss.gov.yk.ca/downloads/adv_directive_booklet.pdf
 - *Planning for Your Future Healthcare Choices: Advance Directives in the Yukon* (brochure):
http://199.247.156.231/downloads/adv_directive_brochure.pdf
 - *Making a Health Care Decision for a Loved One: The Role of a Substitute Decision-Maker*:
www.hss.gov.yk.ca/downloads/substitute_dm_brochure.pdf
 - *Notes for Completing An Advance Directive* (includes forms):
www.hss.gov.yk.ca/downloads/adv_directive_form.pdf