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• Consultant: Janet Dunbrack

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Executive Summary

This Guide is intended to support health authorities in Canada in the development of advance care planning initiatives. The former Calgary Health Region (now Alberta Health Services) and Fraser Health Authority led the development of the Guide with financial support from Health Canada. The two health authorities wish to share the knowledge they have gained in order to help others develop or enhance their own advance care planning initiatives. The Guide is intended to provide information that can be useful to most health authorities and yet is flexible enough to be adapted to the unique circumstances of each one.

Four building blocks

The Guide proposes a model that features the patient and family at its centre, and is composed of the following four basic building blocks:

- Engagement: Organizational and Community
- Education
- System Infrastructure
- Continuous Quality Improvement

The blocks are interconnected and are best developed concurrently. In this Guide, each block is described and illustrated with concrete examples and challenges drawn mainly from the experiences of Calgary Health Region and Fraser Health Authority.

Organizational engagement consists of the support and involvement of senior management, health care providers and other health authority staff. The case for support can be built by demonstrating how the advance care planning initiative aligns with and supports existing organizational policies and priorities, and how it can improve patient care in a number of ways. Levers include provincial/territorial policy and regulatory frameworks, accreditation, and a variety of health and social service frameworks (e.g., chronic disease management, interprofessional practice, patient safety). Developing and implementing an advance care planning initiative requires both human and financial resources, as well as time. Community engagement involves reaching out to the public to engage capable adults and their families in advance care planning by raising awareness, initiating dialogue and connecting people to the mechanisms and organizations involved in advance care planning. An important means of engaging the community is through outreach to faith-based groups, seniors’ organizations and cultural communities. Advance care planning provides a process that supports diversity and inquires about values and goals of individuals from all cultural backgrounds. Experience shows that advance care planning models can be successfully adapted by and for diverse cultural communities.
**Education** involves a variety of mechanisms, such as: engaging, training and supporting health care providers to facilitate advance care planning conversations and processes as part of their core skill set; providing information resources and tools (workbooks, brochures and web-based resources, etc.) for the public and health care providers; and providing tools for recording decisions about care wishes. Advance care planning is best introduced as an interprofessional practice involving all members of the care team. Education, training and support for the entire care team are essential.

**System infrastructure** in support of advance care planning involves a variety of mechanisms to ensure that health care providers are aware of a patient’s care preferences in the various care settings throughout a health authority. These mechanisms can include: patient ownership of their advance care planning documents; highly visible documents in health care charts or in the home; mechanisms for ensuring that care wishes follow the patient through a variety of health care settings; electronic health care records; and consistent goals of care designations throughout the health care facility or region.

**Continuous quality improvement** is best integrated into advance care planning right from the start. The elements of continuous quality improvement include: a corporate culture that promotes quality improvement as a key component of evidence-based practice; development and testing of measurement and evaluation tools; development of performance indicators; mechanisms for sharing what is learned from evaluation; and ongoing incorporation of evaluation results into practice. A quality improvement specialist can be a valuable member of the advance care planning team. Pilot projects also help to improve and strengthen programs. Both Calgary Health Region and Fraser Health Authority used pilot projects to test and improve approaches and to build support within the system and among health care providers for integrating advance care planning into their practice.

**A broad-based approach**

The advance care planning model, with its four interdependent building blocks, links to the policy, regulatory and resource environments in which it functions, resulting in a comprehensive and sustainable approach to advance care planning.

For those interested in additional information, a Resources section at the end of the Guide provides links to advance care planning resources from Calgary Health Region and Fraser Health Authority, as well as to other pathways for further learning.
Introduction

This Guide has been written for health authorities in Canada to support the development of advance care planning (ACP) policies and programs. It is intended to provide general guidance only and would need to be tailored by individual health authorities to their particular situation. Central to the Guide is a model designed to be adapted to the circumstances of each facility or region. For example, the model can be used to inform both individual health care facilities and broader health care systems.

The model is based on the experience of several programs in Canada, Australia and the United States, with a primary focus on Canadian approaches. It is composed of four interdependent building blocks and is situated within a policy and resource context. Linkages to organizational and jurisdictional policies and regulatory frameworks are included in the model, as are ways to link advance care planning to a variety of existing approaches and programs, such as chronic disease management and seniors’ programs.

Each building block is described in terms of concrete examples drawn primarily from the experiences of the former Calgary Health Region (now Alberta Health Services) and Fraser Health Authority (British Columbia). Both are often called upon by other health authorities and provincial/territorial governments to provide advice about the establishment of advance care planning policies and programs.

What Is Advance Care Planning?

Various definitions of advance care planning are in use. All emphasize the elements of reflection, choice and communication. The following definitions may be helpful.

Health Canada’s Glossary Project:
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.

Calgary Health Region:
Advance care planning is a process by which people can: think about their values regarding future healthcare choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their representatives and their healthcare team; and record their choices for healthcare as guidance in the event that they can no longer speak for themselves.
Advance care planning is a process of coming to understand, reflect on, discuss and plan for a time when you cannot communicate and make your own medical decisions. Effective planning is the best way to make sure your views are respected by your loved ones and health providers. This process also will provide great comfort to those who may make end-of-life decisions for you.

Other terms commonly used in advance care planning are defined in the Glossary Project paper (www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/index_e.html).

Other considerations in defining advance care planning
While in some jurisdictions and in exceptional circumstances, persons below the age of majority may be judged sufficiently mature to engage in advance care planning, this Guide deals only with the case of capable adults and does not look into pediatric ACP. It should also be noted that care wishes expressed by individuals may include choices for care they wish to receive and/or the enduring refusal of types of care or interventions that they do not wish to receive.

Advance care planning is not limited to the preparation of a legal advance directive, although it may include this. Some individuals may feel satisfied after they have engaged in a process of communication and reflection and have shared their care wishes with those close to them and/or with their health care providers. Others may wish to prepare a legal advance directive naming a proxy (someone who decides for the patient if he or she has been deemed to be no longer capable of giving informed consent to treatment). In some Canadian jurisdictions, it is possible to include as part of a legal advance directive a documentation of care wishes without naming a proxy (i.e., an instructional directive). In all Canadian jurisdictions, the care wishes of the patient must be taken into consideration if they are known, regardless of whether the patient has prepared a legal advance directive or not.

Some common misconceptions
Advance care planning is a process of communication which assists patients and families in clarifying wishes for care in the event that the patient becomes incapable of giving informed consent to care. It helps provide clear guidance for health care providers in becoming aware of patient preferences. A common misconception about advance care planning is that it is equivalent to a “Do Not Resuscitate” order. In fact, the expression of wishes may include the wish to be kept alive by life support systems for a defined period (e.g., until a child arrives to say goodbye) or indefinitely. Wishes can include a range of personal preferences, such as the type of music the person wants to have played in their room or a favourite quilt that they want on their bed.

Another common misconception is that advance care planning is only for the very old or the very ill. In fact, ACP is for all capable adults. Advance care planning conversations can occur at different life stages and are best initiated prior to a health crisis by skilled health care providers who have developed relationships with individuals and their support networks. Conversations can take place with those who are healthy, those living with a chronic condition or disease, or those approaching the end of life. Healthy young adults may be involved in accidents or suffer sudden illness and may be temporarily or permanently incapable of giving informed consent to care. The expression of their wishes in advance can provide guidance to their family and health care providers. Individuals living with chronic conditions or diseases may engage in ACP conversations at many points along their disease trajectory; their assessment of what constitutes a good quality of life may change as they adapt to different stages of their condition. Those approaching the end of life may feel a sense of urgency to reflect on and communicate wishes if they have not already done so.

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1 A patient’s capacity to give informed consent to treatment is usually assessed by a health care provider or providers, as specified in provincial/territorial legislation dealing with consent to health care.
Beyond health care
Although advance care planning is generally seen as a health care issue, it goes beyond health care to encompass the legal sector, social services and perspectives of citizens both as individuals and as members of voluntary sector organizations. Ideally, the broader societal dialogue about ACP would include all of these sectors. This Guide focuses mainly on the health care sector and advises health authorities to link to other sectors as a means of ensuring that their ACP initiatives are responsive and successful.

Why Advance Care Planning Is Important for Health Care Systems

Advance care planning is an issue of growing interest to health authorities for several reasons. Our population is aging and the burden of chronic disease is increasing. Longer life spans mean that most Canadians will live with at least one chronic disease or condition as they age. Those living with chronic disease may have wishes for the kind of care they would want, or not want, in the event that their disease rendered them temporarily or permanently incapable of communicating their wishes. Advance care planning also aligns with other priorities for health systems such as chronic disease management, quality improvement and patient safety, to name just a few. The case for support of ACP is discussed more fully in Section IV.

There is a growing demand for patient-centered care that respects individual wishes and focuses on a partnership between health care providers and patients. Widely publicized experiences of artificially prolonging life and the anguish of decisions to withdraw treatment have focused public attention on the value of clearly expressed care wishes. Not only does this lessen the moral and emotional burden on loved ones and health care providers, it also helps to anticipate and prevent family conflict related to medical decisions.

Advance care planning will not resolve all difficulties related to care decisions for an incapable patient. It may not be possible to fulfill all of an individual's care wishes. For example, a person may express a wish to die at home, but the material and emotional resources of the family and the resources of the health care system may not be able to sustain care at home until the end of life.

Situations will arise in which the family’s wishes are contrary to the patient’s expressed wishes or to the judgment of health care providers with respect to interventions that are medically advisable. Family members may disagree among themselves. Cases involving differences of opinion between families and care providers have been before the courts and have received media attention. The case law resulting from decisions in these cases will have an effect on advance care planning and on health care practice. For this reason, the model proposed in this Guide advises health authorities to work closely with their legal departments and their provincial/territorial regulatory bodies. Health authorities may wish to include an ethicist on their team.

Advance care planning will not resolve resource allocation issues about investment in life-sustaining interventions versus investment in other health care or social priorities. These are broader societal issues that require public discussion involving all sectors of society. Advance care planning, however, can provide guidance in individual cases. It can result in clarity for all concerned and lessen the anguish of uncertainty and guilt which may accompany the experience of making care decisions for someone who has never expressed values or wishes about their care.
How the Guide was Developed

Advance care planning was identified as a theme at a National Action Planning Workshop on End-of-Life Care held in 2002. The workshop brought together nearly 200 representatives from the federal, provincial and territorial governments, regional health authorities and stakeholder organizations. An interest in ACP was expressed in the following terms:

Encourage Canadians to plan for the ends of their lives:
  • Develop an inventory of tools for providers, individuals and families.
  • Develop standards for health care settings admissions to ensure that physicians or other health care practitioners ask every patient or decision maker about their goals regarding end-of-life care.

Following the 2002 workshop, five community-based working groups were established to move forward on identified themes. Advance care planning later emerged as a cross-cutting theme, which led to the development of information and education resources with support from Health Canada.

Calgary Health Region and Fraser Health Authority identified advance care planning as a priority in their regions in the early years of this decade and began developing policies and programs. In May 2007, the two health authorities co-hosted a Canadian symposium on advance care planning in Calgary. At the symposium, more than 100 participants from many regions of Canada learned about ACP approaches in Canada, the United States and Australia. On the final day of the symposium, participants expressed a wish to see the development of resources and pan-Canadian information exchange mechanisms to support the work they were doing in their regions. In response, Calgary Health Region and Fraser Health Authority secured financial support from Health Canada to develop the Guide.

In February 2008, a draft of this Guide was discussed in Coquitlam, British Columbia, at a meeting of health authority representatives from most Canadian jurisdictions. The valuable suggestions and insights of participants at that meeting have been incorporated in this final version.
Overview of the Advance Care Planning Model

Four Basic Building Blocks

The following model for advance care planning consists of four basic building blocks. Informed by the Respecting Choices® system for advance care planning (Gundersen Lutheran Medical Center, Wisconsin), the model has been followed by health care facilities in a number of countries, including the United States, Australia and Canada. The model is consistent with patient-centered care and places the patient and family\(^2\) at the centre.

Each block of the model is essential and all blocks must connect and function together in order for the model to be effective.

Building Block 1
Engagement: Organizational and Community

Advance care planning engages people at all levels. Successful ACP initiatives engage both the organization and the community. Organizational engagement consists of the involvement and support of health authority leaders and decision makers. It includes engaging all those working or volunteering in the authority who may be involved in policy development, systems, legal and financial management, and direct interaction in ACP conversations or decision making with respect to patient care.

\(^2\) The term “family” includes both the biological family and the family of choice.
Community engagement involves outreach to individuals and groups that are likely to have an interest in advance care planning. In its broadest terms, this includes all capable adults. Community engagement also involves raising public awareness and fostering community involvement in the planning and implementation of ACP initiatives.

Building Block 2
Education
While education is present in all four building blocks, it also merits its own block. Advance care planning consists of a process of reflection, decision and communication regarding choices or wishes. It involves conversations. The experience of many health systems shows that these conversations must be skillfully facilitated if they are to be initiated and sustained. This requires education and support for health care providers and volunteers who engage and support individuals and families in ACP conversations. It also includes education for those in the health authority who may be responsible for any aspect of care such as, for example, personnel from administration or records management. Workshops, online educational modules and web-based resources can be developed for health care providers and other staff. A number of tools such as workbooks and information resources for patients and families can support their involvement.

Building Block 3
System Infrastructure
Systems are needed to ensure that a person’s choices, once made, are acknowledged and acted on, within the limits of what is possible and medically advisable. The patient is the owner of her/his ACP documents, which follow the patient through all health care settings. Systems for ensuring that health care providers are aware of the patient’s wishes can include, for example, mechanisms for recording information in personal health records and visual identifiers in charts or in the home. It is essential that these mechanisms be capable of conveying information throughout the health care system, in all care settings where the patient may receive care. This involves many aspects of the health care system, including admissions and records management.

Building Block 4
Continuous Quality Improvement
Continuous quality improvement is essential to ensuring that interventions are appropriate and that resources are invested effectively. It is also essential for learning what works well and what could be done differently. Quality improvement is important in earning accreditation and in gaining support for ACP programs as they are implemented. It requires the development of indicators, measures and tools for analysis, as well as mechanisms for integrating new knowledge into practice.

Read on . . .
The next section provides an overview of how the model can be developed, including recommendations for getting off to a good start.
This section of the Guide describes how the building blocks of the advance care planning model can be created using concrete examples.

Getting started

Before you begin, it will be useful to define your approach and set goals (short, medium and long term). A logic model can be valuable in guiding your planning (see Section VIII for an example of a logic model). Identify the organizational and community sectors that you want to engage: multiple sectors that cut across silos, a variety of care settings, or sectors that are most willing to participate in the program. You may have to invest considerable time in developing ways to dialogue between sectors until you all arrive at common understandings and goals. Engaging a champion to ensure cross-functional communication will add value to your team. Consider conducting and evaluating one or more pilot programs before moving to full implementation.

Concrete examples

The concrete examples in this section are drawn from the experiences of the former Calgary Health Region (now Alberta Health Services) and Fraser Health Authority. A brief description of these health authorities follows.

Calgary Health Region is one of the largest in Canada, covering a geographic area the size of Switzerland and serving a total population of over 1.2 million people, including Calgary and a range of towns and rural areas. The region is characterized by rapid population growth. It is one of the first areas of the country to regionalize its entire health care system, resulting in considerable intersectoral integration. Calgary Health Region also has an emerging integrated electronic health record system.
Fraser Health Authority serves a population of 1.5 million people in the lower mainland of British Columbia. The region comprises several large towns and rural areas. It is one of the fastest growing health authorities in Canada, employing 21,000 staff and 2,000 physicians. Fraser Health oversees 12 acute care hospitals and 7,000 residential beds, as well as comprehensive home and community care services.

Both health authorities serve similar populations sizes. The profile of the population in Fraser Health Authority is slightly older than in Calgary Health Region because of the large number of retirees who move to British Columbia. The two health authorities have maintained strong communication links and have engaged in ongoing dialogue as their respective approaches have been developed and implemented.

**Potential challenges**

Potential challenges with the building blocks are identified at the end of most sections. These challenges have been identified by health authorities that have implemented ACP initiatives and are based largely on the experience of the two health authorities.

**Critical factors for success**

Before going into the discussion of the building blocks of the model, here are some critical factors for success gathered from the experience of the two health regions. You will see many of these factors again as you work through the rest of this Guide.

- Secure support from organizational leaders.
- Bear in mind that ACP calls for a culture change and is not simply a process that includes systems and policies.
- Be flexible in your implementation process: pay close attention to cues from the public and health care providers and respond appropriately. The implementation process is not linear—include the public and health care providers concurrently.
- Begin with a small group of clinicians who are well informed and thus able to move the initiative forward, and who are committed to making the required changes in practice and in organizational structures.
- Engage a passionate champion for the initiative—someone who can inspire passion for advance care planning in others.
- Gather stories from clinicians and individuals (patients/families) who engage in ACP.
- Have clinicians speak to the difficulties that patients, families and health care providers may experience when ACP does not occur.
- Start small in a confined setting where patients are only minimally in contact with other health care services. Try to pilot the process in more than one type of setting (e.g., renal program, residential care).
• Plan for small changes and look for ways to piggyback ACP onto other initiatives.
• Build the implementation work with input from the stakeholders who know the area and practise in the sectors.
• Embed quality improvement activities in the learning process.
• Engage all disciplines in implementing formal education strategies for health care providers and in sharing the initiation of ACP conversations with patients.
• Engage the community throughout your process.
• Ensure public access to information (website, toll-free telephone line, etc.).
• Ensure access for health care providers to information (intranet, web-based information, etc.).
• Ensure consistent leadership for the initiative by having at least one person devoted full time to ACP implementation.
• Build on successes.

Read on . . .
The following four sections provide a much closer look at each of the basic building blocks and draw from the experience of health authorities that have implemented ACP.

4 Building Block 1 Engagement

Organizational engagement involves securing the support of the health authority’s senior management and opinion leaders by building the case for support for the advance care planning initiative. It also involves engaging care providers, especially team leaders and coordinators, who will participate in the front-line implementation of the initiative, and administrative staff.

Community engagement involves outreach to the public in order to engage capable adults and their families in advance care planning through raising awareness, initiating dialogue about ACP and connecting people to the means of engaging in ACP. By building on existing links to community, engagement can be effective in both urban and rural areas, as well as in areas with differing levels of resources.
**Organizational Engagement**

Securing the support of senior management, decision makers and opinion leaders is essential for the success of an initiative. The following section provides information that may be helpful in building the case for support amongst senior management and others. This includes: aligning with organizational policies and priorities; linking to jurisdictional policy and regulatory frameworks; accreditation; investment of resources (people, time and money); and linking to other health care and social service frameworks.

Senior management in health authorities may resist ACP initiatives on the grounds that other programs should have higher priority given scarce resources. Building a case for support can include demonstrating links to existing organizational policies and pointing out the benefits in terms of patient safety, reducing over-treatment or unwanted treatment, recognizing advance directives and designating goals of care in a consistent way throughout the region, meeting accreditation standards, integrating ACP into an existing successful program, and so on.

It may be a challenge to demonstrate that advance care planning is a worthwhile investment when there are a variety of competing priorities throughout the system. In this case, it will take time to build partnerships and engage in dialogue with aspects of the system that could benefit from the introduction of an ACP program. Starting with a pilot with one of the partner programs may be a possible approach. An evaluation of the pilot can provide evidence on which to build the case for ACP.

Advance care planning is a relatively new concept in Canada. Most provincial or territorial legislation dealing with advance directives dates from the late 1990s or the early years of this decade. Comprehensive ACP programs in regional health authorities are even more recent; the Calgary and Fraser programs began within the past five years. The evidence base for the effectiveness of ACP and its impact on quality of care and other indicators is just being built. Descriptions of initiatives are available, but there has not been sufficient time for a deep base of Canadian evidence to accumulate. This may create a challenge because sceptics will want to wait and see what others have done before considering advance care planning in their own regions. This may be healthy scepticism, but initial evaluations and pilot projects indicate that the benefits of ACP on a region-wide basis can be significant.

**Dealing with organizational resistance**

The following suggestions for dealing with organizational resistance are based on the experience of the former Calgary Health Region (now Alberta Health Services) and Fraser Health Authority:

- Align with clinicians and use opinion leaders.
- Demonstrate alignments with core business areas.
- Use the levers within the organization to show that the ACP initiative could be instrumental in solving problems. For example, if the organization is dealing with workforce issues, show how engaging in ACP processes would mitigate issues such as moral distress or burnout.
- Align with key change strategies within the organization such as interprofessional practice.
- Listen carefully to critics of the initiative and use their feedback to inform the development of your strategies. Incorporate changes and suggestions whenever possible.
- Acknowledge with staff that the shift of practice will present challenges; it is better to name the issue than to ignore it. This helps staff to know that you are aware of their concerns and are trying to address them.
• Encourage management and front-line health care providers to complete the ACP process themselves. This enables them to engage with the program from a personal as well as a professional perspective.
• Engage your legal department in responding to legal questions arising within the organization.
• Share data about: the current status of advance care planning; patient experience; and successes of other ACP initiatives, programs and teams.

**Aligning with organizational policies**

Introducing an ACP initiative into a health care facility or system will likely be most successful if it is linked to existing organizational policies, and if it can be demonstrated that advance care planning aligns with and supports or enhances existing policies. The nature of an organization’s internal policies will vary from one health care system to another.

**Linking to jurisdictional policy and regulatory frameworks**

While it is important to recognize that advance care planning will not necessarily result in the creation of an advance directive by the individual, you will need to be aware of, and linked to, the relevant legislation in your jurisdiction that governs health care consent and advance directives. Each Canadian province and territory (except Nunavut) has unique legislation governing advance directives. A discussion of provincial and territorial legislation and regulations is beyond the scope of this Guide. Links to useful resources can be found at the end of the Guide.

It is advisable to work closely with your health authority’s legal department to learn about the legal implications of advance care planning in your province or territory. You should also consult the office of the public guardian and other appropriate responsibility centres in your provincial/territorial government concerning any legal implications of your ACP initiative. Begin these discussions early in your planning process. It is important to incorporate any necessary legal implications of ACP or associated code designation initiatives into the educational materials you develop for health care providers.

Calgary Health Region has worked closely with its legal staff and Alberta’s Office of the Public Guardian to ensure that its policies with respect to advance care planning and goals of care designation are consistent with provincial law. The region’s legal department provided input into the drafting of the *My Voice—Planning Ahead* workbook and the discussions and documents related to the new ACP policy. The legal department provided advice on specific clinical scenarios, engaged in dialogue with the Chief Medical Officer, Health Records and the ACP team, and also facilitated the gathering of opinions from the legal community. During the development of the ACP program, the Office of the Public Guardian led a collaborative process to revise the legislation. Health care professional associations and regulatory colleges were also involved in these discussions. The result is a high level of clarity and comfort with the new policies and programs amongst health care providers in the region.

Fraser Health Authority has worked within an uncertain legal environment with respect to instructional advance directives in British Columbia; proxy legislation has existed for several years. Consequently, many citizens have not created instructional advance directives, leaving a gap in advance care planning that Fraser Health attempted to fill with its ACP program. New legislation has been passed recently which allows proxy and/or instructional directives. As a result of experience with its ACP program, Fraser Health was able to play a role in advocating for the legislation to be more responsive to consumer and health system realities.
Accreditation

Accreditation Canada\(^3\) now includes advance care planning in its standards for accreditation of hospice palliative and end-of-life care programs, and includes questions about ACP in many other standards for clinical programs. This will likely be a major driver of ACP initiatives for health authorities in the future.

Investment: people, time and money

The development and implementation of an advance care planning initiative will take time and will require the commitment of human and financial resources.

Human resources

Staff time spent on the ACP program may have to be offset by hiring extra staff or finding full-time equivalent positions (FTEs) within the system. Calgary Health Region has the equivalent of approximately seven FTEs on the planning and implementation team (2.5 positions are resourced for policy implementation tasks only).

The Fraser Health ACP program has proceeded in phases according to the availability of funds. For several years, health care providers (especially social workers) had been hearing about the desire for ACP conversations from patients and clients throughout the region. In 2004, a dedicated project leader (a nurse) and a medical lead (the lead physician for Fraser Health hospice palliative care services) were appointed to head up the project. Currently, Fraser Health has one FTE as an implementation coordinator and one FTE clinical nurse specialist for end-of-life care. Other staff have participated in the ACP program as part of their regular work. Although not dedicated to advance care planning, program staff have access to and have utilized a variety of internal resources such as quality improvement personnel.

Volunteers from community-based organizations who are trained in ACP facilitation may be able to support ACP conversations with healthy adults in the community and thereby expand the human resources capacity needed to deliver the program.

Time

Development and implementation of the program will require staff time for such activities as: planning; partnership building; development of materials; training; incorporating conversations with patients, families and other health care providers into clinical practice; and maintaining health records. The required time needs to be acknowledged and budgeted for. The process is not necessarily linear; planning and development can take place concurrently with implementation. It may take two or three years before a system-wide approach is defined and in place.

Funding

Funding is always a challenge. It is best to be realistic about the amount of money that developing and implementing an ACP program will require. Staff time will have to be considered in costing, as will possible physician disincentive because of lack of billing codes for conversations and possibly compensating clinicians for time spent in education sessions. Development of print and web-based materials will cost money. When dedicated funds cannot be secured for an ACP program, it may be possible to secure start-up grants or have several partner programs contribute to the cost.

In today’s health care climate, it is likely that funding may be limited, requiring you to rely on champions and others who are passionate about the program to move it forward, at least in the initial years. It is encouraging to note that, in spite of its funding challenges, the Fraser Health ACP program has achieved a great deal. Its experience has been looked at by other health authorities in Canada and abroad.

\(^3\) Visit the Accreditation Canada website at: [www.accreditation-canada.ca](http://www.accreditation-canada.ca)
Linking ACP to other health care frameworks

Experience has shown that successful advance care planning programs become part of the existing health care culture within a system. Systems naturally resist change. Advance care planning programs can be developed by linking to several possible frameworks which may already exist in the health region and offer the advantage of being accepted and familiar. If ACP is presented as a completely new, independent program, resistance to change can be significant. Linking to existing health care frameworks can help all concerned to incorporate new concepts into ways of working that are familiar.

Examples of other health care frameworks include:

- chronic disease management;
- primary health care models of team and interprofessional practice and networks;
- patient safety with its emphasis on informed, proactive patients;
- long-term care;
- goals of care designations (sometimes called levels of care coding);
- home care;
- strategies for seniors;
- disease-specific strategies and education;
- hospice palliative care or end-of-life care strategies;
- InterRAI (Resident Assessment Instrument) assessment tools;
- partnerships with community-based agencies and support groups; and
- family caregiver strategies (such as that under development in Nova Scotia).

The chronic disease management model and advance care planning

More than nine million Canadians live with one or more chronic diseases. Several Canadian jurisdictions, notably British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Québec, Nova Scotia and Yukon, have responded by adopting a chronic disease management model. The British Columbia model appears below.
The chronic care model offers several opportunities for linkages to advance care planning:

- **Patient self-management**—can include learning about advance care planning and referral to follow-up resources. This is a key component of chronic disease management which has been adapted for use in several countries, including the United States, Canada, England and Australia. Health care providers play a crucial role in the success of these initiatives by encouraging and supporting patients and family caregivers to participate in self-management education and to practise what they have learned.

- **Decision support for physicians and patients**—can include patient care wishes expressed through the ACP process and stimulate physician-patient discussions.

- **Information systems**—can ensure that patient wishes are accessible in all care settings.

- **Delivery system design**—can incorporate knowledge of the patient’s care wishes and the physician’s care judgments.

- **Community support**—can help normalize ACP discussions through outreach to programs for seniors and others.

- **Proactive practice team**—provides opportunities for incorporating ACP discussions and awareness into practice.

Calgary Health Region linked to the chronic disease management model and chose a chronic disease management program as one of the initial sites for implementation of advance care planning. The patient self-management component of its chronic disease management program contains a session on ACP.

Fraser Health Authority incorporates advance care planning in its outpatient education programs and routinely facilitates formal ACP conversations with renal patients. Advance care planning is also introduced routinely in respiratory rehabilitation at one of the Fraser Health hospitals, at a cardiac rehabilitation unit in another hospital and at a seniors’ clinic in one of the communities it serves.
### Primary health care: interprofessional teams and networks

One of the objectives of primary health care interprofessional practice teams is to provide care by the most appropriate team member and to bring the expertise of a diverse team to patient care. Advance care planning initiatives fit this team approach. For example, as the primary care provider, a physician may initiate the conversation with the patient. Longer follow-up conversations may be held between the patient and other members of the team, such as the social worker, nurse or spiritual advisor. The physician can be called in to answer complex medical questions and maintain a coordinating presence.

Primary health care reform emphasizes coordination with other health services, often involving networks, such as the Local Health Integration Networks in Ontario. Advance care planning initiatives are compatible with this coordinated approach because, in order to be effective, all parts of the health care system which the patient may encounter need to know about the patient’s care wishes, advance directive or goals of care designation. Coordinated networks also offer several entry points for introducing ACP—for example, in hospitals, home care, long-term care facilities or community-based clinical practice.

### Patient safety

Patient safety initiatives aim to enhance the quality of health care and reduce preventable adverse events that may occur in health care settings. Several provinces have established mechanisms to support patient safety. An important aspect of patient safety initiatives is helping patients to become proactive, informed consumers who share responsibility for the quality of their care by asking questions and monitoring their care. This is consistent with the patient-centered care model and patient choice which are central to advance care planning. Patient safety also provides the lens of risk reduction and quality enhancement through avoidance of over-treatment or undesired treatment, both of which can occur in the absence of ACP conversations with the patient.

### Long-term care

Long-term care models provide opportunities to introduce advance care planning to capable residents. Residents in long-term care are often living with one or more chronic diseases or conditions and may welcome conversations that allow them to reflect on their care wishes and make informed choices about future care, should they become incapable.

Long-term care in a residential setting can provide opportunities for continuing conversations with health care staff over a sufficient time period to allow the resident and family members to reflect and discuss issues within the family and with care providers. This can normalize the process because the conversation does not have to be pressured and squeezed into an occasional visit with the physician. Such conversations can help residents to exercise choice over their goals of care designations in the event of a downturn in their condition or transfer to another care facility. Opportunities can also occur in long-term care through the use of tools such as the InterRAI assessment instruments which include questions about advance directives and substitute decision makers.

Many residents in long-term care, however, may be incapable of engaging in ACP conversations because of cognitive impairment, but the resident’s family can engage in discussions about what their family member would have wanted and can become familiar with the kinds of decisions they may have to make for the resident in the future.

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5 Many chronic disease management nurses in general practitioners’ offices in Fraser Health play this role.

6 Visit the Canadian Patient Safety Institute website at: www.patientsafetyinstitute.ca
Goals of care (levels of care) designations
Health regions are confronted by the common problem of designing simple ways to communicate prior discussions and decisions regarding goals of care between sectors. Common problems include lack of consistency in how these differing care designations are expressed, even within a region. For example, a Code Level 1 in a long-term care facility may be a Code Level 5 in the hospital to which a patient is transferred. This can cause confusion and delays which create risk and reduce quality of care. Many regional health authorities are working to standardize codes/levels throughout their region.

Another challenge is the translation of patient wishes into valid physician orders that can be acted upon. Some Canadian jurisdictions are exploring or using the POLST (Physician Orders for Life-Sustaining Treatment) model because they see it as a means of engaging physicians in ACP. POLST is a physician-driven model used widely in the United States that includes a conversation initiated by the physician with the patient. The physician then completes a form, which is signed by the patient, summarizing the wishes of the patient with respect to life-sustaining treatment.

Possible drawbacks of the POLST model include a strong focus on only the care choices that appear on the form, which may have the effect of restricting discussions that could lead to the identification of other care choices or issues of concern. Canadian health care providers may have a greater level of comfort with the goals of care approach which offers the same benefits as POLST and is grounded in a holistic and interdisciplinary approach to ACP.

Electronic health records
Conversion to electronic health records that are standardized across a region is a priority for many regional health authorities. This provides an opportunity to ensure that a patient’s care wishes or an advance directive follow the patient through all health care settings. A frequent challenge in advance care planning is lack of knowledge of care wishes, which may be recorded in a chart in one health care setting but not in another. Including a standard question about ACP on admission to a health care facility can normalize and raise awareness of it (e.g., “Do you have any allergies? Do you have an advance care plan?”); information about known care wishes or the identity of a substitute decision maker can then be integrated into a patient’s electronic health record.

The conversion to electronic health records may provide an opening for discussion in the health authority about ACP and advance directives which, in turn, may lead to decisions to develop policies and programs for advance care planning.

Home care
Home care can provide an excellent opportunity for advance care planning, especially in cases involving longer term care. It may be difficult to initiate ACP conversations in acute care situations where the patient or family is not amenable to focusing on possible loss of capacity by the patient. Health care providers involved in longer term home care may have the opportunity to introduce ACP through the process of assessment. Advance care planning conversations can take place during a series of interactions with the patient and family spread over time, allowing for adequate reflection and communication. Organizations which provide home care services in many areas of Canada, such as the Victorian Order of Nurses (VON), have an ACP policy which provides guidelines for their staff.

1 Some health authorities and health care facilities use the term “levels of care.” Calgary Health Region and Fraser Health Authority prefer to use “goals of care” because this term captures the opportunity for the person’s participation in reflecting on their care wishes and identifying their preferences in light of appropriate medical interventions.
2 Examples of POLST forms and other information can be found at: www.ohsu.edu/polst
**Strategies for seniors**

Initiatives for seniors such as healthy aging and aging in place provide opportunities for introducing advance care planning as part of healthy self-management programs. Initiatives for seniors can also be linked to chronic disease management programs. The Ontario Government has supported the development of ACP through the Ontario Seniors’ Secretariat as part of Ontario’s Strategy for Alzheimer’s and Related Dementias. In Australia, the Respecting Patient Choices program supported by the Department of Health and Ageing, is linked to initiatives for seniors. A limitation of using this approach exclusively is the lack of linkage to younger people who could benefit from advance care planning.

**Disease-specific strategies**

Strategies for diseases that have a high prevalence such as cancer or Alzheimer’s disease offer opportunities for advance care planning. The Ontario Government’s ACP initiative has been linked to both seniors’ issues and Alzheimer’s disease and focuses largely on consumer products and enabling people to take more control over their care choices in the event of incapacity. In some jurisdictions, cancer care is linked to end-of-life care and has an ACP component. ALS organizations have shown a particular willingness to engage in ACP initiatives because of the progressive nature of the disease and the need to foresee future care wishes. Renal care programs have also embraced advance care planning.

**Hospice palliative care and end-of-life care**

Advance care planning has often been seen as the preserve of hospice palliative care. Calgary Health Region’s ACP initiatives originated in its Palliative and Hospice Care Service, whereas Fraser Health Authority’s ACP initiatives originated in its Hospice Palliative and End-of-Life Care programs. Both organizations stress, however, that advance care planning is for all capable adults and should not be restricted to those reached by end-of-life care. Their programs have expanded far beyond end-of-life care to encompass a variety of populations.

Hospice palliative care programs are often advocates for advance care planning. The Canadian Hospice Palliative Care Association adopted ACP as its theme for National Hospice Palliative Week for the past three years. Several national initiatives in hospice palliative care have also focused on advance care planning. Many people working in regional health authorities will be familiar with the Canadian Hospice Palliative Care Association’s *Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. The care framework outlined in the Model’s Square of Care and Organization (a matrix addressing the process of providing care in the context of common issues) specifically includes advance directives and goals of care in its decision-making component. It also includes patient/family expectations and hopes among its assessment criteria, and negotiating a plan of care in its care planning component. This framework has been used by several health authorities in Canada.

The Gold Standards Framework for community palliative care used in the United Kingdom is familiar to many Canadians. The Framework contains an ACP component, which used the Fraser Health Authority’s ACP program as one of its resource models.

**InterRAI and other assessment tools for quality improvement**

InterRAI is a collaborative network of researchers in more than 20 countries committed to improving health care for persons who are elderly, frail or disabled, with the goal of promoting evidence-based clinical practice and policy decisions. InterRAI has developed a series of assessment systems based on the establishment of a minimum data set, assessment protocols, and status and outcome measures. Assessment systems exist for 11 areas, including long-term care, home care, acute care and palliative care. The InterRAI assessment systems are used by many health authorities in Canada. Many of the assessment protocols include questions about advance directives and legal substitute decision makers which can provide openings for discussion and links to ACP initiatives. The InterRAI assessment systems also provide important quality improvement mechanisms that can be used in evaluating ACP programs.
Partnerships with community-based organizations and support groups
Service clubs and other community-based organizations provide an opportunity for reaching persons who may decide to engage in ACP conversations, or through them, their circle of family and friends.

Caregiver strategies
Some provinces, such as Nova Scotia, are developing family caregiver strategies. Strategies that recognize and support caregivers can provide links to ACP initiatives. Family caregivers are likely to be involved in advance care planning discussions with the patient and possibly with the physician and other members of the care team. A caregiver is also likely to be called upon to act as a substitute decision maker if the patient becomes incapable of expressing care wishes. Existing ACP initiatives could include the family caregiver in their consumer model and communications products.

Social service care frameworks
Social service frameworks for populations such as the frail elderly or those living with chronic conditions may offer opportunities for linkages because the concerns identified may be similar to those in health care frameworks. Social workers, for example, are often aware of the need for advance care planning for their clients and may already have strong links with health care systems. In some cases, health and social service frameworks may be closely aligned with, or integrated into, jurisdictional policies; several jurisdictions have departments of health and social services, or health and community services.

Getting started
Following are a few suggestions for engaging organizational leaders that capture the information presented above. Build the case for support by becoming familiar with the mandate and policies of your organization. For example:

- Identify linkages between existing policies and programs and advance care planning (e.g., chronic disease management, long-term care, patient safety, quality improvement). Demonstrate how an ACP initiative can strengthen and support existing initiatives.
- Become familiar with policies in your province/territory which could link to an ACP initiative and demonstrate these links in your case for support.
- If your organization is to be reviewed for accreditation, verify whether the standards used by Accreditation Canada include advance care planning.
- Study the demographics of the population you serve: most regions have a growing population of older persons who may be receptive to ACP initiatives.
- Engage in exploratory discussions with a variety of organizations representing the public you serve. The interest and support of these organizations may strengthen the case for an ACP initiative with the senior management of your health authority.
- Analyze the challenges faced by health care providers in your organization to determine how an ACP initiative could support their work by enhancing communication with patients and families and by clarifying care wishes.
- Be realistic about the resources required. This will be a multi-year process and will require staff time to plan and implement. It may require modifying systems such as records management. The examples from Calgary Health Region and Fraser Health Authority show how many staff positions have been devoted to their ACP initiatives to date.
- Become familiar with the legal and regulatory framework in your jurisdiction. There may be requirements in legislation for health care providers to make a reasonable effort to become aware of an incapable patient’s care wishes. This can be an encouragement to develop an ACP initiative.
- Identify the risk management aspects of an ACP initiative as well as the opportunities.
• There may be media attention focused on critical episodes (usually involving conflict between patient/family and health care providers) which may cause your organization to focus on the need for an ACP initiative. Although advance care planning cannot prevent all conflict, it can introduce greater clarity into decision making by patients/families and health care providers.

Concrete examples

The Calgary Health Region ACP initiative has focused on investment in building support and infrastructure in order to enhance success and sustainability over the long term. The leadership team of Calgary Health Region’s Palliative and Hospice Care Service began building the support for advance care planning in 2004 through the development of a discussion paper which focused on the changing epidemiology of dying and the priority need to invest in ACP. A key strategy was to emphasize the role that ACP could play in supporting related clinical priorities in the region, such as patient and family-centred care, safety initiatives, the chronic disease management program, seniors’ health and ethics.

At the same time, the Palliative and Hospice Care Service engaged key opinion leaders as champions on the Board of Directors, as well as senior management and leaders at the clinical level. In garnering support, the Palliative and Hospice Care Service team was able to capitalize on its reputation as a well-established and respected service that had already established partnerships with a number of non-cancer services (for example, those associated with chronic obstructionary pulmonary disease, ALS and HIV/AIDS). These partnerships enabled the Service to secure additional funding for the creation of the ACP implementation framework.

Concurrently, the Health Quality Council of Alberta developed a matrix that identified both dimensions of quality and areas of need. End-of-life care was identified as one of the four areas of need, thereby serving to validate the work being undertaken in ACP by Calgary Health Region.

A risk management consideration for Calgary Health Region as it implements the ACP initiative is differences in the speed of uptake throughout a large system, with clinicians engaging according to differing timelines and processes. This means that patients may come in contact with sectors of care that are not yet aware of ACP processes or resources as they move between sectors. Education and communication are strategies to mitigate these risks.

Engaging Health Care Providers

Securing the support and participation of health care providers is essential to an ACP initiative. Care providers representing all disciplines need to be involved. A special challenge may be engagement of non-aligned (within an organizational sector of your health authority) primary care physicians.

The following advice is based on the experience of several programs:

• Introduce advance care planning as an interprofessional practice strategy.
• Engage all health care team disciplines: nurses, social workers, spiritual advisors, etc., using an interprofessional practice strategy. Engage clinicians in a collaborative manner. Recognize that nurses, social workers and other team members may engage more quickly than physicians.
• Look for ways to link ACP to interprofessional practice initiatives that may be active in your region. Connect with provincial health care professional associations and local universities, colleges and other educational institutions.
• The engagement of physicians is essential for the success of the program. Their leadership is significant in validating the interprofessional approach and prioritizing and integrating this as significant work for the team.
• Engage champions among health care providers who can act as initiators, early adopters and agents of change. Provide tools and resources to enable their involvement.
• Consider how to deal with physician concerns such as billing the time spent in ACP conversations, lack of time and possible discomfort with sharing care decisions with patients. Connect with and elicit the support of the provincial/territorial medical association.

Concrete examples

Physician engagement is a crucial element of the Calgary Health Region implementation framework. Criteria for programs wishing to participate in the My Voice—Planning Ahead segment of the ACP initiative include the support of their respective medical leader or clinical department as a primary factor of success. Physician engagement elevates the chance of success of the program because physicians are often team leaders in interprofessional practice teams and are responsible for writing the physician order for “code level” or resuscitation status. In addition, physicians are often the initial point of contact that a patient will have with the health care system, so they are well-positioned to identify a need for a discussion on advance care planning, and to initiate or encourage the conversation to be led by other members of the care team.

In recognition of the need to successfully engage physicians in the development and implementation of ACP in their region, Calgary Health Region established a medical advisor role. The ACP team is developing a physician engagement and education strategy to complement similar strategies for other health care providers. Resources for health care professionals include a dedicated section of Calgary Health Region’s ACP website.

In addition to the support of the medical leader of their clinical area or department, programs wishing to participate in the My Voice—Planning Ahead program must identify an ACP leader who has time to administer and support the program activities, a project team to take the training, staff time to devote to the program, and administrative and developmental support for the program. The Calgary Health Region Advance Care Planning Team provides implementation support to participating programs, clinician training, train-the-trainer materials and support, and tools and support for the ongoing evaluation of the program (every six months).

Calgary Health Region has begun to engage non-aligned primary care physicians by linking to primary care networks and having these physicians represented on the advisory committee for the initiative. They also conduct mail-outs to all community physicians to explain how ACP can enable the physicians to continue relationships with patients after the latter move to a setting in which the community physician no longer has direct influence over the patients’ care.

Fraser Health Authority has also reached out to non-aligned physicians through the British Columbia Primary Health—Enhanced Family Practice initiative. Written information distributed to physicians’ offices was often found to be ineffective because it tended to be overlooked in the vast amount of information that physicians receive. However, some non-aligned physicians have contacted the ACP program based on information provided to them by their patients; some of these physicians now make ACP materials available to patients in their offices. Physician-to-physician informal contacts have also been successful.
A challenge remains in engaging physicians who are no longer associated with hospitals and therefore do not attend evening presentations or other educational sessions. Fraser Health Authority has a working relationship with the BC Medical Association and plans to develop physician-specific information packages, an initiative being stimulated by the new provincial advance directive legislation.

Chronic disease management nurses in the BC Primary Health—Enhanced Family Practice offices have also contacted the ACP program to access educational materials.

**Community Engagement**

The support and involvement of the community is essential to the success of an ACP initiative and can be an important element in building the case for support with senior management. The community is composed of individuals at all stages of life and health, many of whom are interested, or may become interested, in advance care planning. Some may become strong advocates for your ACP initiative.

Here are a few suggestions for engaging members of the community:

- Identify community groups and services that would be likely to have an interest in ACP and begin a dialogue with them. Consider linking to existing community forums where services or agencies meet together.
- Link with natural coalitions in your community—for example, community health boards and citizens’ action groups of various kinds. Look beyond the normal circle of organizations that you interact with.
- Include community champions on your advisory/planning committees.
- Work with community advisors and health care providers who interact with the public and patients to identify the resources needed to reach members of the public. Refer to materials used in Calgary Health Region and Fraser Health Authority as possible guides.
- Link to existing programs that reach patients and families who access services in the health care system.

**Cultural considerations**

One of the strengths of advance care planning is that it provides a process that supports diversity and inquires about individual values and goals of people from all cultural backgrounds. The experience of some health authorities shows that ACP models can be successfully adapted by and for cultural communities.

Outreach to cultural communities involves more than translating materials into several languages. It also requires some understanding of cultural frameworks. This is the subject of a recent study commissioned by Health Canada on the multicultural aspects of advance care planning in Canada. Although it may be tempting to have distinct cultural descriptors that fit neatly into a box, these stereotypes and assumptions were not only inappropriate but also inaccurate. All cultures felt that if health care professionals could take the time to understand the individual, this would be the most respectful way to provide a dignified death . . . Translating materials, providing interpreters and involving community leaders is one way to help break down the communication difficulties. ACP may be culturally incongruent for some patients, therefore, health care professionals should identify appropriate alternatives for health planning and decision making.
Each health authority will have its own expertise in working with the cultural communities it serves.

Concrete examples

Inclusive health care representation and public involvement were deemed to be integral parts of the development of the Fraser Health ACP program. Consequently, a 20-member steering committee was formed, composed of community and health care leaders from all sectors. Steering committee members included leaders from community programs (volunteer services for seniors, library, ethnocultural communities and other community-based groups), acute care (nursing and medicine), residential care (nursing and medicine), social work and spiritual care. This was crucial in identifying ways to help people focus on advance care planning and to incorporate it into their lives and practice.

Community representatives and health care providers had opportunities to provide feedback on the ACP materials such as the My Voice Workbook©. Presentations were made about the materials to volunteer groups, Rotary Clubs, peer counsellors for seniors, a geriatric nurses’ association and the steering committee. Members of these groups took the Workbook home to discuss with family and friends, and provided feedback and suggestions for improvement to the program.

Fraser Health also involved leaders from a variety of ethnocultural communities to help with the development of the ACP DVD and the translation of documents such as ACP posters and the My Voice Workbook©. All of the community leaders were important links to the public and to their respective communities. For example, a leader from the Punjabi community did a feature on advance care planning on a local Punjabi radio program that included Fraser Health staff who are involved in the ACP initiative.

As the ACP program expanded, responding to community requests for information and presentations became increasingly important. Fraser Health staff spoke to and interacted with seniors’ organizations and other community-based groups such as Rotary Clubs, church groups and hospital auxiliaries. Most of these presentations were initiated at the request of community group members. Advance care planning information was made available at various library locations and presentations took place within community settings such as churches, restaurants, seniors’ facilities and community centres. One of the interesting aspects of community involvement has been the discovery that people of all ages and cultures are often eager to talk about advance care planning—it is not a topic they want to avoid.

Fraser Health Authority shares with Calgary Health Region the guiding principle that advance care planning is for all capable adults, not just those approaching the end of life. Although the Fraser Health ACP program resulted from an expanded mandate for the Hospice Palliative Care Program to address issues in other areas of end-of-life care, the ACP approach has been carried to the general public and many segments of the population, including those in home care, acute care, primary care and residential care.

Fraser Health named its program Let’s Talk, in recognition of the need to change the culture of decision making about care by:

- empowering patients and families to become fully informed participants and to have a voice;
- educating physicians and other health care providers about the need for better communication and involvement of patients and families in the planning process well in advance of a crisis; and
- developing systems that would honour the choices of the patient (e.g., the My Voice Workbook) and support them in new ways around decision making and end-of-life care.
This approach required a strategy that communicated with as many people as possible. Fraser Health placed a strong emphasis on education of the public and health care providers, and development of user-friendly tools and resources. A toll-free telephone line (within British Columbia) was made available to the public and to health care providers.

Calgary Health Region brought community representatives into the planning and development process for its approach to advance care planning. An advisory committee was established, consisting of 30 leaders from a cross-section of disease, age-related and health care professions beyond the traditional palliative care circles, in addition to a number of members of the public whose families had been health care recipients. The advisory committee chair was a senior vice-president responsible for the patient experience portfolio. Members of the advisory committee were commissioned to be ambassadors and advocates for the ACP initiative.

Calgary Health Region also established a community task committee to review materials and resources being developed to enhance public engagement. This group of individuals provided valued feedback on the materials developed.

**Potential challenges**

**Concerns of health care providers**

Most clinicians receive very little education in communicating with patients and families about decision making when a cure is not possible. This can result in the physician feeling uncomfortable about broaching the topic of advance care planning, particularly when a patient is living with a potentially life-threatening illness. A physician may be reluctant even to initiate a conversation about ACP, or may display signs of discomfort during the conversation which can inhibit having a full and meaningful discussion. The focus of university education for physicians is increasingly on learning such communication skills; however, those who have been practising for some time may need additional support to address this gap in their training.

Lack of time for physicians to have lengthy conversations with patients and families is another challenge. Those who work in teams, however, find that such conversations can be conducted and supported by various members of the care team. For example, a conversation with the patient and family about advance care planning may be initiated by a nurse or social worker, and the physician may become involved later, as medical issues arise that need to be addressed. Follow-up conversations may involve other team members.

Even though physicians may wish to be involved in advance care planning with their patients, available time and compensation can present obstacles. Physician billing codes continue to be a challenge because many physicians currently cannot readily bill for time spent in ACP conversations with patients. In order to address this issue and ensure more physician involvement, Calgary Health Region is working in a tri-partite process involving Alberta Health & Wellness, regional health authorities and the Alberta Medical Association to obtain billing codes.

Fraser Health is currently in discussion with the British Columbia Medical Association and the provincial government about the possibility of developing appropriate billing codes. In 2007, a new fee code was introduced allowing general practitioners to bill for a 15-minute conversation about complex medical issues with the patient and/or family. Some general practitioners are using this code to cover ACP conversations. The fee code does not currently apply to specialists.

A further challenge for some physicians and other health care providers has been the culture shift required by shared decision making and power sharing with patients about care choices.
How and where to start an ACP initiative
Here are some things to consider. Do you first establish the structures to support ACP within a health authority, or do you engage the public and then use their engagement to support the need for system development within the authority? The experience of Calgary Health Region and Fraser Health Authority shows that either can be a place to begin. The long-term impacts of starting in one place or the other are still to be determined. What are the costs of building this work if the structures are not in place to support and ensure that the patient voice is communicated and honoured? How might momentum be lost within the health care system if there is not an engaged public pushing for advance care planning?

Engaging the community
How can you best craft the ACP message for public engagement? It is important to recognize that ACP can easily be misconstrued as a “way for health regions to save money.” It is an ongoing challenge to develop public communication that will result in public engagement. It can also be challenging to contain and/or predict community engagement. Sustaining community engagement is often an ongoing challenge.

When identifying community leaders it may be both important and appropriate to include community sectors or agencies not involved in health care. For example, Fraser Health included a senior member of a local library on its steering committee as well as the former Ombudsman of British Columbia.

Developing materials for diverse cultural communities
Translating documents into various languages may not be the right approach as some words can have multiple meanings, or are not known in a particular culture, and are not easily translated. Nevertheless, respecting the importance of making the voice of the patient and family heard is important in all cultures. Exactly how that is incorporated into health care decision making may need to be “translated” into culturally-appropriate language and should include a cultural framework. In Fraser Health’s program, a number of the ACP documents and the DVD were translated directly for some ethnocultural communities, but in other cases members of ethnocultural communities made their own DVDs to communicate the message in entirely different ways.

Read on . . .
In the following section the importance of educating and training staff is discussed, with emphasis on the role of education in supporting facilitated conversations about advance care planning with patients and families.
Education involves a number of activities, tools and processes, including: training and supporting health care providers and volunteers to facilitate conversations and processes related to advance care planning; information resources and tools such as workbooks, brochures and web-based resources for the public and health care providers; and tools for recording personal decisions about care wishes.

Facilitation of ACP conversations is essential to the success of the communication, reflection and decision making undertaken by patients and those close to them. Facilitation can include initiating conversations, asking relevant questions, answering questions that an individual/family may have, providing information resources and workbooks, and calling on the expertise of other team members as required. Anyone on the care team may initiate or continue the conversation with the patient—a physician, nurse, social worker or spiritual care worker, for example. In some cases, the patient may initiate the conversation with whichever member of the care team appears most receptive.

All care team members require education and support to facilitate ACP conversations. The ability to facilitate ACP conversations becomes part of the core skill set for all clinicians. This is essential not only for implementation of the initiative, but also for risk management. Patients and family members may become distressed when discussing ACP. This risk can be mitigated by educating health care providers who can then engage in sensitive discussions and initiate conversations about advance care planning with patients before an acute event occurs.

Those with experience in advance care planning emphasize the importance of not forcing conversations and of not focusing on the goal of having the patient complete a written advance directive. Conversations involving the patient, the family and health care providers are useful in clarifying values and goals regardless of whether a written document is completed as a result of the process. Experienced programs also advise that periodic review of the patient’s wishes and care goals is essential because factors such as health condition, family dynamics and the individual’s perspectives on quality of life change over time. It is important to the sustainability of an ACP initiative that care team members receive regular debriefings and mentoring, as ACP conversations can be demanding. Moreover, clinicians’ skills can be enhanced through such experience and guidance.
Both the health care providers who facilitate ACP conversations and the patient and family require information resources tailored to their needs. A new ACP educational module for health care providers and a teacher’s guide developed by the Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) initiative are available on the website of the Association of Faculties of Medicine of Canada. The EFPPEC module addresses a range of issues, including: capacity and consent; how to initiate a conversation about advance care planning; having the conversation; explaining life-sustaining therapy; ACP and the values and experiences of health care providers; conflict prevention and management; and building organizational capacity for ACP. It also includes educational resources. One of the module’s training exercises involves health care providers doing advance care planning for themselves, which enables them to become aware of their own feelings and attitudes.

Resources for consumers can include brochures, pamphlets, DVDs, audiotapes, workbooks, posters, downloadable audio material for personal listening devices, among others.

**Getting started**

The following advice is based on the experience of several programs:

- Approach education for health care providers as an interprofessional initiative because all members of the care team may be involved in facilitating ACP conversations at different stages. This can be a tool for enhancing team communication and collaboration.
- Develop an educational plan for health care providers. Resources such as the EFPPEC educational module can help to inform the structure of a training program. Educational materials and modules designed for health care providers and other staff by the former Calgary Health Region (now Alberta Health Services) are available online. Fraser Health may also be able to share their educational materials and modules.
- Incorporate training in advance care planning for staff who can support patients and families by facilitating ACP conversations. This is crucial to the successful implementation of the program.
- Consider training volunteers from voluntary sector organizations to work in cooperation with the health care team to initiate and support ACP conversations with healthy adults in the community. This can serve to involve community-based organizations in the ACP initiative and keep investment in the initiative at a manageable level. This possibility is being explored by some health authorities and is still to be validated by experience-based evidence.
- Consider using telephone-based support for the public and for clinicians where appropriate. This could be effective in rural and remote areas as well as urban areas.

**Concrete examples**

The Calgary Health Region ACP initiative consists of two inter-related parts: a consumer-focused program, *My Voice—Planning Ahead*, and the *Advance Care Planning: Goals of Care Designation Policy*. *My Voice—Planning Ahead* provides a mechanism for people to understand and document their choices and views regarding future health care decision making, and may lead to the formulation of a legally valid personal directive (the term used in Alberta to designate an advance directive). The Goals of Care Designation Policy is discussed in Section VI.

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**My Voice—Planning Ahead** supports health care providers, patients and families to engage in the reflections and conversations that enable patients to clarify their future care wishes in the event that they become incapable of speaking for themselves. The program includes training for physicians and other health care team members to engage and support patients and families in advance care planning. It also includes information pamphlets and a workbook for patients to guide them through the process of reflection, conversations with health care providers and their family, and recording values and wishes for care.

Calgary Health Region provides several training programs for staff, based on an approach of widespread education, rather than an expertise model. Its program seeks to utilize and optimize the unique strengths of the various programs within the health authority to advance the philosophy, processes and practice of ACP. The team has worked to capitalize on existing program structures, offered flexible education sessions and worked closely with program leaders to ensure that staff receive the appropriate training.

Several teaching approaches have been developed to provide options for education. The Calgary Health Region Home Care education program is an example which includes three levels of training for staff:

- **Level I** is for all home care clinical/clerical staff and contracted provider leaders— with compulsory completion by the launch of the Advance Care Planning: Goals of Care Designation Policy in late 2008. This level consists of two modules dealing with policy and ACP, each lasting 30 minutes. This level will be integrated into an ongoing education plan for all home care clinical and clerical staff.

- **Level II** is a full-day session for those responsible for facilitating the ACP process with patients and their family members. It provides for skill development in ACP conversations and application of the goals of care designations. It will be integrated into an ongoing education plan/orientation for new case managers, clinical consultants and managers.

- **Level III** is a comprehensive half-day session on ACP designed to enhance the skills of facilitators.

Educator training for Levels II and III is for educators and trainers to conduct Level II and Level III sessions. This training is intended to develop a strong foundation to deliver the program, to customize it for home care and to ensure that the program is sustained.

The outline for an educational presentation on advance care planning and the Goals of Care Designation Policy for long-term care and assisted living are available online at: [www.calgaryhealthregion.ca/programs/advancecareplanning/acpgcdpolicy.htm](http://www.calgaryhealthregion.ca/programs/advancecareplanning/acpgcdpolicy.htm).

The Calgary Health Region engagement resources for consumers include web-based information, brochures, the *My Voice* workbook and information about the region’s resuscitation policy.

The first two years of Fraser Health Authority’s ACP program development focused almost entirely on activities to lay the groundwork. This included formal education for health care providers, development of teaching and learning tools, and creation of a website and setting up a toll-free telephone support line for health care providers to support them in interacting in new ways with patients and families. Fraser Health also conducted pilot projects with its renal program, residential care and other programs, and established a close working relationship with the Respecting Choices® faculty. Four leaders were initially sent from Fraser Health to Wisconsin for instructor training; Fraser Health has since developed its own education programs. By mid-2007, more than 500 health care providers had been trained in advance care planning, and training continues.

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11 The renal program is currently developing a teaching DVD for use in formal ACP staff education.
In 2007, a 30-minute online learning module was made available to all Fraser Health staff. This module was peer reviewed by seven health authorities across Canada and within Health Canada. The ACP training is now offered quarterly and consists of completion of the module and a five-hour classroom component. Staff who have completed the training give it a high rating. Staff who do work for both Fraser Health Authority and community groups may also participate in educational sessions; this helps to create linkages between sectors of care and community groups. Follow-up support is provided to participants by ACP program staff who are available to make presentations to care teams, patients/clients and community groups and in staff meetings. The ACP program staff also provide consultation and clarification as the ACP initiative is implemented.

As a result of this groundwork and ongoing ACP education offered to all Fraser Health staff, the program has been able to develop visible leadership throughout all sectors in Fraser Health. The success of the professional education component is significant—other health regions in British Columbia have contracted Fraser Health to train their staff.

Fraser Health Authority has found that a crucial component of advance care planning is facilitation of the initial and subsequent ACP conversations with clients. The member of the care team who initiates the conversation varies from one care setting to another.

As an example, renal units have experienced success when the nephrologist introduces the topic and then brings in a trained social worker or nurse to facilitate further conversations. The ACP decisions arising from these conversations are communicated to the nephrologist and appropriate discussions and documentation follow. Some assisted living settings discuss advance care planning with clients upon admission, with a manager or a nurse typically initiating the conversation. Some family physicians introduce it at annual physical checkups and yearly thereafter; others engage in ACP conversations with patients who have recently been in hospital or who are living with chronic diseases.

Advance care planning is included in initial assessments and group education sessions led by nurses or social workers in chronic care centres, seniors’ clinics and kidney care centres. More detailed discussions follow with individuals. Specialists also discuss ACP with patients and have detailed conversations regarding medical issues.

A striking finding is the number of individuals who have no close family or personal relationships—for them, these conversations and choices are particularly meaningful and important. Preliminary evaluation of the program with clients indicates that, on average, 2.5 facilitated conversations are needed with the client (and possibly family members as well) in order for the advance care planning process to be successful.

Fraser Health made the discovery that identifying a single care team member as the designated ACP facilitator resulted in other team members not engaging in conversations with patients and families. As a result, the program moved to an interdisciplinary team approach of embedding ACP into professional best practice and away from the approach of designating and certifying facilitators.

Staff involved in the Fraser Health ACP program focus on stories of how the process has worked well for clients who accessed services within the health care system, and of how advance care planning includes more than just decisions about resuscitation, as the following example illustrates:

A client was helped to talk about a project that he wanted to complete before he died of cancer. His sister had heard of the advance care planning program and had connected him to it. His greatest wish was to complete the restoration of an antique car that was sitting in his garage. Once this wish was identified through ACP conversations with the client and his family, he and the family were able to make the car restoration their priority. The project was completed before...
the client died. Both the client and his family reported a sense of life completion; they were also able to grieve before his death. The family’s bereavement was mitigated by feelings of satisfaction that they had helped him to fulfill his wish and had worked together as a family to achieve it. The restored antique car was a legacy of this experience. In the judgment of the family and the Fraser Health staff, the ACP conversations were the catalyst that allowed this process to happen.

During the period from 2004 to 2007, Fraser Health created and revised the My Voice Workbook© and Let's Talk consumer materials and developed a website separate from the hospice palliative care section of the Fraser Health website. The current resources include the My Voice Workbook© in English and Punjabi, an interdisciplinary ACP record, an ACP wallet card, an information booklet and a brochure entitled Making Decisions about CPR. In addition, there are posters in seven languages, educational DVDs in English, Punjabi and Chinese, and an electronic book—Planning in Advance for Your Future Healthcare Choices. Disease-specific considerations have resulted in the creation of educational materials such as a DVD specifically for renal patients.

Fraser Health provides a toll-free information line for British Columbia residents. Fraser Health staff report a growing number of calls from the public and from health care providers outside of the region. Calls from the public outnumber those from health care providers by approximately four to one. Most calls concern requests for ACP materials and clarification about the variety of forms, as well as questions about terminology such as advance directives, advance care planning and power of attorney.

Calls from health care providers come from Fraser Health employees, physicians, community agencies and other health authorities within British Columbia. These callers request ACP materials, information, clarification of forms or terminology, and advice on how to implement ACP in their health authority.

During the past year, there were approximately 175 calls to the toll-free line, and the number of calls increases every year by about 30%. Fraser Health also receives e-mail requests for information from across Canada.

Read on . . .
The next section presents the role of a solid system infrastructure in an effective advance care planning initiative, including some of the mechanisms and tools that have been developed and/or used by some health authorities.
Once a patient has expressed care wishes, the next step is to ensure that, as the individual moves through the health care system, these wishes are made known. In cases where a patient is incapable of giving informed consent to treatment, his or her care wishes can then be acknowledged and respected by the health authority—within the limits of what is possible and medically advisable. This requires systems to be in place to ensure that health care providers are aware of these wishes, as the patient encounters various care settings in the health care network. These systems can include: highly visible documents in health care charts or in the home; mechanisms to ensure that care wishes remain with patients in their trajectory through a variety of health care settings; electronic health care records; and consistent goals of care designations linked to advance care planning across the health care facility or region. In developing and implementing these approaches, it is important to involve managers and staff who look after admissions and records management.

Patients are the owners of their ACP documents (e.g., workbooks or other written material, legal advance directive, goals of care designation form). Health care providers can ensure that these documents are placed in a patient’s chart with a visual identifier (e.g., a coloured plastic folder) or noted in the electronic health record. Each health care sector will make copies of the documents as required.

**Getting started**

- Identify the system requirements to ensure that health care providers in all health care settings are aware of patient wishes in the event that the patient cannot express these wishes. What will it take to deliver the program in terms of documentation and records management?
• Include staff who work in records management, patient registration and admissions when determining system requirements.
• Engage in discussion with paramedics, ambulance attendants and others involved in emergency or first response roles so that they are part of your approach to ensuring that the patient’s wishes are known.
• Determine how your processes for enabling advance care planning will link to the goals of care designation (levels of care coding) that is used in your region: will they be closely integrated as part of your planning and program implementation or will they operate on parallel tracks with some linking mechanisms? How will you ensure that the goals of care designations are consistent throughout your facility or region?

Concrete examples

ACP conversations emphasize patient ownership of ACP documents in Fraser Health Authority. Patients are advised to keep their original ACP documents (if they complete them) and to provide copies to their family, friends or substitute decision maker, and to their physician and local hospital. The green identifying folders described below help to keep ACP documents together in an easily identified way. Patients are routinely encouraged to have ACP conversations with all members of their family, which reinforces the concept of patient ownership.

Fraser Health Authority implemented a new CPR and “Do Not Resuscitate” (DNR) policy for acute care in 2005. This policy includes information about advance directives, reflecting the importance of communication and shared decision making. The DNR orders that are part of this new policy include a record of the process whereby a decision was made: who the physician has spoken with; whether the patient has an advance care plan; and whether the DNR order is in alignment with the patient’s advance care plan. This policy is seen as a crucial building block for embedding ACP into practice. There is a concern to avoid confusion between the terms “DNR” and “transfer to palliative care,” and to reinforce the understanding that DNR does not mean “Do Not Care For.” Fraser Health strives to emphasize those differences in its education sessions and communications with health care providers.

Fraser Health recently began work on a project to designate goals of care in residential care similar to the Calgary Health Region (now Alberta Health Services) model, but its implementation depends on securing funding. An evaluation conducted by Fraser Health on ACP implementation in residential care found that existing coding instruments were still widely used and that there was resistance from health care providers to changing to a new coding system.

A key component of success for Fraser Health has been the adoption of the greensleeve, an 8 ½ x 11 clear green plastic holder, initially in 2005 for DNR orders and later also for ACP documents. The greensleeve is placed on the front of a patient’s chart and is part of the permanent patient record. The use of the greensleeve is mandated for all acute care and residential care in Fraser Health Authority.

The greensleeve will contain the My Voice Workbook©, if the patient has prepared one, the legal advance directive and the Advance Care Planning Record form used by health care professionals to track conversations with patients, family members and substitute decision makers. This record is also meant to include brief notations such as, for example, “My Voice Workbook© introduced,” “ACP conversation initiated with patient.” Its implementation in acute care has been challenging because the record can be perceived as a duplication of information contained in the care providers’ progress notes; it may be more effective in home care. A copy of the Advance Care Planning Record is available at: www.fraserhealth.ca/Services/HomeandCommunityCare/AdvanceCarePlanning/Pages/default.aspx.

12 Fraser Health Authority and Calgary Health Region acknowledge the Respecting Choices® program for developing the greensleeve mechanism.
An evaluation of the use of the greensleeve in acute care showed that its presence in a patient chart indicated that a DNR order was in place. It also found that the greensleeve was being introduced to the ACP Record at a slow rate. Staff said they found it difficult to find time to rewrite this information on the ACP Record. The evaluation concluded that electronic health records would assist in the storage and retrieval of ACP documentation.

A separate community green document holder with attached magnets is provided by the program to be put in a prominent place in the patient’s home (e.g., on the refrigerator). These visual devices allow the patient’s wishes to be quickly identified. For the most part, the My Voice Workbook® is still in the hands of well people within the community; some have already provided copies to their physician and/or local hospital. The impact of the workbooks through the greensleeve mechanism will be felt in future years as these people begin to access services in the health care system.

Calgary Health Region has developed an Advance Care Planning Tracking Record, which is owned by the individual who is responsible for taking it with them as they access services in various health sectors. The document is held in a greensleeve and each sector will take copies of the original for their own records. The ACP Tracking Record will be used to ensure that patients keep clinicians up-to-date about the most recent decisions and information related to their goals of care. The Tracking Record captures the outcomes of ACP conversations in six key areas:

- prognosis and anticipated outcomes of current treatment;
- patient’s values and understanding/expectation of treatment options;
- life-sustaining measures/degree of benefit (e.g., enteral tube feeding, intravenous hydration, dialysis);
- comfort measures;
- resources available (e.g., palliative care, spiritual care, social work, diversity services); and
- goals of care designations.

Calgary Health Region’s Goals of Care Designation Policy is an integral part of its ACP program and links to the My Voice—Planning Ahead portion of the initiative. Patients who have been through the My Voice—Planning Ahead program are more likely to be able to have a meaningful dialogue with their physician or health care team about goals of care. The review of goals of care leads to the designation of goals of care—a process that supports, rather than replaces, the facilitation, reflection and communication vital in advance care planning.

A visual representation used by Calgary Health Region to describe the relationship between advance care planning and the Goals of Care Designation Policy is that of an iceberg:13

**ADVANCE CARE PLANNING: GOALS OF CARE DESIGNATION POLICY**

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13 The image is taken from an educational presentation for Calgary Health Region clinicians working in long-term care and assisted living.
The Advance Care Planning: Goals of Care Designation (Adult) Policy was the result of a broad consultation within the former Calgary Health Region involving clinicians and stakeholders from all sectors of care. The policy standardizes nomenclature regarding care decisions throughout all sectors of care in the region, including acute care, home care, long-term care, assisted living, rural health and emergency services. It supports a communication process that helps care providers and care recipients determine ideal and intentional care choices at any point, including at the end of life. The policy de-emphasizes resuscitation decisions as a sole proxy for care decisions, incorporates the multitude of other common care decisions that people face, and removes the hierarchical nature of care “levels” that have been embedded in systems in the past. The Advance Care Planning: Goals of Care Designation (Adult) Policy is scheduled to be launched throughout the region in late 2008.

The concurrent development of the region’s electronic health record system provides the impetus to format documentation regarding goals of care for integration into the patient’s electronic health record which will be accessible in selective care settings.

The infrastructure development for the Advance Care Planning: Goals of Care Designation (Adult) Policy includes: education (online training modules and workshops for clinicians and train-the-trainer sessions); public communication materials; adaptation of electronic health records and paper records to meet the needs of the policy; and evaluation. The Calgary model stresses interprofessional practice and teamwork, rather than the expert model which is more prevalent in the U.S. The goal is to train all 18,000 health care providers in the region over the next three to four years. Initial evaluation of the framework has been positive—clinicians say they find the framework is clear.

**Potential challenges**

*Developing collaborative processes within the health authority*

The ACP initiatives may involve the entire health system and require a high degree of collaboration. Some health authorities have used the services of experts in these areas to provide input into the development of new processes and infrastructure.

Health care systems are organized through a wide range of ways in many regions of Canada. In some jurisdictions, certain health care providers such as nurses, social workers and physicians are governed by different—and sometimes conflicting—provincial/territorial legislation. In addition, communication among the diverse health care professionals can be challenging if there are no pre-established communication mechanisms.

*Continuity of communication and documentation throughout a health authority*

Infrastructure and information systems across a diverse health region may not be in place to provide continuity of communication and documentation regarding goals of care as a patient makes the transition from one health service to another. Development of these systems and processes is a daunting, but doable, task. While the greensleeve mechanism may involve a paradigm shift, it is also consistent with the move toward patient-centered care and building a sense of partnership with persons receiving health services.

Discussions and decisions that take place in physicians’ offices with patients are often not transferred to other health care settings such as acute, residential and home care. Many regions in Canada are now moving toward the creation of electronic health records. Those involved in advance care planning would need to determine what relevant information as it pertains to ACP should be included in these records, and by what means. While electronic health records are being developed, how will the health authority deal with patient information in the interim?
Consistent terminology throughout the system as the ACP policy is implemented
A risk management consideration with respect to communication and accuracy can arise during the changeover from a previous goals of care designation framework to a new one involving new terminology. Advance preparation work and training can equip staff to minimize the risk of errors in treatment decisions for patients.

Lack of clear documentation may impede honouring patient’s wishes
A further risk management consideration is the risk of patients’ wishes not being honoured due to a lack of clear documentation of those wishes, particularly as the ACP initiative is being implemented progressively throughout a health authority. Mitigation strategies could include: education and support from health care providers who have already completed ACP training; support for decision making by health care providers; and reinforcing the need for patients to bring their ACP documents with them when they access services in different sectors of the health care system.

Read on . . .
The next section addresses the importance of ongoing evaluation and quality improvement in advance care planning initiatives.

Building Block 4
Continuous Quality Improvement

Continuous quality improvement is a given in today’s health care systems. Evaluation enables experience to be critically assessed so that approaches can become most effective and responsive to changing conditions in various settings of care. The elements of continuous quality improvement include: a corporate culture that promotes it as a key component of evidence-based practice; development and testing of measurement and evaluation tools; development of performance indicators (short, medium and long term); mechanisms for sharing what is learned from evaluation; and incorporation of evaluation results into practice on an ongoing basis.
Getting started

• Incorporate evaluation into all programs. This may require the services of a quality improvement specialist, which is a good investment in quality and credibility for the program.
• Develop baseline measurements as a basis for comparison.
• Develop indicators for structure, process and outcomes.
• Develop indicators for the short, medium and long term.
• Develop a process of debriefing and follow-up for incidents (e.g., when patient care does not match the goals of care choices and designations).
• Develop processes for regular review of evaluation results for learning and improving performance.
• Link the ACP program to quality initiatives such as the use of InterRAI assessment tools, accreditation standards developed by Accreditation Canada and patient safety initiatives.
• To the extent that resources and time permit, engage in learning from others. Participate in opportunities for knowledge translation and exchange.
• Consider engaging in research projects involving ACP. This may be a means of enhancing quality improvement and involving staff in rewarding projects.

Concrete examples

The first example comes from the evaluation of the implementation of the Respecting Patient Choices program in Australia. The Australian model is built on the same foundation as the Calgary Health Region and Fraser Health models, namely the Respecting Choices® model from the Gundersen Lutheran Medical Center in Wisconsin. Given the similarities between Australia’s governmental and health care systems and Canada’s, their evaluation findings could be relevant to our health care systems. The Australian Respecting Patient Choices program was deemed to be a success in its initial implementation in the Melbourne region and is now being piloted for dissemination in care facilities for the aged and in hospitals throughout the country. Evaluation was a crucial element in learning how to improve the program and implement it in new locations. Evaluation tools included consultation, feedback, observations, surveys, interviews and data collection.

An evaluation conducted on the implementation of Respecting Patient Choices in 17 long-term care facilities for the aged and in three hospitals in Australia revealed the following key factors for success:14

• integrating the ACP program into the existing health care culture;
• ACP consultation support for the health care facility;
• support from the executive and the organization’s governing body;
• leadership from the executive, clinical leaders and nursing managers;
• system changes to documentation processes;
• education, skill development and support for staff; and
• involvement of the legal system with respect to advance directives.

Barriers to implementation were:

• challenges related to space, staffing (including staff turnover) and time;
• lack of flexibility in the program in response to local conditions; and
• challenges relating to the state legal requirements for advance directives.

These evaluation results echo many of the lessons learned in Calgary Health Region and Fraser Health Authority. Both stress that quality improvement will be most effective if it is integrated into activities from the start.

Calgary Health Region’s quality improvement approach to the implementation of the *My Voice—Planning Ahead* program and the Goals of Care Designation Policy includes a range of evaluation tools for clinicians, patients, facilitators and families or substitute decision makers. These tools are developed by a professional evaluator who is a member of the project team responsible for analysis and feedback to the team. Pre- and post-training and pre- and post-implementation evaluations are done to provide comparative data. In addition, evaluation is conducted during the implementation process.

Calgary Health Region uses the following indicators:

**Short-term indicators**
- number and percentage of patients and health care providers who report finding ACP discussions beneficial (surveys)
- number of program areas that have action plans to implement *My Voice—Planning Ahead*
- number of program areas implementing *My Voice—Planning Ahead*
- self-reported (survey) rating of ACP facilitators’ comfort, confidence, knowledge and skills before and after completing ACP training and integrating it into practice

**Medium-term indicators**
- number and percentage of patients’ family members who report finding ACP discussions beneficial (survey)
- percentage of targeted patients having ACP discussions and percentage of targeted patients completing advance directives (chart review)
- percentage of times that patients’ ACP information transfers accurately across service streams (chart review)
- number of trained ACP facilitators
- number of programs implementing *My Voice—Planning Ahead*
- standardized Advance Care Planning: Goals of Care Designation (Adult) Policy being developed, implemented and supported across Calgary Health Region

**Long-term indicators**
- percentage of patients whose preferences identified in their advance directives are followed as they receive medically appropriate end-of-life care (chart review)
- number and percentage of programs that have an interdisciplinary health care team prepared to facilitate ACP discussions
- percentage of seniors, acutely ill patients and healthy adults who have the opportunity to engage in an ACP discussion (chart review)

The *My Voice—Planning Ahead* program has been piloted in several sites in Calgary Health Region: the ALS clinic, the renal ambulatory care, the *Living Well* chronic disease management program, three cardiac function outpatient clinics and a long-term care centre. In each case, the team chose how to pilot and adapt the program to their own unique needs.

Early evaluation results from 60 patients who participated in the *My Voice—Planning Ahead* process show that 86% found the discussions helpful and 89% reported that the discussions made a positive difference. Overall, patients found ACP discussions helpful across the disease trajectory (several chronic conditions were involved).

Evaluation done prior to training and implementation of the *My Voice—Planning Ahead* program in participating sites showed that the sites had few policies or practices related to advance care planning and that social workers had been the most involved in ACP discussion with patients. A chart audit of close to 300 patient charts from the five participating sites showed that only 8% of patients had an advance directive, and in 39% of these advance directives health care
preferences were not documented. Where treatment preferences were documented, there was a focus only on resuscitation/no resuscitation, which was a limiting view of the possible care preferences. An ongoing evaluation to be conducted one year and two years after implementation will compare these indicators and help determine the impact of the program.

The small number of Calgary Health Region physicians who participated in one-day training sessions in ACP facilitation in 2007 provided positive evaluations. Particularly helpful lessons learned included: framing questions such as “What are your goals for care?”; learning that other members of the team were competent to facilitate the conversations about advance care planning, while the physician might be called on to discuss with the patient questions involving medical expertise; the need to document the series of conversations with patients and families that may occur over time; the value of consistent documentation throughout the system; and linking the conversations with patients to the new process for standardizing codes for goals of care. Challenges identified by physicians were: time constraints in having long conversations with patients; ensuring that physicians were trained by physicians, thus lending greater credibility to the training; and including other members of the care team in the training and implementation process.

Fraser Health Authority has incorporated quality improvement into its ACP program and has initiated several pilot projects. In 2004, a pilot project was started with the Fraser Health renal program, and four pilot projects were carried out in residential care in 2005. In 2006, advance care planning was implemented across all sectors of the community in White Rock/Surrey.

Nephrology patients face difficult decisions about whether to continue or stop treatment. If treatment is stopped, death can be expected within days or weeks. The staff working in the Fraser Health renal program thought that they owed it to their patients to provide support around this decision-making process given the likelihood of mortality (25% of patients each year). The median age of the dialysis population is over 65 years of age; the average life expectancy of a 70-year-old patient starting dialysis is less than three years. Consequently, many renal care staff were trained in the ACP process and the Let’s Talk tools (including the My Voice Workbook© and supporting educational materials) were used in the program. The 2004 pilot of 35 renal patients noted the following findings after advance care planning was initiated:

- 86% of patients continued the ACP conversation with family members.
- 71% completed the My Voice Workbook©.
- 86% had the advance care plan filed on their patient chart.
- 91% of nephrologists were notified of the patient’s advance care plan.
- 100% of patients had their end-of-life wishes honoured.

A review of the pilot further concluded that advance care planning improved care from the patient’s perspective by avoiding prolongation of dying, giving the patient a sense of control, relieving emotional burdens, strengthening personal relationships, and providing access to pain and symptom control at the end of life. From the perspective of the renal program, clear decisions could be made with patients to continue dialysis when benefits outweighed burdens, and staff were able to ensure that the patient felt well cared for through all stages of the disease. As a result of the renal program’s early involvement in the Let’s Talk initiative, the program is currently producing an interactive educational DVD specifically for health care providers in the renal program.

Fraser Health has implemented advance care planning in acute care, residential care and home care settings. The InterRAI assessment instruments used in residential and home care contain questions about advance directives and can be used to introduce clients to the program.
The Fraser Health Authority InterRAI educator liaises with the ACP program. A link to the ACP program is available on the InterRAI assessment tool. Staff completing the assessment can then easily access definitions and other information on ACP which can support a fuller conversation with the client. An evaluation of the results of InterRAI home care assessments during a five-month period in 2007 revealed that only 14% of individuals reported having an advance directive.

An evaluation of the ACP program implemented in all health sectors in White Rock/Surrey found that implementation was challenged, particularly in acute care settings, by staff changes at the executive and front-line level. Uptake in some physician offices was encouraging: an increase in ACP conversations and written advance care plans was noted in addition to an increase in the number of advance care plans filed at the participating hospital.

The evaluation also found that the pressure to discharge patients from acute care presented a challenge to staff being able to engage patients in ACP conversations, which take place over time. Additional challenges in acute care included privacy concerns, staffing levels and lack of time. In response to these challenges, an ACP referral card was developed to give to short-stay patients. The card provides the patient with information on advance care planning, including the toll-free telephone number and web address for the Fraser Health ACP program.

**Potential challenges**

**Quality improvement resources**
Not all health authorities can access the resources of a quality improvement specialist. Evaluate the time and resources at your disposal and determine which quality improvement efforts are realistic.

**Surveys**
When the pre- and post-surveys were done with clinicians, Calgary Health Region learned that it should allow more time for physicians to work within the ACP framework and provide communication guidelines before doing the post-surveys. Calgary Health Region also found that initiating patient feedback forms too soon was intimidating for some physicians who were putting new or enhanced communication skills into practice.

Read on . . .
The final section of this Guide brings the building blocks together, in context, and presents a sample logic model that may serve as a useful planning tool for health authorities considering or undertaking an advance care planning initiative.
Each of the four building blocks of the advance care planning model is essential to the success of an ACP initiative. Keeping this clearly in mind throughout the entire process of development and implementation can be a challenge. While it may be expedient to focus on one or two building blocks when targeted funding becomes available or when a partnership opportunity arises, in the long run, the initiative will be most effective if all four building blocks are developed concurrently and interactively.

Evaluation is sometimes planned to take place only as an activity is ending. The experience of several programs indicates that evaluation and quality improvement are most fruitful if they are planned from the start as an integral part of the program. Similarly, a strong investment in community engagement may lead to frustration if there are no mechanisms for enabling ACP in response to client demand. Without system-wide mechanisms to ensure that care wishes are known and respected, the program will eventually be seen as a failure by health care providers and the public.

**Using a logic model to link the building blocks**

A helpful device for planning and monitoring progress in keeping all four building blocks linked is a logic model, which defines objectives, impacts and resource requirements in all components of an initiative. The former Calgary Health Region (now Alberta Health Services) team has used the logic model as a point of reference throughout the development and implementation phases of its initiative. An example of the logic model appears at the end of this section (page 43).

The illustration below depicts how the essential elements discussed in the Guide are interlinked:

- the **four basic building blocks** of the model with the patient and family at the centre of the model
- the **policy and resource environment** in which your health authority functions

All of these elements are important and function in an interactive and interdependent way. The diagram below may be a useful map for planning as you learn how each of the elements can be developed for your particular health authority, community and jurisdiction. You may find the four basic building blocks useful in constructing your logic model. Given the number of elements to consider, the time you devote to learning and planning will be well spent. As our examples have shown, there is no “right way” to do it or to begin. Your knowledge of your particular realities will determine the best way forward for your health authority.
PUTTING IT ALL TOGETHER: A COMPREHENSIVE APPROACH

Policy environment
- Health authority
- Provincial/territorial
- Legislation
- Regulations
- Other health care/social service frameworks

Resources
- People
- Time
- Funding
## Calgary Health Region, Care at the End of Life (CEOL) Initiative
### Logic Model, April 2007–March 2008

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Activities</th>
<th>Outputs</th>
<th>Short-Term Outcomes One Year (April 2007–March 2008)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematize consistent ideal practice in advanced care planning (ACP)</td>
<td>Continue and expand implementation of My Voice—Planning Ahead as the Calgary Health Region's and Calgary community's vehicle for facilitating ACP discussions in target populations where opportunities exist</td>
<td>• Number of programs implementing My Voice—Planning Ahead • Percentage of targeted patients that have ACP discussions • Number of resources distributed • Number of internal/external website hits</td>
<td>• Patients find the discussions beneficial (ongoing) • Clinicians find the ACP process and accompanying documents beneficial (ongoing) • Increase in the number of programs/service units implementing the My Voice—Planning Ahead program</td>
</tr>
<tr>
<td>Continue and expand implementation of a training program for My Voice—Planning Ahead in target areas, based on a “train the trainer” model</td>
<td>• Number of discussion facilitators trained • Number of trainers trained</td>
<td>• Increase in clinicians’ ACP awareness/basic knowledge • Increase in clinicians’ comfort, confidence, knowledge and skill in ACP facilitation (ongoing) • Increase in the number of trained discussion facilitators • Facilitators integrate training into practice • Policy Resource Teams established</td>
<td></td>
</tr>
<tr>
<td>Develop regional policies related to end-of-life (EOL) care that are standardized across the region and support best practice for care at the end of life</td>
<td>Implement the Advance Care Planning: Goals of Care Designation (Adult) Policy (ACP: GCP Policy)</td>
<td>• Number of clinicians trained (basic and in-depth) • Number of trainers trained • Number of tools and forms developed and available regionally</td>
<td>• Electronic health record and paper records adapted to meet ACP: GCP Policy needs • 80% of clinicians receive basic policy education • Clinicians increase their awareness, knowledge and application of the policy • Systemic support for policy in place • Shift from old designations to new (all sectors) • Policy tools are held and used by clinicians and revised • ACP: GCP Policy tools and forms are developed and regionally available • Processes for determining, documenting, transferring and enacting goals of care designations determined</td>
</tr>
<tr>
<td>Extend palliative and hospice care to a broader patient population</td>
<td>Collaborate with Hospice and Palliative Care and Home Care to identify and address gaps in service and extend care to a broader patient population</td>
<td>Percentage of palliative and hospice beds accessed by non-cancer population</td>
<td>Increased access to hospice and palliative beds for a broader population base</td>
</tr>
<tr>
<td>Promote planning that includes palliative care with all program services</td>
<td>Collaborate with leaders in Long-Term Care and Seniors’ Health to embed CEOL strategies in program best practice/services</td>
<td>Number of clinicians trained to provide best practice EOL care</td>
<td>To be determined</td>
</tr>
<tr>
<td>Collaborate with leaders in Chronic Disease Sectors to embed CEOL strategies in program best practice/services</td>
<td>Number of palliative care specialists placed within Chronic Disease and Long-Term Care programs</td>
<td>To be determined</td>
<td></td>
</tr>
</tbody>
</table>

**Purpose:** To nurture quality of care within a person’s experience at the end of life.

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**Guiding Principles/Assumptions:**
1. Death is a natural and inevitable part of life.
2. The experience of dying and of death both includes and transcends the health care system.
3. Individuals living with advanced illness, together with their families, benefit from care that includes a focus on end-of-life care issues.
4. Individuals and their families bring unique sets of values and beliefs that guide them in making decisions regarding end-of-life care.
5. When provided with the appropriate education and skill development regarding end-of-life care, the quality of work experience for health care practitioners is enhanced.
6. Community collaboration is essential in developing a holistic understanding of death and dying for individuals within that community.
7. Providing quality end-of-life care is a cost-shifting rather than a cost-saving endeavour.
8. Both community and health system leadership are essential to influence the culture shift required for success in this project.
<table>
<thead>
<tr>
<th>Long-Term Outcomes</th>
<th>Impacts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Two to Five Years (April 2008–March 2012)</strong></td>
<td><strong>Six to Ten Years (April 2012–March 2017)</strong></td>
</tr>
<tr>
<td>• Patients’ families find the ACP process beneficial</td>
<td>• Support from community leaders and engagement of community partners is evident through uptake of Calgary Health Region’s ACP activities</td>
</tr>
<tr>
<td>• Increase in percentage of targeted patients having ACP discussions</td>
<td>• 75% of seniors, acutely ill patients and healthy adults are provided the opportunity to have an ACP discussion</td>
</tr>
<tr>
<td>• Increase in percentage of targeted patients completing advance directives</td>
<td>• Regional policies consistently address issues related to care at the end of life</td>
</tr>
<tr>
<td>• Increase in awareness and use of ACP in the community</td>
<td>• Decreased acute care utilization by Long-Term Care and Designated Assisted Living patients</td>
</tr>
<tr>
<td>• When medically appropriate, patients’ wishes as identified in their advance directives are followed across the continuum of care</td>
<td>• Appropriate palliation and EOL care services are offered to individuals facing the end of life and to their families, regardless of disease progress, age or setting</td>
</tr>
<tr>
<td>• All chronically ill patients are provided the opportunity to have an ACP discussion</td>
<td>• EOL care is defined and implemented in best practice standards for all disease group/areas of service</td>
</tr>
<tr>
<td>• Every program/service unit serving chronically ill patients has a multidisciplinary health care team prepared to facilitate ACP discussions</td>
<td>• Health systems monitor EOL care indicators and resource utilization in program planning and quality improvement initiatives</td>
</tr>
</tbody>
</table>

**Implementation of strategies to increase sharing of hospice and palliative services**

To be determined

**To be determined**

**Internal Inputs/Resources:** 9 FTE Project Manager; 3 FTE Palliative Physician; 5 FTE QI Consultant; 62 FTE Admin Support (6); 3.75 FTE Education Specialist; 1 FTE Policy Implementation Coordinator; Physical space and office infrastructure through Southeast Community Portfolio; Seniors Health—Administrative Leadership from Director and Medical Director; Seniors Health and Palliative Care.

**External Inputs/Resources:** Advisory Groups—CEOL Advisory Committee; CEOL Community Task Group; Policy Implementation Advisory Committee; Collaborative Partnership/Mentorship from Palliative Care, Fraser Health Services; Resource Experts—Calgary Health Region’s Legal Affairs, Communications, Health Policy, and Quality Safety & Health Information; Consultants from Respecting Choices™, Gunderson Lutheran Medical Center, Wisconsin.
Resources

Advance Care Planning

The former Calgary Health Region (now Alberta Health Services)—Care at the End of Life Initiative—Advance Care Planning:

www.calgaryhealthregion.ca/programs/advancecareplanning/acpgcdpolicy.htm

Resources for the public and for health care professionals: project overview and background; MyVoice—Planning Ahead resources; Calgary Health Region resuscitation policy revisions; (for health care professionals) evaluation and quality improvement; Advance Care Planning: Goals of Care Designation Policy; educational materials for health care professionals; quality improvement tools.

Materials on the Calgary Health Region website are updated regularly and new materials are added as they become available.

Fraser Health Authority—Advance Care Planning: www.fraserhealth.ca/Services/HomeandCommunityCare/AdvanceCarePlanning/Pages/default.aspx

Resources for the public: general information about advance care planning; My Voice workbook; wallet card; order form; ACP e-book (Planning in advance for your future healthcare choices); brochures and posters; presentation materials and action list from the Inaugural Canadian Symposium on Advance Care Planning (May 2007); CPR and DNR Orders—policy; DNR Physician’s Orders; ACP Record form; ACP Improvement Plan.

Materials on the Fraser Health Authority website are updated regularly and new materials are added as they become available.

Health Quality Council of Alberta—Quality Matrix for Health: www.hqca.ca

Respecting Choices®—Gundersen Lutheran Medical Center: www.gundluth.org/eolprograms

Australia: Respecting Patient Choices: www.respectingpatientchoices.org.au


Other Health Care Frameworks

**Chronic disease management models**
- British Columbia Ministry of Health Chronic Disease Management: [http://www.health.gov.bc.ca/cdm/](http://www.health.gov.bc.ca/cdm/)
- Calgary Health Region: [www.calgaryhealthregion.ca/cdm/](http://www.calgaryhealthregion.ca/cdm/)

**Patient self-management**
- University of Victoria Centre on Aging, Chronic Disease Self-Management program: [www.coaag.uvic.ca/cdsm.html](http://www.coaag.uvic.ca/cdsm.html)
- Stanford University School of Medicine Patient Education Research Center: [http://patienteducation.stanford.edu](http://patienteducation.stanford.edu)

**Primary health care—interprofessional practice**
- Local Health Integration Networks (Ontario): [www.health.gov.on.ca/transformation/lhin/lhin_mn](http://www.health.gov.on.ca/transformation/lhin/lhin_mn)

**Patient safety**
- Canadian Patient Safety Institute: [www.patientsafetyinstitute.ca](http://www.patientsafetyinstitute.ca)

**Long-term care**
- Canadian Healthcare Association: [www.cha.ca](http://www.cha.ca)

**Goals of care designation (levels of care)**
- POLST: [www.ohsu.edu/polst](http://www.ohsu.edu/polst)
- Calgary Health Region Code Level policy background paper

**Home care**
- Canadian Home Care Association: [www.cdnhomecare.ca](http://www.cdnhomecare.ca)

**Strategies for seniors**
- Nova Scotia—Strategy for Positive Aging
- Manitoba—Advancing Age: Promoting Older Manitobans: [www.gov.mb.ca/shas/advancingage](http://www.gov.mb.ca/shas/advancingage)
**Programs and services for seniors**
- Ontario: www.citizenship.gov.on.ca/seniors/english
- British Columbia: www.healthservices.gov.bc.ca/seniors
- Alberta: www.seniors.gov.ab.ca
- Saskatchewan: www.health.gov.sk.ca/seniors
- New Brunswick: www.gnb.ca/0017/Seniors/index-e.asp

**Disease-specific strategies**
- Cancer—Canadian Association of Provincial Cancer Agencies (links to all jurisdictions): www.capca.ca

**Hospice palliative care**
- Canadian Hospice Palliative Care Association: www.chpca.net
  - *A Model to Guide Hospice Palliative Care* and materials for National Hospice Palliative Care Week (theme for 2006–2008 is advance care planning)

**InterRAI**
- http://interrai.org

**Caregiver strategies**
- Nova Scotia