Evidence Brief:
Improving End-of-life Communication, Decision-making and Care in Ontario

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McMaster Health Forum

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Conflict of interest

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Merit review

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Table of Contents

KEY MESSAGES.................................................................................................................. 5

REPORT................................................................................................................................. 7

Key definitions .................................................................................................................... 8

Key features of the health policy and system context in Ontario........................................ 11

THE PROBLEM...................................................................................................................... 14

Many die each year and many more are affected by these deaths........................................ 14

Few people engage in conversations about end-of-life issues ............................................. 14

Current programs and services may not be fully aligned with Ontarians’ needs and preferences ...... 15

Current health system arrangements may limit capacity to improve the situation............... 16

Many agreed upon courses of action, while promising, have not yet been fully implemented...... 18

Additional equity-related observations about the problem.................................................. 24

THREE ELEMENTS OF A COMPREHENSIVE APPROACH FOR ADDRESSING THE PROBLEM ................................................................................................................................. 26

Element 1 - Better align health system arrangements to support end-of-life communication, decision-making and care........................................................................................................ 27

Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care.......................................................................................................................... 31

Element 3 - Strengthen citizens’ capacity to engage in communication and decision-making about end-of-life care.................................................................................................................... 34

Additional equity-related observations about the three elements........................................ 37

IMPLEMENTATION CONSIDERATIONS............................................................................... 38

REFERENCES......................................................................................................................... 41
KEY MESSAGES

What's the problem?
• The challenges in improving end-of-life communication, decision-making and care in Ontario can be understood by considering five manifestations of (or contributors to) the problem:
  o many die each year and many more are affected by these deaths;
  o few people engage in conversations about end-of-life issues;
  o current programs and services may not be fully aligned with Ontarians’ needs and preferences;
  o current health system arrangements may limit capacity to improve the situation; and
  o many agreed upon courses of action, while promising, have not yet been fully implemented.

What do we know (from systematic reviews) about three viable elements of a comprehensive approach to address the problem?
• Element 1 – Better align health system arrangements to support end-of-life communication, decision-making and care
  o We found a large body of synthesized evidence, including several high-quality systematic reviews that revealed benefits for key components of this element, such as home-based palliative and end-of-life care, quality-improvement strategies, public reporting of performance indicators, and knowledge-translation strategies. Findings also reveal the need to be mindful about the potential unintended consequences of public reporting programs, and the risk of widening disparities for low socio-economic patients and those with complex healthcare needs.
• Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care
  o We found a large body of synthesized evidence, including several high-quality systematic reviews, that revealed benefits for key components of this element, such as communication skills training, training in a patient-centred approach, practice-based interventions designed to improve interprofessional collaboration, and financial incentives.
• Element 3 – Strengthen citizens’ capacity to engage in communication and decision-making about end-of-life care
  o We found several high-quality systematic reviews that revealed benefits for key components of this element, including: planned and unplanned mass media campaigns (in terms of their influence on the utilization of health services); interventions before consultations for helping patients address their information needs (e.g., patient coaching with or without complementary written materials); patient decision aids; and interventions for supporting informal caregivers of patients in the terminal phase of a disease (e.g., providing support in the caring role, family life review and grief therapy).

What implementation considerations need to be kept in mind?
• Potential barriers to improving end-of-life communication, decision-making and care in Ontario can be identified at the level of patients/individuals (e.g., some may be reluctant to engage in end-of-life conversations because of cultural norms), providers (e.g., some may grapple with prevalent and persistent misconceptions about current statutes governing healthcare decisions), organizations (e.g., some may lack the capacity to coordinate consistent educational content and activities across settings), and systems (e.g., system leaders may perceive end-of-life care as ‘boutique’ care, which may jeopardize funding sustainability).
• Efforts to address these barriers need to be attentive to potential windows of opportunity (e.g., end-of-life appears to be on the government agenda; numerous initiatives that are currently underway are generating significant momentum, such as the implementation of the 2011 Declaration of Partnership and Commitment to Action; and the upcoming negotiations to establish the next Physician Services Agreement may be conducive to raising end-of-life communication, decision-making and care higher on the governmental agenda).

Evidence >> Insight >> Action
Improving end-of-life communication, decision-making and care has been identified as a pressing health issue in Ontario (and in Canada more generally), as evidenced by recent research(1;2) public opinion polls,(3) expert panels and commissions,(4-6) and a high-profile legal case,(7) which have revealed many challenges in this area. The importance of this issue is also reflected by a strong push from various organizations to support citizens in having informed conversations about end-of-life issues and engaging in formalized advance care planning.(8) Large advocacy coalitions dedicated to quality end-of-life care,(9;10) numerous initiatives to support high-quality integrated palliative and end-of-life care, including implementation of the 2011 Declaration of Partnership and Commitment to Action,(11) as well as an active research community dedicated to this issue.(12)

This issue appears especially important given the increasing proportion of the Ontario population that is over the age of 65, the growing prevalence of patients with life-limiting chronic conditions and complex care needs, and a constantly evolving technological landscape promising life-saving or life-prolonging possibilities.(3;4;13) Nevertheless, Ontario still lacks a comprehensive end-of-life strategy, similar to what exists in two other provinces.(14;15)

In May 2013, the Ontario Medical Association (OMA) announced that it will play a leading role in developing a comprehensive strategy for end-of-life care that would support advance care planning and improve access to high-quality palliative and end-of-life care. The OMA is committed to raising awareness of end-of-life issues and to educating the public on the actions that individuals can take to express wishes that will guide their future healthcare at the end-of-life and during a time of crisis.(16;17)

Taking action to improve end-of-life communication, decision-making and care in Ontario is challenging since it deals with issues that are at “the intersection of law and medicine,”(18) and it requires careful consideration of a broad array of interdependent factors that contribute to the problem. Efforts to address these factors will need to foster inter-sectoral collaborations and continue to build on the momentum generated by initiatives at the local, provincial and national levels.

Box 1: Background to the evidence brief

This evidence brief mobilizes both global and local research evidence about a problem, three elements of a comprehensive approach for addressing the problem, and key implementation considerations. Whenever possible, the evidence brief summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies and to synthesize data from the included studies. The evidence brief does not contain recommendations, which would have required the authors of the brief to make judgments based on their personal values and preferences, and which could pre-empt important deliberations about whose values and preferences matter in making such judgments.

The preparation of the evidence brief involved five steps:

1) convening a Steering Committee comprised of representatives from the partner organization, researchers and the McMaster Health Forum;
2) developing and refining the terms of reference for an evidence brief, particularly the framing of the problem and three viable elements of a comprehensive approach for addressing it, in consultation with the Steering Committee and a number of key informants, and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
3) identifying, selecting, appraising and synthesizing relevant research evidence about the problem, options and implementation considerations;
4) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence; and
5) finalizing the evidence brief based on the input of several merit reviewers.

The three elements of a comprehensive approach for addressing the problem were not designed to be mutually exclusive. They could be pursued simultaneously or in a sequenced way, and each element could be given greater or lesser attention relative to the others.

The evidence brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants’ views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. A second goal of the stakeholder dialogue is to generate action by those who participate in the dialogue and by those who review the dialogue summary and the video interviews with dialogue participants.
This evidence brief and the stakeholder dialogue it was prepared to inform were designed to guide the actions of those involved in improving end-of-life communication, decision-making and care in Ontario in order to further the patients’ interests. The brief reviews the research evidence about: 1) key features of the problem; 2) three elements of a potentially comprehensive approach to address the problem; and 3) key implementation considerations for moving forward.

Within this scope, the evidence brief is focused only on the best available evidence and (as explained in Box 1) does not contain recommendations. In addition, a number of issues were deemed too broad to be addressed within the scope of this brief, including futile medical interventions, assisted suicide, euthanasia and organ donation.

Before exploring the key features of the problem, the evidence brief proposes key definitions to ensure some common conceptual foundations for the deliberations. Then, the brief highlights key features of the health policy and system context in Ontario that need to be considered for improving end-of-life communication, decision-making and care.

Key definitions

This evidence brief uses several key terms that need to be defined at the outset, and if applicable, situates them within the context of Ontario’s legal framework. These concepts are: end-of-life care, palliative care, terminal illness, end-of-life communication and decision-making (which also include advance care planning, goals of care designation and consent to treatment, and documentation), informed consent, substitute decision-maker, cardiopulmonary resuscitation (CPR), do-not-resuscitate (DNR) and allow-natural-death (AND).

In this evidence brief, end-of-life care refers to care that is provided to help those with advanced, progressive and incurable illnesses (including advanced life-limiting chronic conditions) to live as well as possible until they die. It supports the needs of patients, families and caregivers throughout the last phase of life and into grief and bereavement. End-of-life care also includes the management of pain and other symptoms, as well as the provision of psychological, emotional, social, spiritual and practical support.(19)

Palliative care is defined here as interdisciplinary care “focused on relief of pain and other symptoms and support for best possible quality of life for patients with serious illness and their families. It is appropriate at the point of diagnosis of a serious illness and provides an extra layer of support for patients and families.”(20) Palliative care also includes psychological, emotional, social, spiritual and practical support, both for patients and their families, in order to provide comfort and dignity at the end of life.(21;22)

Box 2: Equity considerations

A problem may disproportionately affect some groups in society. The benefits, harms and costs of elements to address the problem may vary across groups. Implementation considerations may also vary across groups.

One way to identify groups warranting particular attention is to use “PROGRESS,” which is an acronym formed by the first letters of the following eight ways that can be used to describe groups†:

- place of residence (e.g., rural and remote populations);
- race/ethnicity/culture (e.g., First Nations and Inuit populations, immigrant populations and linguistic minority populations);
- occupation or labour-market experiences more generally (e.g., those in “precarious work” arrangements);
- gender;
- religion;
- educational level (e.g., health literacy);
- socio-economic status (e.g., economically disadvantaged populations); and
- social capital/social exclusion.

The evidence brief strives to address all Ontarians, but (where possible) it also gives particular attention to two groups:

- frail elderly citizens; and
- first-generation immigrants.

Many other groups warrant serious consideration as well, and a similar approach could be adopted for any of them.

† The PROGRESS framework was developed by Tim Evans and Hilary Brown (Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. Injury Control and Safety Promotion 2003;10(1-2): 11–12). It is being tested by the Cochrane Collaboration Health Equity Field as a means of evaluating the impact of interventions on health equity.
Terminal illness refers to “an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months.” (21)

This brief also draws from the conceptual framework developed by the Canadian Researchers at the End of Life Network (CARENET), which broadly defines end-of-life communication and decision-making as a communication process that includes discussion of death and dying (e.g., as potential outcomes of treatment or illness progression). (23) Elements could include: “bidirectional sharing of illness understanding (both incurable and progressive in nature) including possible survival duration and likely outcomes of therapeutic approaches; expression of a person’s values and what has meaning for him/her and the care goals they have for the current context of care; understanding how this person, their substitute decision maker and their family/informal caregivers prefer to make decisions; expressions by the healthcare team members regarding the benefit or lack of benefit of life-sustaining treatments given the patient’s clinical situation and values; [making] decisions regarding level of care and aligning them with the patient’s goals for their care; consenting to treatment/withholding treatment (including having discussions about resuscitative measures, medical treatment without resuscitative measures, and care focused on comfort); and documenting and communicating the decisions within the health care team, across sectors and among the person, their agent, and/or family.” (23)

CARENET’s conceptual framework also distinguishes three dynamic processes involved in Ontario’s end-of-life communication and decision-making: 1) advance care planning, 2) goals-of-care designation and consent to treatment, and 3) documentation (Figure 1).

Figure 1. Ontario’s end-of-life communication and decision-making [adapted from CARENET, 2013]
Another key concept within the Ontario legal framework is that of substitute decision-maker, which is defined as a person who is appointed to make healthcare decisions on behalf of a patient when a patient is incapable of providing consent to treatment or refusal of treatment. The role of the substitute decision-maker is not to develop an advance care plan or to express wishes on behalf of the patient, but to make decisions based on any known wishes from the patient, or to make decisions in the patient’s best interest when there are no known wishes applicable to the decision to be made. A substitute decision-maker can be appointed through a Power of Attorney for Personal Care. However, even if a person does not prepare a Power of Attorney for Personal Care and becomes incapable of making personal care decisions, the Ontario legislation established a hierarchy list of substitute decision-makers that can be authorized to act in this role.

This legal framework provides the context within which the three processes characterizing end-of-life communication and decision-making can occur in Ontario. The first process relates to advance care planning. It refers to a communication process wherein people plan for a time when they cannot make decisions for themselves. It includes reflection and deliberation about, and determination of, wishes for health and personal care that one would want if one became incapable of consenting to or refusing treatment and care. It includes communication between an individual, their loved ones, their substitute decision-maker, and their healthcare provider(s) about their values and wishes for end-of-life care. It may result in the naming of a person who will provide consent for health or personal care if they become incapable (i.e., a substitute decision-maker) and the specification of treatments or care they do or do not want at the end of life. Advance care planning is not just for the elderly or those diagnosed with life-limiting conditions and terminal illnesses. Anyone can engage in advance care planning with their families, friends, healthcare providers and substitute decision-makers at any stage in their lives. While advance care planning can happen in any setting, the literature would suggest that this optimally should occur in primary care settings.

Advance care planning may lead to an advance care plan. The outcome of this process may vary depending on whether the person is a healthy individual or a patient with a life-limiting condition or terminal illness. Thus, some advance care plans may be more general and highlight the person’s general wishes and values, while other advance care plans may express very specific wishes that are medically oriented if a person has knowledge of the likely progression of their condition and the relevant treatment and care options.

When reflecting about advance care planning within the Ontario legal framework, eight elements must be considered:

- advance care planning is not a discrete issue in the law, but it is part of (and related to) the process for obtaining informed consent;
- an advance care plan, no matter how specific, is an expression of a person’s wishes, and these wishes must be contextualized by a discussion with healthcare providers (about the disease, the prognosis, the treatment options, etc.), and they cannot replace informed consent regarding healthcare decisions, which must be sought by healthcare providers from a capable patient or the substitute decision-maker if the patient is incapable;
- an advance care plan provides direction to the substitute decision-maker, not the healthcare providers (with the exception of an emergency), in order to help the substitute decision-maker feel confident in making future decisions if the patient becomes incapable;
- healthcare providers are only allowed to provide treatment without obtaining consent in case of an emergency, but they are required to follow any known wishes that are applicable to the circumstances;
- the substitute decision-maker is required to follow the patient’s wishes when giving or refusing consent, but also must determine if the wishes are applicable and relevant to the treatment decisions to be made and must interpret what the patients intended and meant by their wishes;
- completing an advance care plan is voluntary;
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The following key features of the health policy and system context in Ontario are particularly germane to end-of-life communication, decision-making and care:

**Health policy context**

- delivery of healthcare is primarily the responsibility of provincial and territorial governments in Canada and financing is shared between the federal and provincial/territorial governments, and the federal government has available to it certain policy levers to improve palliative and end-of-life care, such as transfer payments, setting priorities for research funding, offering assistance to caregivers (e.g., Compassionate Care Benefits), establishing standards for palliative and end-of-life care, and acting as a facilitator for collaborative pan-Canadian initiatives;
- Ontario’s publicly funded health system is distinguished by a long-standing private delivery/public payment agreement between government on the one hand, and physicians and hospitals on the other;
- the agreement with physicians has historically meant that most healthcare is delivered by physicians working in private practice with first-dollar (i.e., no deductibles or cost sharing), public (typically fee-for-service at least in part) payment;

**Key features of the health policy and system context in Ontario**

The following key features of the health policy and system context in Ontario are particularly germane to end-of-life communication, decision-making and care:

- an advance care plan can take many valid forms in Ontario: written (e.g., Power of Attorney for Personal Care), verbal, braille and any other means that a patient may use to communicate;(18) and
- the Power of Attorney for Personal Care is the only legal document in Ontario that can authorize the appointment of a substitute decision-maker for healthcare decisions.(18,25,27)

The second process in end-of-life communication and decision-making is referred to here as *goals-of-care designation and consent to treatment.*(23) It refers to a communication process that usually occurs in a setting where care is provided (e.g., home, hospice, hospital), follows a prescribed communication process according to the Healthcare Consent Act and Substitute Decisions Act, and results in medical decisions. This communication process will lead to medical decisions that get reduced to (or become enacted through) a physician order for scope of treatment, including the use or non-use of life-sustaining treatments that may guide current management (e.g., give primary focus to comfort measures) or future management (e.g. use of cardiopulmonary resuscitation, which is defined below, in the event of cardiac arrest). This process does not assume that prior advance care plans are automatically accepted as medical orders, since they are an expression of wishes and not decisions. Thus, informed consent must always be sought by healthcare providers.(23)

The third process, referred to here as *documentation*, aims to document the medical orders resulting from previous planning and decisions. Various documents are commonly used to capture medical orders such as Physician Orders for Life-Sustaining Treatments (POLST), Medical Orders for the Scope of Treatments (MOST), Goals of Care Designations or other ‘levels of care’ forms. CARENET refers to all these documents as ‘goals of care documents.’ This process usually occurs in specialty/acute care and long-term care settings.(23)

Lastly, three other terms are commonly used in end-of-life communication, decision-making and care: cardiopulmonary resuscitation (CPR), do-not-resuscitate (DNR) and allow-natural-death (AND). CPR refers to “a procedure that is used to restart someone’s heart and breathing. CPR can be mouth to mouth breathing with chest compressions, or it can include electric shocks and machines that breathe for the patient. Ongoing life support in the intensive care unit is often necessary after CPR is performed.”(21) DNR refers to “a written medical directive that documents a patient’s decision regarding his/her desire to avoid cardiopulmonary resuscitation.”(28) Finally, AND refers “to decisions not to have any treatment or procedure that will delay the moment of death. It applies only when death is about to happen.”(8)
the private practice element of the agreement has typically meant that physicians have been wary of potential infringements on their professional and commercial autonomy (e.g., directives about the nature of the care they deliver or the way in which they organize and deliver that care);

other healthcare providers such as nurses, physiotherapists and dietitians, as well as teams led by these providers, are typically not eligible for public fee-for-service payment (or at least not on terms that make independent healthcare practices viable on a large scale);

other healthcare and community programs and services such as prescription drug coverage, home care, long-term care homes and hospice care receive partial public coverage in Ontario, but not with the same type of first-dollar coverage provided for hospital-based and physician-provided care (e.g., co-payment is required for publicly funded long-term care homes and home care clients often pay for out-of-pocket expenses over and above the home care services funded by the provinces);

in September 2011, an engagement process was launched in Ontario to establish a shared Declaration of Partnership and Commitment to Action, which is a consensus document on a vision for palliative care in Ontario that outlines shared priorities and actions for the Ministry of Health and Long-Term Care (MOHLTC), Local Health Integration Networks (LHINs), Hospice Palliative Care Ontario, the Provincial End-of-Life Care Network, and other partners in order to achieve the vision;

as noted previously, two statutes currently govern consent and capacity to make healthcare decisions in Ontario: the Health Care Consent Act (24) and the Substitute Decisions Act(25) and

the provincial Consent and Capacity Board is an administrative tribunal with the authority to hold hearings dealing with the Health Care Consent Act and the Substitute Decisions Act.

Health system context

the 14 LHINs have responsibility for decisions relating to the planning, funding and integration of healthcare, and the LHINs have made palliative care a priority and developed three-year implementation plans for regional actions;

the 14 Regional Hospice Palliative Care/End-of-Life Care Networks – one for each LHIN – have the mandate to bring together partners across the continuum of care (e.g., hospitals, Community Care Access Centres, Community Support Services, physicians and educators) to improve the local system that delivers palliative care, and these 14 networks are both closely linked as part of the Provincial End-of-Life Care Network and being integrated within the LHINs’ regional plans(29)

the 14 Community Care Access Centres (CCACs) – one for each LHIN – have responsibility for the assessment, care planning, care coordination and quality monitoring of publicly funded home health services, as well as for providing information about and supporting referral to and navigation of available community services;

34 residential hospices – 24 of which are currently operational – were approved by the MOHLTC in 2005 to deliver palliative care, and public funding covers nursing and personal support based on a 10-bed model and is included within local CCAC allocations as ‘base amounts’;

some palliative services are also available through community support services (CSS) across Ontario, including: volunteer hospice visiting services, pain and symptom management teams to support primary care providers in the community, and palliative care education and consultation services;

some educational programs focused on palliative care are available to physicians and other front-line staff in the community and in long-term care homes, either directly or indirectly through community and long-term care facility palliative care interdisciplinary educational programs offered through community and long-term care facilities;

in several regions, LHINs and healthcare providers have been active in developing and testing coordinated interprofessional models of palliative care, drawing from lessons learned from end-of-life initiatives as well as from evaluations of projects and initiatives funded under the Aging at Home strategy announced in 2007(30)

a variety of pilot programs are currently underway in LHINs that aim to improve the integration of care teams, education for providers, and provide more seamless transitions of care; and
the current 26 Health Links (of an anticipated total of 77 Health Links) operate at the sub-LHIN level to mobilize the delivery of integrated care across the continuum of care for those with complex needs.\(^{(31)}\)

Further to the above description of the role of CCACs:

- home health services include care delivered by regulated professions (e.g., nursing, rehabilitation services, social work, dietetic and pharmacy services) as well as personal support and homemaking services;
- CCACs can also provide or arrange medical supplies, dressing and treatment equipment for the provision of nursing, physiotherapy, occupational therapy, speech-language pathology and dietetics services; and
- the MOHLTC approved funding in 2011 for 70 CCAC nurse practitioners in palliative care, who support clients with complex needs, those at high risk and those with chronic needs.
THE PROBLEM

The challenges in improving end-of-life communication, decision-making and care in Ontario can be understood by considering five manifestations of or contributors to the problem: 1) many die each year and many more are affected by these deaths; 2) few people engage in conversations about end-of-life issues; 3) current programs and services may not be fully aligned with Ontarians’ needs and preferences; 4) current health system arrangements may limit capacity to improve the situation; and 5) many agreed upon courses of action, while promising, have not yet been fully implemented.

Many die each year and many more are affected by these deaths

In 2011-2012, more than 252,000 Canadians died (more than 96,000 of them in Ontario).(32) In 2009, the top 10 leading causes of death in Ontario were cancer, heart disease, cerebrovascular disease, chronic lower respiratory disease, accidents, diabetes, Alzheimer’s disease, influenza and pneumonia, intentional self-harm, and kidney disease.(33)

A considerable number of people must cope each year with the emotional, moral, ethical, legal and financial burdens of end-of-life decisions. The Canadian Hospice Palliative Care Association estimates that “each death in Canada affects the immediate well-being of an average of five other people, or more than 1.25 million Canadians each year.”(34)

The demand for supporting end-of-life communication, decision-making and care will continue to grow, partially driven by the aging population and the growing burden of life-limiting chronic diseases.(4) The challenges associated with end-of-life communication, decision-making and care are particularly salient for a number of patient groups who could benefit from end-of-life planning and access to palliative care, such as patients 80 years of age or older admitted to hospital because of an acute medical or surgical condition, and patients 55 years of age or older with life-limiting chronic diseases (e.g., chronic obstructive pulmonary disease, congestive heart failure, cirrhosis, metastatic cancer or stage IV lymphoma, and end-stage dementia).(35)

Few people engage in conversations about end-of-life issues

Despite the desire of many Ontarians to achieve greater control over end-of-life decisions, most do not have any plan about end-of-life care. Indeed, CARENET and partners sponsored a national poll conducted by Ipsos-Reid in March 2012,(3) which found that:

- 86% of Canadians have never heard of advance care planning;
- less than 50% have had a discussion with a family member or friend about healthcare treatments if they were ill and unable to communicate;
- only 9% of Canadians had ever spoken to a healthcare provider about their wishes for care;
more than 80% do not have a written plan (although it is important to note that the Ontario legislation states that wishes may be expressed in writing, verbally, braille and by any other means that a person may use to communicate); and

only 46% of Canadians have chosen a substitute decision-maker who could make decisions on their behalf if they were unable to communicate.

Current programs and services may not be fully aligned with Ontarians’ needs and preferences

End-of-life issues are quite complex with their interplay of medical, legal, cultural, spiritual, social and economic considerations. Moreover, achieving meaningful end-of-life communication and decision-making requires some degree of awareness and knowledge of current statutes governing healthcare decisions, the likely progression of illnesses and their prognoses, life-sustaining technologies, and the meanings of various medical orders (e.g., CPR, DNR and AND). Yet patients and families are not well supported by the health and legal system to engage in end-of-life communication and decision-making. (36) Herewith some examples of the types of programs and services that do not exist at scale in Ontario:

- information campaigns to disseminate clear and consensual end-of-life care terminology that should be used in end-of-life communication, decision-making and care to ensure a common understanding of the terms and what they mean within Ontario’s legal framework;
- a comprehensive public education and awareness campaign about palliative and end-of-life care (with the exception of the Speak Up and Speak Up Ontario! campaigns focusing on advance care planning) that can increase public understanding about palliative and end-of-life care (in relation to chronic disease management), and encourage understanding of the importance of early referral to palliative care; (11)
- specialized services to provide personal support and coaching to citizens preparing advance care plans, and link them to expert information and tools (including decision aids to help patients or their substitute decision-makers work through end-of-life issues); and
- information campaigns and toolkits for lawyers who support clients in advance care planning.

Yet even well prepared patients and families can encounter problems with existing programs and services. Although most people express the desire to die at home, surrounded by their loved ones, and without unnecessary intrusive medical interventions, almost 70% still die in hospitals. (34) It is estimated that 90% of dying Canadians could benefit from palliative care programs and services, however, the country’s health systems are currently unable to provide such programs and services to 70% of those in need. (5;34) While end-of-life palliative care has historically focused on cancer and the treatment of associated pain, the same range of palliative care is typically not available for or offered to a broad range of other conditions and types of patients (e.g., patients with dementia, kidney disease, heart disease and chronic obstructive pulmonary disease). (4;11)

In addition, patients are often referred to palliative care programs and services when they are diagnosed as ‘close to death,’ (11;37) which appears increasingly inadequate to meet the growing and complex needs of patients who have different illnesses and death trajectories. (5) Four trajectories are commonly described in the literature:

- sudden death – typical of an accidental death; (5)
- “short period of evident decline – typical of cancer;” (38)
- “long-term limitations with intermittent exacerbations and sudden dying – typical of organ system failure;” (38) and
- “prolonged dwindling – typical of dementia, disabling stroke, and frailty.” (38)

The palliative care needs of patients, families and caregivers are likely to vary according to the illness and death trajectory. Timely referral to palliative care programs and services that reflect the full variety of illness trajectories (i.e., that include the third and fourth trajectories in the list and not just the second trajectory) likely remains the exception more than the norm. (11;39) Timely referral to respite care services and counselling as well as grief and bereavement services, for informal/family caregivers, also continues to present challenges. (11)
Current health system arrangements may limit capacity to improve the situation

A variety of features about the delivery, financial and governance arrangements within Ontario’s health system may also limit capacity to improve end-of-life communication, decision-making and care.

Delivery arrangements

Delivery arrangements in Ontario’s health system contribute to four sets of challenges to end-of-life communication and decision-making.

- **A lack of timely access to physicians and/or other healthcare providers, particularly in primary care:** It is estimated that 9.2% of Ontarians do not have access to a regular physician (40) and 3.2% of sicker adults in the province do not have a regular physician or place to go for medical care.(41) Among those sicker adults who do have a place to go for care, only half of them could see a doctor or nurse on the same or next day the last time they were sick.(41) Since it is suggested that advance care planning should occur principally in primary care settings,(23) this lack of access poses a significant challenge for those most in need of engaging in end-of-life conversations. In addition, it constitutes an important barrier to access palliative care (and to early referral) since not having a regular physician is “associated with fewer visits to general practitioners or specialists, who can play a role in the early screening and treatment of medical conditions.”(40)

- **Healthcare providers may be ill-prepared to engage in end-of-life communication and decision-making:** This challenge could be partially explained by a lack of understanding about how patients make decisions, as well as a lack of training in communication, shared decision-making and cultural competency skills.(36) In addition, there is confusion among healthcare providers about who is best positioned to have advance care planning discussions with patients, who can interpret patients’ wishes, who can provide consent if the patients are incapable, how we should collectively ensure that patients and families are in a better state to make choices and decisions about end-of-life care, when it should be done and how. That being said, it has been recently argued that advance care planning could actually play a significant role in bringing patients and families to a state of better decisional readiness to make “the best possible in-the-moment medical decisions.”(42)

- **A lack of a valid approach to accurately document goals of care and decisions that is aligned with Ontario’s legal framework:** Many healthcare facilities are requiring patients or their substitute decision-makers to complete advance care planning forms or ‘levels of care’ forms before being admitted, which could be considered as medically and legally misguided.(18) For instance, advance care planning must be voluntary and cannot be a requirement for the admission into a healthcare facility, and patients have the right to express their wishes in any way they prefer.(18) Additionally, these forms are often tick box forms that are very broad in scope and with vague language, and completed when the patients do not have all the information about the likely progression of their health conditions and the anticipated consequences of various care options.(18) Healthcare providers often directly seek directions from these forms to decide on specific treatment and care without engaging in a conversation with (and seeking informed consent) from competent patients or their substitute decision-makers.(18;43) Lastly, these forms were often prepared in other jurisdictions without the necessary adjustments to the Ontario legal framework.(18)

- **A lack of availability (or knowledge) of established advance care plans and expressed wishes:** Those who have completed advance care plans often do not provide clear directions to their substitute decision-maker or they have appointed a substitute decision-maker who is unlikely to know their wishes.(4) In addition, most patients end up dying in a hospital setting while being cared for by healthcare providers who had no pre-existing relationship with them, (44) and are unaware that a patient previously prepared an advance care plan or appointed a substitute decision-maker.(43) To address this issue, the government of Alberta created in 2008 the Personal Directives Registry, thereby allowing Albertans to register ‘personal directives’ (e.g., an advance care plan). The registry does not contain the actual directives, but allows healthcare providers to find out if someone has such directives and how to contact the substitute decision-maker(s) when needed.(45) No such registry is currently available in Ontario.
Another relevant initiative is the use of the Greensleeve pioneered in British Columbia by the Fraser Health Authority in 2004, which is a green plastic page protector placed at the front of a patient’s chart (or binder) to identify all advance care planning documents.(46)

Current delivery arrangements also contribute to four sets of challenges to timely access to high-quality integrated palliative care.

- **A lack of integration of palliative care programs and services for those with a life-threatening illness that meets their needs as early in their death trajectories as needed, and in a way that it is responsive to variations in these trajectories:** It is estimated that only 16-30% of those in need receive palliative care,(47) and most die in institutional settings rather than dying at home as they wished. The 2011 Declaration of Partnership and Commitment to Action stated that there is “inadequate/inequitable access to integrated, comprehensive, high quality pain and symptom management and comfort support,” and that there is significant disparity across regions in the “provision of complex care, advanced chronic disease management, hospice palliative care, and end-of-life care.”(11) The Declaration also pointed out the lack of integration between chronic disease management and palliative care across the continuum of care, spanning from diagnosis to end-of-life and bereavement.(11)

- **A lack of support for patients and caregivers to transition from one care setting to another:** Patients and their caregivers have difficulty “locating navigation and access support” in the province.(11) This lack of support may have significant consequences by increasing the risks of miscommunication about patients’ wishes, goals of care and decisions made.(48)

- **A lack of adequate training and education in the palliative care approach in different settings (in general and specifically related to patients with certain conditions like dementia) across various healthcare disciplines:** The need for training and education appear particularly salient given the perception of front-line staff (both clinicians and non-clinicians) that they lack the knowledge and skills to provide quality care to dying patients.(49)

- **A lack of personal support for informal and family caregivers while they are providing care, but also during the grief and bereavement period:** As a report from the Canadian Medical Association pointed out, “much of the burden of continuing care falls on informal (unpaid) caregivers. More than one million employed people aged 45-64 provide informal care to seniors with long-term conditions or disabilities and 80% of home care to seniors is provided by unpaid informal caregivers [in Canada].”(50) Yet, practical, social, emotional and informational support is lacking and inconsistently available across the province to help informal and family caregivers,(11;51) which can have a negative impact on their physical and mental health, as well as on their personal and professional lives.(52-55)

**Financial arrangements**

Three gaps in financial arrangements also contribute to the limited capacity to improve end-of-life communication, decision-making and care.

- **A lack of (awareness of) incentives for physicians to engage in advance care planning discussions and shared decision-making:** The Ontario Health Insurance Plan (OHIP) has a fee code that can be used for end-of-life planning, although many physicians reportedly are unaware of it, which may partially explain why some providers are not inclined to engage in end-of-life conversations, especially on busy days and with patients who are not acutely ill. The potential role of financial incentives was revealed by a recent study conducted in the United States suggesting that they may encourage post-graduate medical trainees based in hospitals to engage in end-of-life conversations and to document their patients’ wishes for end-of-life care in their medical records.(56) Furthermore, a recent systematic review revealed that the lack of reimbursement and the fee-for-service payment system were perceived as barriers to implementing shared decision-making in clinical practice.(57)

- **Limited funding to support healthcare providers to offer comprehensive out-of-hospital care at the end of life (e.g., personal support workers, nurses and nurse aides providing services and palliative care physicians providing oversight of such outpatient services):** Hospital-based acute inpatient care has become the default option for end-of-life care, because the resources exist there and all
the care is covered at no direct expense to patients. In addition, current financial arrangements do not allow funding to follow patients as they transition through the health system.(11)

- **A lack of financial support for patients and informal/family caregivers:** The economic burden carried by patients and informal/family caregivers is substantial, but is often not factored into cost analyses, nor adequately compensated. This gap is particularly salient for caregivers who are not family members and for family caregivers who are retired or unemployed without employment insurance, since they are not eligible for current programs. Only family caregivers who meet very specific eligibility criteria can benefit from the federal Compassionate Care Benefits (58) and Ontario’s unpaid Family Medical Leave.(59) A recent evaluation of the Compassionate Care Benefits program also revealed that the limited public awareness of the existence of the program, the complex application process and requirements, and the limited support offered (both in terms of financial assistance and length of coverage) limit the program’s impact.(60) Lastly, the limited coverage of select medications and equipment, as well as the out-of-pocket expenses related to care at the end of life can also create additional financial stress for patients and their informal/family caregivers.(4;5;51)

**Governance arrangements**

Lastly, four key gaps in current governance arrangements also limit the capacity for improving end-of-life communication, decision-making and care:

- **a lack of accountability** – The 2011 Declaration of Partnership and Commitment to Action highlighted that “overall shared accountability for the person and family and for the achievement of health system’s triple aim goals [better health and better care at lower cost] is unclear.”(11) Indeed, a recent environmental scan revealed that there are currently no formal indicators at the system and service delivery levels to assess, monitor and report on the quality of palliative and end-of-life care in Ontario.(61) This appears consistent with a recent cross-sectional study demonstrating that Ontario hospitals are not incorporating performance indicators related to end-of-life communication, decision-making and care into their public reporting or balanced scorecards;(62)

- **a lack of patient and public engagement in planning and governance** – The stakeholders involved in the 2011 Declaration of Partnership pointed out that “family and caregiver voices are not currently reflected in local and system level planning and governance.”(11) Greater engagement could help to ensure that palliative and end-of-life policies, along with the organization of services, are more closely aligned with the values, needs and preferences of patients and their informal/family caregivers;

- **a variability in standards of care** – There is currently no “provincial level mechanism for standardization of clinical processes or system-design best practices”;(11) and

- **a lack of data about the workforce with expertise in palliative and end-of-life care** – There is a perceived shortage of healthcare providers with expertise in palliative and end-of-life care.(11) However, there is currently a lack of data about the current workforce, including physicians, physician’s assistants, nurses, nurse practitioners, home care assistants, various types of therapists, counsellors and social workers with expertise in palliative and end-of-life care.

**Many agreed upon courses of action, while promising, have not yet been fully implemented**

A number of promising steps have been taken, or are being taken, to improve end-of-life communication, decision-making and care in Canada and abroad. For instance, a few Canadian governments as well as a few countries have moved forward with the development of end-of-life care strategies, action plans and frameworks over the past decade (profiled in Table 1). Examples include the Canadian Strategy on Palliative and End-of-Life Care, which brought together researchers, practitioners and decision-makers from 2002-2007 to tackle various issues, such as best practices and quality care, education for formal caregivers, public information and awareness, research and surveillance.(63) Recently, two Canadian jurisdictions have moved forward with the adoption of an end-of-life action plan (British Columbia) and the introduction of a bill regarding end-of-life care (Québec).(14;15)
In Ontario, the provincial government adopted a three-year End-of-Life Care Strategy in 2005 to improve end-of-life care services at home and in the community, with Health Accord funding ending in 2008. (64-66) A recent initiative generated a lot of momentum and led to the development of a multi-stakeholder action plan. In 2011, the MOHLTC, the LHINs and the Quality Hospice Palliative Care Coalition engaged more than 80 stakeholders from across the healthcare continuum in developing a Declaration of Partnership and Commitment to Action for “advancing high quality, high value palliative care in Ontario.” (11) This collaborative achieved a common vision and model of ‘virtual’ extended interprofessional teams. It also laid out a series of tangible actions to be taken to broaden access (and improve timely access) to palliative care, to support caregivers, to improve service capacity, to improve integration and continuity of care, to strengthen accountability, and to improve public awareness. (11) While there are varying degrees of implementation across stakeholder groups, a number of concrete actions have been taken. For instance, in addition to developing individual implementation plans, the LHINs have agreed to a core set of deliverables to accomplish by March 2014, such as:

- increasing the number of Ontarians who receive palliative care outside of hospitals by 5-10%;
- strengthening the regional palliative structure;
- implementing a palliative care indicator as part of the Ministry-LHIN Performance Agreement;
- implementing a Palliative Balanced Scorecard;
- implementing performance and outcome tracking feedback at the client/provider/team levels;
- updating accountability agreements with health service providers;
- implementing a care coordination role; and
- establishing outreach processes across all providers and across the continuum of care.

In addition, the Hospice Palliative Care Provincial Steering Committee was set up to re-establish the momentum for, and to lead the implementation of, the action plan from the Declaration, to ensure that implementation efforts are aligned with the Declaration and are consistent with the LHINs’ regional plans, and to pursue a dialogue to identify further opportunities to improve palliative care in Ontario.
Table 1: Profile of select government strategies, actions plans and frameworks in Canada and abroad

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Strategy title</th>
<th>Year published</th>
<th>Key goals/objectives/priorities</th>
<th>Implementation progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>Canadian Strategy on Palliative and End-of-Life Care (63)</td>
<td>2002</td>
<td>• established a federal strategy for palliative and end-of-life care that created working groups to focus on the development of five key end-of-life theme areas: best practices and quality care, education for formal caregivers, public information and awareness, research and surveillance</td>
<td>Strategy ended in 2007: a report listed several key accomplishments during its implementation (63)</td>
</tr>
<tr>
<td>British Columbia</td>
<td>The Provincial End-of-Life Care Action Plan for British Columbia (14)</td>
<td>2013</td>
<td>• redesigning health services to deliver timely coordinated end-of-life care;</td>
<td>No publicly available monitoring or evaluation reports about this action plan were identified</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• providing individuals, caregivers and healthcare providers with palliative care information, education, tools and resources; and</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• strengthening health system accountability and efficiency</td>
<td></td>
</tr>
<tr>
<td>Alberta</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
<td>There are minimal references to palliative care in the provincial Continuing Care Strategy (67) or to advance care planning in the Aging Population Policy Framework.(68) However, there is currently no comprehensive provincial end-of-life strategy, and stakeholders (e.g., the Alberta Hospice Palliative Care Association) continue to encourage the government to create a strategy. There is directional policy in development in both Alberta Health and Alberta Health Services. The Advance Care Planning/Goals of Care Policy is currently implemented within only a few zones of Alberta Health Services, but should be implemented in all zones soon.(69)</td>
</tr>
<tr>
<td>Ontario</td>
<td>Declaration of Partnership and Commitment to Action (11)</td>
<td>2011</td>
<td>• developing a common vision and action plan across the health sector for advancing high-quality, high-value palliative care in Ontario</td>
<td>The LHINs, MOHLTC, and Quality Hospice Palliative Care Coalition have agreed to take action consistent with the Declaration within their respective scope of influence and control in order to advance the recommendations from the Declaration. A Hospice Palliative Care Provincial Steering Committee was struck in 2013 to provide overall guidance of the collaborative efforts to improve palliative care across Ontario. The Steering Committee has committed to providing an Annual Status Report on progress made in implementing action commitments beginning this year.</td>
</tr>
<tr>
<td></td>
<td>End-of-Life Strategy (64)</td>
<td>2005</td>
<td>• shifting care of the dying from acute care settings to appropriate alternate settings of individual preference;</td>
<td>Health Accord funding disseminated under this strategy ended in 2008.</td>
</tr>
</tbody>
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Evidence >> Insight >> Action
### Evidence >> Insight >> Action

<table>
<thead>
<tr>
<th>Country</th>
<th>Description</th>
<th>Year</th>
<th>Details</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Québec</td>
<td>Act Respecting End-of-Life Care (Bill 52)(15)</td>
<td>2013</td>
<td>• to ensure that patients at the end of life are provided care that is respectful of their dignity and their autonomy, and to recognize the primacy of wishes expressed freely and clearly</td>
<td>No publicly available monitoring or evaluation reports about this bill were identified</td>
</tr>
<tr>
<td>Australia</td>
<td>Advance Planning for Quality Care at End of Life - Action Plan 2013–2018 (70)</td>
<td>2013</td>
<td>• encouraging patients to express wishes and engage in formalized advance care planning; • providing care consistent with patients’ wishes; • respecting patients’ preferences about where they want to die and providing support to provide this; • ensuring families and carers are clear about patients' wishes in advance; and • educating health professionals to consider advance care planning for end of life as an expected part of clinical care</td>
<td>No publicly available monitoring or evaluation reports about this action plan were identified</td>
</tr>
<tr>
<td>International</td>
<td>The National Palliative Care Strategy - Supporting Australians to Live Well at the End of Life (71)</td>
<td>2010</td>
<td>• improving the appreciation of dying and death as a normal part of the life continuum; • enhancing awareness of the benefits of timely and appropriate access to palliative care services; • providing quality palliative care to all Australians on a needs basis; • supporting collaborative, proactive governance of national palliative care strategies, resources and approaches; and • building the capacity of relevant sectors in health and human resources to provide effective palliative care</td>
<td>No publicly available monitoring or evaluation reports about this strategy were identified</td>
</tr>
<tr>
<td>Israel</td>
<td>End of Life Care Policy (72)</td>
<td>2005</td>
<td>• ensuring access to end-of-life care to every person in need by integrating palliative care services into the mandatory benefits package</td>
<td>No publicly available monitoring or evaluation reports about this strategy were identified</td>
</tr>
<tr>
<td>New Zealand</td>
<td>The New Zealand Palliative Care Strategy (73)</td>
<td>2001</td>
<td>• raising the profile of palliative care among communities and health and disability providers; • increasing awareness of palliative care services; and • developing a ‘palliative care culture’</td>
<td>No publicly available monitoring or evaluation reports about this strategy were identified</td>
</tr>
</tbody>
</table>
### Improving End-of-Life Communication, Decision-making and Care in Ontario

<table>
<thead>
<tr>
<th>Location</th>
<th>Title</th>
<th>Year</th>
<th>Key Points</th>
<th>Monitoring/Evaluation</th>
</tr>
</thead>
</table>
| Singapore         | National Strategy for Palliative Care                               | 2011 | • ensuring all patients with palliative care needs are identified and assessed;  
                          • providing care to all patients with palliative care needs using a palliative care approach;  
                          • ensuring patients with complex needs have access to specialized palliative care services;  
                          • delivering palliative care in a coordinated manner to ensure continuity of care across settings and over time; and  
                          • providing palliative care in a cost-effective manner and making it affordable to all who need it | No publicly available monitoring or evaluation reports about this strategy were identified |
| United Kingdom    | Living Matters, Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland | 2010 | • understanding palliative and end-of-life care;  
                          • providing best available care by responsive and competent staff;  
                          • recognizing and initiating conversations about what matters;  
                          • providing timely information and choice; and  
                          • coordinating care, support and continuity | No publicly available monitoring or evaluation reports about this strategy were identified |
|                   | End of Life Care Strategy - Promoting High Quality Care for All Adults at the End of Life | 2008 | • raising the profile of end-of-life care through partnering with primary care trusts and local authorities;  
                          • establishing an integrated approach to planning, contracting and monitoring of service delivery;  
                          • identifying and caring for people approaching the end-of-life;  
                          • assessing patients’ needs and wishes and incorporating these preferences into a care plan;  
                          • establishing a central coordinating facility providing a single point of access through which all services can be coordinated;  
                          • enabling rapid access to care;  
                          • embedding education and training for all levels of staff to provide end-of-life care;  
                          • evaluating structure, process and outcomes of care to improve the quality of care; and  
                          • ensuring funds to support the overall large cost of end-of-life care | The first National Health Service Mandate was published in 2012. This mandate states that NHS should provide the highest standards of care, particularly to older people and at the end of people’s lives. Beginning in 2013, NHS England is responsible for planning end-of-life care services. |
|                   | Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland | 2008 | • ensuring that all patients and carers with palliative and end-of-life care needs are identified and appropriately assessed and reviewed;  
                          • developing care plans for all patients and carers with palliative and end-of-life care needs at every stage of the patient journey;  
                          • supporting all patients and carers with palliative and end-of-life care needs to fully participate in developing care plans;  
                          • equipping all health and social care professionals with the knowledge, skills and competency to provide palliative and end-of-life care; and  
                          • ensuring that the aims of this action plan are met in a sustainable manner, with quality assessments | The 2012 national overview report acknowledges the amount of work undertaken across sectors and across Scotland. The report further reinforces the need to focus on the following areas: early identification of patients who may require palliative care, advance care planning, palliative and end-of-life care in acute hospitals, electronic palliative care summary and do not attempt cardiopulmonary resuscitation. |

†The information provided in this column is based on what we were able to locate through publicly available information.
In addition to the strategies, action plans and frameworks profiled in Table 1, there have been several initiatives in recent years that have provided clear signals that there may be interest in greater efforts in Ontario to support actions to improve end-of-life communication, decision-making and care. Table 2 provides a list of select initiatives and how they could address a number of the challenges previously discussed in this brief.

### Table 2: List of select initiatives to improve end-of-life communication, decision-making and care in Ontario

<table>
<thead>
<tr>
<th>Few people engage in conversations about end-of-life issues</th>
</tr>
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<tbody>
<tr>
<td>• the Advance Care Planning National Framework Task Group (with support from the Canadian Hospice Palliative Care Association and other stakeholders) released a national framework for advance care planning with the aim to guide activities, programs and standards of practice across the country; (79)</td>
</tr>
<tr>
<td>• several public awareness campaigns – Speak Up, Speak Up Ontario, and National Advance Care Planning Day (April 16th) – are underway [<a href="http://www.advancecareplanning.ca">www.advancecareplanning.ca</a>];</td>
</tr>
<tr>
<td>• the Canadian Virtual Hospice [<a href="http://www.virtualhospice.ca">www.virtualhospice.ca</a>] provides support and personalized information about palliative and end-of-life care to patients, families, healthcare providers, researchers and educators;</td>
</tr>
<tr>
<td>• “Time to Talk about the End of Life” public education forums are organized by the Consent and Capacity Board;(80)</td>
</tr>
<tr>
<td>• educational sessions for the public and healthcare providers about advance care planning in relation to healthcare consent are organized by the Health Care Consent and Advance Care Planning Community of Practice;(81)</td>
</tr>
<tr>
<td>• a coalition of Ontario hospitals developed a quick guide for patients and healthcare providers offering information about advance care planning in relation to informed consent;(82)</td>
</tr>
<tr>
<td>• the government of Ontario produced the Guide for Advance Care Planning;(83) and</td>
</tr>
<tr>
<td>• a public awareness campaign to encourage open discussions about end of life and earlier referrals to palliative care is currently being developed by the Communications and Awareness Working Group, which will address action commitments made in the 2011 Declaration of Partnership and Commitment to Action.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current programs and services are not fully aligned with Ontarians’ needs and preferences</th>
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<tbody>
<tr>
<td>• Quality End-of-Life Care Coalition of Canada released a Framework for a National Strategy on Palliative and End-of-Life Care (84) and its Blueprint for Action 2010-2020;(85) and</td>
</tr>
<tr>
<td>• CARENET researchers developed the CANHELP tool to bring the voice of vulnerable patients and their families to the table and help them express their unmet needs.(1)</td>
</tr>
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<table>
<thead>
<tr>
<th>Delivery arrangements</th>
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<tbody>
<tr>
<td>• Significant steps have been taken and continue to be taken to improve access in primary care</td>
</tr>
<tr>
<td>• all 17 medical schools across Canada are now educating future physicians in palliative care;(5)</td>
</tr>
<tr>
<td>• training opportunities are offered by various organizations, such as the Canadian Nurses Association;(5) the Royal College of Physicians and Surgeons of Canada and the College of Family Physicians of Canada (a one year conjointly accredited program in palliative medicine which is currently under review);(5) the Learning Essential Approaches to Palliative Care (LEAP);(86) and the Centre for Education and Research on Aging &amp; Health in Northwestern Ontario;(87)</td>
</tr>
<tr>
<td>• core competencies in palliative and end-of-life care have been identified for family doctors,(88) nurses,(89,90) social workers,(91) and personal support workers;(92)</td>
</tr>
<tr>
<td>• the College of Physicians and Surgeons of Ontario released a policy to assist physicians in providing medically and ethically appropriate care at the end of life (93) and launched a series of conversations to achieve optimal care [endoflife.cpso.on.ca];</td>
</tr>
<tr>
<td>• the Provincial Hospice Palliative Care Steering Committee created a subcommittee to ensure that clinicians are engaged and supportive of the work being undertaken with regard to the 2011 Declaration of Partnership and Commitment to Action;</td>
</tr>
<tr>
<td>• several organizations have published guidelines for healthcare providers, such as the College of Nurses of Ontario;(94) the Registered Nurses’ Association of Ontario;(95) and Cancer Care Ontario;(96)</td>
</tr>
<tr>
<td>• Bruyère Continuing Care released a learning module to improve the cultural competencies of healthcare workers;(97) and</td>
</tr>
<tr>
<td>• CARENET released a conversation guide to help physicians talk with patients and families about end-of-life care.(35)</td>
</tr>
<tr>
<td>• the ACCEPT study conducted by CARENET researchers is an initiative to audit documentation practices.(98)</td>
</tr>
<tr>
<td>• the ACCEPT study conducted by CARENET researchers is an initiative to audit the availability (or knowledge) of prior advance care plans and expressed wishes.(98)</td>
</tr>
<tr>
<td>• the Way Forward [hpcintegration.ca] is a federally funded program (2012-2015), which should result in a national framework for an integrated palliative approach to care across settings;</td>
</tr>
</tbody>
</table>
Improving End-of-life Communication, Decision-making and Care in Ontario

- Cancer Care Ontario released a strategy to improve the quality of palliative care services for cancer patients (99) and implemented the Provincial Palliative Care Integration Project to improve the quality of palliative care for cancer patients;(100)
- As noted in the context section:
  - a variety of pilot programs are currently underway in LHINs across the province that aim to improve the integration of care teams, education for providers, and provide more seamless transitions of care;
  - LHINs and providers have also led the development of coordinated, innovative models of palliative care drawing from lessons learned from end-of-life care initiatives as well as evaluations of projects and initiatives funded under the Aging at Home strategy; and
  - Integrated Client Care Project (ICCP) Palliative implementation sites, launched in September 2011, are delivering and testing team-based palliative care models that aim to improve the client and caregiver experience, provide support through the stages of illness preceding death and afterwards, expand access to care, and improve pain and symptom management.

Lack of support for patients and caregivers to transition from one care setting to another
- the Change Foundation funded in 2012 the Northumberland Community Partnership to support Partners Advancing Transitions in Healthcare, a co-design experience to improve people’s healthcare experiences moving across the continuum of care.(101)

Lack of personal support for informal and family caregivers while they are providing care, but also during the grief and bereavement period
- the Ontario government launched a website [https://www.respiteservices.com] to provide information and links to local respite services for people with disabilities and their families across 38 Ontario communities; and
- the Ontario Community Support Association developed a search engine to find caregiver services and resources across the province [http://homeandcommunitysupport.ca/care_guide/caregiver.asp]

Financial arrangements
A lack of incentives for physicians to engage in advance care planning discussions and shared decision-making
- N/A
Limited funding to support healthcare providers to offer comprehensive end-of-life care at the end of life
- the government of Ontario provided time-limited funding to its End-of-Life Care Strategy from 2005-2008, although since the funding period has expired decisions to continue funding palliative care are now at the discretion of the LHINs;(65)
- the government of Ontario announced in 2011 an additional $7M in operating funding to residential hospices to cover 100% of their nursing/personal care services, and $8M annually for 70 new community-based palliative nurse practitioners; and
- the government of Ontario allocated $5M to the creation of the Community Palliative Care On-Call program through the 2008 Physician Services Agreement.

Lack of financial support for patients and informal/family caregivers
- N/A

Governance arrangements
Lack of accountability
- the Data and Performance Measures Working Group, which is reporting to the provincial steering committee overseeing the implementation of the 2011 Declaration, is currently identifying best practices in data and performance measurement in palliative care across the province and other jurisdictions; and
- CARENET researchers developed the CANHELP tool to help evaluate program delivery and support accountability by reporting the ratings of care from patients and families, and defining unmet needs.(1)

Lack of patient and public engagement in planning and governance
- N/A
Variability in standards of care
- several organizations have proposed standards for hospice palliative care;(102-104) for palliative and end-of-life care;(100) for volunteer practices;(105) and for nursing practices;(106)
- the College of Physicians and Surgeons of Ontario adopted a policy to guide physicians in end-of-life communication and decision-making;(93) and
- the Provincial End-of-Life Network released in 2010 a system design framework to guide the development of regional systems of hospice palliative care.(107)

Lack of data about the workforce with expertise in palliative and end-of-life care
- a study in progress led by researchers at the Institute for Clinical Evaluative Sciences is aiming to create and validate an algorithm to identify palliative care physicians within administrative databases and to determine the extent of the care they provide.

Additional equity-related observations about the problem

An important element of the problem that requires further discussion is how the problem may disproportionately affect certain groups or populations. With respect to end-of-life communication, decision-making and care, many groups warrant particular attention within this broad topic area. However, this evidence brief focuses on two groups for illustrative purposes: frail elderly citizens and first-generation immigrants.

Evidence >> Insight >> Action
The frail elderly are commonly characterized as vulnerable individuals, over 65 years of age, with functional impairments, who are dependent on others for activities of daily living. Their illness trajectory is often portrayed as a “prolonged dwindling” of cognitive and physical disabilities.\(^{(38)}\) The number of frail elderly is expected to increase dramatically in Ontario given the growing aging population and the growing prevalence of chronic conditions and multimorbidity. Indeed, 43% of adults over the age of 65 have two or more chronic conditions.\(^{(108)}\) A review of community surveys also found that multimorbidity is affecting the most vulnerable groups in society (e.g., people who are less educated, have low incomes and/or are living in rural communities).\(^{(109;110)}\) In addition, the Ontario population is characterized by more and more people living alone and by decreases in extended family networks.\(^{(53)}\) As evidence of this, the number of nuclear families has fallen by 18% in just five years since 2001; 51.5% of the population is not married; 42.7% of households have no children; and one in four families are led by a single parent.\(^{(111)}\) While many Ontarians would like the option of a home death, this is impossible without considerable dedicated family and social support, especially given the complex care needs of the frail elderly.

First-generation immigrants constitute another group that warrant particular attention. Indeed, Ontario is a very multicultural society with a large and vibrant immigrant population, mostly concentrated in large urban areas.\(^{(112)}\) It is estimated that 6.5% of all immigrants (and 15.6% of immigrants who are 65 years and older) in Ontario are unable to carry on a conversation in English or French.\(^{(112)}\) These immigrants are likely to face significant challenges when engaging in end-of-life conversations with healthcare providers who are not proficient in their mother tongues (e.g., expressing their wishes, and providing informed consent or refusal for treatment and care).\(^{(113)}\) Furthermore, they are likely to face significant barriers to navigate the system and access support, such as the barriers observed with the Compassionate Care Benefits program.\(^{(114)}\) But beyond language, it is also challenging to engage in culturally appropriate conversations about end-of-life care when there is a lack of common background or a lack of shared knowledge and understanding between patients and their healthcare providers. Indeed, culture (and religion) may shape the values and norms regarding various dimensions of end-of-life care, ranging from the patient’s and family’s perspective on health, suffering, death and dying; on advance care planning; on hospice and palliative care; on the use of Western medicine; on the role of informal/family caregiving; on information and prognosis disclosure; and on the role of the patient and family in the decision-making process.\(^{(115-118)}\) Thus, the multicultural makeup of Ontario stresses the need for culturally-sensitive end-of-life communication, decision-making and care to meet the needs and expectations of a growing immigrant population.
THREE ELEMENTS OF A COMPREHENSIVE APPROACH FOR ADDRESSING THE PROBLEM

Many elements could be selected as a starting point for deliberations. To promote discussion about the pros and cons of potentially viable solutions, we have selected three elements (among many) of a comprehensive approach for improving end-of-life communication, decision-making and care in Ontario.

These elements are: 1) better align health system arrangements to support end-of-life communication, decision-making and care; 2) educate, train and support healthcare providers in end-of-life communication, decision-making and care; and 3) strengthen citizens’ capacity to engage in communication and decision-making about end-of-life care.

The three elements were identified and selected through a process of consultation with the Steering Committee and with key informants. The three elements were not designed to be mutually exclusive. They could be pursued simultaneously or sequentially, or elements could be drawn from each element to create a new (fourth) element. They are presented separately to foster deliberations about their respective components, the relative importance or priority of each, their interconnectedness and the potential of (or need for) sequencing, and their feasibility.

In the following section of the evidence brief, we review available research evidence about each element in turn. While some of the research evidence may not deal specifically with end-of-life communication, decision-making and care, it was included since it can provide relevant insights and spur reflection about each element. The principal focus is on what is known about these elements based on findings from systematic reviews as well as economic evaluations or costing studies. We present the findings from systematic reviews along with an appraisal of whether their methodological quality (using the AMSTAR tool)(119) is high (scores of 8 or higher out of a possible 11), medium (scores of 4-7) or low (scores less than 4) (see the appendix for more information about the quality-appraisal process).
Element 1 - Better align health system arrangements to support end-of-life communication, decision-making and care

The first element involves the development (or updating) of a comprehensive strategy for end-of-life care that aligns governance, financial and delivery arrangements to support end-of-life communication, decision-making and care. This element might include:

1. establishing a process for engaging the public and other stakeholders in developing (or updating) a comprehensive provincial strategy for end-of-life communication, decision-making and care (e.g., setting a provincial vision, benchmarks and accountability measures);
2. establishing a stakeholder- and/or research-driven process to ensure conceptual clarity/consistency in the use of end-of-life care terminology so that the public, caregivers, healthcare providers, policymakers and other stakeholders have a common understanding of the terms and what they mean within Ontario's current legal framework;
3. establishing a governmental-appointed task force or committee to review consent and advance care planning documents and policies used within healthcare facilities to ensure that they are aligned with Ontario’s legal framework, and develop standard forms that could be used across facilities;
4. identifying effective models, programs and services for improving access to quality palliative care, including the medical orders with the best outcomes;
5. identifying what combination of palliative care providers achieve the best outcomes, and implementing strategies to evaluate how many palliative care providers (i.e., physicians, physician's assistants, nurses, nurse practitioners, home care assistants, various types of therapists, counsellors and social workers with expertise in palliative care) are needed/demanded (and where) in the province, and quantifying the number of training positions (e.g., residency spots) needed to meet this need/demand;
6. identifying the settings (e.g., hospital, hospice or home) where palliative care programs and services achieve the best outcomes;
7. implementing quality monitoring and improvement systems to improve programs and services, but also to inform how care is meeting or should be designed to meet patients’/families’ needs, by whom care should be provided and where;
8. publicly reporting end-of-life/palliative care performance indicators in hospital report cards and many organizations’ (including primary care organizations’) quality-improvement plans;
9. establishing a central administrative ‘gatekeeper’ or ‘hub’ to support the coordination and integration of palliative care programs and services in the province (including well-defined care pathways and packages of care that could support early referral for all non-sudden-death trajectories);
10. establishing a province-wide medical interpreter service to support end-of-life communication and decision-making for patients, their substitute decision-makers, their families and their caregivers who are not proficient in English or French;
11. establishing an information system that links patient information, plans of treatment and goals of care records to assist with transitions from one setting to another (e.g., an internet cloud-based registry); and
12. establishing a coordinated knowledge-translation strategy to support the communication of best practices about the most effective governance, financial and delivery arrangements for end-of-life communication, decision-making and care.

Element 1 is aligned with the following system redesigns and shared priorities identified in Ontario’s 2011 Declaration of Partnership: broadening access and increasing timeliness of access; improving the integration and continuity across care settings; and strengthening accountability and introducing mechanisms for shared accountability.(11)

A large body of synthesized research evidence has been accumulated that can be drawn upon to inform various components of element 1. Four key observations can be made:

- several high-quality systematic reviews found benefits for key components of this element, including home-based palliative and end-of-life care, quality-improvement strategies, public reporting of performance indicators, and knowledge-translation strategies;
• we found no systematic reviews that have relevance to establishing a process to ensure conceptual clarity/consistency in the use of end-of-life care terminology (sub-element 2), and reviewing consent and advance care planning documents and policies are aligned with Ontario’s legal framework (sub-element 3);

• Health Quality Ontario is currently undertaking a ‘mega-analysis’ to synthesize the evidence regarding various end-of-life care issues that have relevance to sub-elements 4 and 6 (e.g., are outcomes better in palliative care programs, hospices or hospitals? are outcomes better when ‘do not resuscitate’ is the default or an explicit choice?), which should be completed in March 2014; and

• other relevant systematic reviews are currently in progress and could inform various components of element 1: palliative care disparities between non-cancer patients and cancer patients (sub-element 4)(120) continuous quality improvement and quality improvement initiatives in the intensive care setting (sub-element 7),(121;122) and trained medical interpreters in face-to-face clinical settings (sub-element 10),(123)

A summary of the key findings from the synthesized research evidence is provided in Table 3. For those who want to know more about the systematic reviews or economic evaluations contained in Table 3 (or obtain citations for the reviews), a fuller description is provided in Appendix 1.

Table 3: Summary of key findings from the synthesized research evidence relevant to Element 1 - Better align health system arrangements to support end-of-life communication, decision-making and care

<table>
<thead>
<tr>
<th>Category of finding</th>
<th>Summary of key findings</th>
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<tbody>
<tr>
<td>Benefits</td>
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<tr>
<td>• Establishing a process for engaging the public and other stakeholders</td>
<td>o Three reviews found benefit for public engagement in enhancing public awareness, understanding and competencies.(124-126)</td>
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</table>
| | • Identifying effective models, programs and services for improving access to quality palliative care | o Several systematic reviews revealed benefits for:  
* multicomponent palliative care services;(127)  
* community, hospice and home-based end-of-life care versus conventional hospital-based care;(128;129)  
* palliative care day services;(130) and  
* case conferencing to enhance palliative symptom management.(131) |
| | • Identifying what combination of palliative care providers achieve the best outcomes | o Several reviews found benefits for:  
* palliative and hospice care teams;(132)  
* healthcare support workers;(133) and  
* volunteers.(134) |
| | • Identifying the settings where palliative care programs and services achieve the best outcomes | o Two recent and high-quality reviews revealed that home-based palliative and end-of-life care:  
* reduces the likelihood of dying in hospital;(135;136)  
* is associated with greater patient satisfaction;(135;136) and  
* reduces symptom burden without adding to the caregiver’s grief.(136) |
| | • Implementing quality monitoring and improvement systems | o Several reviews found benefits of various quality improvement strategies, including:  
* self-audit (137) as well as audit and feedback;(138;139)  
* pay-for-performance;(140)  
* safety checklists;(140)  
* practice guidelines (140) and decision support systems;(139)  
* quality improvement collaboratives;(141;142)  
* accreditation;(143)  
* communication-related quality improvement interventions (e.g., consultative teams);(144) and  
* small-group discussions in continuing professional education.(139) |
| | • Publicly reporting end-of-life/palliative care performance indicators | o Three reviews, including two medium- and high-quality reviews, found the following benefits for public reporting:  
* quality measures are likely to improve over time;(145) |
### McMaster Health Forum

- knowledge about and attitude towards the use of quality information improved;(146) and
- small but increasing impact on consumers’ decision-making,(147)

**Establishing a province-wide medical interpreter service**
- Two reviews found benefits for trained professional interpreters on communication (i.e., errors and comprehension), utilization, clinical outcomes, and satisfaction with care.(148;149)

**Establishing an information system**
- A recent and medium-quality review found that electronic health information systems reduce medication errors and generate accurate and complete patient data.(150)

**Establishing a coordinated knowledge-translation strategy**
- A recent and high-quality review found that information products designed to support the uptake of systematic review evidence were effective under certain conditions: there is a single clear message, the change is relatively simple to accomplish, and there is a growing awareness by users of the evidence that a change in practice is required.(151)

### Potential harms

- Publicly reporting end-of-life/palliative care performance indicators
  - One recent and medium-quality review found that public reporting may have a widening effect on racial disparities in healthcare,(152) but another recent and high-quality review found inconsistent evidence about the effects of public reporting on access to care.(145)

### Costs and/or cost-effectiveness in relation to the status quo

- Identifying effective models, programs and services for improving access to quality palliative care
  - Two economic evaluations found that:
    - home-based palliative medicine consulting service significantly reduced total and variable costs in the 18-month period following enrolment;(153) and
    - advanced illness coordinated care programs delivered by allied health personnel reduced six-month costs in comparison with usual care, but the difference was not statistically significant.(154)

### Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)

- Uncertainty because no systematic reviews were identified
  - Establishing a stakeholder- and/or research-driven process to ensure conceptual clarity/consistency in the use of end-of-life care terminology
  - Establishing a governmental-appointed task force or committee to review consent and advance care planning documents and policies used within healthcare facilities

- Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review
  - Establishing a central administrative ‘gatekeeper’ or ‘hub’ to support coordination and integration
    - A recent and high-quality Cochrane review found no studies examining the effects of end-of-life care pathways, compared with usual care (no pathway) or with care guided by another end-of-life care pathway across all healthcare settings (e.g. hospitals, residential aged care facilities, community).(156)

- No clear message from studies included in a systematic review
  - Establishing a process for engaging the public and other stakeholders
    - There is limited evidence to reliably assess the impact of public engagement in healthcare policy development;(124;157;158) as well as priority setting and resource allocation.(159)

- Establishing effective models, programs and services for improving access to quality palliative care
  - There is inconsistent and inconclusive evidence about the effectiveness of specialized palliative care programs and services.(160-162)

- Identifying what combination of palliative care providers achieve the best outcomes
  - There is limited evidence about the effectiveness of care by hospital-based palliative teams (163) and home care workers.(164)

- Establishing a central administrative ‘gatekeeper’ or ‘hub’ to support coordination and integration
  - A recent and high-quality Cochrane review found a lack of evidence regarding that interagency collaboration, compared to standard services, could lead to improved health outcomes.(165)

- Publicly reporting end-of-life/palliative care performance indicators
  - There is inconsistent or limited evidence about the effects of public reporting on:
    - consumer, professional and organizational behaviours;(145;166)
    - safety;(167)
    - patient-centredness;(147;167)
    - access to care;(145;152) and
    - mortality rates.(145)

- Establishing an information system
  - Two recent and medium-quality reviews found a lack of evidence regarding the effectiveness of:
    - patient-held medical records for patients with chronic diseases;(168) and
    - electronic information systems on resource utilization, healthcare cost and health outcomes.(150)

- Establishing a coordinated knowledge-translation strategy
  - Several systematic reviews, including one recent and high-quality review, found insufficient evidence to
<table>
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<tr>
<th>Key elements of the policy option if it was tried elsewhere</th>
<th>Stakeholders’ views and experience</th>
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</table>
| • **Establishing a process for engaging the public and other stakeholders**  
  o A recent and medium-quality review examining interactive and deliberative public engagement concluded that the degree to which these processes are likely to be successfully implemented is shaped by a range of contextual variables (e.g., organizational commitment and issue characteristics).(126) | • **Establishing a province-wide medical interpreter service**  
  o An old and medium-quality review identified barriers to the implementation of interpreter services such as cultural beliefs, attitudes, practices and issues that may result in individuals dismissing the utilization of interpreters (e.g. gender preferences in interpreters by patients).(149) |
| • **Establishing a central administrative ‘gatekeeper’ or ‘hub’ to support coordination and integration**  
  o A recent and high-quality Cochrane review found that collaboration amongst multiple agencies is often difficult to implement, more expensive than standard service delivery, and may undergo changes due to external factors. Such collaboration necessitates clearly stated objectives that are relevant to all agencies involved, as well as a monitoring and evaluation processes.(165) | • **Publicly reporting end-of-life/palliative care performance indicators**  
  o An older and low-quality review exploring the evidence about the public release of performance data revealed that, while hospitals may be responsive to publicly reported information, consumers and providers rarely search out this type of information and do not understand or trust it.(147) |
| • **Publicly reporting end-of-life/palliative care performance indicators**  
  o An older and medium-quality review examining the effectiveness of public reporting practices must be embedded in ongoing efforts of relationship building with diverse audiences, trying to clearly understand their information needs and how they use such information, and educating them about the value and meaning of the information.(172) | • **Establishing a coordinated knowledge-translation strategy**  
  o Several systematic reviews have identified facilitators for policymakers’ and stakeholders’ use of research evidence, the most commonly cited being facilitated interactions between the users and producers of research evidence, and ensuring timely access to research evidence. Barriers included a lack of awareness and familiarity, a lack of usefulness, a lack of motivation, and other external barriers. (151;171;173-180)  
  o A recent and medium-quality review revealed that such barriers may be overcome by adapting and presenting the findings in formats more directly tailored to their needs (e.g., providing summaries, overviews and policy briefs added value to systematic reviews, or evaluating their methodological quality and the applicability of the findings to particular settings).(178) |
Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care

The second element involves providing education and training for healthcare providers (e.g., physicians, nurses, pharmacists, allied health professionals, lay community health workers, personal care workers, home care workers and volunteers), as well as supporting healthcare providers in offering consistent communication, support for decision-making, and care. This element might include:

1. appointing a task force to identify core competencies for all relevant disciplines and to clarify who is best positioned to engage patients and families in end-of-life communication and decision-making at what stage of the process, and/or in what settings (e.g., family physicians, acute care physicians, advanced practice nurses, social workers, or other healthcare providers);
2. educating and training providers to facilitate culturally appropriate communication and decision-making with patients/families/caregivers in a way that encourages them to express their beliefs, values and preferences about end-of-life care, and also improves rapport building, prognosis disclosure, illness understanding, roles in decision-making and informed consent;
3. educating and training providers in multidisciplinary and shared care approaches;
4. educating and training non-palliative care clinicians in the palliative approach;
5. disseminating among providers clear and consensual end-of-life care terminology that should be used in end-of-life communication, decision-making and care to ensure a common understanding of the terms and what they mean within Ontario’s legal framework;
6. establishing an information system that provides reminders and prompts to healthcare providers to ensure that goals of care documents are prepared and respected;
7. encouraging Family Health Teams and other primary care groups to incorporate advance care planning into their quality-improvement plans;
8. establishing targeted payments to incentivize physicians to engage in end-of-life communication and decision-making with patients/families/caregivers (e.g., reviewing OHIP’s fee codes); and
9. implementing same-day/advanced access scheduling in primary care practices to support timely access to care (including palliative care).

Element 2 is aligned with the following system redesigns and shared priorities identified in Ontario’s 2011 Declaration of Partnership: strengthening service capacity and human capital in all care settings.(11)

We also found a large body of synthesized research evidence that can inform various components of element 2. Three key observations can be made:

- several high-quality systematic reviews found benefits for key components of this element, including: communication skills training,(181) training in a patient-centered approach,(182) practice-based interventions designed to improve interprofessional collaboration,(183) and financial incentives;(184)

- we found no systematic reviews that have relevance to disseminating among providers clear and consensual end-of-life care terminology (sub-element 5) and encouraging Family Health Teams and other primary care groups to incorporate advance care planning into their quality-improvement plans (sub-element 7); and

- there are currently several systematic reviews in progress that could inform various components of element 2: face-to-face communication about sensitive future matters including end of life (sub-element 2) (185) and communication skills training in primary care and rehabilitation settings (sub-element 2);(186) training and supporting for palliative care volunteers (sub-element 4);(187;188) and manual paper reminders (sub-element 6).(189)

A summary of the key findings from the synthesized research evidence is provided in Table 4. For those who want to know more about the systematic reviews or economic evaluations contained in Table 4 (or obtain citations for the reviews), a fuller description is provided in Appendix 2.
Table 4: Summary of key findings from the synthesized research evidence relevant to Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care

<table>
<thead>
<tr>
<th>Category of finding</th>
<th>Summary of key findings</th>
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<tbody>
<tr>
<td><strong>Benefits</strong></td>
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<tr>
<td>Appointing a task force to identify core competencies and to clarify who is best positioned to engage in end-of-life communication and decision-making</td>
<td>A recent but low-quality study found benefit for postgraduate medical educational interventions to improve physicians’ reported confidence to provide end-of-life care, although there was a lack of evidence to determine if these skills can be maintained over time. (190)</td>
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</table>
| Educating and training providers to facilitate culturally appropriate communication and decision-making | Several medium and high-quality reviews found benefits for:  
  - multifaceted continuing education and training opportunities (e.g., a combination of oral presentations and written information) that are flexible towards participant’s needs and learning preferences (191,192)  
  - communication skills training (181,193,194) including role-play, feedback, and small group discussions (195) and  
  - short and long-term training in patient-centred approaches (182) |
| Educating and training providers in multidisciplinary and shared care approaches | An older and medium-quality review examining the effectiveness of teaching teamwork to medical students and house staff found modest benefits in the short term. (196) |
| Establishing an information system that provides reminders and prompts | A recent and medium-quality review examining the effectiveness of interventions to improve team effectiveness (197) found benefit for:  
  - simulation training;  
  - crew resource management training;  
  - team-based training; and  
  - continuous quality improvement activities. |
| Establishing targeted payments to incentivize physicians to engage in end-of-life communication and decision-making | An older but high-quality review examining the impact of practice-based interventions designed to improve poor interprofessional collaboration found some evidence that it can improve healthcare processes and outcomes. (183) |
| Establishing same-day/advanced access scheduling | An older and medium-quality review on interprofessional education found that it enables knowledge and skills necessary for collaborative working. (198) |
| Implementing same-day/advanced access scheduling | A recent and high-quality Cochrane overview of systematic reviews examined the impact of financial incentives on healthcare professional behaviour and patient outcomes (184) and found benefit for three types of incentives:  
  - payment for each service, episode or visit;  
  - payment for providing care for a patient or specific population;  
  - payment for providing a pre-specified level or providing a change in activity or quality of care;  
| This same overview (184) found that financial incentives are generally:  
  - effective in improving processes of care;  
  - effective in improving referrals and admissions; and  
  - effective in improving prescribing costs outcomes. |
<p>| Implementing same-day/advanced access scheduling | A recent and medium-quality review found benefit for advanced access scheduling in the primary care setting (a system promoting patient-driven scheduling in contrast with pre-arranged appointments). Such system appears to improve wait time and no-show rate. |
| Potential harms | Implementing same-day/advanced access scheduling |
| Costs and/or | Implementing same-day/advanced access scheduling |
| No reviews or economic evaluations provided information about costs of the sub-elements | A recent and medium-quality review found limited evidence that some patients may be more likely to be lost to follow-up in an advanced access system. (201) |</p>
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<tr>
<th>Key elements of the policy option if it was tried elsewhere</th>
<th>Evidence &gt;&gt; Insight &gt;&gt; Action</th>
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<tbody>
<tr>
<td>Appointing a task force to identify core competencies and to clarify who is best positioned to engage in end-of-life communication and decision-making</td>
<td>o A recent but low-quality study found that curriculum planners in end-of-life care need to switch the focus from time-based clinical rotations towards a variety of educational experiences designed to meet the expected competencies of graduating residents. (190)</td>
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<tr>
<td>Educating and training providers to facilitate culturally appropriate communication and decision-making</td>
<td>o Two recent and medium-quality reviews found that effective communication skills training strategies: (195) lasted for at least one day, were learner-centred, and focused on practising skills and must not be conceived as a one-time intervention but followed periodically with additional sessions to ensure proper implementation of the intervention. (194)</td>
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<tr>
<td>o An older and low-quality review suggests that effective active-mode learning techniques for geriatrics knowledge and skills should employ multiple education efforts, such as written materials combined with feedback, and strong communication channels between instructors and learners. (213)</td>
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<tr>
<td>Stakeholders’ views and experience</td>
<td>Educating and training providers to facilitate culturally appropriate communication and decision-making</td>
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<tr>
<td>o A recent and medium-quality review identified many barriers in the uptake of continuing professional development in the rural setting, including costs and accessibility. (191)</td>
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<td>o An older and medium-quality review revealed that healthcare professionals often find it difficult to discuss ‘bad news’ with patients, especially where culturally competent care is needed. (192)</td>
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Element 3 - Strengthen citizens’ capacity to engage in communication and decision-making about end-of-life care

The third element involves strategies to raise awareness about and support end-of-life communication and decision-making, but also strategies to change cultural and social norms that constitute barriers to conversations about end-of-life care. This element might include:

1. disseminating among the public clear and consensual end-of-life care terminology that should be used in end-of-life communication, decision-making and care to ensure a common understanding of the terms and what they mean within Ontario’s legal framework;
2. launching a social marketing campaign to raise public awareness about palliative and end-of-life care (in relation to chronic disease management), and encourage understanding of the importance of early referral to palliative care;
3. coordinating and intensifying a strategy to engage citizens in a provincial dialogue to normalize end-of-life conversations;
4. providing information and education to help citizens understand how to engage in the process of advance care planning (i.e. encourage an understanding of the importance of communicating their wishes for future healthcare and considering who would speak on their behalf when they are no longer capable to do so, and how advance care planning relates to consent and developing plans of treatments);
5. establishing a specialized service providing personal support and coaching to citizens preparing advance care plans, and linking them to expert information and use of tools as needed;
6. developing toolkits for lawyers who support clients in advance care planning;
7. incentivizing citizens to communicate their wishes for future health and personal care, expressing and sharing those wishes with their family and especially their substitute decision-maker(s);
8. identifying and making available patient decision aids to help patients (or their substitute decision-makers) be prepared to engage with healthcare providers in end-of-life communication and decision-making;
9. implementing system navigators and transition coaches to coordinate palliative care services and support patients/families/caregivers transitioning from one setting to another; and
10. establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services, for informal/family caregivers.

Element 3 is aligned with the following system redesigns and shared priorities identified in Ontario’s 2011 Declaration of Partnership: strengthening caregiver supports and building public awareness.(11)

We also found a large body of synthesized research evidence that can inform various components of element 3. Three key observations can be made:
• several high-quality systematic reviews found benefits for key components of this element, including: mass media campaigns (in terms of their influence on the utilization of health services),(214) interventions before consultations for helping patients address their information needs,(215) face-to-face coaching sessions,(216) patient decision aids,(217) and interventions for supporting informal caregivers of patients in the terminal phase of a disease;(218)
• we found no systematic reviews that have relevance to disseminating among the public clear and consensual end-of-life care terminology (sub-element 1), developing toolkits for lawyers who support clients in advance care planning (sub-element 6), and incentivizing citizens to communicate their wishes (sub-element 7); and
• there are currently three systematic reviews in progress that could inform various components of element 3: two Cochrane reviews examining the effectiveness of advance care planning for end-stage kidney disease and end-of-life care more broadly (sub-element 4);(219;220) and one review examining the effectiveness of interventions designed to support children at the time of bereavement (sub-element 10).(221)
A summary of the key findings from the synthesized research evidence is provided in Table 5. For those who want to know more about the systematic reviews or economic evaluations contained in Table 5 (or obtain citations for the reviews), a fuller description is provided in Appendix 3.

### Table 5: Summary of key findings from the synthesized research evidence relevant to Element 3 - Strengthen citizens’ capacity to engage in communication and decision-making about end-of-life care

<table>
<thead>
<tr>
<th>Category of finding</th>
<th>Summary of key findings</th>
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<tbody>
<tr>
<td><strong>Benefits</strong></td>
<td>• Launching a social marketing campaign to raise public awareness</td>
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<td></td>
<td>o Two medium-quality reviews found benefits for social marketing interventions (including online campaigns) in:</td>
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<td>▪ encouraging voluntary health behaviour change(222;223) and</td>
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<td></td>
<td>▪ bringing about environmental and policy-level changes. (223)</td>
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<td></td>
<td>o One medium-quality review found that shorter interventions generally achieved larger impacts and greater adherence. (222)</td>
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<td>• Coordinating and intensifying a strategy to engage citizens in a provincial dialogue to normalize end-of-life conversations</td>
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<td></td>
<td>o A recent and medium-quality review (224) found benefits for the use of public deliberation methods (e.g., citizen panels and juries, consensus conferences, planning cells) in:</td>
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<td>▪ bringing insights into social values;</td>
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<td></td>
<td>▪ improving understanding of complex issues (particularly ethical and social dilemmas); and</td>
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<td></td>
<td>▪ enhancing civic-mindedness.</td>
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<td></td>
<td>• Providing information and education to help citizens understand how to engage in the process of advance care planning</td>
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<td></td>
<td>o An old but high-quality review found benefits for planned mass media campaigns and unplanned mass media coverage on the utilization of health services. (214)</td>
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<td>• Establishing a specialized service providing personal support and coaching</td>
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<td>o Three systematic reviews, including two high-quality Cochrane reviews, found some (yet limited) benefits for patient coaching (with or without complementary written materials) on:</td>
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<td>▪ improved patient participation in the consultation process; (216;225)</td>
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<td>▪ increased consultation length; (215) and</td>
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<td>▪ greater patient satisfaction. (215)</td>
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<td>• Identifying and making available patient decision aids</td>
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<td>o Several systematic reviews, including a recent and high-quality Cochrane review, found that patient decision aids had positive effects on:</td>
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<td>▪ knowledge about options (217;226;227) without increasing anxiety; (228)</td>
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<td></td>
<td>▪ decision-making processes; (226)</td>
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<td></td>
<td>▪ level of decisional conflict; (227)</td>
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<td></td>
<td>▪ informed values-based choices; (217)</td>
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<td></td>
<td>▪ patient-practitioner communication; (217)</td>
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<td></td>
<td>▪ patients’ involvement; (217) and</td>
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<td></td>
<td>▪ realistic perception of outcomes. (217)</td>
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<td></td>
<td>• Implementing system navigators and transition coaches</td>
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<td></td>
<td>o A recent and medium-quality review examining navigator models relevant to chronic disease management for older adults and their effectiveness found benefits for integrated and coordinated care guided by a navigator, using a variety of interventions such as care plans and treatment goals. (229)</td>
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<td></td>
<td>o An old and low-quality review examining the effectiveness of cancer patient navigation found some evidence of benefits in increasing participation in cancer screening and adherence to diagnostic follow-up care after the detection of an abnormality. (230)</td>
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<td></td>
<td>• Establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services</td>
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<td></td>
<td>o A recent and high-quality Cochrane review examining the effectiveness of interventions for supporting informal caregivers of patients in the terminal phase of a disease (e.g., providing support in the caring role, family life review, grief therapy) found benefits in helping to reduce caregivers’ psychological distress. (218)</td>
</tr>
<tr>
<td></td>
<td>o An old but medium-quality review examining the effectiveness of intervention strategies designed to help caregivers cope with the burden of caregiving (e.g., support group, education, psycho-education, counselling, respite care, and multicomponent) found benefit for multicomponent interventions. (231)</td>
</tr>
</tbody>
</table>

Evidence >> Insight >> Action
### Potential harms

- Establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services
  - An old but medium-quality review examining interventions to support the dementia family caregiver suggests that respite care was “responsible for an increase in burden.” (232)

### Costs and/or cost-effectiveness in relation to the status quo

- Launching a social marketing campaign to raise public awareness
  - A recent and medium-quality review found that online social marketing interventions, in contrast with sophisticated print interventions, offered a small effect with the advantage of lower costs and larger reach. (222)
- Establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services
  - An old but high-quality review examining different models of community-based respite care for frail older people and their carers suggests that day care is at least as costly as usual care. (233)
  - A recent economic evaluation did not find large benefits from the health economic point of view of selective bereavement interventions (e.g., visiting service for older widowed individuals) when such interventions target the entire population. (234)

### Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)

- Uncertainty because no systematic reviews were identified
  - Disseminating among the public clear and consensual end-of-life care terminology that should be used in end-of-life communication, decision-making and care
  - Developing toolkits for lawyers who support clients in advance care planning
  - Incentivizing citizens to communicate their wishes
- Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review
  - NA

- No clear message from studies included in a systematic review
  - Providing information and education to help citizens understand how to engage in the process of advance care planning
    - An old but high-quality review found limited evidence about the characteristics of successful mass media campaigns, and notably about how messages should be framed. (214)
  - Identifying and making available patient decision aids
    - A recent and high-quality Cochrane review examining the effectiveness of decision aids for people facing health treatment or screening decisions (217) found inconclusive evidence about:
      - the effects of decision aids on adherence to the decision, and costs/resource use; and
      - the degree of detail that decision aids need in order to have positive effects.
  - Establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services
    - An old but high-quality review found limited evidence about the effectiveness of breaks in care in improving the well-being of informal carers of frail and disabled older people living in the community. (235)
    - An old but high-quality review examining different models of community-based respite care for frail older people and their carers found improvements in terms of burden and mental or physical health. (233) However, an old but high-quality review found a lack of evidence regarding the effectiveness of respite care for people with dementia and their caregivers, (236) and another old and low-quality review found inconsistent evidence regarding respite care for caregivers and people with severe mental illness. (237)

### Key elements of the policy option if it was tried elsewhere

- Launching a social marketing campaign to raise public awareness
  - A recent but low-quality review found that social marketing interventions usually lack a clear underlying theory necessary to guide and evaluate interventions. (238)
- Establishing a specialized service providing personal support and coaching
  - An old but high-quality Cochrane review revealed that timing of the intervention may affect the effectiveness of patient coaching. (215)

### Stakeholders’ views and experience

- Identifying and making available patient decision aids
  - An old and medium-quality review examining information giving and decision-making in patients with advanced cancer found that almost all patients expressed a desire for full information, but only about two-thirds wished to participate actively in decision-making. (239)
- Establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services
  - A recent but low-quality review examining pediatric palliative and end-of-life care (240) identified 10 key areas where patients and their families are in need:
    - interactions with staff;
    - healthcare delivery and accessibility;
    - information needs;
    - bereavement needs;
    - psychosocial needs;
    - spiritual needs;
Additional equity-related observations about the three elements

In our review of the research evidence, we found several systematic reviews dealing explicitly with frail elderly citizens and a few addressing first-generation immigrants. Two reviews identified for the first element – better align health system arrangements to support end-of-life communication, decision-making and care – examined the effects of public-reporting interventions on ethnic minorities. While these reviews do not deal explicitly with our prioritized groups, they could spur reflections on the adverse consequences of public reporting of performance data on vulnerable populations like first-generation immigrants and frail elderly citizens. For instance, a recent and medium-quality review found that public reporting may have a widening effect on racial disparities in healthcare (through ‘cherry-picking patients’ who may help physicians and healthcare organizations score well, or avoiding those who may cause them to score poorly),(152) while another recent and high-quality review found inconsistent evidence about the effects of public reporting on access to care.(145) Findings from these reviews suggest that we should be mindful about the potential implications of public reporting programs, and the possible risk of widening disparities for low socio-economic patients and those with complex healthcare needs.

The synthesized research evidence described in this brief does not allow for drawing strong conclusions about the most effective way to engage first-generation immigrants in end-of-life communication, decision-making and care. While two medium-quality reviews identified for the first element found benefits for trained professional interpreters on communication (i.e., errors and comprehension), utilization, clinical outcomes, and satisfaction with care,(148;149) one of these reviews revealed that interpreter services are no panacea. In fact, there are important barriers that may affect their implementation, such as cultural beliefs, attitudes, practices and other issues that may result in individuals dismissing the utilization of interpreters (e.g., gender preferences in interpreters by patients).(149) In addition, two medium-quality reviews and one high-quality review found for the second element – educate, train and support healthcare providers in end-of-life communication, decision-making and care – a lack of evidence regarding the effectiveness of cultural competence training on minority healthcare quality (202;203) and in reducing health disparities.(204) These examples illustrate the challenges of overcoming the cultural and linguistic barriers facing first-generation immigrants regarding end-of-life care.
IMPLEMENTATION CONSIDERATIONS

Given that the potential facilitators to action often seem more self-evident than the potential barriers, and that some barriers may be so important that they force a re-evaluation of whether a particular way forward is even worth serious discussion at a particular moment in time, we focus here initially on the potential barriers to improving end-of-life communication, decision-making and care in Ontario.

Barriers can be identified at the level of patients/individuals (e.g., some citizens may be reluctant to engage in end-of-life conversations because of cultural norms, may be frustrated by past citizen engagement initiatives, or may not be inclined to engage in formalized advance care planning without tangible incentives), providers (e.g., some providers may grapple with prevalent and persistent misconceptions about current statutes governing healthcare decisions, may be unwilling or hesitant to fully support a shared decision-making approach, or may not recognize that the practice they are currently engaged in is misguided), organizations (e.g., some organizations may be unwilling or uninterested in making long-term sustainable financial commitments due to budget uncertainty that many may face for their existing programs and services, or lack the capacity to coordinate consistent educational content and activities across settings) and systems (e.g., system leaders may face difficulties in developing a shared vision given their constraints and competing priorities, and some may perceive end-of-life care as ‘boutique’ care).

A detailed list of potential barriers to implementing the three elements is provided in Table 6 as a way to spur reflection about some of the considerations that may influence choices about an optimal way forward. We have listed the barriers that were identified in a range of sources (not just empirical studies) and we have not rank ordered them in any way.

**Table 6: Potential barriers to implementing the elements**

<table>
<thead>
<tr>
<th>Element 1 - Better align health system arrangements to support end-of-life communication, decision-making and care</th>
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<tbody>
<tr>
<td><strong>Patients/individuals</strong></td>
</tr>
<tr>
<td>• may be frustrated by past citizen engagement efforts which have not meaningfully influenced policymaking,</td>
</tr>
<tr>
<td><strong>Providers</strong></td>
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<tr>
<td>• may be resistant to greater patient and public engagement in developing healthcare policies.(157)</td>
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<tr>
<td><strong>Organizational leaders</strong></td>
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<tr>
<td>• may lack the incentives necessary to change practices or to commit to improving (or including a focus on) palliative and end-of-life care;</td>
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<tr>
<td>• may perceive end-of-life care as ‘boutique’ care, which may jeopardize funding sustainability;(5)</td>
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<tr>
<td>• may be unwilling or uninterested in making long-term sustainable financial commitments towards greater efforts to improve palliative and end-of-life care due to budget uncertainty that many may face for their existing programs and services; and</td>
</tr>
<tr>
<td>• may face difficulties in developing a shared vision for improving end-of-life communication, decision-making and care given their constraints and competing priorities.</td>
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<tr>
<td><strong>System leaders</strong></td>
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<tr>
<td>• may have difficulty engaging citizens and stakeholders who can articulate diverse viewpoints regarding a comprehensive strategy;</td>
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<tr>
<td>• may perceive end-of-life care as ‘boutique’ care, which may jeopardize funding sustainability;(5)</td>
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<tr>
<td>• may face difficulties in developing a shared vision for improving end-of-life communication, decision-making and care given their constraints and competing priorities, but also because society (through the Courts, legislations, public dialogues and public institutions) has not defined key social mores surrounding death and end-of-life decision-making;</td>
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<tr>
<td>• may have difficulty with multi-agency/collaborative initiatives that are subject to changes outside their control;(165)</td>
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<tr>
<td>• may be resistant to patient and public engagement;(157) and</td>
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<tr>
<td>• may be reluctant to engage in end-of-life conversations because of cultural norms.(5)</td>
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<table>
<thead>
<tr>
<th>Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care</th>
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</thead>
<tbody>
<tr>
<td><strong>Patients/individuals</strong></td>
</tr>
<tr>
<td>• N/A</td>
</tr>
<tr>
<td><strong>Providers</strong></td>
</tr>
<tr>
<td>• may be reluctant to engage in end-of-life conversations because of cultural norms;(5)</td>
</tr>
<tr>
<td>• may be reluctant, or ill-equipped, to appropriately disclose prognoses to patients and families;(36)</td>
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<tr>
<td>• may lack understanding about how patients/families and substitute decision-makers make decisions;(36)</td>
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</table>
| • may grapple with prevalent and persistent misconceptions about current statutes governing healthcare decisions (e.g., issues
The implementation of the three elements can also be influenced by policymakers’ and stakeholders’ capacity to take advantage of potential windows of opportunity. These windows of opportunity could facilitate or trigger the improvement of end-of-life communication, decision-making and care in Ontario. Some of these potential windows of opportunity apply to all elements, whereas others are element-specific. A list of potential windows of opportunities for implementing the three elements, again not rank ordered in any way, is provided in Table 7 to spur further reflection.

<table>
<thead>
<tr>
<th>Element 3 - Strengthen citizens’ capacity to engage in communication and decision-making about end-of-life care</th>
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<tr>
<td><strong>Patients/individuals</strong></td>
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<tr>
<td>• may be unwilling or hesitant to fully support a shared decision-making (SDM) approach given the potential for infringement on their decision-making autonomy;(^{(26)})</td>
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<tr>
<td>• may not have sufficient time and resources to implement SDM or may not be aware of, or in agreement with, specific components of the SDM approach;(^{(57)})</td>
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<td>• may not be inclined to engage in end-of-life conversations since current fee-for-service model does not support SDM;(^{(57)})</td>
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<td>• may have concerns about malpractice liability,(^{(57)}) especially given recent media coverage of a high-profile legal case;(^{(7)})</td>
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<td>• may not be inclined to obtain additional training without tangible incentives;</td>
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<td>• may not recognize that the practice they are currently engaged in is suboptimal given their lack of knowledge and understanding about healthcare consent in relation to advance care planning;</td>
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<td>• may be unwilling to participate in strategies to support the implementation of practice guidelines that may challenge their professional attitudes or behaviours, or personal or religious beliefs around end-of-life care;</td>
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<td>• may lack accurate documentation of end-of-life treatments;(^{(36)}) and</td>
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<tr>
<td>• may lack access to prior advance care plans/expressed wishes.(^{(36)})</td>
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<tr>
<td><strong>Organizational leaders</strong></td>
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<tr>
<td>• may not recognize that the practice they are currently engaged in is misguided given the lack of knowledge and understanding about healthcare consent in relation to advance care planning;</td>
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<tr>
<td>• may lack the capacity to coordinate consistent educational content and activities across settings;</td>
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<tr>
<td>• may be unwilling or interested in making long-term sustainable financial commitments towards greater education, training and support for healthcare providers due to budget uncertainty that many may face for their existing programs and services; and</td>
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<tr>
<td>• may not see value in investing heavily in education and training, especially those with frequent staff turnover and limited resources.</td>
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<tr>
<td><strong>System leaders</strong></td>
</tr>
<tr>
<td>• may be unwilling or interested in making long-term sustainable financial commitments towards greater education, training and support for healthcare providers due to budget uncertainty that many may face for their existing programs and services.</td>
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The McMaster Health Forum provided in Table 7 is not rank ordered in any way.
Table 7: Potential windows of opportunity for implementing the elements

<table>
<thead>
<tr>
<th>Type</th>
<th>Element 1 - Better align health system arrangements to support end-of-life communication, decision-making and care</th>
<th>Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care</th>
<th>Element 3 - Strengthen citizens’ capacity to engage in communication and decision-making about end-of-life care</th>
</tr>
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<tbody>
<tr>
<td>General</td>
<td>There is an opportunity to build on past and ongoing initiatives that have brought together numerous stakeholders to develop common visions, guiding principles, and tangible actions to improve end-of-life communication, decision-making and care. (11; 79; 85)</td>
<td>There are also opportunities to learn from integrated programs that already exist in other Canadian jurisdictions that serve as models for consideration within the context of Ontario’s health system design and its legal framework.</td>
<td>In August 2012, the Canadian Medical Association adopted two resolutions at its annual General Council to “foster a public debate on end-of-life care issues in Canada” and to “develop a comprehensive framework of end-of-life care policies.” (241) A year later, end-of-life care was still a topical issue and several new resolutions were adopted to improve access to high-quality integrative palliative care, advance care planning, as well as physicians’ education and training. (242)</td>
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<td>In January 2013, Dr. Samir Sinha presented Living Longer, Living Well, a comprehensive report on how to help seniors stay healthy and live at home longer, to the Government of Ontario. This report addresses end-of-life communication and decision-making, as well as access to palliative care, and called for a comprehensive provincial strategy: “There is ample evidence to suggest an effective end-of-life care strategy that includes access to palliative care and formalizes the process of advance care planning will have the ability to reduce health system costs and support the long-term viability of our health care system.” (243)</td>
<td>In May 2013, the CIHR Institute of Aging announced its 2013-2018 strategic plan which highlights several research priorities, many relevant to improving end-of-life communication, decision-making and care, such as: supporting families, caregivers, professionals and policymakers with regard to treatment decisions and end-of-life issues; models and programs for supporting families and caregivers in making informed decisions (i.e., various care and treatment options, as well as ethical and legal considerations; and approaches making it possible to prepare for the final stages of aging throughout life). (244)</td>
<td>In June 2013, Ontario Premier Kathleen Wynne, stated that it was time to have a provincial discussion about end-of-life care. The two opposition parties agreed with the need to take action and proposed the creation of a legislative committee to examine the issue. (245)</td>
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<td>The negotiations to establish the next Physician Services Agreement will begin no later than December 2013. These negotiations will target a variety of service areas for enhancement and investment, and could be conducive to raising end-of-life communication, decision-making and care higher on the governmental agenda.</td>
<td>The growing popularity of ‘death cafés’ could provide a venue for promoting end-of-life conversations. (246)</td>
<td>The Advocacy Centre for the Elderly and a law firm received a research grant to develop a research paper on this area of law for the Law Commission of Ontario. This research paper should be completed by February 2014. In March 2013, the Ontario Ministry of Labor introduced Bill 21 to create three new unpaid leaves of absence under the Employment Standards Act, two of which could support family caregivers providing palliative and end-of-life care: the Family Caregiver Leave and the Critically Ill Child Care Leave. (247)</td>
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<td>The LHINs recently assumed control over the functions that had been supported by the Palliative and End of Life Network between 2005 and 2013, and end-of-life issues appear on many LHINs’ (and Health Links’) lists of initiatives.</td>
<td>Educating, training and supporting health providers in this area appear to be on the agenda of a growing number of professional associations and colleges in Ontario (and in Canada more broadly).</td>
<td>Speak Up and Speak Up Ontario! aims to raise awareness about advance care planning and the need to start the conversation about end-of-life-care. (8)</td>
</tr>
</tbody>
</table>

Evidence >> Insight >> Action
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Evidence >> Insight >> Action
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Please note that the appendices were sent as a separate electronic document. A hard copy of the appendices will be available upon request the day of the event.