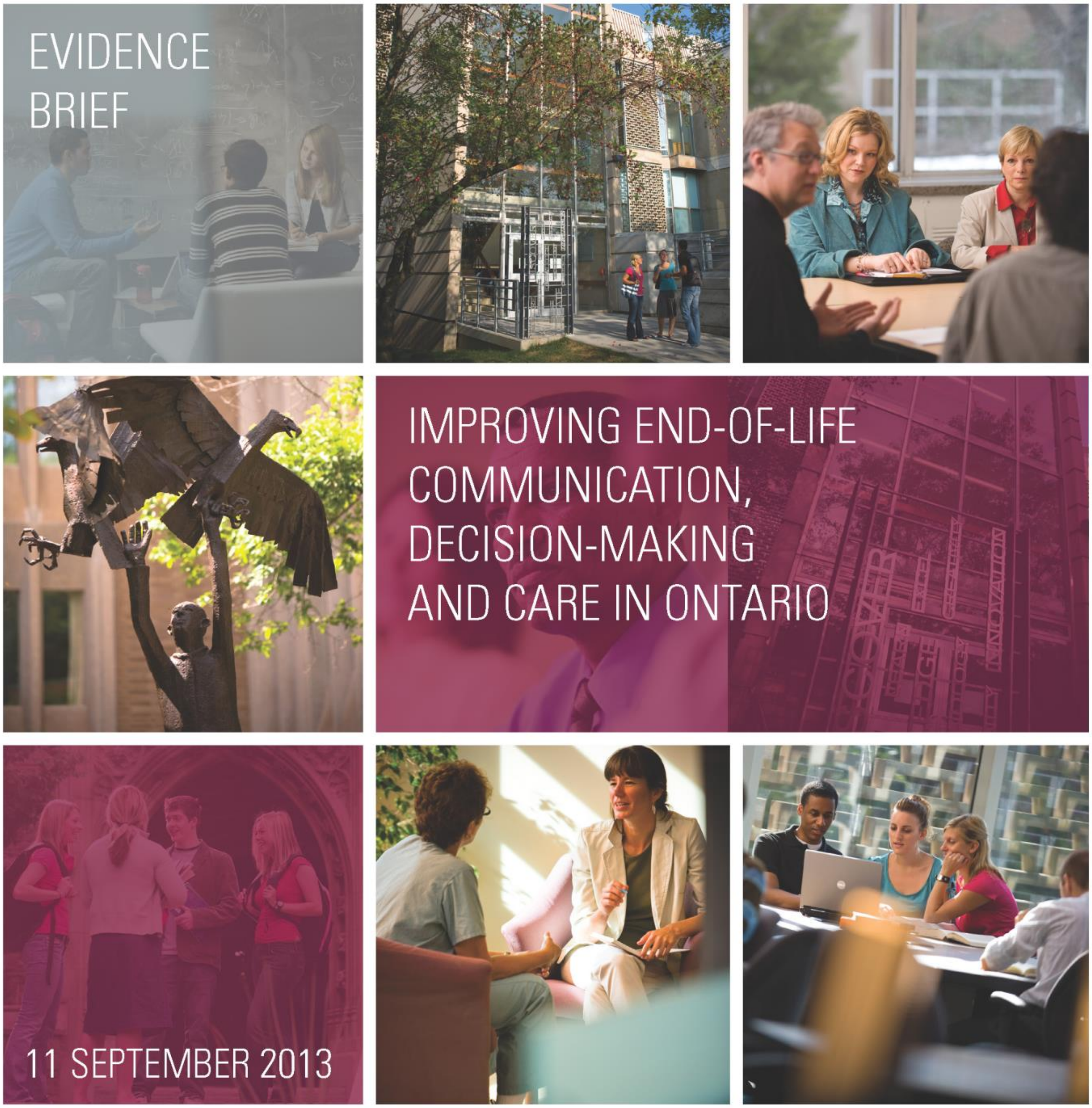
McMaster
University

McMaster
HEALTH FORUM



EVIDENCE
BRIEF

IMPROVING END-OF-LIFE COMMUNICATION, DECISION-MAKING AND CARE IN ONTARIO

11 SEPTEMBER 2013

EVIDENCE >> INSIGHT >> ACTION

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

11 September 2013

McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at the regional/provincial level and at national levels, the Forum harnesses information, convenes stakeholders, and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

Authors

François-Pierre Gauvin, PhD, Lead, Evidence Synthesis and Francophone Outreach, McMaster Health Forum

John N. Lavis, MD PhD, Director, McMaster Health Forum, and Professor, McMaster University

Funding

The evidence brief and the stakeholder dialogue it was prepared to inform were funded by the Ontario Medical Association and by McMaster University's Labarge Optimal Aging Initiative. The McMaster Health Forum receives both financial and in-kind support from McMaster University. The views expressed in the evidence brief are the views of the authors and should not be taken to represent the views of the Ontario Medical Association or McMaster University.

Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the evidence brief. The funders played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the evidence brief.

Merit review

The evidence brief was reviewed by a small number of policymakers, stakeholders and/or researchers in order to ensure its scientific rigour and system relevance.

Acknowledgements

The authors wish to thank Amanda Chen and Aunima Bhuiya for assistance with reviewing and summarizing the evidence. We are grateful to Steering Committee members and merit reviewers for providing feedback on previous drafts of the brief. We are especially grateful to Eric Wasylenko for his insightful comments and suggestions. The views expressed in the evidence brief should not be taken to represent the views of these individuals.

Citation

Gauvin FP, Lavis JN. Evidence Brief: Improving End-of-life Communication, Decision-making and Care in Ontario. Hamilton, Canada: McMaster Health Forum, 11 September 2013.

Product registration numbers

ISSN 1925-2242 (print)
ISSN 1925-2250 (online)

Table of Contents

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:
    - many die each year and many more are affected by these deaths;
    - few people engage in conversations about end-of-life issues;
    - current programs and services may not be fully aligned with Ontarians' needs and preferences;
    - current health system arrangements may limit capacity to improve the situation; and
    - 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
    - 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
    - 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
    - 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).

REPORT

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 <u>not</u> 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 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.

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.

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)

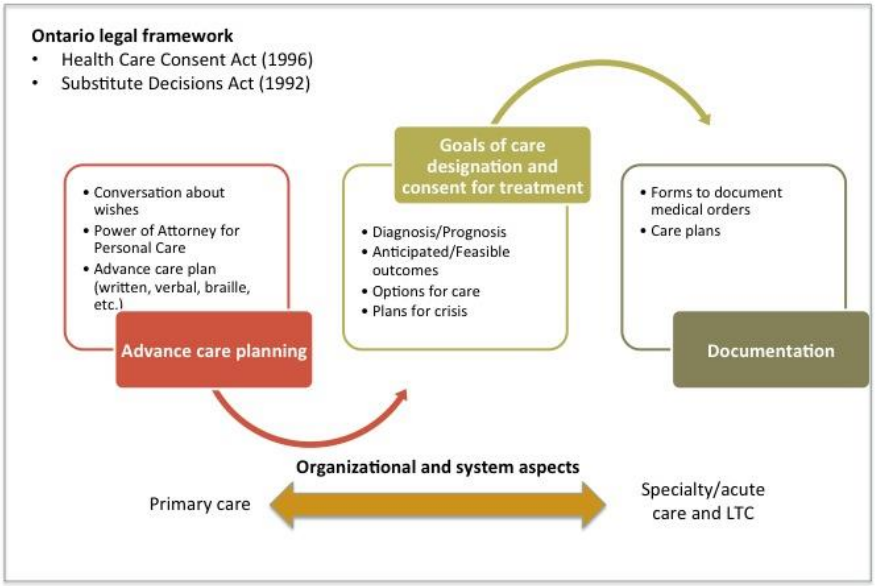
Palliative care is defined here as interdisciplinary care "focused on relief of pain and other symptoms and support for best possible quality of life for patients with serious illness and their families. It is appropriate at the point of diagnosis of a serious illness and provides an extra layer of support 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)

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 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]*



These three processes must be understood in the context of two statutes currently governing consent and capacity to make healthcare decisions in Ontario: the Health Care Consent Act (24) and the Substitute Decisions Act.(25) One of the most fundamental concepts within this legal framework is *informed consent.* The Health Care Consent Act states that a person has the right to consent to or refuse a treatment, admission to a healthcare facility or personal assistance services, if they have the mental capacity to do so. This means that a person must have the 'ability' or 'capacity' to understand and appreciate the consequences of a healthcare decision.(24) Healthcare providers in Ontario cannot interpret and follow a patient's advance care plan directly and thus bypass the requirement to get informed consent from the patient, or from their substitute decision-maker if the patient is mentally incapable.(18)

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.(18) 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 of substitute decision-makers that can be authorized to act in this role.(18)

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.(23) 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.(8) While advance care planning can happen in any setting, the literature would suggest that this optimally should occur in primary care settings.(23)

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.(18)

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;(18)
- 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;(18)
- 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);(18;26)
- 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; (18)
- 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;(18;26)
- completing an advance care plan is voluntary;(18)

- 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)

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:

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;

- 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, (11) 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 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)

Box 3: Mobilizing research evidence about the problem

The available research evidence about the problem was sought from a range of published and "grey" research literature sources. Published literature that provided a comparative dimension to an understanding of the problem was sought using three health services research "hedges" in MedLine, namely those for appropriateness, processes and outcomes of care (which increase the chances of us identifying administrative database studies and community surveys). Published literature that provided insights into alternative ways of framing the problem was sought using a fourth hedge in MedLine, namely the one for qualitative research. Grey literature was sought by reviewing the websites of a number of Canadian and international organizations, such as the Canadian Institute for Health Information, Canadian Palliative Hospice Care Association, Canadian Researchers at the End of Life Network, Health Canada, Health Council of Canada, Ontario Ministry of Health and Long-Term Care, Quality End-of-Life Care Coalition of Canada, and Agency for Healthcare Research and Quality (USA).

Priority was given to research evidence that was published more recently, that was locally applicable (in the sense of having been conducted in Canada), and that took equity considerations into account.

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 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, British Columbia has moved forward with the adoption of an end-of-life action plan and Québec has introduced a bill regarding end-of-life care.(14;15)

Table 1: Profile of select government strategies, actions plans and frameworks in Canada and abroad

Jurisdiction		Strategy title	Year published	Key goals/objectives/priorities	Implementation progress†
Canada	National	Canadian Strategy on Palliative and End-of-Life Care (63)	2002	- 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	Strategy ended in 2007: a report listed several key accomplishments during its implementation (63)
	British Columbia	The Provincial End-of-Life Care Action Plan for British Columbia (14)	2013	- redesigning health services to deliver timely coordinated end-of-life care; - providing individuals, caregivers and healthcare providers with palliative care information, education, tools and resources; and - strengthening health system accountability and efficiency	No publicly available monitoring or evaluation reports about this action plan were identified
	Alberta	N/A			There are several 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)
	Ontario	Declaration of Partnership and Commitment to Action (11)	2011	- developing a common vision and action plan across the health sector for advancing high-quality, high-value palliative care in Ontario	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.
		End-of-Life Strategy (64)	2005	- shifting care of the dying from acute care settings to appropriate alternate settings of individual preference;	Health Accord funding disseminated under this strategy ended in 2008.

				• enhancing client-centred and interdisciplinary service delivery capacity in the community; and • improving access, coordination and consistency of services and supports across the province	An evaluation indicated several areas of improvements at the system level (e.g., greater collaboration and communication that have enhanced the integration, coordination and consistency in end-of-life care) and at the patient level (e.g., patients and families feeling more supported to navigate the system and expressing that more of their wishes were being met)(65)
	Québec	Act Respecting End-of-Life Care (Bill 52)(15)	2013	• 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	No publicly available monitoring or evaluation reports about this bill were identified
International	Australia	Advance Planning for Quality Care at End of Life - Action Plan 2013–2018 (70)	2013	• 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	No publicly available monitoring or evaluation reports about this action plan were identified
		The National Palliative Care Strategy - Supporting Australians to Live Well at the End of Life (71)	2010	• 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	No publicly available monitoring or evaluation reports about this strategy were identified
	Israel	End of Life Care Policy (72)	2005	• ensuring access to end-of-life care to every person in need by integrating palliative care services into the mandatory benefits package	No publicly available monitoring or evaluation reports about this strategy were identified
	New Zealand	The New Zealand Palliative Care Strategy (73)	2001	• 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'	No publicly available monitoring or evaluation reports about this strategy were identified

	Singapore	National Strategy for Palliative Care (74)	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 (75)	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 (76)	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 (77)	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.(78)

† The information provided in this column is based on what we were able to locate through publicly available information.

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 for the strategy ending in 2008.(64-66) A recent initiative generated a lot of momentum and led to the development of a multi-stakeholder action plan. As noted previously, 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.

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

Few people engage in conversations about end-of-life issues
• 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) • several public awareness campaigns – Speak Up, Speak Up Ontario!, and National Advance Care Planning Day (April 16th) – are underway [www.advancecareplanning.ca]; • the Canadian Virtual Hospice [www.virtualhospice.ca] provides support and personalized information about palliative and end-of-life care to patients, families, healthcare providers, researchers and educators; • "Time to Talk about the End of Life" public education forums are organized by the Consent and Capacity Board;(80) • 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) • 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) • the government of Ontario produced the Guide for Advance Care Planning;(83) and • 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.
Current programs and services are not fully aligned with Ontarians' needs and preferences
• 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

- 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)

Delivery arrangements

Lack of timely access to physicians and/or other healthcare providers, particularly in primary care

- Significant steps have been taken and continue to be taken to improve access in primary care

Healthcare providers are ill-prepared for end-of-life communication and decision-making

- all 17 medical schools across Canada are now educating future physicians in palliative care;(5)
- 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 & Health in Northwestern Ontario;(87)
- 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)
- 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];
- 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;
- 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)
- Bruyère Continuing Care released a learning module to improve the cultural competencies of healthcare workers;(97) and
- CARENET released a conversation guide to help physicians talk with patients and families about end-of-life care.(35)

Lack of a valid approach to accurately document goals of care and decisions that is aligned with Ontario's legal framework

- the ACCEPT study conducted by CARENET researchers is an initiative to audit documentation practices.(98)

Lack of availability (or knowledge) of prior advance care plans and expressed wishes

- 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)

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 is responsive to variations in these trajectories

- 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;
- 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 out-of-hospital 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.

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 suggests 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 potentially 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).

Box 4: Mobilizing research evidence about elements of a comprehensive approach for addressing the problem

The available research evidence about elements of a comprehensive approach for addressing the problem was sought primarily from Health Systems Evidence (www.healthsystemsevidence.org), which is a continuously updated database containing more than 3,000 systematic reviews (and more than 1,600 economic evaluations) of delivery, financial and governance arrangements within health systems. The reviews (and economic evaluations) were identified by searching the database for records addressing features of each of the elements and sub-elements.

The authors' conclusions were extracted from the reviews whenever possible. Some reviews contained no studies despite an exhaustive search (i.e., they were "empty" reviews), while others concluded that there was substantial uncertainty about the elements based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the reviews' quality, the local applicability of the reviews' findings, equity considerations, and relevance to the issue. (See the appendices for a complete description of these assessments.)

Being aware of what is not known can be as important as being aware of what is known. When faced with an empty review, substantial uncertainty, or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an element could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a review that was published many years ago, an updating of the review could be commissioned if time allows.

No additional research evidence was sought beyond what was included in the systematic review. Those interested in pursuing a particular element may want to search for a more detailed description of the element or for additional research evidence about the element.

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

Category of finding	Summary of key findings
Benefits	• **Establishing a process for engaging the public and other stakeholders** o Three reviews found benefit for public engagement in enhancing public awareness, understanding and competencies.(124-126) • **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)

	▪ 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** o 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** o 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** o 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** o 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** o 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) • **Identifying what combination of palliative care providers achieve the best outcomes** o A recent economic evaluation found that an inpatient palliative care team led to lower total healthcare costs following hospital discharge.(155)
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 o **Establishing a stakeholder- and/or research-driven process to ensure conceptual clarity/consistency in the use of end-of-life care terminology** o **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 o **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 o **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) o **Identifying 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) o **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) o **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) o **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) o **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) o **Establishing a coordinated knowledge-translation strategy** ▪ Several systematic reviews, including one recent and high-quality review, found insufficient evidence to

	draw conclusions about the effectiveness of interventions that have been designed for encouraging the use of research evidence by health policymakers and managers.(169-171)

Key elements of the policy option if it was tried elsewhere	- **Establishing a process for engaging the public and other stakeholders**
	  - 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 central administrative 'gatekeeper' or 'hub' to support coordination and integration**
	  - 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**
	  - An older and low-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)

Stakeholders' views and experience	- **Establishing a province-wide medical interpreter service**
	  - 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)
	- **Publicly reporting end-of-life/palliative care performance indicators**
	  - An older and medium-quality review examining the effects of pay-for-performance and public reporting on racial disparities in healthcare revealed that leaders of major performance incentive programs in the United States believed that current programs were not designed to reduce disparities, and often lack characteristics that may be important in reducing disparities (e.g., collecting race and ethnicity data, emphasizing conditions of higher prevalence in minorities, rewarding improvement, and encouraging nationally prominent organizations to establish disparity guidelines and/or measures).(152)
	  - 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)
	- **Establishing a coordinated knowledge-translation strategy**
	  - 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)
	  - 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

Category of finding	Summary of key findings
Benefits	• **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** ○ 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) • **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) ○ A recent and medium-quality review examining interventions to improve team effectiveness (197) found benefit for: ▪ simulation training; ▪ crew resource management training; ▪ team-based training; and ▪ continuous quality improvement activities. ○ 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) ○ An older and medium-quality review on interprofessional education found that it enables knowledge and skills necessary for collaborative working.(198) • **Establishing an information system that provides reminders and prompts** ○ A recent and medium-quality review found that reminders can have modest and short-term improvements in clinical behaviours across a range of settings.(199) ○ A medium-quality review that was recently published examined the effectiveness of interventions to increase advance directive completion rate, including various interventions like chart-reminders and computer-generated reminders. The review found that the use of passive informative material (e.g., posters, leaflets or videos) in isolation does not significantly increase advance directive completion rates, in contrast with interactive informative intervention, as well as multiple sessions and direct interaction between patients and health care professionals. (200) • **Establishing targeted payments to incentivize physicians to engage in end-of-life communication and decision-making** ○ 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. • **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** ○ 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)
Costs and/or	• No reviews or economic evaluations provided information about costs of the sub-elements

cost-effectiveness in relation to the status quo	
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 o **Disseminating among providers clear and consensual end-of-life care terminology that should be used in end-of-life communication, decision-making and care** o **Encouraging Family Health Teams and other primary care groups to incorporate advance care planning into their quality-improvement plans** • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review o Not applicable • No clear message from studies included in a systematic review o **Educating and training providers to facilitate culturally appropriate communication and decision-making** ▪ Several medium and high-quality reviews found a lack of evidence regarding: o the effectiveness of cultural competence training on minority healthcare quality (202;203) and in reducing health disparities.(204) o the effectiveness of communication skills training on: ▪ healthcare professional 'burnout';(181) ▪ patients' mental or physical health; (181) ▪ patient satisfaction;(181;205) and ▪ communicative behaviour;(205) o key features of effective communication skills training (e.g. types, duration and intensity of communication skills training);(181;206) o the effectiveness of interventions to improve healthcare professionals' adoption of shared decision-making.(207;208) and o the effectiveness of brief training focused on the improvement of interpersonal care.(209) o **Educating and training providers in multidisciplinary and shared care approaches** ▪ There is inconsistent or limited evidence from medium and high-quality reviews regarding the effectiveness of interprofessional education on: o communication skills and clinical skills;(210) o attitudes and perceptions;(198;210) and o professional practice and healthcare outcomes.(211) o **Educating and training non-palliative care clinicians in the palliative approach** ▪ An older and medium-quality review found a lack of evidence regarding the impact of education interventions in palliative care for primary care physicians in changing professional practice, although some benefits for multifaceted approaches were observed.(212) o **Implementing same-day/advanced access scheduling** ▪ A recent and medium-quality review examining the effectiveness of advanced access scheduling in the primary care setting found mixed evidence on patient satisfaction, as well as a lack of evidence on clinical outcomes.(201)
Key elements of the policy option if it was tried elsewhere	• **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** 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) • **Educating and training providers to facilitate culturally appropriate communication and decision-making** o Two recent and medium-quality reviews found that effective communication skills training strategies: ▪ lasted for at least one day, were learner-centred, and focused on practising skills;(195) and ▪ must not be conceived as a one-time intervention but followed periodically with additional sessions to ensure proper implementation of the intervention.(194) 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)
Stakeholders' views and experience	• **Educating and training providers to facilitate culturally appropriate communication and decision-making** 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) 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)

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);(4)
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 to 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

Category of finding	Summary of key findings
Benefits	• **Launching a social marketing campaign to raise public awareness** o Two medium-quality reviews found benefits for social marketing interventions (including online campaigns) in: ▪ encouraging voluntary health behaviour change;(222;223) and ▪ bringing about environmental and policy-level changes. (223) o One medium-quality review found that shorter interventions generally achieved larger impacts and greater adherence.(222) • **Coordinating and intensifying a strategy to engage citizens in a provincial dialogue to normalize end-of-life conversations** 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: ▪ bringing insights into social values; ▪ improving understanding of complex issues (particularly ethical and social dilemmas); and ▪ enhancing civic-mindedness. • **Providing information and education to help citizens understand how to engage in the process of advance care planning** 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) • **Establishing a specialized service providing personal support and coaching** 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: ▪ improved patient participation in the consultation process;(216;225) ▪ increased consultation length;(215) and ▪ greater patient satisfaction.(215) • **Identifying and making available patient decision aids** o Several systematic reviews, including a recent and high-quality Cochrane review, found that patient decision aids had positive effects on: ▪ knowledge about options (217;226;227) without increasing anxiety;(228) ▪ decision-making processes;(226) ▪ level of decisional conflict;(227) ▪ informed values-based choices; (217) ▪ patient-practitioner communication; (217) ▪ patients' involvement;(217) and ▪ realistic perception of outcomes.(217) • **Implementing system navigators and transition coaches** 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) 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) • **Establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services** 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) 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)

Potential harms	• **Establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services** o 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** o 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** o 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) o 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 o **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** o **Developing toolkits for lawyers who support clients in advance care planning** o **Incentivizing citizens to communicate their wishes** • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review o NA • No clear message from studies included in a systematic review o **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) o **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. o **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** o 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** o 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** o 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** o 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;

	- pain and symptom management; - cultural needs; - siblings' needs; and - decision-making. o An old but high-quality review (235) found that the uptake of respite care was influenced by "carer attitudes to caring and respite provision; the caregiving relationship; knowledge of, and availability of, services; the acceptability to, and impact of respite care on, care recipients; hassles resulting from the use of respite care; quality of respite care; and the appropriateness and flexibility of service provision." o The same review (235) revealed that carers expressed "needs for active information provision about services, support offered early in the caregiving career, access to a variety of services with flexible provision, reliable transport services, continuity of care, good-quality care, appropriate environments, care that provides benefits for care recipients (socialization and stimulation), and appropriate activities for care recipients' levels of abilities and interests."

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 the 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

Element 1 - Better align health system arrangements to support end-of-life communication, decision-making and care
Patients/individuals • may be frustrated by past citizen-engagement efforts which have not meaningfully influenced policymaking. *Providers* • may be resistant to greater patient and public engagement in developing healthcare policies.(157) *Organizational leaders* • may lack the incentives necessary to change practices or to commit to improving (or including a focus on) palliative and end-of-life care; • may perceive end-of-life care as ‘boutique’ care, which may jeopardize funding sustainability;(5) • 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 the budget uncertainty that many may face for their existing programs and services; and • may face difficulties in developing a shared vision for improving end-of-life communication, decision-making and care given their constraints and competing priorities. *System leaders* • may have difficulty engaging citizens and stakeholders who can articulate diverse viewpoints regarding a comprehensive strategy; • may perceive end-of-life care as ‘boutique’ care, which may jeopardize funding sustainability;(5) • 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; • may have difficulty with multi-agency/collaborative initiatives that are subject to changes outside their control;(165) • may be resistant to patient and public engagement;(157) and • may be reluctant to engage in end-of-life conversations because of cultural norms.(5)
Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care
Patients/individuals • N/A *Providers* • may be reluctant to engage in end-of-life conversations because of cultural norms;(5) • may be reluctant, or ill-equipped, to appropriately disclose prognoses to patients and families;(36) • may lack understanding about how patients/families and substitute decision-makers make decisions;(36) • may grapple with prevalent and persistent misconceptions about current statutes governing healthcare decisions (e.g., issues

pertaining to consent and capacity, expressed wishes vs. consent, who can interpret wishes, who can provide consent);(26)

- may be unwilling or hesitant to fully support a shared decision-making (SDM) approach given the potential for infringement on their decision-making autonomy;(57)
- 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)
- may not be inclined to engage in end-of-life conversations since the current fee-for-service model does not support SDM;(57)
- may have concerns about malpractice liability,(57) especially given recent media coverage of a high-profile legal case;(7)
- may not be inclined to obtain additional training without tangible incentives;
- 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;
- 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;
- may lack accurate documentation of end-of-life treatments;(36) and
- may lack access to prior advance care plans/expressed wishes.(36)

Organizational leaders

- 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;
- may lack the capacity to coordinate consistent educational content and activities across settings;
- may be unwilling or uninterested in making long-term sustainable financial commitments towards greater education, training and support for healthcare providers due to the budget uncertainty that many may face for their existing programs and services; and
- may not see value in investing heavily in education and training, especially those with frequent staff turnover and limited resources.

System leaders

- may be unwilling or uninterested 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.

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

Patients/individuals

- may be ill-prepared for end-of-life conversations (e.g., lack of understanding of life-sustaining technologies, conflicts, the illness and its prognosis, etc.);(36)
- may be reluctant to engage in end-of-life conversations because of cultural norms;(5)
- may grapple with prevalent and persistent misconceptions about current statutes governing healthcare decisions (e.g., issues pertaining to consent and capacity, expressed wishes vs. consent, who can interpret wishes, who can provide consent);(26)
- may have limited literacy skills preventing them from engaging meaningfully in end-of-life conversation, decision-making and care;
- may derail a public dialogue by broadening it to contentious moral and legal issues (e.g., assisted suicide, euthanasia) or by framing it as a way to deny access to care, or as a cost-reduction strategy that may accelerate end of life (e.g., death panels);
- may prefer a model of decision-making that does not fit a shared decision-making approach;(57)
- may not be inclined to engage in end-of-life conversations and formalized advance care planning without tangible incentives, especially healthy individuals; and
- may lack access to physicians and/or other healthcare providers.(36)

Providers

- may derail a public dialogue by broadening it to contentious moral and legal issues (e.g., assisted suicide and euthanasia) or by framing it as a way to deny access to care, or as a cost-reduction strategy that may accelerate end of life (e.g., death panels).

Organizational leaders

- may be resistant to patient and public engagement.(157)

System leaders

- may face difficulties in developing a shared vision for public education and social marketing campaigns and tailoring those messages to local contexts;
- may have difficulty ensuring that educational activities reach all those who could benefit, including hard-to-reach groups; and
- may be unwilling or uninterested in making long-term sustainable financial commitments towards greater patient and public engagement due to the budget uncertainty that many may face for their existing programs and services.

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 7: Potential windows of opportunity for implementing the elements

Type	Element 1 - Better align health system arrangements to support end-of-life communication, decision-making and care	Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care	Element 3 - Strengthen citizens' capacity to engage in communication and decision-making about end-of-life care
General	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) There are also opportunities to learn from integrated programs that already exist in other Canadian jurisdictions and that can serve as models for consideration within the context of Ontario's health system design and its legal framework. 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) 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) 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) 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) 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.		
Element-specific	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. 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.	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).	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) The growing popularity of 'death cafés' could provide a venue for promoting end-of-life conversations.(246) 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: Family Caregiver Leave and Critically Ill Child Care Leave.(247)

REFERENCES

1. Heyland DK, Cook DJ, Rocker GM, Dodek PM, Kutsogiannis DJ, Skrobik Y et al. Defining priorities for improving end-of-life care in Canada. Canadian Medical Association Journal 2010;182(16):E747-E752.
2. Heyland DK, Barwich D, Pichora D, Dodek P, Lamontagne F, You JJ et al. Failure to engage hospitalized elderly patients and their families in advance care planning. Journal of the American Medical Association 2013;1-10.
3. Canadian Hospice Palliative Care Association. National Ipsos-Reid Poll Indicates Majority of Canadians Haven't Talked About Their Wishes for Care. Canadian Hospice Palliative Care Association 2012;Available from: http://www.advancecareplanning.ca/news-room/national-ipsos-reid-poll-indicates-majority-of-canadians-haven?t-talked-about-their-wishes-for-care.aspx
4. Schuklenk U, van Delden JJM, Downie J, McLean S, Upshur R, Weinstock D. The Royal Society of Canada Expert Panel: End-of-Life Decision Making. Ottawa, Canada: Royal Society of Canada; 2011.
5. Carstairs S. Raising the Bar: A Roadmap for the Future of Palliative Care in Canada. Ottawa, Canada: The Senate of Canada; 2010.
6. Ontario Ministry of Finance. Commission on the Reform of Ontario's Public Services. Toronto, Canada: Government of Ontario; 2012.
7. Cribb R. Supreme Court Decision on Hassan Rasouli Will Clarify End-of-Life Medical Decisions. The Toronto Star 2012;Available from: http://www.thestar.com/news/canada/2012/12/10/supreme_court_decision_on_hassan_rasouli_will_clarify_endoflife_medical_decisions.html
8. Canadian Hospice Palliative Care Association. Speak Up. Canadian Hospice Palliative Care Association 2013;Available from: http://www.advancecareplanning.ca
9. Quality End-of-Life Care Coalition of Canada. Executive Summary. Quality End-of-Life Care Coalition of Canada 2012;Available from: http://www.qelccc.ca/media/3806/microsoft_word_-_3_executive_summary_2012.pdf
10. Hospice Palliative Care Ontario. Quality Hospice Palliative Care Coalition of Ontario. Quality Hospice Palliative Care Coalition of Ontario 2013;Available from: http://www.qhpcco.ca
11. Leadership Collaborative. Advancing High Quality, High Value Palliative Care in Ontario - Declaration of Partnership and Commitment to Action. Toronto, Canada: 2011.
12. Canadian Researchers at the End of Life Network. About Us. Canadian Researchers at the End of Life Network 2013;Available from: http://www.thecarenet.ca/index.php?option=com_content&view=section&layout=blog&id=7&Itemid=55
13. Gauvin FP, Wilson M, Alvarez E. Identifying Optimal Treatment Approaches for People with Multimorbidity in Ontario. Hamilton, Canada: McMaster Health Forum; 2013.
14. British Columbia Ministry of Health. The Provincial End-of-Life Care Action Plan for British Columbia: Priorities and Actions for Health System and Service Redesign. Victoria, Canada: British Columbia Ministry of Health; 2013.
15. National Assembly. An Act Respecting End-of-Life Care (Bill 52). Quebec City, Canada: National Assembly; 2013.

16. Ontario Medical Association. End Of Life Care Must Be A Priority: New OMA President. Ontario Medical Association 2013;Available from: https://www.oma.org/Mediaroom/PressReleases/Pages/EndOfLifeCareMustBeAPriority.aspx
17. Wooder S. Priority For End Of Life Care Strategy. Ontario Medical Association 2013;Available from: https://www.oma.org/Mediaroom/PM/Pages/PriorityForEndOfLifeCareStrategy.aspx?source=0702&link=PA
18. Wahl J. Health Care Consent and Advance Care Planning: Fairly Good Law, Good Intent, but Not Always Good Practice. Toronto, Canada: Advocacy Centre for the Elderly; 2013.
19. Spathis A, Booth S. End of life care in chronic obstructive pulmonary disease: In search of a good death. International Journal of Chronic Obstructive Pulmonary Disease 2008;3(1):11-29.
20. Hammes BJ. Having your own say - getting the right care when it matters most. Washington, D.C., United States: CHT Press; 2012.
21. Canadian Researchers at the End of Life Network. Understanding Medical Terms. Canadian Researchers at the End of Life Network 2013;Available from: http://www.thecarenet.ca/index.php?option=com_content&view=article&id=86&Itemid=82
22. Canadian Hospice Palliative Care Association. What is Palliative Care? Canadian Hospice Palliative Care Association 2013;Available from: http://www.chpca.net/family-caregivers/faqs.aspx
23. Canadian Researchers at the End of Life Network. End-of-Life Communication and Decision-Making - A Conceptual Framework. Kingston, Canada: Canadian Researchers at the End of Life Network; 2013.
24. Legislative Assembly of Ontario. Health Care Consent Act - S.O. 1996, Chapter 2, Schedule. Legislative Assembly of Ontario 1996;Available from: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm
25. Legislative Assembly of Ontario. Substitute Decisions Act - S.O. 1992, Chapter 30. Legislative Assembly of Ontario 1992;Available from: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_92s30_e.htm
26. Wahl J. 25 Common Misconceptions about the Substitute Decisions Act and the Health Care Consent Act. Advocacy Centre for the Elderly 2008;Available from: http://www.advocacycentreelderly.org/appimages/file/25%20Common%20Misconceptions.pdf
27. Community Legal Education Ontario. What is a Power of Attorney? Community Legal Education Ontario 2013;Available from: www.cleo.on.ca/en/publications/power/what-power-attorney
28. Santonocito C, Ristagno G, Gullo A, Weil MH. Do-not-resuscitate order: A view throughout the world. Journal of Critical Care 2013;28(1):14-21.
29. Provincial End-of-Life Care Network. Ontario Hospice Palliative Care Networks. Toronto Canada: Provincial End-of-Life Care Network; 2012.
30. Ministry of Health and Long-Term Care. Ontario's Aging at Home Strategy. Ministry of Health and Long-Term Care 2013;Available from: http://www.health.gov.on.ca/en/public/programs/ltc/33_ontario_strategy.aspx
31. Ontario Medical Association. Health Links 101: Integrated Health Care for Patients with Complex Needs. Toronto, Canada: Ontario Medical Association; 2013.
32. Statistics Canada. Deaths, Estimates, by Province and Territory. Statistics Canada 2012;Available from: http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo07a-eng.htm
33. Statistics Canada. Ten leading causes of death, by sex and geography,2009 — Ontario. Statistics Canada 2012;Available from: http://www.statcan.gc.ca/pub/84-215-x/2012001/tbl/t019-eng.htm

34. Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2012;Available from: http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf

35. You JJ, Fowler RA, Heyland DK, on behalf of the Canadian Researchers at the End of Life Network (CARENET). Just Ask: Discussing goals of care with patients in hospital with serious illness (online). Canadian Medical Association Journal 2013;1-8.

36. Canadian Researchers at the End of Life Network. Preliminary Findings from the DECIDE Study: Decision-Making about Goals of Care for Hospitalized Medical Patients (not published yet). Canadian Researchers at the End of Life Network 2013;

37. Bacon J. The Palliative Approach: Improving Care for Canadians with Life-Limiting Illnesses. Ottawa, Canada: Canadian Hospice Palliative Care Association; 2012.

38. Lynn J, Adamson DM. Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age. Santa Monica, United States: RAND Health; 2003.

39. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. British Medical Journal 2005;330(7498):1007-11.

40. Statistics Canada. Access to a regular medical doctor, 2010. Statistics Canada 2013;Available from: http://www.statcan.gc.ca/pub/82-625-x/2011001/article/11456-eng.htm

41. Health Quality Ontario. Quality Monitor Health Quality Ontario: 2012 Report on Ontario's Health System. Toronto, Canada: Health Quality Ontario; 2012.

42. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: Preparing for end-of-life decision making. Annals of Internal Medicine 2010;153(4):256-61.

43. Rosen LJ. Responding to Challenges of Advance Care Planning. Halifax, Canada: 2013 National Health Law Forum: Critical Issues in Health Law; 2013.

44. Morrison S. Addressing the End of Life. McMaster Daily News 2013;Available from: http://dailynews.mcmaster.ca/article/addressing-the-end-of-life/

45. McLaren C. Alberta creates electronic registry for personal directives. Canadian Medical Association Journal 2009;180(7):708.

46. Fraser Health. Medical Orders for Scope of Treatment (MOST) and Advance Care Planning (ACP). Fraser Health 2012;Available from: http://www.fraserhealth.ca/media/Medical%20Orders%20for%20Scope%20of%20Treatment%20(MOST)%20and%20Advance%20Care%20Planning%20(ACP).pdf

47. Parliamentary Committe on Palliative and Compassionate Care. Not to be Forgotten: Care of vulnerable Canadians. Ottawa, Canada: The Senate of Canada; 2011.

48. Canadian Institute for Health Information. End-of-Life Hospital Care for Cancer Patients. Ottawa, Canada: Canadian Institute for Health Information; 2013.

49. Brazil K, McAiney C, Caron-O'Brien M, Kelley ML, O'Krafka P, Sturdy-Smith C. Quality end-of-life care in long-term care facilities: Service providers' perspective. Journal of Palliative Care 2004;20(2):85-92.

50. Canadian Medical Association. Healthcare Transformation in Canada: Change that Works, Care that Lasts. Toronto, Canada: Canadian Medical Association; 2010.

51. Williams M, Eby JA, Crooks VA, Stajduhar K, Giesbrecht M, Vuksan M et al. Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? BMC Public Health 2011;11:335.

52. Canadian Hospice Palliative Care Association. Valuing Caregiving and Caregivers: Family Caregivers in the Integrated Approach to Palliative Care. Ottawa, Canada: The Way Forward initiative: an Integrated Palliative Approach to Care; 2013.
53. Canadian Healthcare Association. Respite Care in Canada. Ottawa, Canada: Canadian Healthcare Association; 2012.
54. Canadian Hospice Palliative Care Association. Fact Sheet: The Role of Family and Informal Caregivers. Canadian Hospice Palliative Care Association 2013;Available from: http://www.chpca.net/media/153773/caregiver_day_-_fact_sheet.pdf
55. Canadian Institute for Health Information. Supporting Informal Caregivers - The Heart of Home Care. Ottawa, Canada: Canadian Institute for Health Information; 2010.
56. Lakin JR, Le E, Mourad M, Hollander H, Anderson WG. Incentivizing residents to document inpatient advance care planning. JAMA Internal Medicine 2013.
57. Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. Patient Education and Counseling 2008;73(3):526-35.
58. Service Canada. Employment Insurance Compassionate Care Benefits. Government of Canada 2013;Available from: http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml
59. Ontario Ministry of Labor. Family Medical Leave. Government of Ontario 2013;Available from: http://www.labour.gov.on.ca/english/es/pubs/guide/family.php
60. Williams A, Crooks VA, Giesbrecht M, Dykeman S. Evaluating Canada's Compassionate Care Benefit: From the Perspective of Family Caregivers. Hamilton, Ontario: McMaster University; 2010.
61. Canadian Hospice Palliative Care Association. Palliative Care in the Community: An Environmental Scan of Frameworks and Indicators. Ottawa, Canada: The Way Forward Initiative: An Integrated Palliative Approach to Care; 2013.
62. Weiss A, Downar J. Ontario hospitals are not using palliative care performance indicators in their balanced scorecards. Journal of Pain and Symptom Management 2013.
63. Health Canada. Canadian Strategy on Palliative and End-of-Life Care - Final Report of the Coordinating Committee. Ottawa, Canada: Health Canada; 2007.
64. Ministry of Health and Long-Term Care. Backgrounder: Ontario's End-of-Life Care Strategy. Toronto, Canada: Ministry of Health and Long-Term Care; 2005.
65. Seow H, King S, Vaitonis V. The impact of Ontario's end-of-life care strategy on end-of-life care in the community. Healthcare Quarterly 2008;11(1):56-62.
66. Seow H, Barbera L, Howell D, Dy SM. Did Ontario's end-of-life care strategy reduce acute care service use? Healthcare Quarterly 2010;13(1):93-100.
67. Alberta Health. Continuing Care Strategy: Aging in the Right Place. Edmonton, Canada: Alberta Health; 2008.
68. Government of Alberta. Aging Population Policy Framework. Edmonton, Canada: Government of Alberta; 2010.
69. Alberta Health Services. Advance Care Planning/Goals of Care Policy. Alberta Health Services 2013;Available from: http://www.albertahealthservices.ca/3922.asp
70. NSW Ministry of Health. Advance Planning for Quality Care at End of Life - Action Plan 2013–2018. North Sydney, Australia: NSW Ministry of Health; 2013.
71. Commonwealth of Australia. The National Palliative Care Strategy – Supporting Australians to Live Well at the End of Life. Sydney, Australia: Commonwealth of Australia; 2010.

72. Bentur N, Gross R. End of Life Care Policy. Gütersloh, Germany: Health Policy Monitor; 2005.
73. Ministry of Health. The New Zealand Palliative Care Strategy. Wellington, New Zealand: Ministry of Health; 2001.
74. Lien Centre for Palliative Care, Duke-NUS Graduate Medical School. Report on the National Strategy for Palliative Care. Singapore: Lien Centre for Palliative Care; Duke-NUS Graduate Medical School; 2011.
75. Department of Health SSaPS. Living Matters/Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland. Belfast, United Kingdom: Department of Health,Social Services and Public Safety; 2010.
76. Department of Health. End of Life Care Strategy - Promoting High Quality Care for All Adults at the End of Life. London, United Kingdom: Department of Health; 2008.
77. NHS Scotland. Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland. Edinburgh, Scotland: NHS Scotland; 2008.
78. NHS Scotland, Scottish Partnership for Palliative Care. Living and Dying Well: Reflecting on Progress. Edinburgh, Scotland: NHS Scotland; 2012.
79. Advance Care Planning National Framework Task Group. Advance Care Planning in Canada: National Framework. Ottawa, Canada: Canadian Hospice Palliative Care Association; 2012.
80. Consent and Capacity Board. Public Information Program. Consent and Capacity Board 2013;Available from: http://www.ccboard.on.ca/scripts/english/publications/publicinformationprogram.asp
81. Health Care Consent and Advance Care Planning Community of Practice. Advance Care Planning in Relation to Health Care Consent: Training Materials. Speak Up 2013;Available from: http://advancecareplanning.ca/making-your-plan/how-to-make-your-plan/provincial-territorial-resources/advance-care-planning-in-relation-to-health-care-consent-training-materials.aspx
82. Providence Healthcare SJHC, St Michael's Hospital. Advance Care Planning: A Quick Guide for Healthcare Consumers and Healthcare Providers. Toronto, Canada: Centre for Medical Ethics; 2006.
83. Government of Ontario. Guide to Advance Care Planning. Toronto, Canada: Government of Ontario; 2002.
84. Quality End-of-Life Care Coalition of Canada. Framework for a National Strategy on Palliative and End-of-Life Care. Ottawa, Canada: Quality End-of-Life Care Coalition of Canada; 2005.
85. Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010-2020. Ottawa, Canada: Quality End-of-Life Care Coalition of Canada; 2010.
86. McMaster University. Continuing Education - LEAP (Learning Essential Approaches to Palliative and End of Life Care). McMaster University 2013;Available from: http://fhs.mcmaster.ca/palliativecare/leap.html
87. Kortes-Miller K, Habjan S, Kelley ML, Fortier M. Development of a palliative care education program in rural long-term care facilities. Journal of Palliative Care 2007;23(3):154-62.
88. Association of Faculties of Medicine of Canada. Educating Future Physicians in Palliative and End-of-Life Care. Association of Faculties of Medicine of Canada 2008;Available from: http://www.afmc.ca/efppec/pages/main.html
89. Canadian Nurses Association. Competencies. Canadian Nurses Association 2013;Available from: http://www.cna-aiic.ca/en/becoming-an-rn/rn-exam/competencies/
90. Canadian Association of Schools of Nursing. Palliative and End-of-Life Care: Entry-to-Practice Competencies and Indicators for Registered Nurses. Ottawa, Canada: Canadian Association of Schools of Nursing; 2011.

91. Canadian Hospice Palliative Care Association. Social Work Competencies on Palliative Education - SCOPE. Canadian Hospice Palliative Care Association 2013;Available from: http://www.chpca.net/projects-and-advocacy/projects/scope.aspx
92. Quality Palliative Care in Long Term Care Alliance. Personal Support Worker Competencies. Thunder Bay, Canada: Quality Palliative Care in Long Term Care Alliance; 2012.
93. College of Physicians and Surgeons of Ontario. Decision-Making for the End of Life. Policy Statement #1-06 ed. Toronto, Canada: College of Physicians and Surgeons of Ontario; 2006.
94. College of Nurses of Ontario. Guiding Decisions about End-of-Life Care. Toronto, Canada: College of Nurses of Ontario; 2009.
95. Registered Nurses' Association of Ontario. End-of-Life Care During the Last Days and Hours. Toronto, Canada: Registered Nurses' Association of Ontario; 2011.
96. Cancer Care Ontario. Advance Care Planning with Cancer Patients. Toronto, Canada: Cancer Care Ontario; 2011.
97. Berniquez F. Helping Health Care Workers Understand Multicultural Practices and Beliefs at End of Life. Ottawa, Canada: Bruyère Continuing Care; 2006.
98. Canadian Researchers at the End of Life Network. Advance Care Planning Evaluation in Hospitalized Elderly Patients: A Multicenter, Prospective Study - The ACCEPT Study. Canadian Researchers at the End of Life Network 2013;Available from: http://www.thecarenet.ca/index.php?option=com_content&view=article&id=155&Itemid=97
99. Cancer Care Ontario. Improving the Quality of Palliative Care Services for Cancer Patients in Ontario. Toronto, Canada: Cancer Care Ontario; 2006.
100. Cancer Care Ontario. Palliative Care Program. Cancer Care Ontario 2013;Available from: https://www.cancercare.on.ca/cms/one.aspx?pageId=8706
101. The Change Foundation. PATH Project. The Change Foundation 2013;Available from: http://www.changefoundation.ca/projects/path/
102. Canadian Hospice Palliative Care Association. A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Ottawa, Canada: Canadian Hospice Palliative Care Association; 2002.
103. Accreditation Canada. Hospice Palliative and End-of-Life Care Services. Accreditation Canada 2013;Available from: http://www.accreditation.ca/accreditation-programs/qmentum/standards/hospice-palliative-and-end-of-life-services/
104. Canadian Hospice Palliative Care Association, Canadian Network of Palliative Care for Children. Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice. Ottawa, Canada: Canadian Hospice Palliative Care Association; 2006.
105. Task Group on Volunteer Competencies and Best Practices. A Model for Volunteer Best Practices in Canadian Hospice Palliative Care. Ottawa: Canadian Hospice Palliative Care Association; 2003.
106. CHPCA Nursing Standards Committee. Canadian Hospice Palliatice Care Nursing Standards of Practice. Ottawa, Canada: Canadian Hospice Palliative Care Association; 2009.
107. Provincial End-of-Life Care Network. A Provincial System Design Framework: A Primer on Possible Components of Ontario's Hospice Palliatice Care System. Toronto, Canada: Provincial End-of-Life Care Network; 2010.
108. Canadian Institute for Health Information. Seniors and the Health Care System: What is the Impact of Multiple Chronic Conditions? Ottawa, Canada: Canadian Institute for Health Information; 2011.

109. Health Council of Canada. How Do Sicker Canadians with Chronic Disease Rate the Health Care System? Toronto, Canada: Health Council of Canada; 2011.

110. Health Council of Canada. Population Patterns of Chronic Health Conditions in Canada - A Data Supplement to Why Healthcare Renewal Matters: Learning from Canadians with Chronic Health Conditions. Toronto, Canada: Health Council of Canada; 2007.

111. The Change Foundation. Because This Is the Rainy Day: A Discussion Paper on Home Care And Informal Caregiving for Seniors with Chronic Health. Toronto, Canada: The Change Foundation; 2011.

112. Ontario Trillium Foundation. Diversity in Ontario: A Community Profile. Toronto, Canada: Ontario Trillium Foundation; 2011.

113. Norris WM, Wenrich MD, Nielsen EL, Treece PD, Jackson JC, Curtis JR. Communication about end-of-life care between language-discordant patients and clinicians: Insights from medical interpreters. Journal of Palliative Care 2005;8(5):1016-24.

114. Flagler J, Dong W. The uncompassionate elements of the Compassionate Care Benefits Program: A critical analysis. Global Health Promotion 2010;17(1):50-9.

115. Lopez S. Honoring cultural diversity at the end-of-life. Social Work Today 2007;7(6):36.

116. Ebrahim S, Bance S, Bowman KW. Sikh perspectives towards death and end-of-life care. Journal of Palliative Care 2011;27(2):170-4.

117. Donovan R, Williams A, Stajduhar K, Brazil K, Marshall D. The influence of culture on home-based family caregiving at end-of-life: A case study of Dutch reformed family care givers in Ontario, Canada. Social Science and Medicine 2011;72(3):338-46.

118. Bowman KW, Singer PA. Chinese seniors' perspectives on end-of-life decisions. Social Science and Medicine 2001;53(4):455-64.

119. Shea BJ, Grimshaw JM, Wells GA, Boers M, Andersson N, Hamel C et al. Development of AMSTAR: A measurement tool to assess the methodological quality of systematic reviews. BMC Medical Research Methodology 2007;7:10.

120. Effiong A, Muhajarine N, Effiong AI. Palliative Care for the Management of Chronic Illness. PROSPERO International prospective register of systematic reviews 2013;Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42011001794#.UffJXxZgDO0

121. Rogers S. Continuous quality improvement: Effects on professional practice and patient outcomes. Cochrane Database of Systematic Reviews 2009.

122. Sun G, Gaines J, Perla R, MacEachern M, Davis M, Shrank W. Systematic review of quality improvement initiatives in the intensive care setting. PROSPERO International prospective register of systematic reviews 2012.

123. Tsuruta H, Karim D, Sawada T, Mori R. Trained medical interpreters in a face-to-face clinical setting for patients with low proficiency in the local language (Protocol). Cochrane Database of Systematic Reviews 2013;(3):CD010421.

124. Conklin A, Morris Z, Nolte E. What is the evidence base for public involvement in health-care policy? Results of a systematic scoping review. Health Expectations 2012.

125. Menon D, Stafinski T, Martin D, Windwick B, Singer P, Caulfield T. State of the Science Review: Incorporating Public Values and Technical Information into Health Care Resource Allocation Decision-Making. Edmonton, Canada: Alberta Innovates - Health Solutions; 2003.

126. Abelson J, Montesanti S, Li K, Gauvin F, Martin E. Effective Strategies for Interactive Public Engagement in the Development of Healthcare Policies and Programs. Ottawa, Canada: Canadian Health Services Research Foundation; 2010.

127. Hall S, Kolliakou A, Petkova H, Froggatt K, Higginson IJ. Interventions for improving palliative care for older people living in nursing care homes. Cochrane Database of Systematic Reviews 2011;(3):CD007132.
128. Thomas RE, Wilson D, Sheps S. A literature review of randomized controlled trials of the organization of care at the end of life. Canadian Journal on Aging 2006;25(3):271-93.
129. Harding R, Karus D, Easterbrook P, Raveis VH, Higginson IJ, Marconi K. Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. Sexually Transmitted Infections 2005;81(1):5-14.
130. Stevens E, Martin CR, White CA. The outcomes of palliative care day services: A systematic review. Palliative Medicine 2011;25(2):153-69.
131. Phillips JL, West PA, Davidson PM, Agar M. Does case conferencing for people with advanced dementia living in nursing homes improve care outcomes: Evidence from an integrative review? International Journal of Nursing Studies 2013;50(8):1122-35.
132. Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AG, Cook A et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? Journal of Pain and Symptom Management 2003;25(2):150-68.
133. Herber OR, Johnston BM. The role of healthcare support workers in providing palliative and end-of-life care in the community: A systematic literature review. Health and Social Care in the Community 2013;21(3):225-35.
134. Wilson DM, Justice C, Thomas R, Sheps S, Macadam M, Brown M. End-of-life care volunteers: A systematic review of the literature. Health Services Management Research 2005;18(4):244-57.
135. Shepperd S, Wee B, Straus SE. Hospital at home: Home-based end of life care. Cochrane Database of Systematic Reviews 2011;(7):CD009231.
136. Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews 2013;6:CD007760.
137. Gagliardi AR, Brouwers MC, Finelli A, Campbell CM, Marlow BA, Silver IL. Physician self-audit: A scoping review. Journal of Continuing Education in the Health Professions 2011;31(4):258-64.
138. Ivers N, Jamtvedt G, Flottorp S, Young JM, Odgaard-Jensen J, French SD et al. Audit and feedback: Effects on professional practice and healthcare outcomes. Cochrane Database of Systematic Reviews 2012;6:CD000259.
139. Scott I. What are the most effective strategies for improving quality and safety of health care? Internal Medicine Journal 2009;39(6):389-400.
140. So JP, Wright JG. The use of three strategies to improve quality of care at a national level. Clinical Orthopaedics and Related Research 2012;470(4):1006-16.
141. Nadeem E, Olin SS, Hill LC, Hoagwood KE, Horwitz SM. Understanding the components of quality improvement collaboratives: A systematic literature review. Milbank Quarterly 2013;91(2):354-94.
142. Schouten LM, Hulscher ME, van Everdingen JJ, Huijsman R, Grol RP. Evidence for the impact of quality improvement collaboratives: Systematic review. British Medical Journal 2008;336(7659):1491-4.
143. O'Beirne M, Oelke ND, Sterling P, Lait J, Zwicker K, Lewanczuk R et al. A Synthesis of Quality Improvement and Accreditation Mechanisms in Primary Healthcare. Ottawa, Canada: Canadian Foundation for Healthcare Improvement; 2012.
144. Fawole OA, Dy SM, Wilson RF, Lau BD, Martinez KA, Apostol CC et al. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. Journal of General Internal Medicine 2013;28(4):570-7.

145. Totten A, Wagner J, Tiwari A, O'Haire C, Griffin J, Walker M. Closing the Quality Gap Series: Public Reporting as a Quality Improvement Strategy. Evidence Report No. 208 ed. Rockville, United States: Agency for Healthcare Research and Quality; 2012.

146. Faber M, Bosch M, Wollersheim H, Leatherman S, Grol R. Public reporting in health care: How do consumers use quality-of-care information? A systematic review. Medical Care 2009;47(1):1-8.

147. Marshall MN, Shekelle PG, Leatherman S, Brook RH. The public release of performance data: What do we expect to gain? A review of the evidence. Journal of the American Medical Association 2000;283(14):1866-74.

148. Karliner LS, Jacobs EA, Chen AH, Mutha S. Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature. Health Services Research 2007;42(2):727-54.

149. Flores G. The impact of medical interpreter services on the quality of health care: A systematic review. Medical Care Research and Review 2005;62(3):255-99.

150. Lau F, Kuziemsky C, Price M, Gardner J. A review on systematic reviews of health information system studies. Journal of the American Medical Informatics Association 2010;17(6):637-45.

151. Murthy L, Shepperd S, Clarke MJ, Garner SE, Lavis JN, Perrier L et al. Interventions to improve the use of systematic reviews in decision-making by health system managers, policy makers and clinicians. Cochrane Database of Systematic Reviews 2012;9:CD009401.

152. Chien AT, Chin MH, Davis AM, Casalino LP. Pay for performance, public reporting, and racial disparities in health care: How are programs being designed? Medical Care Research and Review 2007;64(5 Suppl):283S-304S.

153. Lukas L, Foltz C, Paxton H. Hospital outcomes for a home-based palliative medicine consulting service. Journal of Palliative Medicine 2013;16(2):179-84.

154. Engelhardt JB, McClive-Reed KP, Toseland RW, Smith TL, Larson DG, Tobin DR. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: A randomized trial. American Journal of Managed Care 2006;12(2):93-100.

155. Gade G, Venohr I, Conner D, McGrady K, Beane J, Richardson RH et al. Impact of an inpatient palliative care team: A randomized control trial. Journal of Palliative Medicine 2008;11(2):180-90.

156. Chan R, Webster J. End-of-life care pathways for improving outcomes in caring for the dying. Cochrane Database of Systematic Reviews 2010;(1):CD008006.

157. Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. Cochrane Database of Systematic Reviews 2006;(3):CD004563.

158. Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N et al. Systematic review of involving patients in the planning and development of health care. British Medical Journal 2002;325(7375):1263.

159. Mitton C, Smith N, Peacock S, Evoy B, Abelson J. Public participation in health care priority setting: A scoping review. Health Policy 2009;91(3):219-28.

160. Garcia-Perez L, Linertova R, Martin-Olivera R, Serrano-Aguilar P, Benitez-Rosario MA. A systematic review of specialised palliative care for terminal patients: which model is better? Palliative Medicine 2009;23(1):17-22.

161. Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care: A systematic review. Journal of the American Medical Association 2008;299(14):1698-709.

162. Luckett T, Davidson PM, Lam L, Phillips J, Currow DC, Agar M. Do community specialist palliative care services that provide home nursing increase rates of home death for people with life-limiting

illnesses? A systematic review and meta-analysis of comparative studies. Journal of Pain and Symptom Management 2013;45(2):279-97.

163. Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AG et al. Do hospital-based palliative teams improve care for patients or families at the end of life? Journal of Pain and Symptom Management 2002;23(2):96-106.

164. Devlin M, McIlfatrick S. The role of the home-care worker in palliative and end-of-life care in the community setting: A literature review. International Journal of Palliative Nursing 2009;15(11):526-32.

165. Hayes SL, Mann MK, Morgan FM, Kelly MJ, Weightman AL. Collaboration between local health and local government agencies for health improvement. Cochrane Database of Systematic Reviews 2012;10:CD007825.

166. Ketelaar NA, Faber MJ, Flottorp S, Rygh LH, Deane KH, Eccles MP. Public release of performance data in changing the behaviour of healthcare consumers, professionals or organisations. Cochrane Database of Systematic Reviews 2011;(11):CD004538.

167. Fung CH, Lim YW, Mattke S, Damberg C, Shekelle PG. Systematic review: The evidence that publishing patient care performance data improves quality of care. Annals of Internal Medicine 2008;148(2):111-23.

168. Ko H, Turner T, Jones C, Hill C. Patient-held medical records for patients with chronic disease: A systematic review. Quality and Safety in Health Care 2010;19(5):e41.

169. Bostrom AM, Slaughter SE, Chojecki D, Estabrooks CA. What do we know about knowledge translation in the care of older adults? A scoping review. Journal of the American Medical Directors Association 2012;13(3):210-9.

170. Brouwers MC, Garcia K, Makarski J, Daraz L. The landscape of knowledge translation interventions in cancer control: What do we know and where to next? A review of systematic reviews. Implementation Science 2011;6:130.

171. Goldner EM, Jeffries V, Bilsker D, Jenkins E, Menear M, Petermann L. Knowledge translation in mental health: A scoping review. Healthcare Policy 2011;7(2):83-98.

172. Wallace J, Teare GF, Verrall T, Chan BTB. Public Reporting on the Quality of Healthcare: Emerging Evidence on Promising Practices for Effective Reporting. Ottawa, Canada: Canadian Health Services Research Foundation; 2007.

173. Innvaer S, Vist G, Trommald M, Oxman A. Health policy-makers' perceptions of their use of evidence: A systematic review. Journal of Health Services Research and Policy 2002;7(4):239-44.

174. Lavis JN, Hammill AC, Gildiner A, McDonagh RJ, Wilson MG, Ross SE et al. A Systematic Review of the Factors that Influence the Use of Research Evidence by Public Policymakers. Hamilton, Canada: Final report submitted to the Canadian Population Health Initiative; 2005.

175. Lavis J, Davies H, Oxman A, Denis JL, Golden-Biddle K, Ferlie E. Towards systematic reviews that inform health care management and policy-making. Journal of Health Services Research and Policy 2005;10 Suppl 1:35-48.

176. Orton L, Lloyd-Williams F, Taylor-Robinson D, O'Flaherty M, Capewell S. The use of research evidence in public health decision making processes: Systematic review. PLoS One 2011;6(7):e21704.

177. Wallace J, Nwosu B, Clarke M. Barriers to the uptake of evidence from systematic reviews and meta-analyses: A systematic review of decision makers' perceptions. BMJ Open 2012;2(5).

178. Chambers D, Wilson PM, Thompson CA, Hanbury A, Farley K, Light K. Maximizing the impact of systematic reviews in health care decision making: A systematic scoping review of knowledge-translation resources. Milbank Quarterly 2011;89(1):131-56.

179. Wallace J, Byrne C, Clarke M. Making evidence more wanted: A systematic review of facilitators to enhance the uptake of evidence from systematic reviews and meta-analyses. International Journal of Evidence-Based Healthcare 2012;10(4):338-46.

180. Barwick MA, Schachter HM, Bennett LM, McGowan J, Ly M, Wilson A et al. Knowledge translation efforts in child and youth mental health: A systematic review. Journal of Evidence-Based Social Work 2012;9(4):369-95.

181. Moore PM, Rivera MS, Grez AM, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. Cochrane Database of Systematic Reviews 2013;3:CD003751.

182. Dwamena F, Holmes-Rovner M, Gaulden CM, Jorgenson S, Sadigh G, Sikorskii A et al. Interventions for providers to promote a patient-centred approach in clinical consultations. Cochrane Database of Systematic Reviews 2012;12:CD003267.

183. Zwarenstein M, Goldman J, Reeves S. Interprofessional collaboration: Effects of practice-based interventions on professional practice and healthcare outcomes. Cochrane Database of Systematic Reviews 2009;(3):CD000072.

184. Flodgren G, Eccles MP, Shepperd S, Scott A, Parmelli E, Beyer FR. An overview of reviews evaluating the effectiveness of financial incentives in changing healthcare professional behaviours and patient outcomes. Cochrane Database of Systematic Reviews 2011;(7):CD009255.

185. Parry R, Land V, Seymour J. Communicating face-to-face about sensitive future matters including end of life: A systematic review of evidence from fine-grained observational research. PROSPERO International prospective register of systematic reviews 2012.

186. Oliviera VC, Ferreira PH, Lsm CT, Ferreira ML, Pinto RZ, Filho RFN et al. Is communication skills training effective to improve patients' clinical outcomes? A systematic review (Protocol). PROSPERO International prospective register of systematic reviews 2012.

187. Horey D, Street AF, O'Connor M, Peters L, Lee S. Training and supportive programs for palliative care volunteers in community settings (Protocol). Cochrane Database of Systematic Reviews 2011;12.

188. Horey D, Humbold B. Interventions for supporting palliative care volunteers in policy, organization and service settings (Protocol). Cochrane Database of Systematic Reviews 2011.

189. Pantoja T, Romero A, Green ME, Wyatt J, Grimshaw J, Denig P et al. Manual paper reminders: Effects on professional practice and health care outcomes (Protocol). Cochrane Database of Systematic Reviews 2009.

190. Shaw EA, Marshall D, Howard M, Taniguchi A, Winemaker S, Burns S. A systematic review of postgraduate palliative care curricula. Journal of Palliative Medicine 2010;13(9):1091-108.

191. Phillips JL, Piza M, Ingham J. Continuing professional development programs for rural nurses involved in palliative care delivery: An integrative review. Nurse Education Today 2012;32(4):385-92.

192. Bugge E, Higginson IJ. Palliative care and the need for education - Do we know what makes a difference? A limited systematic review. Health Education Journal 2006;65(2):101-25.

193. McGilton KS, Boscart V, Fox M, Sidani S, Rochon E, Sorin-Peters R. A systematic review of the effectiveness of communication interventions for health care providers caring for patients in residential care settings. Worldviews on Evidence-Based Nursing 2009;6(3):149-59.

194. Eggenberger E, Heimerl K, Bennett MI. Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. International Psychogeriatrics 2013;25(3):345-58.

195. Berkhof M, van Rijssen HJ, Schellart AJ, Anema JR, van der Beek AJ. Effective training strategies for teaching communication skills to physicians: An overview of systematic reviews. Patient Education and Counseling 2011;84(2):152-62.
196. Chakraborti C, Boonyasai RT, Wright SM, Kern DE. A systematic review of teamwork training interventions in medical student and resident education. Journal of General Internal Medicine 2008;23(6):846-53.
197. Buljac-Samardzic M, Dekker-van Doorn CM, van Wijngaarden JD, van Wijk KP. Interventions to improve team effectiveness: A systematic review. Health Policy 2010;94(3):183-95.
198. Hammick M, Freeth D, Koppel I, Reeves S, Barr H. A best evidence systematic review of interprofessional education: BEME Guide no. 9. Medical Teacher 2007;29(8):735-51.
199. Cheung A, Weir M, Mayhew A, Kozloff N, Brown K, Grimshaw J. Overview of systematic reviews of the effectiveness of reminders in improving healthcare professional behavior. Systematic Reviews 2012;1:36.
200. Tamayo-Velazquez MI, Simon-Lorda P, Villegas-Portero R, Higueras-Callejon C, Garcia-Gutierrez JF, Martinez-Pecino F et al. Interventions to promote the use of advance directives: An overview of systematic reviews. Patient Education and Counseling 2010;80(1):10-20.
201. Rose KD, Ross JS, Horwitz LI. Advanced access scheduling outcomes: A systematic review. Archives of Internal Medicine 2011;171(13):1150-9.
202. Price EG, Beach MC, Gary TL, Robinson KA, Gozu A, Palacio A et al. A systematic review of the methodological rigor of studies evaluating cultural competence training of health professionals. Academic Medicine 2005;80(6):578-86.
203. Chipps JA, Simpson B, Brysiewicz P. The effectiveness of cultural-competence training for health professionals in community-based rehabilitation: a systematic review of literature. Worldviews on Evidence-Based Nursing 2008;5(2):85-94.
204. Lie DA, Lee-Rey E, Gomez A, Bereknyei S, Braddock CH, III. Does cultural competency training of health professionals improve patient outcomes? A systematic review and proposed algorithm for future research. Journal of General Internal Medicine 2011;26(3):317-25.
205. Uitterhoeve RJ, Bensing JM, Grol RP, Demulder PH, VAN AT. The effect of communication skills training on patient outcomes in cancer care: A systematic review of the literature. European Journal of Cancer Care 2010;19(4):442-57.
206. Barth J, Lannen P. Efficacy of communication skills training courses in oncology: A systematic review and meta-analysis. Ann Oncol 2011;22(5):1030-40.
207. Légaré F, Ratté S, Stacey D, Kryworuchko J, Gravel K, Graham ID et al. Interventions for improving the adoption of shared decision making by healthcare professionals. Cochrane Database of Systematic Reviews 2010;(5):CD006732.
208. Légaré F, Turcotte S, Stacey D, Ratté S, Kryworuchko J, Graham ID. Patients' perceptions of sharing in decisions: A systematic review of interventions to enhance shared decision making in routine clinical practice. Patient 2012;5(1):1-19.
209. Cheraghi-Sohi S, Bower P. Can the feedback of patient assessments, brief training, or their combination, improve the interpersonal skills of primary care physicians? A systematic review. BMC Health Services Research 2008;8:179.
210. Lapkin S, Levett-Jones T, Gilligan C. A systematic review of the effectiveness of interprofessional education in health professional programs. Nurse Education Today 2013;33(2):90-102.

211. Reeves S, Zwarenstein M, Goldman J, Barr H, Freeth D, Hammick M et al. Interprofessional education: Effects on professional practice and health care outcomes. Cochrane Database of Systematic Reviews 2008;(1):CD002213.

212. Alvarez MP, Agra Y. Systematic review of educational interventions in palliative care for primary care physicians. Palliative Medicine 2006;20(7):673-83.

213. Thomas DC, Johnston B, Dunn K, Sullivan GM, Brett B, Matzko M et al. Continuing medical education, continuing professional development, and knowledge translation: Improving care of older patients by practicing physicians. Journal of the American Geriatrics Society 2006;54(10):1610-8.

214. Grilli R, Ramsay C, Minozzi S. Mass media interventions: Effects on health services utilisation. Cochrane Database of Systematic Reviews 2002;(1):CD000389.

215. Kinnersley P, Edwards A, Hood K, Cadbury N, Ryan R, Prout H et al. Interventions before consultations for helping patients address their information needs. Cochrane Database of Systematic Reviews 2007;(3):CD004565.

216. Wetzels R, Harmsen M, Van WC, Grol R, Wensing M. Interventions for improving older patients' involvement in primary care episodes. Cochrane Database of Systematic Reviews 2007;(1):CD004273.

217. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews 2011;(10):CD001431.

218. Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database of Systematic Reviews 2011;(6):CD007617.

219. Houttekier D, Cohen JCFDL. Advance care planning for end-of-life care (Protocol). Cochrane Database of Systematic Reviews 2012;2.

220. Effiong A, Shinn L, Pope T, Raho J. Advance care planning for end-stage kidney disease (Protocol). Cochrane Database of Systematic Reviews 2013.

221. Brennan CA, Williams MAL. Interventions to support children through bereavement (Protocol). Cochrane Database of Systematic Reviews 2009.

222. Cugelman B, Thelwall M, Dawes P. Online interventions for social marketing health behavior change campaigns: A meta-analysis of psychological architectures and adherence factors. Journal of Medical Internet Research 2011;13(1):e17.

223. Stead M, Gordon R, Angus K, McDermott L. A systematic review of social marketing effectiveness. Health Education 2007;107(2):126-91.

224. Carman KL, Heeringa JW, Heil SKR, Garfinkal S, Windham A, Gilmore D et al. Public deliberation to elicit input on health topics: Findings from a literature review. Rockville, United States: Agency for Healthcare Research and Quality; 2013.

225. Haywood K, Marshall S, Fitzpatrick R. Patient participation in the consultation process: A structured review of intervention strategies. Patient Education and Counseling 2006;63(1-2):12-23.

226. Estabrooks C, Goel V, Thiel E, Pinfold P, Sawka C, Williams I. Decision aids: Are they worth it? A systematic review. Journal of Health Services Research and Policy 2001;6(3):170-82.

227. Knops AM, Legemate DA, Goossens A, Bossuyt PM, Ubbink DT. Decision aids for patients facing a surgical treatment decision: A systematic review and meta-analysis. Annals of Surgery 2013;257(5):860-6.

228. O'Brien MA, Whelan TJ, Villasis-Keever M, Gafni A, Charles C, Roberts R et al. Are cancer-related decision aids effective? A systematic review and meta-analysis. Journal of Clinical Oncology 2009;27(6):974-85.

229. Manderson B, McMurray J, Piraino E, Stolee P. Navigation roles support chronically ill older adults through healthcare transitions: A systematic review of the literature. Health and Social Care in the Community 2012;20(2):113-27.

230. Wells KJ, Battaglia TA, Dudley DJ, Garcia R, Greene A, Calhoun E et al. Patient navigation: State of the art or is it science? Cancer 2008;113(8):1999-2010.

231. Acton GJ, Kang J. Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. Res Nurs Health 2001;24(5):349-60.

232. Schoenmakers B, Buntinx F, DeLepeleire J. Supporting the dementia family caregiver: The effect of home care intervention on general well-being. Aging Ment Health 2010;14(1):44-56.

233. Mason A, Weatherly H, Spilsbury K, Arksey H, Golder S, Adamson J et al. A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. Health Technology Assessment 2007;11(15):1-157, iii.

234. Onrust S, Smit F, Willemse G, van den Bout J, Cuijpers P. Cost-utility of a visiting service for older widowed individuals: Randomised trial. BMC Health Services Research 2008;8:128.

235. Shaw C, McNamara R, Abrams K, Cannings-John R, Hood K, Longo M et al. Systematic review of respite care in the frail elderly. Health Technology Assessment 2009;13(20):1-224, iii.

236. Lee H, Cameron M. Respite care for people with dementia and their carers. Cochrane Database Syst Rev 2004;(2):CD004396.

237. Jeon YH, Brodaty H, Chesterson J. Respite care for caregivers and people with severe mental illness: Literature review. Journal of Advanced Nursing 2005;49(3):297-306.

238. Luca NR, Suggs LS. Theory and model use in social marketing health interventions. Journal of Health Communication 2013;18(1):20-40.

239. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: A systematic review. Social Science and Medicine 2005;61(10):2252-64.

240. Stevenson M, Achille M, Lugasi T. Pediatric palliative care in Canada and the United States: A qualitative metasummary of the needs of patients and families. Journal of Palliative Medicine 2013;16(5):566-77.

241. Canadian Medical Association. Resolutions Adopted - 145th Annual Meeting of the Canadian Medical Association. Canadian Medical Association 2012;Available from: http://www.cma.ca/multimedia/CMA/Content_Images/Inside_cma/Annual_Meeting/2012/resolutions/2012GC-Resolutions_en.pdf

242. Canadian Medical Association. Resolutions Adopted - 146th Annual Meeting of the Canadian Medical Association. Canadian Medical Association 2013;Available from: http://www.cma.ca/2013-resolutions-adopted-unconfirmed

243. Sinha SK. Living Longer, Living Well. Toronto, Canada: Government of Ontario; 2012.

244. Canadian Institutes of Health Research. CIHR Institute of Aging - Research Priorities 2013-2018. Canadian Institutes of Health Research 2013;Available from: http://www.cihr-irsc.gc.ca/e/46837.html

245. Editorial. Rare Agreement in Ontario on Need for End-of-Life Discussions. The Toronto Star 2013;Available from: http://www.thestar.com/opinion/editorials/2013/06/24/rare_agreement_in_ontario_on_need_for_endoflife_discussions_editorial.html

246. Hamilton Spectator. Death Café Serves Up Tea, Cake and Conversation About Dying. Hamilton Spectator 2013;Available from: http://www.thespec.com/news-story/3850302-death-caf-serves-up-tea-cake-and-conversation-about-dying/

247. Legislative Assembly of Ontario. Bill 21 - Employment Standards Amendment Act (Leaves to Help Families). Legislative Assembly of Ontario 2013;Available from: http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&Intranet=&BillID=2738

248. El-Jawahri A, Greer JA, Temel JS. Does palliative care improve outcomes for patients with incurable illness? A review of the evidence. Journal of Supportive Oncology 2011;9(3):87-94.

249. Critchley P, Jadad AR, Taniguchi A, Woods A, Stevens R, Reyno L et al. Are some palliative care delivery systems more effective and efficient than others? A systematic review of comparative studies. Journal of Palliative Care 1999;15(4):40-7.

250. Wilkinson EK, Salisbury C, Bosanquet N, Franks PJ, Kite S, Lorentzon M et al. Patient and carer preference for, and satisfaction with, specialist models of palliative care: A systematic literature review. Palliative Medicine 1999;13(3):197-216.

251. Salisbury C, Bosanquet N, Wilkinson EK, Franks PJ, Kite S, Lorentzon M et al. The impact of different models of specialist palliative care on patients' quality of life: A systematic literature review. Palliative Medicine 1999;13(1):3-17.

252. Shaw KL, Clifford C, Thomas K, Meehan H. Improving end-of-life care: A critical review of the gold standards framework in primary care. Palliative Medicine 2010;24(3):317-29.

253. Dy S, Aslakson R, Wilson R, Fawole O, Lau B, Martinez K et al. Closing the Quality Gap: Revisiting the State of the Science: Improving Health Care and Palliative Care for Advanced and Serious Illness. Rockville, United States: Agency for Healthcare Research and Quality; 2012.

254. Evans R, Stone D, Elwyn G. Organizing palliative care for rural populations: A systematic review of the evidence. Family Practice 2003;20(3):304-10.

255. Johnston B, McGill M, Milligan S, McElroy D, Foster C, Kearney N. Self care and end of life care in advanced cancer: Literature review. European Journal of Oncology Nursing 2009;13(5):386-98.

256. Trivedi D, Goodman C, Gage H, Baron N, Scheibl F, Iliffe S et al. The effectiveness of inter-professional working for older people living in the community: A systematic review. Health and Social Care in the Community 2013;21(2):113-28.

257. McPheeters M, Kripalani S, Peterson N, Idowu R, Jerome R, Potter S et al. Quality Improvement Interventions to Address Health Disparities. Rockville, United States: Agency for Healthcare Research and Quality; 2013.

258. Conry MC, Humphries N, Morgan K, McGowan Y, Montgomery A, Vedhara K et al. A 10 year (2000-2010) systematic review of interventions to improve quality of care in hospitals. BMC Health Services Research 2012;12:275.

259. Coory M, White VM, Johnson KS, Hill DJ, Jefford M, Harrison S et al. Systematic review of quality improvement interventions directed at cancer specialists. Journal of Clinical Oncology 2013;31(12):1583-91.

260. Brennan SE, Bosch M, Buchan H, Green SE. Measuring team factors thought to influence the success of quality improvement in primary care: A systematic review of instruments. Implementation Science 2013;8:20.

261. Brennan SE, Bosch M, Buchan H, Green SE. Measuring organizational and individual factors thought to influence the success of quality improvement in primary care: A systematic review of instruments. Implementation Science 2012;7(1):121.

262. Powell AE, Rushmer RK, Davies HT. A Systematic Narrative Review of Quality Improvement Models in Health Care. Edinburgh, Scotland: NHS Quality Improvement Scotland; 2009.

263. Kaplan HC, Brady PW, Dritz MC, Hooper DK, Linam WM, Froehle CM et al. The influence of context on quality improvement success in health care: A systematic review of the literature. Milbank Quarterly 2010;88(4):500-59.

264. Berger ZD, Joy SM, Hutfless S, Bridges JF. Can public reporting impact patient outcomes and disparities? A systematic review. Patient Education and Counseling 2013.

265. Anderson LM, Scrimshaw SC, Fullilove MT, Fielding JE, Normand J. Culturally competent healthcare systems: A systematic review. American Journal of Preventive Medicine 2003;24(3 Suppl):68-79.

266. Henderson S, Kendall E, See L. The effectiveness of culturally appropriate interventions to manage or prevent chronic disease in culturally and linguistically diverse communities: A systematic literature review. Health and Social Care in the Community 2011;19(3):225-49.

267. Boaz A, Baeza J, Fraser A. Effective implementation of research into practice: An overview of systematic reviews of the health literature. BMC Research Notes 2011;4:212.

268. Perrier L, Mrklas K, Lavis JN, Straus SE. Interventions encouraging the use of systematic reviews by health policymakers and managers: A systematic review. Implementation Science 2011;6:43.

269. Bunn F, Sworn K. Strategies to promote the impact of systematic reviews on healthcare policy: A systematic review of the literature. Evidence & Policy 2011;7(4):403-28.

270. Moore G, Redman S, Haines M, Todd A. What works to increase the use of research in population health policy and programmes: A review. Evidence & Policy 2011;7(3):277-305.

271. Mitton C, Adair CE, McKenzie E, Patten SB, Waye PB. Knowledge transfer and exchange: Review and synthesis of the literature. Milbank Quarterly 2007;85(4):729-68.

272. Kinley J, Froggatt K, Bennett MI. The effect of policy on end-of-life care practice within nursing care homes: A systematic review. Palliative Medicine 2013;27(3):209-20.

273. Campbell CL, Campbell LC. A systematic review of cognitive behavioral interventions in advanced cancer. Patient Education and Counseling 2012;89(1):15-24.

274. Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. Journal of the American Medical Association 2004;291(19):2359-66.

275. Neville CC, Byrne GJ. The impact of residential respite care on the behaviour of older people with dementia: Literature review. International Journal of Older People Nursing 2007;2(1):2-8.

APPENDICES

The following tables provide detailed information about the systematic reviews and economic evaluations or costing studies identified for each option. Each row in a table corresponds to a particular document and the documents are organized by element (first column). The focus of the document is described in the second column. Key findings from the document that relate to the element are listed in the third column, while the fourth column records the last year the literature was searched as part of the review (or the year that the economic evaluation or costing study was published).

The fifth column presents a rating of the overall quality of any systematic review (no such 'scoring' system exists for economic evaluations and costing studies). The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial, or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered "high scores." A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8.

The last three columns convey information about the utility of the document in terms of local applicability, applicability concerning prioritized groups, and issue applicability. For each review, the third-from-last column notes the proportion of studies that were conducted in Canada, while the second-from-last column comments on the proportion of studies included in the review that deal explicitly with one of the prioritized groups. The last column indicates the review's issue applicability in terms of the proportion of studies focused on end-of-life communication, decision-making and care. Similarly, for each economic evaluation and costing study, the last three columns note whether the country focus is Canada, if it deals explicitly with one of the prioritized groups and if it focuses on end-of-life communication, decision-making and care.

All of the information provided in the appendix tables was taken into account by the evidence brief's authors in compiling Tables 3-5 in the main text of the brief.

Appendix 1: Systematic reviews and economic evaluations relevant to Element 1 - Better align health system arrangements to support end-of-life communication, decision-making and care

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
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)	Examining the peer-reviewed empirical evidence on outcomes of public involvement in healthcare policy (124)	The outcome of public involvement in healthcare policies remains largely underdeveloped and poorly documented. There is little to no evidence for the longer-term impact demonstrated by public involvement. There is no clear conclusion on the effectiveness of policy development from involvement activities. There is some evidence for the developmental role of public involvement (e.g. enhancing awareness, understanding and competencies among lay participants), but the unclear definition of success impedes on forming a conclusion about public involvement. There is limited data available to address the primary research questions.	2010	3/9 (AMSTAR rating from McMaster Health Forum)	5/19	0/19	0/19
	Examining priority setting and resource allocation for public engagement (159)	As the literature covers all levels of government, decision-makers are likely to find information relevant to their own setting and situation. The pressures that decision-makers face to satisfy demands for a greater public role in priority setting is indicative of their involvement in public engagement processes. Most decision-makers use multiple methods to engage multiple publics, and according to the researcher's perspective, it provides a balance that may lead to a more rounded understanding of the public's desires. In addition, the willingness to seek public input in an ongoing, sustainable fashion over time provides a promising way of obtaining public engagement in priority setting.	2006	3/10 (AMSTAR rating from McMaster Health Forum)	35/391	0/391	0/391
	Examining interventions to incorporate public values in healthcare resource allocation decision-making and to assess their utility (125)	Evidence from the review shows wide-spread recognition of the need for priority setting in healthcare at all levels. The agreement that healthcare resource allocation decision-making should be values-based and the processes must accommodate the values of citizens within the specific nation, region or community, is consistent. Relevant factors for priority setting include population needs, equity, costs, effectiveness of interventions or technologies, health status, severity and nature of disease, potential for health gain, socioeconomic status, age, and cause of disease or condition.	2002	6/9 (AMSTAR rating from McMaster Health Forum)	7/117	0/117	5/117

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		There is minimal formal evaluation of the various models described in the literature, and researchers suggest the need for future research to critique the proposed models.					
	Examining the effects of consumer involvement and comparing various methods of involvement in healthcare policy development and related research, clinical practice guidelines and information materials developed for patients (157)	The impact of consumer involvement on healthcare policy creation and related research and the development of clinical practice guidelines, remains uncertain due to lack of research. The review notes the benefits of consumer involvement, in comparison to no consumer involvement, appear to be greatest in the creation of patient information materials. Research evidence indicates involving consumers in the creation of information materials for patients produces material with improved readability and relevance, and that is more understandable to patients without elevating their anxiety.	2005	9/11 (AMSTAR rating from www.rxforchange.ca)	0/6	0/6	0/6
	Examining the current state of knowledge on effective strategies for interactive public engagement in developing healthcare policy and program delivery at a provincial/regional level (126)	Interactive public engagement – that is, informed discussion among citizens that is designed to contribute to decision-making – can be implemented successfully in a variety of situations. The degree to which these processes are likely to be successfully implemented is shaped by a range of contextual variables. Organizational commitment and issue characteristics seem to play more important roles than other contextual variables. Public engagement mechanisms should be adapted to the wider context of policy development around the issue, including the type of topic, the group(s) to be engaged, the history of the issue and the perceived power dynamics. The skills required to conduct interactive processes can be learned in a supportive organizational environment.	2009	6/9 (AMSTAR rating from Program in Policy Decision-making)	7/12	0/12	0/12

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		Participants in well-designed interactive public engagement processes tend to report high levels of satisfaction with the communication of objectives, adequacy of the materials provided to inform discussions, and the logistics and management of the deliberation. Increased levels of topic-specific learning are also commonly reported. Interactive public engagement methods can influence participant views but are less likely to change more dominant views (top rankings, highest priorities). Group debate is an important contributor to perceived satisfaction with the process and the subjective outcomes of the event. Process satisfaction does not necessarily correspond with the perceived impact of participation on policy decision-making. Partnerships play a central role in promoting the effectiveness of community-based public engagement strategies. The institutionalization of these partnerships beyond their active phase is critical to enabling sustainable change.					
	Examining the effects of involving patients in the planning and development of healthcare (158)	A review of more than 300 papers on involving patients in the planning and development of healthcare found that few studies described the effects of involving patients in the planning and development of healthcare. Case studies reporting on project administrators' views about the impacts of patient engagement support the view that involving patients has contributed to changes to services. The effects of patient involvement on accessibility and acceptability of services or impact on the satisfaction, health or quality of life of patients has not been examined.	2000	5/9 (AMSTAR rating from Program in Policy Decision-making)	2/40	0/40	0/40
Establishing a stakeholder- and/or research-driven process to ensure conceptual	No reviews identified						

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
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							
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	No reviews identified						
Identifying effective models, programs and services for improving access to quality palliative	Examining the effectiveness of multicomponent palliative care service delivery interventions	The review discusses three interventions that helps assess the effectiveness of multicomponent palliative care: assessing residents' suitability for specialist palliative care and making recommendations to their physicians, developing palliative care expertise in care homes, and moving residents with end-stage dementia to special units in the care home.	2010	10/10 (AMSTAR rating from Program in Policy Decision-	0/3	3/3	3/3

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
care, including the medical orders with the best outcomes	for residents of care homes for older people (127)	There is evidence that multicomponent palliative care interventions improve quality of care and the decline in discomfort within the residents. It is noted that there is a clear absence on the definition of palliative care intervention. High satisfaction is noted among end-of-life care in residents and their families during care interventions. There is evidence that the intervention led to higher referrals to hospice services, fewer hospital admissions and an increased in documented advance care planning discussions. The review explains there is a range of barriers that can potentially impede the integration of palliative care services (e.g., specialist palliative care services) such as the large turnover rates of staff in home care.		making)			
	Examining the efficacy of various palliative care interventions to improve patients' quality of life, physical and psychological symptoms, satisfaction with care, family caregiver outcomes, health service utilization, and quality of end-of-life care (248)	There is evidence that the implementation of palliative care intervention improved patients' quality of life, satisfaction with care and end-of-life outcomes. There is significant statistical difference in favouring palliative care intervention, among patients and corresponding relatives. There is a lack of evidence to support palliative care intervention for reducing patient's physical and psychological well-being and symptoms, due to methodological challenges, and the difficulty in comparing trials from shared care among different institutions. Minimal clinical care directed towards patients results in insufficient impact on their quality of life. Adequate statistical appraisal must be taken into consideration during investigations in order to detect clinical and statistical differences.	Not reported in detail	1/9 (AMSTAR rating from Program in Policy Decision-making)	1/22	0/22	9/22
	Examining randomized controlled trials that assess the organization of end-of-life care for patients in palliative	Three overall themes were revealed in the review: the effect of providing palliative care through dedicated community teams, the effects of specific palliative care interventions, and the costs of palliative compared to conventional care. The review indicates that community or home-based end-of-life care is more favourable in comparison to conventional hospital-based medical care for	Not reported in detail	4/10 (AMSTAR rating from Program in Policy Decision-making)	2/23	7/23	19/23

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	care (128)	improving symptoms and patients' quality of life. There is inadequate evidence to conclude the effectiveness of the organization for end-of-life care. The review indicates there are a limited number of randomized controlled trials available in order to analyze an accurate overview of end-of-life care.					
	Examining the effectiveness of different models of palliative care delivery systems (249)	There is evidence to suggest that home care services attached to inpatient hospices reach more patients than those that provided home care only, and that pain relief and symptom control is marginally better in hospices with beds. The review finds no significant difference between the comparisons for patient quality-of-life measures or satisfaction with services. Conventional home care services are 30% more costly than hospice home care or conventional care for oncology care.	1997	6/11 (AMSTAR rating from Program in Policy Decision-making)	0/4	Not reported in detail	4/4
	Examining the impact of specialist models of palliative care on consumer satisfaction, opinion and preference (250)	The review revealed a higher preference for hospice care than conventional hospital care among patients. There is little to no difference in preference for caregivers. There are barriers to overcome, such as patient and caregiver criticisms of hospital-based palliative care: communication, treatment from staff, care environment and coordination with other palliative care services in the community. The review suggests that there are difficulties in collecting information about patient and caregiver satisfaction within a palliative care environment.	1998	5/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	Not reported in detail	28/79
	Examining the impact of different models of specialist palliative care on the quality of life of patients (251)	The researchers note the dearth of quality evidence that is required to be conclusive on the impact of different models of specialist palliative care on patients' quality of life. There is evidence to suggest inpatient palliative care provided better pain control than home care or conventional hospital care, however, according to the researchers these findings are considered dated.	1998	7/9 (AMSTAR rating from Program in Policy Decision-making)	1/22	1/22	22/22

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		Specialist interventions (e.g. hospital care palliative care support teams) have limiting effects to the improvement of pain control for patients in palliative care. There are insufficient findings on the impact and advantages on quality of life from specific palliative care. The researchers in this systematic literature review note extensive methodological difficulties.					
	Examining the effectiveness of palliative care for patients with the human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS) (129)	The researchers in the review found evidence that home palliative care and inpatient hospice care significantly improved patient outcomes, especially pain and symptom control, anxiety, insight, spiritual wellbeing and quality of life. Many studies in this review lack standardized measures, terminology and experimental methods in addition to lacking detailed service description. However the researchers note that due to clinical evidence, palliative care is integral for the earlier stages of the diseases. Barriers to the implementation of palliative care for patients with HIV or AIDS are presented in the availability of resources for low-income countries, low-income communities in high-income countries, and inadequate training for healthcare practitioners of palliative care in these regions.	2003	5/10 (AMSTAR rating from Program in Policy Decision-making)	2/32	0/32	18/32
	Examining the effectiveness and cost-effectiveness of specialized palliative care models (160)	Based on low methodological quality studies, specialized palliative care is more effective than conventional care during the control of pain and other symptoms, and reduces hospital stays for patients. Overall patient satisfaction increases with specialized palliative care. The researchers did not find full economic evaluations and none of the studies found one program more effective or cost-effective than another. There is evidence to suggest there are no differences in control of symptoms and quality of life between a full service of advice and support provided by the PCT in the hospital setting to other health care professionals, patients and relatives vs. a more limited intervention based on telephone consultation between PCT and the staff directly involved with the patient. Researchers concluded there are no	2008	7/10 (AMSTAR rating from Program in Policy Decision-making)	0/4	0/4	4/4

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		differences in effectiveness between hospital-based hospices and home-based hospices. The researchers note there is a lack of comparative studies, which causes an uncertainty on the effectiveness and the cost-effectiveness of specialized palliative care.					
	Examining the provision of palliative care day services to determine whether such services have a measurable effect on attendees' well-being (130)	The systematic review notes there are positive impacts on patients' quality of life from attending palliative care day services. Older patients that attend palliative care day services gain valuable experience by engaging with others in a supportive environment. Individual studies demonstrated patients from palliative care day services received medical care and therapies, and experienced increased feelings of psychological wellbeing, self-worth, self-esteem and reduction of social isolation. There is little evidence to understand the effect on patients' quality of life. The subjectivity of the patient experiences causes a challenge for the researchers to measure the impact of palliative care day services. There are also a limited number of studies associated with palliative care day services. The researchers suggest high-quality empirical studies in order to determine the full potential of palliative care day services and its effect on a patient's wellbeing.	2009	6/10 (AMSTAR rating from McMaster Health Forum)	0/31	1/31	31/31
	Examining the impact of the Gold Standards Framework since its introduction in 2001 on end-of-life care within primary care (252)	The studies in the review illustrate Gold Standards Framework to be an effective program that facilitates improvement and consistency of practice-based processes and organizational structures. It is accessible to most practices and improves general practice processes and quality of palliative care by allowing healthcare professionals to be more informed about end-of-life issues. Healthcare professionals are able to better understand the needs of older patients. Implementation of the Gold Standards Framework requires effective management processes and sufficient resourcing. Motivation and drive is required to initially start Gold Standards Framework within a healthcare	2009	6/9 (AMSTAR rating from Program in Policy Decision-making)	0/27	0/27	27/27

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		institution. Lack of integration with other healthcare professionals and lack of palliative care training undermine the goals of Gold Standards Framework. Methodological limitations and the framework's direct impact on patients and caregivers are not known. Ongoing evaluation must be a key aspect during the integration of Gold Standards Framework. New audit tools and standardized monitoring is essential for the continuance of utilizing this intervention.					
	Examining the effectiveness of case conferencing as an intervention to improve palliative care outcomes for older people living with advanced dementia in nursing homes (131)	The review finds evidence to suggest that case conferencing enhances palliative symptom management for patients with advanced dementia living in nursing homes. Case conferencing improves palliative care by engaging with caregivers, relatives and internal and external health providers in order to provide a personal care plan. Evidence is required to determine the efficacy and cost-effectiveness of case conferencing.	2010	7/10 (AMSTAR rating from McMaster Health Forum)	0/9	9/9	9/9
	Examining the effectiveness of health care and palliative care interventions to improve outcomes for patients with advanced and serious illness (253)	Consistent evidence was found in a large number of studies for the effectiveness of interventions targeting continuity for improvement in patient satisfaction, pain using patient-centered interventions, and communication and decision-making on healthcare utilization outcomes in the intensive care unit. Only a small number of studies identified a statistically significant improvement for the outcome of quality of life, and no studies found improvement for the outcome of overall symptoms. Researchers were able to identify few published studies in the hospice setting, pediatric populations or those addressing distress in the population, which can be prioritized for further research.	2011	8/10 (AMSTAR rating from McMaster Health Forum)	0/90	23/90	90/90
	Examining the comparative effectiveness of community specialist palliative care services (SPCSs) offering home nursing on	The evidence that community SPCSs providing home nursing have increased the rate of home deaths compared with alternative services was inconclusive. Although the results were heterogeneous, none of the studies discovered a significant effect in favor of an alternative intervention. In the studies that measured symptoms, quality of life or costs, the outcomes either favored SPCSs offering home nursing, or did not differ between	2011	7/11 (AMSTAR rating from Program in Policy Decision-making)	0/10	0/10	10/10

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	increase rates of home death with other models (162)	interventions. Implications for future research encourage comparison between standard care with and without home-based nursing.					
	Examining the organization of rural palliative care and the views of professionals in rural areas (254)	Very little research was found on the topic of palliative care for rural populations. This evidence indicates an inequity of services, and that there is a significant opportunity for improvement among patients with terminal illnesses in these areas. The majority of the studies were from Australia, which may reflect a greater investment in rural health research than in other countries.	2001	6/10 (AMSTAR rating from Program in Policy Decision-making)	2/26	0/26	26/26
	Examining how people manage their illnesses themselves, in the advanced stages, when experiencing end-of-life care (255)	Due to the limited research in this area, researchers could not reach firm conclusions about how people with advanced cancer manage their illnesses themselves at the end-of-life. Self-care strategies such as information utilization and distraction techniques were mainly identified by researchers, rather than by patients and carers themselves. Although this review found evidence related to how people manage their end-of-life care, these behaviours were often presented to patients as options to choose from. None of the studies specifically asked patients for their experience in managing their illness themselves. For persons coping with life limiting conditions, activities that were beneficial were symptom-focused. They were even more useful if it helped them manage their pain and debilitate their symptoms.	2007	6/10 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0/18	18/18
	Examining the effectiveness of specialized palliative care (161)	There is inadequate evidence to support the effectiveness of specialized palliative care for patients with terminal illnesses in terms of quality of life, patient and caregiver satisfaction and economic costs. Consistent evidence was only available for improved caregiver satisfaction. Quality of life was frequently used as an outcome measure for the evaluation of palliative care effectiveness, and this is appropriate given its emphasis in mission statements of numerous palliative care organizations. However, it is important to note that existing measures for quality of life were not developed for terminally ill patients.	2008	7/10 (AMSTAR rating from Program in Policy Decision-making)	1/22	0/22	22/22

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		Although specialized palliative care programs are expanding rapidly, rigorous evaluation of these programs is challenging, and existing studies do not provide conclusive evidence.					
	Examining palliative care disparities between non-cancer patients and cancer patients (120)	Systematic review in progress: findings not reported					
	Examining the cost-effectiveness of a home-based palliative medicine consulting service (153) *Note that this is an economic evaluation or costing study.	Findings revealed that total hospitalizations, total hospital days, total and variable costs, and probability of a 30-day readmission were significantly reduced in the 18-month period following enrolment in a home-based palliative medicine consulting service. However, probability of an emergency department visit was not reduced.	2013 (year published)	Not appropriate for economic evaluations and costing studies	0/1	0/1	1/1
	Examining the cost-effectiveness of the Advanced Illness Coordinated Care Program delivered by allied health personnel to improve care for patients coping with advanced illness and in need of preparation for end-of-life care (154) *Note that this is an economic evaluation or costing study.	Findings revealed that the Advanced Illness Coordinated Care Program improved satisfaction with care and helped patients develop and revise more advance directives, sooner, without affecting mortality. The evaluation also revealed that six-month costs were lower than with usual care, but the difference was not statistically significant.	2006 (year published)	Not appropriate for economic evaluations and costing studies	0/1	0/1	1/1

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
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 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	Examining the effectiveness of care by hospital-based palliative teams (163)	Evidence in this review gives limited support to hospital-based palliative care teams. Minimal effects were found for patient outcomes, particularly symptoms, for carers and for the service as a whole. Many patients are admitted acutely to hospital because their symptom control deteriorates and can no longer be coped with at home. Patients need active specialist palliative care to restore symptom control at this time. If discharge is delayed, the patient will likely spend the last days in hospital. It is thus important to have improved hospital care to facilitate discharge appropriately. Researchers propose the need for evaluation of the cost-effectiveness of hospital-based palliative care teams to better meet the needs of patients in hospitals.	1999	7/11 (AMSTAR rating from www.rxforchange.ca)	1/13	0/13	13/13
	Examining models of interprofessional working (IPW) for practice with community dwelling older people (256)	The included studies reported three models of IPW: case management, collaboration and integrated team. Evidence supports that intensive case management is needed for ongoing care, and the involvement of inter-organizational agreements and multi-professional supports may achieve longer term benefits. The proportion of studies that demonstrate improved outcomes is similar across the three main IPW models. More than half of the studies reported improved health/functional/clinical and process outcomes, which includes patient satisfaction. The evidence available on service use and costs is mixed, but this is usual considering the complex care practices in IPW.	2010	7/10 (AMSTAR rating from Program in Policy Decision-making)	3/37	23/37	3/37
	Examining the effectiveness of palliative and hospice care teams (PCHCTs) (132)	Findings indicate that PCHCTs are useful in many chronic care situations, and this is in agreement with conclusions in other literature. The evidence was strongest in patient pain and symptom control. Even though there may be a shift from in-patient hospital care to home care, the quality of economic assessments varied. At present, no definitive conclusion can be made on the relationship between costs and benefits. In summary, the analyses from this review support funding and development of palliative care teams as a way to improve care and potentially reduce hospital costs, although these costs can be transferred to other care sectors.	2000	9/11 (AMSTAR rating from Program in Policy Decision-making)	2/44	0/44	44/44

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	Examining the tasks and roles of health care support workers (HCSWs) when caring for people at the end-of-life and their families (133)	Upon synthesizing the included studies, researchers identified five core domains that reflected HCSWs' care-giving roles in supporting palliative patients in their desire to remain at home. The domains are personal care, emotional and social support, domestic support, respite care for family carers, and collaborating with professional and family carers. Some challenges related to the role of HCSWs include inadequate training, role ambiguity and emotional attachment. These factors may be potential sources of increased work-related stress levels. Evidence shows that a substantial proportion of HCSWs had no nationally recognized qualification.	2011	6/10 (AMSTAR rating from McMaster Health Forum)	0/9	0/9	9/9
	Examining the evidence regarding end-of-life care volunteers (134)	Three themes were revealed from this review: (1) the roles of end-of-life volunteers, (2) volunteer training and other organizational requirements, and (3) impact of volunteering on volunteers and on end-of-life care. Evidence suggests that considerable benefits are achieved as a direct result of end-of-life volunteers. These benefits are a result of end-of-life care volunteers performing many necessary or extra functions of value. Their contributions are significant, especially because of the limitations imposed on paid staff by their professional roles. A study raised the importance of volunteers to assist dying persons who have no family members. Volunteers can have many roles in assisting dying persons, and these roles should be tailored to the skills and interests of every volunteer. These roles can broadly be classified as social support or organizational support roles. It is suggested that these skills and interests should be developed through initial training and continuing education. Given the possible benefits of volunteers, maximizing their contribution should be the goal of every end-of-life care organization.	2004	3/9 (AMSTAR rating from Program in Policy Decision-making)	1/18	0/18	18/18
	Examining the role of home care workers, specifically focusing on formal carers provided by social	There is evidence about the positive aspects of home care workers' contribution in physical and social support, and their key role in caring for patients at home. However, negative aspects were also identified in several areas, including limited availability of services, lack of continuity of care, time constraints, lack of flexibility and poor communication with other services.	2009	1/9 (AMSTAR rating from Program in Policy Decision-	Not reported in detail	Not reported in detail	Not reported in detail

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	services departments, in palliative and end-of-life care within the community (164)	Researchers expressed that there is a lack of research available on the role of home care workers that focuses specifically on the provision of palliative and end-of-life care. As the role of home care workers is often unclear from both the perspective of a healthcare professional and patient perspective, it is important to develop a clearer definition.		making)			
	Examining the cost-effectiveness of an inpatient palliative care team (155) *Note that this is an economic evaluation or costing study.	Findings revealed that patients cared for by an inpatient palliative care team reported greater satisfaction with their care experience and providers' communication, had fewer intensive care unit admissions on readmission, and had lower total healthcare costs following hospital discharge.	2008 (year published)	Not appropriate for economic evaluations and costing studies	0/1	0/1	1/1
Identifying the settings (e.g., hospital, hospice or home) where palliative care programs and services achieve the best outcomes	Examining if providing home-based end-of-life care reduces the likelihood of dying in hospital, and what effect this has on patients' symptoms, quality of life, health service costs and caregivers compared with inpatient hospital or hospice care (135)	Evidence shows that patients who receive end-of-life home care are more likely to die at home compared with those receiving usual care. Two of the four studies reported greater satisfaction in patients who were receiving end-of-life care at home in comparison to those receiving end-of-life care at the hospital. There is variability in hospital admissions among the studies. The author notes the organization of end-of-life home care will depend on the configuration of existing health services, as this will place additional demands on primary care. The studies suggest advanced and extensive end-of-life home care services may be necessary to increase the proportion of home care. There is a lack of evidence to illustrate the impact these services have on family members and caregivers.	2011	8/11 (AMSTAR rating from Program in Policy Decision-making)	0/4	4/4	4/4
	Examining the effect of home palliative care services for adult patients with advanced illness and their family caregivers, on patients' odds of	Readily available research evidence supports the benefit of home palliative care in supporting patients to die at home and reducing symptom burden without adding to the caregiver's grief. It has been shown that with the availability of home palliative care services, more than double the patients with illnesses such as cancer, congestive heart failure and chronic obstructive pulmonary disease are able to die at home. Despite these positive effects, areas that displayed inconclusive evidence include pain control, satisfaction	2012	11/11 (AMSTAR rating from McMaster Health Forum)	1/23	12/23	23/23

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	dying at home (136)	with care and cost-effectiveness. The effects of increased chances of dying at home is clinically significant, and the existence of home palliative care services can be justified as they exist to fulfill the desire of many people to live at home during the last days of their lives. With the analyses, policymakers are now able to calculate the extent to which home palliative care services need to be expanded.					
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	Examining the effectiveness of quality improvement (QI) strategies in reducing disparities in health and healthcare (257)	The ability of quality improvement interventions to improve health and healthcare is large; however the strength of the evidence is insufficient to yield a clear conclusion. Individual studies suggest there are benefits in particular subgroups known to suffer from disparities in health. The review suggests strategies such as collaborative care models and the role of targeted patient education in accordance with language and literacy levels. Appropriate planning and monitoring may be suitable for implementation. Some studies focused on the effect of QI interventions on disparities in depression for the elderly. These interventions required intense demand on resources and strong communication. It is unclear if these studies can translate to other healthcare settings. The effectiveness of interventions to reduce disparities remains unclear due to inconsistent findings from current literature.	2011	8/10 (AMSTAR rating from Program in Policy Decision-making)	0/19	3/19	0/19
	Examining the effects of audit and feedback on the practice of healthcare professionals and patient outcomes and on factors that may explain variation in the effectiveness of audit and feedback (138)	The review suggests there is evidence that audit and feedback lead to small improvements in professional healthcare practice. The effect of the intervention varied among the studies in the review, but overall the studies showed a range from little to no effect, to a substantial effect on professional behaviour and patient outcomes. The intervention may be more effective when the healthcare professional is not performing well; the auditor is a supervisor or colleague, there are multiple application of the intervention, as well as verbal and written feedbacks, clear targets and an action plan. It is unclear if the intervention is more effective after a combination of interventions.	2010	9/11 (AMSTAR rating from Program in Policy Decision-making)	11/140	0/140	0/140
	Examining the effectiveness of	Communication in the care of patients with advanced and serious illness can be improved using quality improvement interventions, particularly for	2011	7/10 (AMSTAR rating from	1/20	7/20	20/20

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	communication-related quality improvement interventions for patients with advanced and serious illness, and to explore the effectiveness of consultative and integrative interventions (144)	healthcare utilization. Interventions may be more effective using a consultative approach. Four common interventions are discussed in the review including family meetings, palliative care teams and physician-patient communication, quality improvement interventions, and ethnic consultations. The studies for communication quality improvement in family meetings discussed the improved provider and patient/family communication after an increase in active communication strategy, longer conferences and more time for family members to discuss with healthcare professionals. In palliative care teams, four out of five studies evaluated healthcare utilization as an outcome, and two of these studies found a significant effect on healthcare utilization (e.g. fewer intensive care unit admissions and reduced used of non-beneficial aggressive treatment). In physician-patient communication studies, there was a significant increase in communication about end-of-life issues and prognosis; however there is little evidence to illustrate the impact on patient satisfaction. A computerized intervention that provides financial incentives to healthcare providers improved quality of communication in medical encounters. In the studies concerning ethnic consultations, there was a significant decrease in both intensive care unit length of stays and aggressive interventions. Almost three-quarters of the studies found significant effects of the intervention when they evaluated healthcare utilization outcomes (e.g. intensive care unit length of stay). Evidence suggests consultative studies might be more effective. There is little evidence for the overall improvement of patient and/or family satisfaction.		Program in Policy Decision-making)			
	Examining the	There is some evidence to suggest clinical and communication involvement	2010	5/10 (AMSTAR	Not	0/73	0/73

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	evidence regarding three questions: (1) does pay-for-performance improve the quality of care; (2) do surgical safety checklists improve the quality of surgical care; and (3) do practice guidelines improve the quality of care? (140)	during development of intervention and outcomes may increase the likelihood of positive results. Quality of care and reduction of mortality and morbidity could be enhanced by implementing pay-for-performance, surgical checklists and explicit practice guidelines. The review indicates the outcomes for the interventions are limited due to being highly contextual, a small scope for the review, and other considerations that must be taken into account. The effects of integrating these interventions are largely unknown in addition to the lack of examination of the potential strategies to enhance quality of care. The authors indicate there is limited literature in the search of pay-for-performance to health administration journals. Pay-for-performance interventions, to be effective, must consider reduction in disparities, improvement in access to care, and unexpected outcomes. The key issues described in the review are the involvement of clinicians at all stages of development, with explicit and comprehensive plans for communication and implementation of the interventions. The authors indicate the contribution for better results and economic analyses are currently unknown.		rating from McMaster Health Forum)	reported in detail		
	Examining the effectiveness of interventions to improve quality of care in a hospital setting and making recommendations for future effective and accessible interventions (258)	Overall, there is little evidence on hospital interventions with a theoretically based design or implementation. The authors suggest minimal transfer of health research may be due to the lack of theoretical design. There is some evidence that technical interventions have a tendency to achieve more substantial improvements in quality of care than interpersonal interventions. Technical interventions allowed for the involvement of teams of experts prior to an intervention, which helps identify local barriers and establish a plan by establishing key areas of quality improvement. Barriers to achieving quality improvements may be related to external factors (e.g. administration) that may impede the improvement of teamwork. The review suggests interpersonal interventions must emphasize patient recognition prior to the intervention. Collaborative research is also noted as a	2010	5/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/20	3/20

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		suggestion by the authors to implement future theory based interventions.					
	Examining the effectiveness of quality improvement interventions (QIIs) directed at cancer specialists (259)	Three cluster randomized controlled trials (cRCTs) were included in this review, of which none showed clear benefits of the QIIs tested. Some uncontrolled studies reported benefits of QIIs, but the results need to be taken cautiously due to the possibility of uncontrolled confounding and reporting bias. The key message derived from this review is that there is a lack of published evidence from studies on decisions of cancer specialists regarding choice of QII. Seeing the lack of published data in this area, researchers encourage any group willing to implement a QII to report the outcomes regardless of its apparent success or failure. This would reduce concerns about dissemination and publication bias.	2012	8/10 (AMSTAR rating from McMaster Health Forum)	3/12	0/12	0/12
	Examining the evidence to provide guidance on selecting instruments that appropriately measure team-level factors that influence the process and outcomes of continuous quality improvement (CQI) (260)	The measurement of factors that influence CQI is complex, and unique features of primary care settings heighten the importance of certain factors. The most efficient way to measure aspects of teamwork context is to combine short scales (two to three items), found in many instruments, to measure single constructs. In CQI studies, measures of team process are underutilized, but they are seen to have the potential to reflect the extent to which teams enact formal teamwork behaviours, and the extent to which these behaviours influence CQI outcomes. These measures are a measure of fidelity, and they can provide data about why CQI interventions are successful in some contexts and not others. The measurement of team climate for innovation is widespread in healthcare, and it has a strong theoretical basis. Although it is relevant to CQI, researchers found no examples of its use in this context. Two areas that require careful consideration are to ensure conceptual clarity when selecting and developing instruments, and to enhance conceptual	2012	4/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/306	0/306

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		consistency of team-level factors in QI studies.					
	Examining the evidence on quality improvement collaboratives (QICs), with an emphasis on identifying common components of QICs in health care (141)	The majority of controlled studies of QICs focus on chronic medical conditions. In contrast, there are no published controlled studies in behavioural health. Studies included in this review provided evidence that QICs can affect changes at the provider level, particularly the process of care variables (e.g., medication management and patient education). Some studies showed positive findings for provider outcomes. However, this conclusion needs to be taken cautiously because most of the outcomes measures were derived from medical records and did not directly assess changes in provider behaviour. This trend is similarly observed at the patient level where few studies directly assessed patient outcomes. QICs showed a relatively similar overall structure. As very few studies compared QICs' critical features, it was not possible to link active QIC features to specific outcomes.	2012	3/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/24	0/24
	Examining the effectiveness of quality improvement collaboratives in enhancing the quality of care (142)	Systematic review of nine controlled trials found a positive effect of quality improvement collaboratives on processes of care and patient outcomes. The review additionally examined the findings of 60 uncontrolled reports, of which 53 trials indicated specific improvements in patient care and organizational performance due to participation in a quality improvement collaborative.	2006	4/11 (AMSTAR rating from www.rxforchange.ca)	Not reported in detail	0/72	0/72
	Examining the evidence regarding instruments to collate, categorize and evaluate quantitative self-report instruments (261)	Many potentially relevant instruments to measure the factors that modify the effect of continuous quality improvement (CQI) in primary care settings were identified. Due to the large number of factors measured, the process to select appropriate instruments is complicated. There are challenges in developing these instruments. First, the definition of a CQI intervention is vague, thus making it important to establish the essential components of CQI interventions. Second, measures of the use of CQI interventions need to include non-content related dimensions of intervention fidelity. These dimensions include intervention intensity, quality of delivery and adherence to protocols. Lastly, the validity of self-report	2010	4/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/551	0/551

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		instruments needs to be assessed against a criterion measure of actual behaviour. It should be noted that a positive development of instruments to measure context in small healthcare settings is observed. Testing is still required to measure the suitability of instruments in new settings. The guidance provided in this review should lessen the burden of locating relevant measures and may enhance the contribution of research by increasing the quality of measurement and the potential to synthesize findings across studies.					
	Examining how self-audit have been operationalized, and the factors that influence self-audit conduct and outcomes (137)	Few studies met the inclusion criteria, all of which reported positive results, such as improved compliance with care delivery guidelines and patient outcomes. There was a high degree of variation in program content and format, thus researchers were not able to identify specific program features that were associated with the observed benefits. It was observed that all programs involved certain features that stimulated learning and practice changes. Self-audit has the potential to lead to learning and actual practice improvements. Due to the lack of research in this area, exploratory studies may be required to develop, implement and evaluate self-audit programs.	2010	3/10 (AMSTAR rating from McMaster Health Forum)	0/10	0/10	0/10
	Examining how quality improvement (QI) processes and accreditation in primary healthcare can affect outcomes of care, patients' perceptions of care, healthcare utilization and costs, and primary healthcare providers' perceptions (143)	Upon reviewing high quality of evidence, researchers made strong recommendations for the use of QI. It is recommended that QI should be used to increase colorectal screening and foot examination rates for diabetic patients. The outcomes of QI strategies are difficult to evaluate due to varied and multifaceted approaches. Implications for future research suggest studying the effect of QI on a broader range of patient outcomes, and evaluating its impact on healthcare utilization, cost effectiveness, and patient and provider perceptions. Primary healthcare accreditation currently exists in Canada, U.S., Australia, New Zealand, U.K., Scotland and the Netherlands. Canada has been one of the most influential in the development of primary care accreditation.	2011	6/10 (AMSTAR rating from McMaster Health Forum)	4/77	0/77	0/77

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		Implications for future research in this area suggest evaluating the effect of accreditation on patient outcomes, and its impact on healthcare utilization, cost effectiveness, and patient and provider perceptions.					
	Examining the effectiveness of communication-related quality improvement interventions for patients with advanced and serious illness, and to explore the effectiveness of consultative and integrative interventions (144)	The majority of interventions that evaluated healthcare utilization outcomes found statistically significant effects of the intervention. However, most studies that evaluated outcomes of satisfaction, quality of life and symptom control showed insignificant improvement. A higher proportion of consultative studies found a statistically significant improvement from the intervention, which could potentially suggest consultative interventions are more effective than integrative ones. This benefit can be a result of consultative teams focusing specifically on communication-related issues as opposed to balancing them with other clinical responsibilities.	2011	7/10 (AMSTAR rating from Program in Policy Decision-making)	1/20	8/20	20/20
	Examining the evidence about quality improvement models in health care (262)	Five models are evaluated separately to outline important conceptual differences between them, but in practice, these distinctions are not always clear-cut. The models all have to require the same set of necessary, but not sufficient, conditions for successful implementation. These include: active engagement of health professionals, active participation of middle and senior managers, support of board members, use of multifaceted interventions and many others. Key components of Total Quality Management (TQM)/Continuous Quality Improvement (CQI) include emphasizing quality improvement as an ongoing activity to continuously improve the needs of internal and external customers. The second model is Business Process Reengineering, and it uses a radical approach to organizational change. This model is rarely implemented to its full extent.	Not reported in detail	2/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	Not reported in detail	Not reported in detail

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		The third model is Institute for Healthcare Improvement (IHI) and rapid cycle change. Front-line staff bring the key questions into action through Plan-Do-Study-Act cycles (PDSAs), which provides a framework for repeated small-scale tests of change linked to reflection. The fourth model is lean thinking, and it focuses on meeting the needs of internal or external customers with minimal wasted time, effort or cost. The approaches are found more useful in streamlining processes in support departments rather than clinical services. The final model is Six Sigma, and it is the newest of the five approaches. It identifies variations in a process to distinguish between chance variation and assignable variation.					
	Examining contextual factors associated with quality improvement (QI) success and synthesizing these factors based on their common characteristics (263)	The review revealed that the current body of work is in the early stage. Common factors that were used in studies to relate to QI success include organizational characteristics (e.g., size, ownership, teaching status), leadership from top management, competition, organizational culture, years involved in QI and data infrastructure. Factors that were consistently examined to associate with QI success, but reported less frequently, include board leadership for quality, organizational structure, customer focus, physician involvement in QI, microsystem motivation to change, resources and QI team leadership. Researchers state that current research suffers from conceptual ambiguity and methodological weaknesses. As a result, they could not make definitive conclusions about the influence of specific contextual factors in QI success.	2009	5/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/47	0/47
	Examining the effectiveness of various quality improvement strategies for enhancing healthcare (139)	Research evidence suggests clinician/patient-driven quality improvement strategies are more effective compared to manager/ policymaker-driven approaches. The most effective quality improvement strategies included clinician-directed audit and feedback, decision support systems and the use of small-group discussions in continuing professional education.	2008	2/11 (AMSTAR rating from Program in Policy Decision-making)	12/97	0/97	0/97

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	Examining the effectiveness of continuous quality improvement (CQI) in improving professional practice and ultimately healthcare outcomes (121)	Systematic review in progress: findings not reported					
	Examining the evidence on commonly tested quality improvement algorithms and its outcome measurements in the intensive care unit setting (122)	Systematic review in progress: findings not reported					
Publicly reporting end-of-life/palliative care performance indicators in hospital report cards and many organizations' (including primary care organizations) quality-improvement plans	Examining evidence on promising practices for effective public reporting on healthcare quality (172)	Review suggests that for public reporting to be effective, attention must be focused on the reporting program's objectives, audience, content, product, distribution and impacts. Review also indicates public reporting should be part of broader efforts to develop and nurture a relationship with the report's intended audience in order to increase accountability and quality within the healthcare system.	Not reported	2/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0	0
	Examining the effectiveness of public reporting of healthcare quality information as a quality improvement strategy (145)	Public reporting is more likely to be associated with changes with healthcare provider behaviours than with selection of health services providers by patients or families. Some studies that contained a focus on long-term care reported that public reporting creates incentives that lead to unintended negative behaviour by providers. Public reporting has been associated with a small decline in mortality after controlling for trends in reductions in mortality. Organizations and individual healthcare providers may improve processes or structures in an effort to improve their performance on the outcomes of the	2011	7/10 (AMSTAR rating from Program in Policy Decision-making)	8/198	13/198	22/198

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		public report in order to maintain reputation, attract more patients and secure more contracts. Public reporting of healthcare quality can change behaviours in general advocacy for higher quality of care and better information for decision-makers. Characteristics of public reporting that may positively impact quality of care are being acceptable or appropriate, accessible and actionable. Contextual factors could make healthcare decisions more amendable from the influence of public reports, and involve the characteristics of the specific decision, the organization making the specific decision and the characteristics of the decision-makers. Competitive market, baseline performance, nursing home characteristics, patient characteristics, and variation in quality result in increased reporting of quality of care. Quality measures that are publicly reported improve over time. Change in delivery may not necessarily lead to improved quality of care. The heterogeneity of the outcomes creates difficulties in drawing definitive conclusions. Public reporting has drawbacks such as reduced access to services, reduced patient engagement, increased anxiety, misclassification of healthcare providers that may lead to poor reputations, compromised data quality, and manipulation of publicly reported data.					
	Examining the impact that public reporting (PR), which will be extended to the outpatient setting, has on patient outcomes and disparities (264)	The review reveals there is a lack of evidence on the impact of public reporting on patient outcomes and limited evidence of favourable public reporting on the outcomes in nursing homes. There is a research gap that exists with regards to patient-relevant outcomes and public reporting. The scarcity of studies creates difficulties for the researchers to determine a clear conclusion on public reporting.	2013	7/10 (AMSTAR rating from McMaster Health Forum)	0/25	Not reported in detail	0/25
	Examining the effectiveness of the public release of performance data in changing the	The small amount of evidence available provides no consistent evidence that the public release of performance data changes consumer behaviour or improves care. Evidence that the public release of performance data may have an impact on the behaviour of healthcare organizations or professionals is lacking.	2011	8/9 (AMSTAR rating from Program in Policy	1/4	0/4	0/4

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	behaviour of healthcare consumers, professionals or organizations (166)			Decision-making)			
	Examining the effectiveness of publishing patient care performance data in improving quality of care (167)	Evidence is limited, particularly about individual providers and practices. Rigorous evaluation of many major public-reporting systems is lacking. Evidence suggests that publicly releasing performance data stimulates activity to improve quality at the hospital level. The effect of public reporting on safety, health outcomes and patient-centredness remains uncertain.	2006	5/11 (AMSTAR rating from McMaster Health Forum)	0/45	0/45	0/45
	Examining how consumers use publicly reported quality of care information (146)	Fourteen included studies examined quality information, usually 'Consumer Assessment of Healthcare Providers and Systems', with respect to its impact on the consumer's choice of health plans. Easily readable presentation formats and explanatory messages improve knowledge about and attitude towards the use of quality information; however, the weight given to quality information depends on other features. These features include free provider choice and costs. In real-world settings, viewing quality information is a strong determinant for choosing higher quality-rated health plans.	2008	4/9 (AMSTAR rating from Program in Policy Decision-making)	0/14	0/14	0/14
	Examining the effects of pay-for-performance and public reporting on racial disparities in healthcare (152)	In this review, only one empirical study provided data on how pay-for-performance and public reporting programs may have a neutral, narrowing or widening effect on racial disparities in healthcare. A major public reporting program increased disparities in coronary artery bypass graft rates. Interviews with leaders of 15 major performance incentive programs in the United States indicated that current programs are not designed to reduce disparities, and often lack characteristics that may be important in reducing disparities.	2006	4/9 (AMSTAR rating from Program in Policy Decision-making)	0/1	0/1	0/1
	Examining the evidence about the public release of performance data (147)	Seven U.S. reporting systems about the performance of hospitals, health professionals and healthcare organizations have been the subject of published empirical evaluations. Observational and descriptive methods predominate. Consumers rarely search out the information, and do not understand or trust it. It also has a small, though increasing, impact on their decision-making. Physicians are skeptical about such data and only a small fraction makes use of it, whereas hospitals appear to be most responsive to the data. In a limited number of studies, the publication of performance data has been associated with an improvement in health outcomes.	1999	3/9 (AMSTAR rating from Program in Policy Decision-making)	0/7	0/7	0/7
Establishing a	Examining the effects	The review indicates there is inadequate evidence to provide	2009	6/6	0	0	0

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
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)	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 (156)	recommendations for the use of end-of-life pathways in healthcare.		(AMSTAR rating from Program in Policy Decision-making)			
	Examining the impact of collaboration between government agencies and local health agencies on health outcomes.(165)	Interagency collaboration between local health agencies and government is often accepted as best practice. However, there is insufficient evidence to support the use of interagency collaboration to improve health outcomes. The review notes collaboration amongst multiple agencies is often difficult to implement, more expensive than standard service delivery, and may undergo changes due to external factors. Successful collaborations require clearly outlined objectives that are relevant to all agencies involved in the partnership, monitoring of all outcomes, and include an evaluation process to assess effectiveness.	2009	9/9 (AMSTAR rating from Program in Policy Decision-making)	0/11	0/11	0/11
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	Examining if professional medical interpreters have a positive impact on clinical care for limited English proficiency (LEP) patients (148)	There is evidence that there is positive impact of professional interpreters in clinical care such as reduced disparities in healthcare utilization between patients with a language barrier and those receiving treatment from a clinician who spoke the same language. The review suggests there is a decrease in communication errors, increased patient comprehension, equalized healthcare utilization, improved clinical outcomes and increase satisfaction with communication for limited English patients. The lack of standardized measures for studies creates difficulties for the researchers to come to a clear conclusion. Training ranges for professional medical interpreters creates variation in the studies and consequently provides mixed results.	2005	5/9 (AMSTAR rating from Program in Policy Decision-making)	0/28	0/28	0/28

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		The researchers note a lack of formal cost analyses of professional medical interpreters in published literature which results in ambiguity, and further research must be conducted.					
	Examining the effectiveness of interventions to improve cultural competence in healthcare systems (265)	The review indicates the effectiveness of interventions to improve cultural competence in healthcare systems is scarce, or the included studies did not examine the outcome measures outlined in the review.	2001	6/9 (AMSTAR rating from Program in Policy Decision-making)	0/6	0/6	0/6
	Examining the impact of interpreter services on the quality of healthcare (149)	The review concludes trained professional interpreter and bilingual healthcare providers appear to improve communication, patient satisfaction and outcomes, and reduce errors. The 36 studies within the review reveal individuals who do not access interpreters have poor self-reported understanding of their diagnosis and planned treatment. Studies found highest levels of satisfaction are obtained after the introduction of bilingual and telephone interpreters. There were no formal cost analyses in any of the 36 studies. Barriers to the implementation of interpreter services in healthcare include differences in cultural beliefs, attitudes, practices and issues that may result in individuals dismissing the utilization of interpreters (e.g. gender preferences in interpreters by patients). The researchers note the methodological inconsistencies within the studies undermine the assessment of interpreter services on the quality of healthcare.	2003	4/10 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0/36	0/36
	Examining strategies for promoting cultural competence in health service delivery to culturally and linguistically diverse (CALD) communities (266)	The systematic review identified six outcomes from the 16 of the 24 studies: improved communication between healthcare providers and patients, increased satisfaction with the health system, greater knowledge and awareness about services and health, expanded cultural understanding between health service providers and CALD patients, significant increases in screening rates, and increases in follow-up appointment bookings. Studies about health education programs highlighted the health workers	2009	6/9 (AMSTAR rating from Program in Policy Decision-making)	1/24	0/24	0/24

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		being culturally sensitive and appropriate. The use of bilingual community health workers can promote greater uptake of disease prevention strategies, translate into greater knowledge and awareness services, and health programs delivered by their own people are deemed to be culturally sensitive and appropriate. The researchers note there is limited research in this area and it presents ambiguous and unstable conclusions.					
	Examining the effects of trained medical interpreters in face-to-face clinical settings for patients with low proficiency in the local language, on the quality of communication between patient and provider, the quality of healthcare and outcomes, and the cost benefit and effectiveness of interventions by trained medical interpreters (123)	Systematic review in progress: findings not reported					
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	Examining evidence on health information system (HIS) evaluation studies to inform HIS practice and research (150)	There is some evidence for improved quality of care with the use of HIS, such as reducing medication errors, and generating accurate and complete electronic patient data. Some areas where HIS did not lead to significant improvement include resource utilization, healthcare cost and health outcomes. The strength of the evidence varies by topic, HIS feature, setting and evaluation metric. HIS success is influenced by in-house systems, developers as users, integrated decision support and benchmark practices.	2008	7/11 (AMSTAR rating from McMaster Health Forum)	6/50	0/50	0/50

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
(e.g., an internet cloud-based registry)	Examining whether patients with chronic disease having a patient-held medical record (PHR), compared to usual care, improves clinical care, patient outcomes or satisfaction (168)	The effectiveness of PHRs has not been convincingly demonstrated in the included studies. A large proportion of included studies did not have a sufficient number of patients to show a significant difference between groups. There was also a lack of evidence that supported the implementation of PHR in any chronic disease population. The utility of a PHR in the palliative care patient group is questionable due to the relatively short time frame for using such an intervention compared with other patient groups. It is suggested that population characteristics may influence the effectiveness of a PHR in other illness groups.	2009	7/10 (AMSTAR rating from Program in Policy Decision-making)	1/14	0/14	1/14
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	Examining the extent, nature and settings of knowledge-translation (KT) research during the care of older adults (169)	There are uncertainties to the use of knowledge-translation research due to the scarcity of reviews focusing on care of older adults. Only two of the 53 systematic reviews contained pertinent information about the care of older adults, which reveals an identifiable gap. Within the two systematic reviews, the knowledge-translation research primarily focuses on the care of adults in long-term facilities and outpatient clinics. Among these settings, knowledge-translation research was inconsistent and involved little about care processes. There is insufficient guidance for the implementation of the knowledge-translation strategy due to the lack of applicable literature. The review did not assess the effectiveness of the knowledge-translation strategy. This provides a barrier during strategy recommendations to healthcare professionals about the uptake of evidence in the long-term care sector. There is evidence to suggest that the use and effectiveness of the knowledge-translation strategy is an important aspect of the improvement of quality of care in older adults.	2009	4/10 (AMSTAR rating from McMaster Health Forum)	10/53	0/53	0/53
	Examining and assessing systematic reviews to gain a better understanding of knowledge-translation (KT) research within the	There is little evidence to be positively conclusive on the use of knowledge-translation intervention. There is evidence to suggest that the quality of the knowledge-translation intervention is unsystematic and the impact on patient care is uncertain. There is evidence that suggests promise of effectiveness in many knowledge-translation interventions.	2010	4/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/34	2/34

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	context of cancer control (170)	The review discusses barriers that need to be addressed among data synthesis, complexities within the specific issue and overall research quality. The review explains methodological rigor is required in order to overcome these barriers.					
	Examining the effectiveness of interventions designed to increase the use of research in clinical practice (267)	The review revealed a higher effectiveness of intervention by implementing multifaceted interventions, including audit and feedback, computerized decision support and opinion leaders, for research in clinical practice in comparison to single interventions. The review identified insufficient use of systematic reviews that involved the implementation of research into clinical practice. Effective factors involved in the better understanding of research in clinical practice include greater transparency and precision in the promotion of evidence-based research in clinical practice.	2009	2/10 (AMSTAR rating from McMaster Health Forum)	5/13	0/13	3/13
	Examining the facilitators to the uptake by decision-makers, of evidence from systematic, meta-analyses and the databases containing them (179)	The review revealed the effectiveness of the uptake of evidence from systematic reviews and meta-analyses by the following: time effectiveness, knowledge improvement, guide research, overcoming cost barriers and translation from knowledge-to-action process. The review suggests the uptake of evidence from systematic reviews and meta-analyses expands evidence implementation and policymaking. Overcoming barriers pertaining to the use of systematic reviews and meta-analyses involves training the facilitators with the search process.	2010	4/10 (AMSTAR rating from Program in Policy Decision-making)	6/15	0/15	0/15
	Examining knowledge-translation resources to identify the effectiveness of the intervention (171)	This review reveals that the effectiveness of knowledge-translation interventions is determined through vigilant preparation. There is evidence where implementation of dissemination activities (e.g. mailing clinical guidelines, website posts on physician associations) produced behavioural change and outcomes in comparison to passive approaches for intervention. Barriers that need to be addressed are the negligence of strategies for knowledge uptake and the level of motivation among researchers.	2010	2/9 (AMSTAR rating from Program in Policy Decision-making)	62/187	0/187	24/187

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		There is a lack of evaluative research which limits the knowledge of long-term benefits for the utilization of knowledge-translation intervention.					
	Examining the effectiveness of knowledge-translation intervention through its research evidence (180)	Barriers to be addressed are primarily concerning individual readiness for change and the need for customizable interventions for health system managers and their organizations. The review explains behaviour observations for interventions are labour-intensive, costly and contain researcher bias. The review suggests knowledge-translation strategy is still in its infancy and requires focus on proper strategy and implementation process. Past implementation suggests an emphasis on adult education and its learning strategies (e.g. role playing, video review, group discussion) rather than its learning content in order for rapid practical use.	2009	7/9 (AMSTAR rating from McMaster Health Forum)	0/12	0/12	0/12
	Examining the effects of information products designed to support the uptake of systematic review evidence by health system managers, policymakers and healthcare professionals (151)	Mass mailing a printed bulletin which summarizes systematic review evidence may improve evidence-based practice when there is a single clear message, if 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. If the intention is to develop awareness and knowledge of systematic review evidence, and the skills for implementing this evidence, a multifaceted intervention that addresses each of these aims may be required. However, there is insufficient evidence to support this approach.	2011	9/10 (AMSTAR rating from Program in Policy Decision-making)	1/8	0/8	0/8
	Examining the barriers to the uptake of evidence from systematic reviews and meta-analyses from the decision-makers' perspective (177)	This systematic review revealed that strategies to improve the uptake of evidence from reviews and meta-analyses will need to overcome a wide variety of obstacles. The review described the reasons why knowledge users, especially physicians, do not call on systematic reviews, such as lack of use, lack of awareness, lack of access, lack of familiarity, lack of usefulness, lack of motivation, and external barriers.	2010	7/10 (AMSTAR rating from Program in Policy Decision-making)	5/27	0/27	0/27
	Examining knowledge translation resources and tools to maximize the impact of	This systematic scoping review identified knowledge-translation resources that address barriers to the use of systematic reviews by policymakers. These barriers may be overcome by resources that adapt and present the findings in formats more directly tailored to their needs. Knowledge-translation	2009	5/9 (AMSTAR rating from Program in Policy	5/20	0/20	3/20

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	systematic reviews in healthcare decision-making (178)	resources, including summaries, overviews, and policy briefs, added value to systematic reviews. They did this by, for example, evaluating their methodological quality or assessing the reliability of their conclusions or their generalizability to particular settings. More evaluations of these resources are required to ensure users' needs are being met, to justify their funding, and to demonstrate their impact.		Decision-making)			
	Examining interventions encouraging the use of systematic reviews by health policymakers and managers (268)	There is insufficient evidence to draw conclusions about the effectiveness of interventions that encourage health policymakers and managers to use systematic reviews in decision-making.	2010	9/10 (AMSTAR rating from Program in Policy Decision-making)	3/3	0/3	0/3
	Examining potential strategies for increasing the impact of systematic reviews on policy (269)	Facilitators for the use of systematic reviews included involving policymakers in the review process, making reviews relevant to local settings and contexts, collaboration between researchers and policymakers, and disseminating results from systematic reviews in user-friendly formats	2011	5/9 (AMSTAR rating from Program in Policy Decision-making)	7/13	0/13	0/13
	Examining the use of research in population health policy and programs (270)	There is little evidence about which strategies increase the use of evidence in population health policy and programs. There is some evidence that tailored targeted messages combined with access to registries of research evidence may increase the use of research evidence in policy development. None of the included studies provided evidence that interaction between researchers and policymakers has an impact on the use of research evidence. Training in the appraisal of research and its use appears to increase participants' skills in critical appraisal and possibly their perceptions about the value of research (but not their use). One study evaluated the impact of using knowledge brokers, but did not find evidence to support their effectiveness.	2011	3/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0	0

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	Examining the use of research evidence in public health decision-making processes (176)	Barriers to the use of research evidence included: decision-makers' perceptions of research evidence; the gulf between researchers and decision-makers; the culture of decision-making; competing influences on decision-making; and practical constraints. Mechanisms of overcoming barriers to research use were suggested in many studies, but were largely untested. They include research targeted at the needs of decision-makers, research clearly highlighting key messages, and capacity building. Minimal evidence on the role of research evidence in decision-making to reduce inequalities was identified.	2010	7/10 (AMSTAR rating from Program in Policy Decision-making)	7/18	0/18	0/18
	Examining the factors that influence the use of research evidence in ways to improve the usefulness of systematic reviews for healthcare managers and policymakers (174;175)	Interactions between researchers and healthcare policymakers and timing/timeliness appear to increase the prospects for research use among policymakers. Interviews with healthcare managers and policymakers suggest that they would benefit from having information that is relevant for decisions highlighted for them (e.g. contextual factors that affect a review's local applicability and information about the benefits, harms/risks and costs of interventions), and having reviews presented in a way that allows for rapid scanning for relevance and then graded entry (such as one page of take-home messages, a three-page executive summary and a 25-page report). Managers and policymakers have mixed views about the helpfulness of recommendations. An analysis of websites found that contextual factors were rarely highlighted, recommendations were often provided, and graded entry formats were rarely used.	2008	No rating tool available for this type of document	Not reported in detail	0/17	0/17

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	Examining the evidence from interview studies of facilitators of, and barriers to, the use of research evidence by health policymakers (173)	The most commonly reported facilitators for research use were personal contact, timely relevance, and the inclusion of summaries with policy recommendations. The most commonly reported barriers were absence of personal contact, lack of timeliness or relevance of research, mutual mistrust, and power and budget struggles.	2000	No rating tool available for this type of document	3/24	0/24	0/24
	Examining the evidence base for knowledge transfer and exchange (271)	The review found inadequate evidence base for doing "evidence-based" KTE for health policy decision-making.	2005	No rating tool available for this type of document	8/18 (implementation studies)	0/18	0/18

Appendix 2: Systematic reviews and economic evaluations relevant to Element 2 – Educate, train and support healthcare providers in end-of-life communication, decision-making and care

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
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)	Examining postgraduate curricula in palliative care and incorporating the most effective components into a family medicine education program (190)	In this review, any amount or type of educational intervention was shown to improve the resident's reported confidence to provide end-of-life care. Evidence identified that communication skills in palliative care can be effectively taught with the use of simulated patients. However, it was difficult to determine if these skills can be maintained as only the confidence level was measured post intervention. Researchers suggest the need for a multifaceted approach to meet all of the educational requirements of postgraduate learners in end-of-life care. In conclusion, given the increased attention on patient-care outcomes, 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 a graduating resident.	2008	3/10 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0/28	28/28

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
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	Examining the effectiveness of cultural competency training on patient-centred outcomes; assessing the quality of studies and strength of effect; and proposing a framework for future research(204)	The review found a lack of research evidence showing a positive relationship between cultural competency training and improved patient outcomes.	2010	8/10 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	7/7	0/7
	Examining the methodological rigour of studies evaluating cultural competence training of healthcare professionals (202)	The review found a lack of evidence about the impact of cultural competence training on minority health care quality.	2003	6/10 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	64/64	0/64
	Examining the effectiveness of cultural-competence training for health professionals in community-based rehabilitation (203)	The review found a lack of evidence about the effectiveness of cultural-competence training for health professionals in community-based rehabilitation.	2006	6/10 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	Not reported in detail	Not reported in detail
	Examining the impact of implementing end-of-life care policy with regard to the use of the Gold Standards Framework in Care Homes (GSFCH) program, the Liverpool Care Pathway (LCP) and educational and training interventions to support the provision of end-of-life care within nursing care	Although this review focuses on policy within the U.K., the GSFCH programs were found to be adaptable for international use. Outcomes from the two programs, GSFCH and LCP, were used to capture the impact of transferring end-of-life care policy from theory to reality in U.K. nursing care homes. However, it is unsure as to whether end-of-life care provision in nursing care homes was evidenced through the implementation of the two programs or whether the nursing care home met specific end-of-life care outcomes evidenced in practice. Researchers indicate the need to further research the provision of end-of-life care to residents within U.K. nursing care homes, and the process	2010	5/10 (AMSTAR rating from McMaster Health Forum)	0/8	0/8	8/8

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	homes in U.K. (272)	involved in transferring and sustaining end-of-life care policy into practice.					
	Examining the impact of continuing professional development programs on rural nurses' palliative care capabilities (191)	The low level evidence in the included studies prevented researchers from making any definitive recommendations about the development of continuing professional development programs for rural nurses. It is suggested that palliative care continuing education programs need to be multifaceted, and flexible towards participants' needs and learning preferences. Many barriers are identified in the uptake of continuing professional development in the rural setting, including the cost and accessibility having the greatest impact on nurses' participation rates.	2010	6/10 (AMSTAR rating from Program in Policy Decision-making)	3/10	0/10	10/10
	Examining factors that influence informal adult education to care for patients with progressive illness (192)	Consistent evidence identified that adult education should be based on a multifaceted approach, and it is suggested to include a combination of oral presentation and written information. Evidence demonstrates a need for educational improvement in several areas of palliative care. Healthcare professionals often find it difficult to discuss 'bad news' with patients, and this situation is additionally amplified where culturally competent healthcare is needed.	2002	4/9 (AMSTAR rating from Program in Policy Decision-making)	2/33	1/33	3/33
	Examining whether communication skills training (CST) is effective in improving the communication skills of HCPs involved in cancer care, and in improving patient health status and satisfaction (181)	Communication skills training appears to be effective in improving healthcare professionals' skills related to information gathering and supportive skills. There is no evidence to support a beneficial effect of communication skills training on healthcare professional 'burnout', patients' mental or physical health, and patient satisfaction. The authors were unable to determine the long-term effects of communication skills training. The lack of evidence creates difficulties for the authors to form a clear conclusion on the efficacy of communication skills training (e.g. types, duration and intensity of communication skills training), and if consolidation workshops could improve the impact of communication skills training.	2012	11/11 (AMSTAR rating from Program in Policy Decision-making)	/15	1/15	3/15
	Examining the effects of interventions for healthcare	There is evidence to suggest healthcare professional training in patient-centred approach leads to positive patient satisfaction and beneficial	2010	8/11 (AMSTAR rating from	1/17	0/17	6/17

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	providers that aim to promote patient-centred approaches in clinical consultations (182)	effects with their care. Improvement in communication with patients and clarification of patients' concerns in consultation is also noted by the authors. The review indicates short-term training is as successful as longer training. The addition of condition-specific materials to healthcare professional training is necessary, however it is not sufficient to produce behavioural changes. The authors describe the improvement of patient health behaviour and outcomes appear to require integrating strategies for specific conditions. The studies employed direct measures of consultation processes which are required to demonstrate success of the interventions. The applicability of the intervention in low- and middle-income countries requires further analysis.		www.rxforchange.ca)			
	Examining the effectiveness of interventions to improve healthcare professionals' adoption of SDM (207)	The authors of this review could not form firm conclusions regarding which type of intervention is the most effective at increasing the adoption of SDM by healthcare professionals. From this matter, there are no clear conclusions with respect to the impact on the length of the consultation time. Healthcare professionals identified time constraints as the most common barrier for the implementation of SDM. The review identified zero studies assessing healthcare professionals' uptake of decision support interventions. There is no evidence of harm to patients during these interventions. The studies in the review did not include economic evaluations.	2009	9/10 (AMSTAR rating from Program in Policy Decision-making)	1/5	0/5	0/5
	Examining the effectiveness of interventions to improve health professionals' adoption of shared decision-making in routine clinical practice, as seen by patients (208)	Only three of the studies in the review had a positive impact of patient-mediated intervention with a healthcare professional who was responsible for sharing decisions with the patient. This suggests combined interventions are a promising means of translating shared decision-making into clinical practice. A firm conclusion on the authors' objectives is not determined due to the limited evidence. There is no clear evidence whether decision-making should be implemented in primary care. Most of the studies focused on the implementation of shared decision-making in clinical practice for physicians and not for other allied healthcare workers. This limits the authors' understanding of shared decision-making in nursing, rehabilitation, dietary medicine and other clinical settings. None of the	2009	7/11 (AMSTAR rating from Program in Policy Decision-making)	4/21	0/21	0/21

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		studies in the review had economic evaluations, but it is indicated that these are required to understand the efficacy of the interventions.					
	Examining the effectiveness of training strategies for teaching communication skills to qualified physicians (195)	Training strategies included feedback on communication skills and performance, role-play with other participants, modelling by the trainers, discussing the written and oral communication skills, and small group discussions. Training programs were effective if they are learner-centered, practice-oriented and the duration was at least a day. The authors suggest that communication skills should be practised after training occurred.	2009	6/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/12	0/12
	Examining the effectiveness of communication skills training on the care of people with dementia (194)	There is significant evidence that communication skills training in dementia care improves the quality of life and wellbeing of patients by increasing positive interactions in various care settings. Communication skills training may be better to deal with difficult situations, but will not prevent them (e.g. aggressive behaviour, distress and depression). The review indicates there are no interventions towards improving communication between physicians and patients with dementia, which was an alarming revelation for the authors. The authors additionally suggest communication skills training must not be conceived as a one-time intervention, but followed periodically with additional sessions to ensure proper implementation of the intervention. The intervention is not insufficient to be the sole factor for changes to the organizational framework, and requires attention to external factors, obstacles and other influences.	2010	6/10 (AMSTAR rating from Program in Policy Decision-making)	0/12	0/12	0/12
	Examining the effectiveness of communication skills training (CST) courses in oncology by a comprehensive systematic review and meta-analysis (206)	The effects of the training courses for the improvement of communication skills are moderate with additional benefit of consolidation workshops or supervision after basic training. There is no clear definition as to which specific communication skills should be addressed during the intervention. The review indicates there are limited studies on the investigation of the impact on patients after communication skills training for healthcare professionals. There is urgency for studies in clinical practice. The authors recommend the next step is to determine the necessary duration and setup of communications skills training. The review also suggests mandatory communication skill training for healthcare providers in oncology.	2008	6/11 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0/13	2/13

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	Examining the effectiveness of communication training for healthcare professionals (including doctors and nurses) on patient outcomes in cancer care (205)	The review indicates no firm conclusions can be made about the effect of communication training programs in real patient encounters. There is some evidence that illustrates patient satisfaction and communicative behaviour, but the extent of these benefits in a clinical setting is inconclusive. Multiple comparisons and categories were utilized in the studies and the authors indicate that this may potentially pose a weakness and convolute the results. The authors suggest developing a conceptual framework for measuring patient satisfaction may improve the results for the studies. The review highlights the need to evaluate the goals and content of training programs, to determine a primary outcome, and for the program to involve transfer of acquired skills into daily practice.	2007	8/10 (AMSTAR rating from Program in Policy Decision-making)	0/7	0/7	0/7
	Examining the effectiveness of communication interventions for healthcare providers delivering care in residential care settings (193)	Few studies used controlled trials, which were expected when using complex interventions. Most research indicated that quality care requires effective staff-patient communication, and providing related training to staff can have an impact on several patient and staff outcomes. There was considerable variation in the reviewed studies to evaluate which intervention was more effective. There was a poor level of evidence in the reviewed studies. However, despite these limitations, all intervention studies did find a positive change in staff's communicative behaviours and skills and a decreased level of agitation and anger for the resident. Staff indicated that training improved their level of knowledge of communication strategies.	2007	4/9 (AMSTAR rating from Program in Policy Decision-making)	0/6	0/6	0/6
	Examining the effectiveness of (i) feedback of real patient assessments of interpersonal care skills, (ii) brief training focused on the improvement of interpersonal care, and (iii) interventions that combine both (i) and (ii) (209)	The conclusions drawn from this review about the effectiveness of patient based feedback, brief training and their combination are preliminary due to the small number of trials identified. It was unclear whether patient-based feedback is an effective quality improvement tool for changing physicians' interpersonal care behaviour. A positive effect was observed involving trainees, but another study involving experienced physicians showed no effect. The difference in results could potentially be explained by the difference in intensity of	2007	6/10 (AMSTAR rating from Program in Policy Decision-making)	0/9	0/9	0/9

Element	**Focus of systematic review or economic evaluation**	**Key findings**	**Year of last search**	**AMSTAR (quality) rating**	**Proportion of studies that were conducted in Canada**	**Proportion of studies that deal explicitly with one of the prioritized groups**	**Proportion of studies that focused on EOL communication, decision-making and care**
		feedback. In regards to brief training, the only study with positive effects was the oldest of all training studies. This may have resulted from lower baseline levels of physician interpersonal skills. It is suggested that effective interventions require combinations of didactic components with practice rehearsal and feedback from peers.					
	Examining active-mode learning techniques for geriatrics knowledge and skills in the U.S. (213)	There is a substantial amount of research in geriatrics training for community-based physicians, but much of it is unpublished or incompletely evaluated. There is evidence that interventions which will result in physician behaviour change most likely employ multiple education efforts, such as written materials combined with feedback, and strong communication channels between instructors and learners. A hallmark of successful educational interventions is that a needs assessment is crucial for active learning. Most of the included programs did not perform a needs assessment. Researchers conclude that in order for care for older people to be improved, it is necessary to be more proactive in developing and evaluating continuing medical education programs.	2004	3/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	2/13	0/13
	Examining the evidence on practices in initiating and pursuing conversations about sensitive future matters including death, dying and planning for end-of-life.(185)	Systematic review in progress: findings not reported					
	Examining the effectiveness of communication skills training on the patients' clinical outcomes in primary care and	Systematic review in progress: findings no reported					

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	rehabilitation settings (186)						
Educating and training providers in multidisciplinary and shared care approaches	Examining published curricula designed to teach teamwork to medical students and house staff (196)	All of the reviewed teamwork curricula used reasonable educational strategies, including engaging subjects in active learning and the use of referenced teamwork models. Within the context of relatively stable medical teams, most used reflection or structured feedback on performance. Most curricula involved learners for a short period of time, with very few exceeding eight weeks. Despite the use of validated instruments in several curricula in the review, the evaluation methodologies were weak. Some features limited the ability to draw conclusions from these evaluations, such as self-assessments of knowledge, perceived skill attainment and a lack of long-term follow-up of learner outcomes. In summary, the review has demonstrated that reported curricula have used appropriate educational principles, and most appear to be modestly effective in the short term.	2006	5/11 (AMSTAR rating from www.rxforchange.ca)	0/13	0/13	0/13
	Examining the evidence on interventions to improve team effectiveness and to identify their 'evidence based'-level (197)	Different outcomes were used to evaluate the effectiveness of interventions, which makes it difficult to compare or synthesize findings. The majority of the studies used non-technical team skills as outcomes, including communication, cooperation, coordination and leadership. A positive association was observed between the intervention and non-technical team skills in most studies. However, most studies presented a low or very low level of evidence. Only eight of the 48 included studies had a high or moderate quality of evidence, and these studies found positive associations with team behaviour, attitudes, self-efficacy, individual effectiveness, emotional exhaustion, de-personalization and perception of care. Gaps in the literature include the lack of research in this area that was conducted in long-term care. Most research was conducted in acute care, providing growing evidence	2008	4/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	1/48	0/48

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		that communication skills and coordination in high risk, complex medical departments can be improved by simulation training and training based on Crew Resource Management.					
	Examining the effectiveness of university-based interprofessional education (IPE) for health students (210)	There was some evidence of attitudinal changes post-intervention for the interprofessional groups. Mixed results were obtained related to the learning outcomes of IPE. One study reported improved clinical decision-making by medical students, while another study showed that the knowledge scores of the control group improved compared to the intervention group. One-third of the studies implemented campus- or classroom-based IPE approaches, and this was considered to be the most appropriate method to ensure delivery of IPE to large cohorts of students. All of the studies had certain methodological shortcomings. Most used convenience sampling which limits the potential to generalize findings.	2011	6/10 (AMSTAR rating from McMaster Health Forum)	1/9	0/9	0/9
	Examining the impact of practice-based interventions designed to improve poor interprofessional collaboration (IPC), compared to no intervention or to an alternate intervention, on one or more of the following outcomes: patient satisfaction, and effectiveness and efficiency of the provided health care (183)	Practice-based interventions to improve IPC appeared to improve healthcare and patient outcomes. Positive impact was found in daily interdisciplinary rounds at an acute care hospital setting, but showed no impact on length of stay in a community hospital telemetry ward. Monthly multidisciplinary team meetings appeared to improve prescription of psychotropic drugs in nursing homes. There was mixed results of videoconferencing compared to audio conferencing. A decreased number of case conferences per patient and shorter length of treatment were observed, but no differences were seen in occasions of service or the length of stay. Findings suggest practice-based interventions aimed at improving collaboration through practice changes may improve healthcare and patient outcomes. However, due to the small number of studies included, the results should be considered promising rather than proven. Researchers recommend the use of rigorous evaluation accompanying practice-based IPC interventions before further research evidence allows	2007	9/11 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/5	0/5

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		for widespread interventions.					
	Examining the evidence on interprofessional education (IPE) and assessing its influence on particular outcomes (198)	Drivers of IPE development can occur in a top-down or bottom-up fashion. Top-down drivers include government policy and the need to reduce medical errors. Such top-down drivers require translation into action, and this usually involves medical and nursing school deans, which are called a transition driver. On the other hand, bottom-up drivers include interests to improve collaboration and to ensure knowledge transfer to relevant professionals. To ensure a positive experience for participants, authenticity and customization of IPE to reflect appropriate and relevant service delivery settings are important. IPE education generally enables practitioners to learn the knowledge and skills for collaborative efforts, but it is less able to positively influence attitudes and perceptions towards others in the service delivery team. Lessons to bring into practice include the importance of staff development in the facilitation of IPE. Staff should seek funding for robust evaluations of IPE to accurately measure its impact on attitudes and behaviour.	2003	4/11 (AMSTAR rating from www.rxforchange.ca)	1/21	0/21	0/21
	Examining the effectiveness of interprofessional education (IPE) compared to education interventions in which same health and social care professionals learn independently from one another and compared to no education intervention (211)	Four of the six studies reported positive outcomes in a number of areas, including culture of emergency department and patient satisfaction, collaborative team behaviour and reduction of clinical error rates, care management delivered to domestic violence victims, and mental health practitioner competencies in delivery of patient care. 50% of the studies reported that benefits of IPE were sustained over time. Despite these positive outcomes, other studies reported that IPE interventions had no impact on healthcare processes or patient health care outcomes. As a result of the mixed results, the effectiveness of IPE remains unclear. The included studies all shared a common key limitation. They compared the effects of IPE interventions with control groups which received no education intervention. Therefore, it prevents researchers from assessing	2006	9/11 (AMSTAR rating from www.rxforchange.ca)	0/6	0/6	0/6

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		the effects of IPE compared to the predominant uniprofessional education model. Future implication for research suggests employing more rigorous designs, larger sample sizes and more appropriate control groups.					
Educating and training non-palliative care clinicians in the palliative approach	Examining the impact of education interventions in palliative care for primary care physicians in changing professional practice (212)	Researchers reported that palliative care education for primary care physicians is poorly studied. The quality of the studies was poor, and no strong conclusions can be drawn due to the heterogeneity of the included studies. Evidence suggests that multifaceted approaches in education interventions in palliative care are likely to be beneficial for primary care physicians.	2005	5/11 (AMSTAR rating from www.rxforchange.ca)	Not reported in detail	0/18	18/18
	Examining the effectiveness of training and support strategies for palliative care volunteers on palliative care clients and their families, volunteers and service quality (187)	Systematic review in progress: findings not reported					
	Examining the effectiveness of interventions for supporting palliative care volunteers in policy, organization and service settings (188)	Systematic review in progress: findings not reported					
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	No reviews identified						

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
ensure a common understanding of the terms and what they mean within Ontario's legal framework							
Establishing an information system that provides reminders and prompts to healthcare providers to ensure that goals of care documents are prepared and respected;	Examining the effectiveness of reminders in changing professional behaviour in clinical settings (199)	Positive effects were observed when reminders are incorporated into various clinical settings. They may be more successful if they are designed to meet the specific needs of the clinical setting they are serving. A recent development is the use of checklists as a form of reminder, and it has been observed to dramatically improve patient morbidity and mortality. The effect of reminders can meaningfully impact clinical practice since they are generally inexpensive and easy to implement. Researchers identify the lack of information on long-term effect of reminders. Implication for future research suggests focusing on possible effect modifiers and moderators to explain the variation observed across primary studies of reminders.	2009	6/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/35	0/35
	Examining the effectiveness of interventions to increase advance directive (AD) completion rate (200)	Similar conclusions were reached in the four included reviews. Various interventions have shown to increase AD completion rates within a period of four years. Several factors have given rise to this phenomenon, including demographic, technological, cultural, ethical and legal considerations. There is evidence suggesting passive information material alone does not significantly increase AD completion rates. When interactive informative interventions are employed, AD completion rates increase. The majority of the studies identify that multiple sessions is the most effective method for direct interaction between patients and health care professionals. Effectiveness further increases when patients have the opportunity to interact with an expert in the field. To put legislation into practice, it is necessary to set up successful interventions to expand ADs use.	Not reported in detail	5/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/7	7/7

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	Examining how manual paper reminders change professional practice and improve healthcare outcomes (189)	Systematic review in progress: findings not reported					
Encouraging Family Health Teams and other primary care groups to incorporate advance care planning into their quality-improvement plans;	No reviews identified						
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)	Examining the impact of financial incentives on healthcare professional behaviour and patient outcomes (184)	Overall, researchers concluded that payment for service, payment for providing care for a patient or specific population, payment for providing a pre-specified level of care or providing change in activity or quality of care, were effective. Mixed results were obtained for mixed or other system interventions, and payment for working for a specified time period was generally ineffective. Financial incentives were found to be effective in improving processes of care, referrals and admissions, and prescribing costs. They showed mixed effects for consultation or visit rates, and they were found to be generally ineffective in promoting compliance with guidelines. However, these results should be treated with caution due to the low to moderate quality of evidence of the studies included in each review.	2010	10/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/4	0/4
Implementing same-day/advanced access	Examining the effectiveness of advanced access scheduling in the primary care setting (201)	There is consistent evidence of decrease in the time to third-next-available appointment with advanced access scheduling. In general, advanced access yielded neutral to small positive improvements in no-show rates, continuity and patient satisfaction. Its effects on clinical outcomes	2010	6/9 (AMSTAR rating from Program in Policy	0/28	0/28	0/28

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
scheduling in primary care practices to support timely access to care (including palliative care)		remained mixed. Clinicians often assume that shorter wait times for appointments will lead to improved patient satisfaction, but this is not always the case. Among working patients, patients with chronic illness, women and older patients, scheduling an appointment at a convenient time is more important than speed of access. There is some evidence supporting the concern that some patients may be lost in follow-up in an advanced access system. While advanced access scheduling is gaining popularity, it is important to realistically expect its potential benefits. It yielded marked improvements for practices with high no-show rates, but it becomes less effective for practices with lower baseline no-show rates.		Decision-making)			

Appendix 3: Systematic reviews and economic evaluations relevant to Element 3 – Strengthen citizens' capacity to engage in communication and decision-making about end-of-life care

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communica tion, decision-making and care
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	No reviews identified						
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	Examining the effectiveness of online interventions to achieve population-wide change in voluntary lifestyle behaviours (222)	The review finds the overall impact of online interventions to be small and suggests these interventions should be regarded as a relative advantage in comparison to different intervention media. Time is considered a critical factor as impact and adherence fade over time. Motivation is considered the potential critical factor that drives study and intervention adherence in addition to impact. The studies shows online intervention are considered as good as print interventions, but have an economic advantage of lower costs and being able to reach a larger audience.	2011	6/11 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0/29	0/29
	Examining to what extent papers about social marketing health	The overall finding for the review illustrates the utilization of health behaviour theory and models in the development of social marketing campaigns are not adequately used. Benefits to the utilization of theory and	2009	2/10 (AMSTAR rating from	Not reported in detail.	0/24	0/24

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	interventions report use theory, which theories are most commonly used, and how theory was used (238)	model include resourceful instruments for intervention design, and evaluation for various settings, target audiences and health topics. It is suggested that theory and model can be used in order to emphasize the contribution that their use can bring into the social marketing intervention.		McMaster Health Forum)			
	Examining the effectiveness of social marketing interventions in influencing individual behaviour and bringing about environmental and policy-level changes in relation to alcohol, illicit drugs and physical activity (223)	The review suggests a better understanding of the principles of social marketing is needed among program designers, evaluators, journal editors and reviewers. The researcher states there is some evidence that interventions using social marketing principles can be effective. There is potential for social marketing interventions to effect 'upstream' change – to change the behavior of professionals, organizations and policymakers. Competition is noted by the researchers as a strategy that might hinder consumers from adopting a desired behaviour change. The review supports the notion of a combined theoretical framework and consumer research as an important prerequisite for social marketing effectiveness in order to help translate theoretical constructs into acceptable and persuasive interventions. Methodological limitations impede a clear conclusion to the researchers' purpose of the study.	2003	5/11 (AMSTAR rating from McMaster Health Forum)	1/54	1/54	0/54
Coordinating and intensifying a strategy to engage citizens in a provincial dialogue to normalize end-of-life conversations	Examining the use of public deliberation as a method for increasing public input for health research (224)	Public deliberation is presented in the literature as a specific area of political science, and it encourages members of the public to engage in and to be informed about issues that shape their public life. Evidence remains consistent in suggesting that public deliberation is a method of obtaining public input on decisions that are important to society. The goals of public deliberation are to obtain informed public opinion, to obtain input that includes underrepresented individuals and groups, to bring insights into social values and ethical principles, and to promote the acceptance of public decisions. In addition, the effects of deliberation on participants improve understanding of the complexity of decisions and enhance civic-mindedness. Identified issues that are best suited for public deliberation involve ethical	2010	4/10 (AMSTAR rating from McMaster Health Forum)	0/193	0/193	0/193

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		and social dilemmas. It is also important to note that the potential to find common ground is a requirement for issues addressed through public deliberation.					
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)	Examining the effectiveness of mass media on the utilization of health services (214)	A high-quality but old review found that all of the studies (which were of variable quality) apart from one concluded that planned mass media campaigns and unplanned mass media coverage could have a positive influence on the utilization of health services.	1999	10/11 (AMSTAR rating from www.rxforchange.ca)	1/20	0/20	0/20
	Examining the effectiveness of advance care planning for end-stage kidney disease (220)	Systematic review in progress: findings not reported					
	Examining the effectiveness of advance care planning for end-of-life care (219)	Systematic review in progress: findings not reported					
Establishing a specialized service providing personal support and coaching to citizens preparing advance care	Examining the effectiveness of interventions which are delivered before consultations, and which have been designed to help	The review indicates that interventions before consultations designed to help patients address their information needs within consultations produce limited benefits to patients. The increase in questions asked demonstrates the most direct effect of the intervention and led to a small increase in patient satisfaction. Consultation length was small and not statistically significant. Coaching as an intervention	2006	10/11 (AMSTAR rating from McMaster Health Forum)	2/33	0/33	0/33

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
plans, and linking them to expert information and use of tools as needed	patients (and/or their representatives) address their information needs within consultations (215)	led to a greater increase in patient satisfaction. Clinician training is notable in the review as it is suggested that clinician training can lead to greater efficiency in consultations and greater patient satisfaction. The effects of patient knowledge are difficult to interpret and require further research. Further research into clinician training is recommended by the authors in order to fully evaluate the effects of these types of interventions. Trials are needed to establish whether patient-focused interventions combined with intensive training of clinicians can produce benefits. More studies need to consider the timing of interventions.					
	Examining the effectiveness of interventions in primary medical care that improve the involvement of older patients in their health care (216)	Due to the limited number of eligible studies, researchers were unable to assess the whole range of possible interventions to improve the involvement of older patients in their health care. Positive effects were found in the involvement of older patients. The conclusions have to be taken cautiously due to the relatively low quality and small study samples. The provision of a pre-visit booklet and a pre-visit session led to increased questioning and more active behaviour in the intervention group. In one study, those in the intervention group were associated with more satisfaction with interpersonal aspects of care. Researchers suggest a balance between the respect for patients' autonomy and stimulating their active participation in health care. They further encourage face-to-face coaching sessions.	2004	10/11 (AMSTAR rating from McMaster Health Forum)	0/3	3/3	0/3
	Examining the effectiveness of intervention strategies designed to enhance patient participation in the consultation process (225)	Feedback to providers of patient-reported outcome measures was the most commonly employed intervention strategy in this review. Often, patients complete questionnaires, termed PROMs, which are designed to capture patients' perspectives of health and impact of disease. The majority of the studies found that application of PROMS improved patient-provider interaction. The positive effect of intervention to patient-provider communication was found in studies employing both patient- and provider-targeted	2004	3/9 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	0/146	0/146

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		interventions. Key elements of successful patient participation and patient-centred care include identification of shared goals, negotiation of treatment decisions and agreement about relative responsibilities of disease management. Evidence from the included studies found that a wide range of intervention strategies was successful in enhancing patient participation in the consultation process.					
	Examining the effectiveness of cognitive behavioural interventions for people with advanced cancer (273)	Four major themes were identified in this review of the use of cognitive behavioural interventions (CBIs) in patients with advanced cancer: (1) there is a limited number of randomized clinical trials testing CBIs in people with advanced cancer; (2) most studies showed statistically insignificant treatment effects; (3) student methods were inconsistently described; and (4) samples of these studies showed little racial or ethnic diversity. The small number of randomized clinical trials testing CBIs in people with advanced cancer is due to the consideration that it is unethical to withhold treatment, especially from the most severely ill of the advanced care patients. Limited data about efficacy of CBIs prevented researchers from reaching a definitive conclusion about the effects of CBIs. Furthermore, the interpretation of the effectiveness of the CBIs was limited by challenges to the internal validity of the studies.	2011	4/9 (AMSTAR rating from Program in Policy Decision-making)	2/11	0/11	0/11
Developing toolkits for lawyers who support clients in advance care planning	No reviews identified						
Incentivizing citizens to communicate their wishes for future health and personal care to their family and especially their	No reviews identified						

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
substitute decision-maker(s)							
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	Examining the effectiveness of consumer decision aids (CDAs) (226)	Structured decision aids demonstrated no influence on treatment preferences. Similarly, most reports did not show an influence of the structured decision aid on the decision-making process, which is measured by assessing elements of the decision-making process such as satisfaction with decision, satisfaction with decision-making process, anxiety, perceived control over decision, perceived involvement in decision-making, perceptions of choice, decisional conflict, realistic expectations, value congruence and perceived benefits. Evidence from the included reports did show an improvement in knowledge from the introduction of structured decision aids.	Not reported in detail	6/10 (AMSTAR rating from Program in Policy Decision-making)	6/22	0/22	0/22
	Examining the ways to communicate evidence that improve patient understanding, involvement in decisions and outcomes (274)	Evidence suggests that actively listening, providing information in small 'digestible' amounts, and pausing to check for patient understanding will likely improve understanding and potentially shorten visit times by excluding information that patients neither need nor want. When the patient is distressed, delaying discussions of evidence until the patient is more receptive is encouraged, and will likely minimize misunderstandings. Once treatment options have been proposed to the patient, researchers suggest a five-step approach: (1) understand the patient's experience and expectations; (2) build partnership; (3) provide evidence, including a balanced discussion of uncertainties; (4) present recommendations; and (5) pause to check for understanding and agreement.	2003	0/10 (AMSTAR rating from Program in Policy Decision-making)	2/8	0/8	0/8
	Examining the available evidence on the effects of decision aids in surgery (227)	Evidence demonstrates that patients who utilized decision aids were more knowledgeable about treatment options and experienced less decisional conflict. Their observed anxiety level is similar to patients who received general patient information. Patients who used decision aids generally chose a more conservative treatment option. In summary, the use of decision aids appears to enhance patient engagement in decision-making. This is a desirable effect as more patients prefer to be actively involved in the decision-making process.	2011	6/11 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/17	0/17
	Examining the effectiveness of	Evidence supports the increased benefits of decision aids compared to usual care interventions for improving patient's knowledge of treatment options.	2009	9/11 (AMSTAR rating from	17/86	0/86	0/86

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	decision aids for people facing treatment or screening decisions (217)	Detailed decision aids only marginally improved knowledge compared to simpler versions, but they exhibited other benefits such as more accurate risk perceptions. Mixed evidence is available of the impact of decision aids on increasing or decreasing choice of options. The positive effects of decision aids encourage them to be used in clinical practices. Conditions that are necessary for a successful implementation include good quality decision aids to meet the needs of the population, practitioners willing to use decision aids, effective systems for delivering decision support, and practitioners and healthcare consumers who are skilled in shared decision-making.		www.rxforchange.ca)			
	Examining the available evidence of cancer-related decision aids (DAs) (228)	Evidence describes that DAs have some benefits in enhancing decision-making in cancer. They consistently increase knowledge in the screening, prevention and treatments processes, and do not result in an increase in patient anxiety. However, the small number of studies and patients limited the researcher's ability to reach definitive conclusions about the impact of cancer-related DAs in the prevention or treatment context. The more extensive DAs compared with the less extensive ones showed increased knowledge in the prevention and treatment contexts.	2007	4/11 (AMSTAR rating from Program in Policy Decision-making)	5/34	0/34	0/34
	Examining interventions to support decision-making and information provision in patients with advanced cancer (239)	Evidence from the review positively describes the patient's desire to collaborate with their doctors in decision-making. Patients with a younger age and higher educational level likely play a more active role in decision-making. However, researchers were unsuccessful in finding evidence of the effect of participation in decision-making on subsequent quality of life or psychological outcomes. Advanced cancer patients are similar to early cancer patients in their desire for information on all aspects of their disease. The concept of being informed gives patients a sense of control. As the patient's disease progresses, it is discovered that he/she usually want to surrender control. On the other hand, those who have improved during their treatment generally want increased involvement in subsequent decisions.	2003	4/10 (AMSTAR rating from Program in Policy Decision-making)	21/47	/47	47/47

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		Studies included in this review have shown that patients often misunderstand the extent of their disease, the prognosis and the aims of treatments. This lack of information may result from several reasons: (1) lack of time of the doctor; (2) patients may not understand the given information; and (3) the information may be rejected as part of a process of denial. It is concluded that better information-giving and opportunity for patients to participate in decision-making require a shift in attitude of the doctor. Furthermore, it is important to understand that passing on a poor prognosis or ceasing active treatment does not adversely affect the patients by destroying hope. Rather, sensitive information and involving the patient are important steps to reset their goals.					
Implementing system navigators and transition coaches to coordinate palliative care services and support patients/families/caregivers transitioning from one setting to another	Examining qualitative evidence regarding cancer patient navigation (230)	In general, patient navigation shares some common features: (1) it is provided to individual patients for a defined episode of cancer-related care; (2) it has a definite endpoint when services are complete; (3) it targets a defined set of health services; (4) it focuses on identifying individual patient-level barriers to accessing cancer care; and (5) it aims to reduce delays in accessing cancer care services. There is some evidence that patient navigation is associated with improvements in breast, prostate and colorectal cancer screening and adherence to follow-up visits. However, researchers could not draw definitive conclusions about its efficacy in published studies because of certain limitations, such as lack of a control group, lack of randomization to treatment or comparison groups, etc. There are currently no formally recognized certification programs for patient navigators. If it is determined that patient navigators are effective, a thorough evaluation will be needed to ensure such programs are effective and cost-effective.	2007	2/9 (AMSTAR rating from Program in Policy Decision-making)	1/17	0/17	0/17

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	Examining the potential impact of existing navigator models relevant to chronic disease management for older adults (229)	The navigator role for chronically ill older patients remains a relatively new one, and few articles have evaluated their impact on outcomes for the chronically ill older population. Several factors can impact the potential success of a navigation program. Most older adults are transitioning between a hospital to home, and evidence suggests that this intervention should commence prior to discharge. If the patient is at high risk of re-hospitalization, it is important to ensure that the navigator has the clinical skills to accurately assess and recognize 'red flags' in the course of contact with the patient. There is mixed evidence regarding the effectiveness of navigator roles. It is suggested that all healthcare providers should incorporate navigation concepts into their work, which is to ensure that all roles have responsibility for patients' comfort and well-being. Despite the mixed record of success in individual programs, the navigator role has shown sufficient promise in assisting older patients' transition from higher levels of care.	2011	5/10 (AMSTAR rating from Program in Policy Decision-making)	2/9	9/9	0/9

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
Establishing formal and culturally adapted respite care services and counselling, as well as grief and bereavement services, for informal/family caregivers	Examining qualitative and survey-based research on pediatric palliative and end-of-life care pertaining to the needs of patients and their families (240)	Continuity, consistency and coordination are factors that facilitate relationship building, promote caring and encourage sharing of expertise and information about the child between healthcare providers (HCPs). HCPs identified the need for patients to consistently receive care, even outside the hospital, such as home visits. Although the number of deaths in the intensive care unit has appeared to decrease, parents reported the obstacles to home death. They pinpoint the need for services and competent pediatric trained HCPs to be available and accessible to them and the patients. Some studies reported the need for more information, and parents generally want to be updated more frequently about their child's condition. In addition, information given to parents is often reported as confusing and contradictory, especially for non-English-speaking families. Parents consistently report the need to extend care from the time of diagnosis through to the bereavement period. They wish to have access to bereavement services immediately after or even before their child's death. The need for patient dignity and respect was reported in numerous studies as a patient need, but it also plays a crucial role in communication needs. It was demonstrated that patients and families need emotional support, and patients need access to other peers who are going through similar experiences. Research highlighted that parents strive to maintain hope while accepting their child's prognosis. Other areas of focus for pediatric palliative care include pain and symptom management, cultural needs and siblings' needs.	2010	2/9 (AMSTAR rating from Program in Policy Decision-making)	4/21	1/21	21/21
	Examining effectiveness and cost-effectiveness of breaks in care in improving the well-being of informal carers of frail and disabled older people living in the community (235)	No effect was found of respite care on carer burden. Important aspects of carer needs include flexibility of services and the ability to respond to carer needs at short notice. A positive, beneficial effect was observed for respite care on carer depression, but this was not statistically significant. The amount of day care provision was proposed to be an important consideration for carers. In many cases, day care is unavailable at times when respite care is most needed, such as evenings and weekends. Evidence demonstrates no effect of respite care on anxiety in both the short	2005	8/10 (AMSTAR rating from Program in Policy Decision-making)	9/104	104/104	0/104

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
		or long term. Anxiety in carers often results in social isolation, and caring for a failing relative with dementia also creates a grieving situation. Qualitative reviews propose that carers feel a sense of guilt if their relative is unhappy about attending day care. Overall, provision of respite care can be of benefit to carers' well-being in certain situations. Home care emerged as a preference, and also demonstrated benefits over day care in relation to carer depression.					
	Examining the effectiveness of different types of professional dementia home care interventions (232)	Psychosocial interventions in dementia home care had insignificant benefits on caregivers' burden, and there was a negligible decrease in depression in caregivers. There are few studies of controlled designs that had focused on respite care. Caregivers of patients reported an increase in burden, and some reasons are: (1) it is difficult to hand over a relative with dementia; and (2) caregivers are concerned with nursing quality and may feel uncomfortable taking time off. Communication technology-based intervention had almost no effect on depression of the family caregiver. Furthermore, as the structure intervention program was a low profile type of support and directed caregivers to an automatic telephone system, it may negatively influence the caregivers' feelings. Although case management has been popular in the past decade, it did not provide caregivers with effective support to decrease depressive feelings. The impact of physical exercise on the stress related to caregiving is expected to be highly positive. In accordance with other reviews, this review demonstrated weak evidence that supporting family caregivers could be beneficial. However, such support is indispensable in dementia home care.	2007	7/11 (AMSTAR rating from Program in Policy Decision-making)	3/29	29/29	0/29
	Examining the effectiveness of respite care for people with dementia and their	No significant effects on caregiver outcomes were found with the interventions. Two possible explanations for this result are: (1) respite care has no effects on caregivers in reality; and (2) any resultant effects are imperceptible.	2007	9/10 (AMSTAR rating from Program in Policy	0/3	3/3	0/3

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	caregivers (236)	No meaningful conclusions can be drawn for practice. Researchers have suggested the possibility that studies of respite care focus too much on caregivers and too little on the care recipient. Furthermore, the lack of evidence reflects a lack of high quality research in this area.		Decision-making)			
	Examining the effectiveness of intervention strategies designed to help caregivers cope with the burden of caregiving (231)	There is evidence that suggests interventions designed to reduce caregiver burden have no effect on burden, and in certain cases, a negative effect on burden was observed in the group with the intervention. Although burden has been the most common measure to evaluate the effect of caregiving interventions, it is questioned when used to evaluate the effect of caregiver outcomes due to its subjective and objective qualities. This review identifies that it is critical to identify outcomes that are most likely changed by intervention, and burden, a multi-dimensional concept, may not be the best outcome to demonstrate the effectiveness of caregiver interventions.	1999	7/11 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	Not reported in detail	Not reported in detail
	Examining the impact of residential respite care on the behaviour of older people with dementia (275)	Evidence that supports the impact residential respite care has on the behaviour of older people with dementia is mixed. Of the six studies reviewed, the results ranged from an improvement in behaviour to no change and some worsening in behaviour. However, two studies with the greatest methodological rigor both provided evidence of a reduction in behavioural symptoms with residential respite care. As residential respite care is one of many options for assisting with the care of older people with dementia, so a medium effect on their behaviour is predicted. Due to the insufficient sample sizes, there may be under-estimation of the effect of residential respite care. Implication for future research encourages the use of rigorous designs and more accurate characterization of subjects.	Not reported in detail	6/9 (AMSTAR rating from Program in Policy Decision-making)	1/6	6/6	0/6
	Examining the evidence on respite care of people affected by severe mental illness and to identify key implications for	The issues and problems related to respite care remained relatively unchanged in the past decade. Minimal research on respite care has been conducted with caregivers of mental illness; instead, the majority of the studies focus on caregivers of people with dementia. A possible reason is the relatively short history of the extension of respite care models to caregivers of psychiatric patients.	2002	3/10 (AMSTAR rating from Program in Policy Decision-making)	Not reported in detail	Not reported in detail	Not reported in detail

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	nursing practice in provision of respite care for family caregivers of people with severe mental illness (237)	Key research gaps identified include: (1) lack of quality, quantity, type, choice and utilization of respite care services; (2) lack of research on impact and effectiveness of respite care services; (3) lack of research on ethnic or cultural differences in terms of respite care need and use; (4) identification of suitable outcome measures for mental health respite care services; (5) and strengthening the practices of healthcare professionals working with family caregivers when providing respite care.					
	Examining the effectiveness of supportive interventions that aim to improve the psychological and physical health of informal caregivers of patients in the terminal phase of their illness (218)	Nine of the 11 studies were directly targeting caregivers, and evidence showed that these interventions helped in the short term to buffer against psychological distress. However, the quality of this evidence is low due to the limited amount of trial data. The review suggests that healthcare practitioners should enquire about the concerns of families and friends caring for a loved one, and should also consider that they may potentially benefit from additional support to cope with the stress from caring. However, the review was unable to identify which types of support provided more benefit. Implications for future research suggest that the interventions evaluated should be repeated in more rigorous trials.	2010	10/11 (AMSTAR rating from McMaster Health Forum)	0/11	0/11	11/11
	Examining the effectiveness of interventions designed to support children at the time of bereavement, and to provide information regarding the most effective interventions in a pediatric population (221)	Systematic review in progress: findings not reported					
	Examining the cost-effectiveness of a visiting service for older widowed individuals (234)	Findings revealed that selective bereavement interventions like the visiting service do not produce large benefits from the health economic point of view when they target the entire population of all widowed individuals.	2008 (year published)	Not appropriate for economic evaluations and costing studies	0/1	0/1	1/1

Element	Focus of systematic review or economic evaluation	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on EOL communication, decision-making and care
	*Note that this is an economic evaluation or costing study.						

McMaster University

McMaster
HEALTH FORUM

>> Contact us

1280 Main St. West, MML-417
McMaster University
Hamilton, ON Canada L8S 4L6
Tel: +1.905.525.9140 x 22121
Fax: +1.905.521.2721
Email: mhf@mcmaster.ca

>> Follow us

mcmasterhealthforum.org
healthsystemsevidence.org

tinyurl.com/mhf-iTunesU
tinyurl.com/mhf-YouTube
tinyurl.com/mhf-Facebook
tinyurl.com/mhf-Twitter

EVIDENCE >> INSIGHT >> ACTION