

EVIDENCE >> INSIGHT >> ACTION

## McMaster Health Forum

### The 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.

### About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-14 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the view of others. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

### About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panel on how to improve access to palliative care in Ontario. This brief includes information on this topic, including what is known about:

- the underlying problem;
- three possible options to address the problem; and
- potential barriers and facilitators to implement these options.

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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# McMaster Health Forum



It is estimated that 90% of Canadians in the final stages of life could benefit from palliative care.

## **The context:**

### Why is improving access to palliative care a high priority?

>> The demand for high-quality palliative care is likely to increase with the aging population, the growing number of patients with life-limiting chronic conditions and complex care needs, and advances in healthcare.

In 2011-2012, more than 252,000 Canadians died (more than 96,000 of them in Ontario), and many more are affected by these deaths. It is estimated that each death affects the immediate well-being of approximately five other people, or more than 1.25 million Canadians each year.(14)

## Glossary

### Access

Access is defined as the “extent to which an individual who needs care and services is able to receive them; more than having insurance coverage or the ability to pay for services; determined by the availability and acceptability of services, cultural appropriateness, location, hours of operation, transportation needs, costs and other factors.”(5)

### Chronic disease

Chronic diseases are “diseases of long duration and generally slow progression.”(10) Examples of chronic diseases include cancer, chronic respiratory diseases, diabetes, heart disease and stroke.

### Comfort measures

Comfort measures refer to “treatments to keep you comfortable (e.g., pain relievers, psychological support, oxygen, etc.) but not to keep you artificially alive or cure any illnesses.”(12)

### Informal/family caregiver

An informal/family caregiver is an individual who is providing unpaid and on-going care or social support to a family member, neighbour or friend who is in need due to physical, cognitive or mental health conditions.(14)

Providing comfort and dignity for those with a life-limiting or terminal illness and their families, is at the heart of palliative care.(4) The demand for palliative care is likely to increase significantly because of three trends:

- the aging population;
- the growing number of patients with life-limiting chronic conditions and complex care needs; and
- new advances in healthcare promising life-saving or life-prolonging possibilities.

Ensuring that all those in need have timely access to high-quality palliative care is challenging. It is estimated that 90% of Canadians in the final stages of life could benefit from palliative care. However, the health system is currently unable to provide palliative care to 70% of those in need.(14;22)

Improving access to palliative care is a pressing health issue in Ontario (and across Canada more generally). Many organizations in Ontario are working to support high-quality palliative care. However, Ontario does not yet have a coordinated strategy for palliative care like other provinces such as British Columbia and Quebec.(17;23)

In May 2013, the Ontario Medical Association (OMA) announced that it will play a leading role in promoting the development of a provincial strategy to improve care at the end of life, including access to palliative care.(24) The OMA represents more than 34,000 physicians, residents and medical students across the province. The OMA is seeking the views and experiences of Ontario citizens in order to guide its efforts.



In this section of the brief, we provide some information about what palliative care is, what the benefits are, who provides it and where.

## What is palliative care?

Palliative care is a type of specialized care that involves many different types of providers. It aims to offer the best quality-of-life for both those with a life-limiting or terminal illness, and their families.

Palliative care includes four components:

- pain management;
- symptom management (e.g., nausea, anxiety, depression or fatigue);
- social, psychological, emotional and spiritual support; and
- caregiver support.(4)

Palliative care is appropriate as soon as the diagnosis of a serious illness is made, not just when someone is approaching death. Palliative care can also support grieving families.(4)

## What are the benefits?

Patients and families living with a life-limiting or terminal illness can benefit from palliative care.

Palliative care is often associated with cancer, but it can help with other illnesses such as Alzheimer's disease, AIDS, Lou Gehrig's disease, multiple sclerosis and chronic conditions like respiratory diseases, diabetes, heart diseases and stroke.(4)

## Glossary

### Life-limiting illness

Life-limiting illness are “illnesses that can be reasonably expected to cause the death of the individual within a foreseeable future.”(17)

### Palliative care

Palliative care is a type of specialized care that involves many different types of providers. It aims to offer the best quality of life for those with a life-limiting or terminal illness, and their families. It includes pain management, symptom management, social, psychological, emotional and spiritual support, as well as caregiver support.(4)

### Primary care

Primary care is defined as “the first level of contact with the medical care system provided primarily by family doctors, (e.g., office visits, emergency room visits and house calls).”(5)

### Terminal illness

A terminal illness is “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.”(12)

A palliative care approach can provide many benefits for patients and their families, including:

- greater involvement in healthcare decisions about treatment and care;
- better quality-of-life;
- longer life; and
- fewer hospitalizations.(25)

## Who provides it and where?

The majority of people with a life-limiting or terminal illness are cared for by an informal or family caregiver. However, in certain situations, a palliative care team may be necessary to support these caregivers. The composition of a team varies depending on the needs of the patients and their families.(4) A team often includes:

- the patient's family physician;
- nurses with expertise in palliative care;
- physicians with expertise in palliative care;
- pharmacists;
- social workers;
- spiritual counsellors;
- volunteers providing support (e.g., companionship, respite services and transportation); and
- other professionals (e.g., home support workers, nutritionists, physiotherapists and occupational therapists).(4)

Palliative care can be offered in various settings, including:

- at home;
- in hospitals (e.g., in palliative care units);
- in long-term care facilities; and
- in hospices. (4)



## >> Health system in Ontario

- 14 geographically defined Local Health Integration Networks (LHINs) have responsibility for the planning, funding and integration of healthcare. They have made palliative care a priority and developed three-year regional action plans.
- 14 Regional Hospice Palliative Care/End-of-Life Care Networks – one for each LHIN – have the mandate to improve the local system that delivers palliative care. The networks are part of the Provincial End-of-Life Care Network.
- 14 Community Care Access Centres (CCACs) – one for each LHIN – have responsibility for connecting people with the care they need at home and in their community.
- 34 residential hospices in Ontario – 24 of which are currently operational – were approved by the ministry of health in 2005 to deliver palliative care.
- Some palliative services are also available through community support services 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.
- 26 Health Links (of an anticipated total of 77) mobilize the delivery of integrated care for those with complex needs.



The health system is currently unable to provide palliative care to 70% of those in need.

## **The problem:**

# Why is improving access to palliative care challenging?

>> Improving access to palliative care is challenging because many factors affecting patients and families, healthcare providers and the health system must be considered.

Several factors contribute to the challenges of improving access to palliative care in Ontario. Some of these factors relate to patients and families, to healthcare providers or to the health system more broadly.

## Informal/family caregivers are not well supported

Informal/family caregivers play a crucial role in providing care for their loved ones, including palliative care. A recent Ontario study found that patients who receive palliative care are primarily cared for by their spouse or partner (57%) or their children or children-in-law (29%).(9)

However, support for informal/family caregivers is lacking and inconsistently available across the province.(11) This includes:

- practical, social and emotional support;
- informational support (e.g., advice, guidance, suggestions or useful information to help them navigate a complex health system);
- respite care services and counselling;
- grief and bereavement services; and
- financial support.

The economic burden for informal/family caregivers is also substantial. A Canadian study revealed that caregivers often have to pay more than 25% of the costs of palliative care associated with home-based services.(30) This often includes some medications, equipment and personal care services. Such expenses can create additional financial stress for patients and their informal/family caregivers.(22;31;32)

Caregivers who are not family members and family caregivers who are retired or unemployed without employment insurance are not currently eligible for financial assistance programs. Only family caregivers who meet very specific eligibility criteria can benefit from the federal Compassionate Care Benefits (33) and Ontario's unpaid Family Medical Leave programs.(34) A recent evaluation of the Compassionate Care Benefits program also revealed that many people do not know about it. Also, the program's application process and requirements are complex, and there is limited support offered (both in terms of the amount and length of coverage).(35)

This lack of support can have a negative impact on the physical and mental health of informal/family caregivers, as well as on their personal and professional lives.(26-29) A study conducted in Ontario found that 12% of caregivers providing palliative care at home for their loved ones showed signs of distress.(9)

## Most people are not referred to palliative care until they are 'close to death', and many are never referred

Palliative care is appropriate as soon as the diagnosis of a serious illness is made, not just when someone is approaching death.(4) However, patients are often only referred to palliative care very late in their illnesses, when they are diagnosed as 'close to death.'(11;25) Many are never referred.(14)

This is inadequate to meet the growing and complex needs of patients and families who are facing different illnesses.(22) While some people die suddenly, the health status of other people can decline over several weeks, months or years. Timely referral to palliative care programs and services that reflect the full variety of illnesses remains the exception more than the norm.(11;36)

This situation could be explained, in part, by the fact that some illnesses are more predictable than others. For example, the illness trajectory of someone with lung cancer may be more predictable than the illness trajectory of someone with heart failure. Therefore, some healthcare providers may have difficulty determining when patients could benefit from palliative care.(37)

### >> **First-generation immigrants**

First-generation immigrants may face important challenges in accessing palliative care. Ontario is a multicultural society with a large and vibrant immigrant population, mostly concentrated in large urban areas.(1) 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.(1)

These immigrants are likely to face significant challenges when engaging in conversations about palliative care with healthcare providers who are not proficient in their patients' first language.(13) These patients are also likely to face significant barriers to navigate the system and access support.(15)

Beyond language, culture (and religion) may shape the values and norms regarding various dimensions of palliative care. This can include the patient's and family's perspective on health, suffering, death and dying, the use of Western medicine, the role of informal/family caregiving, the provision of information about the likely outcome of the illness, and the role of the patient and family in the decision-making process.(18-21) The multicultural makeup of Ontario suggests that culturally-sensitive palliative care is required to meet the needs and expectations of a growing immigrant population.

## Improving access to palliative care in Ontario

Many Ontarians also do not have access to a regular physician. It is estimated that 9.2% of Ontarians do not have access to a regular physician,(38) and 3.2% of sicker adults in the province do not have a regular physician or place to go for medical care.(39) For sicker adults who do have a place to go for care, only half could see a doctor or nurse on the same or next day the last time they were sick.(39) This is a key barrier to accessing palliative care (and to early referral). A recent Canadian report noted that 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.”(38)

Many healthcare providers are also not prepared to provide palliative care. Training and education in the palliative care approach for healthcare providers working in different settings and with patients with certain conditions like dementia, is currently inadequate. The need for better training and education seems very important given that front-line staff (both clinicians and non-clinicians) often think that they lack the knowledge and skills to provide quality care to dying patients.(40)

In addition, palliative care has been focused on cancer and the treatment of associated pain for a long time. The same range of palliative care is often not available for, or offered to people with other illnesses such as dementia, kidney diseases, heart diseases or lung diseases.

There is also a lack of public awareness about palliative care in general, as well as the specific options available to patients and families living with life-limiting and terminal illnesses.(11) This lack of awareness may result in patients and families not requesting palliative care when they could benefit from it.



## Current programs and services are fragmented and do not completely meet the needs and preferences of Ontarians

Palliative care in Ontario has been described as a patchwork of services “with very little integration, a lot of overlap and significant gaps.”(41)

A large consultation conducted in 2011 that brought together many key organizations revealed a lack of integration between caring for chronic diseases and palliative care, including diagnosis, end-of-life care and bereavement support.(11)

Current programs and services also do not fully meet the needs and preferences of Ontarians. Most people express the desire to die at home and be surrounded by their loved ones, but almost 70% still die in hospitals.(14)

This could be explained in part by the lack of funding to support comprehensive care at the end of life outside of hospitals. This might include funding for personal support workers, nurses and nurse aides providing services, and palliative care physicians providing oversight. In fact, many services outside of hospitals and many hospices require considerable community donations to operate.

Hospital-based 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, funding does not follow patients as they move through different parts of the health system.(11)

### >> Frail older adults

Accessing palliative care may be particularly challenging for frail older adults. The number of frail older adults is expected to increase dramatically in Ontario. Not only is the population getting older, but more and more people have multiple chronic conditions. It is estimated that 43% of adults over the age of 65 have two or more chronic conditions.(3)

Frail older adults increasingly live alone with few extended family members. The number of families with two adults and children fell by 18% from 2001-2006, 51.5% of the population is not married, 42.7% of households have no children, and approximately 25% of families are led by a single parent.(9)

While many Ontarians would like to receive palliative care at home, this may be impossible for frail older adults who have complex care needs and limited family support.

## >> A few recent initiatives

### Federal/Pan-Canadian Initiatives

- The federal government launched the Canadian Strategy on Palliative and End-of-Life Care in 2002, which tackled various issues, such as best practices and quality care, education for formal caregivers, public information and awareness, research and surveillance. This initiative was terminated in 2007.(2)
- 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.
- 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.

### Provincial Initiatives

- In 2005, the Ontario government adopted a three-year End-of-Life Care Strategy, but the funding ended in 2008.(6-8)
- In 2011 the Ministry of Health and Long-Term Care, the Local Health Integration Networks, and the Quality Hospice Palliative Care Coalition initiated a process to develop an action plan. The process involved more than 80 organizations from across the healthcare sector in developing a plan of action for “advancing high quality, high value palliative care in Ontario.”(11) While some concrete actions have been taken since then, the recommendations from this consultation have not been fully implemented by all participating organizations.
- 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.
- 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](http://homeandcommunitysupport.ca/care_guide/caregiver.asp)]
- The government of Ontario made funding announcements to improve access to palliative care, for example:
  - \$7 million in operating funding to residential hospices to cover 100% of their nursing/personal care services;
  - \$8 million annually for 70 new community-based palliative nurse practitioners; and
  - \$5 million for the creation of the Community Palliative Care On-Call program.



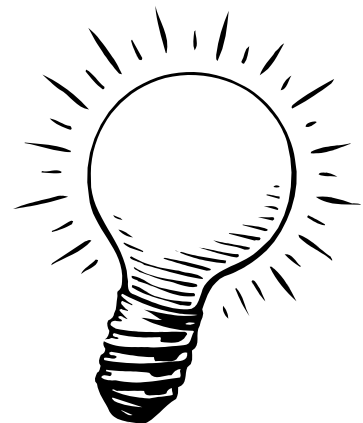
### Regional Initiatives

- A variety of pilot programs are currently underway in Local Health Integration Networks (LHINs) across the province, that aim to improve the integration of care teams and education for providers, and provide more seamless transitions of care.
- The Hamilton Niagara Haldimand Brant LHIN invested \$1,146,963 in 2012 in new and expanded Palliative Care Shared Care Outreach Teams throughout the region. This supports the LHIN's ACTION: A Call To IntegratiOn Now initiative, to ensure that citizens get the best care, in the right place, at the right time.(16)

The lack of patient, family and caregiver involvement in designing policies, programs and services may also contribute to this situation. The consultation conducted in 2011 pointed out that “family and caregiver voices are not currently reflected in local and system level planning and governance.”(11) Including these voices could help ensure that policies, along with the organization of services, are more closely aligned with the values, needs and preferences of patients and their informal/family caregivers.

Many promising initiatives are currently underway,  
but bringing about change takes time, resources  
and commitment from many players

There have been some promising steps taken by governments at all levels, as well as by researchers, to improve access to palliative care in Ontario and across Canada. These efforts aim to improve, for example, the quality of palliative care, education and training for healthcare providers, public information and awareness, research and surveillance, and also to share best practices in palliative care. However, efforts of this kind take time, resources and commitment from many players to bring about change. The box above (continued from page 12) provides a list of a few recent initiatives.





We have selected three options (among many) for which we are seeking your input.

## Options:

### How can we address the problem?

>> To promote discussion about the pros and cons of potential solutions, we have selected three options for improving access to palliative care in Ontario.

Many options could be selected as a starting point for discussion. We have selected three options (among many) for which we are seeking public input:

- 1) improving public awareness about palliative care;
- 2) supporting patients and families to navigate the system; and
- 3) engaging the public in the development of a provincial strategy.

The three options do not have to be considered separately. They could be pursued together or in sequence. New options could also emerge during the discussions.

In the following sections, we examine what is known about the pros and cons for each option, by summarizing the findings of systematic reviews of the research literature. A systematic review is a summary of all the studies addressing a clearly formulated question. The authors use systematic and explicit methods to identify, select and evaluate the quality of the studies, and to summarize the findings from the included studies.

Not all systematic reviews are of high quality. We present the findings from systematic reviews along with an appraisal of the quality of each review:

- low-quality reviews: conclusions drawn from these reviews can be applied with a low degree of confidence;
- medium-quality reviews: conclusions drawn from these reviews can be applied with a medium degree of confidence; and
- high-quality reviews: conclusions drawn from these reviews can be applied with a high degree of confidence.

## **Option 1** – Improving public awareness about palliative care

The first option aims to improve public awareness about palliative care in general. It also aims to raise awareness about how palliative care can be beneficial for those with life-limiting chronic conditions.

Greater public awareness could increase early referrals to palliative care for those in need. It could also help raise awareness about the current gaps in services,(14) build commitment for addressing these gaps, and empower the public to advocate for change. For example, this could include advocating for the development of a provincial strategy and for greater support for informal/family caregivers.

One way to improve awareness could be to launch a social marketing campaign about palliative care. Social marketing campaigns use communication strategies to change behaviour or beliefs relating to the acceptability of an idea by a target group in the population. Social marketing campaigns are often used to change health-related behaviours, such as quitting smoking or becoming aware of breast cancer.

We found two systematic reviews (both of medium quality) that examined the effectiveness of social marketing campaigns. The reviews found that social marketing campaigns can be effective in:

- encouraging voluntary health behaviour change;(42;43) and
- bringing about changes in the environment in which we live and in public policies.(43)

We also found that shorter interventions generally achieved larger impacts.(42) In addition, online social marketing campaigns have similar effects to sophisticated print campaigns, but online campaigns have the advantages of reaching more people and lower costs.(42)

## **Option 2 – Supporting patients and families to navigate the system**

The second option aims to support patients and families living with a life-limiting or terminal illness as they ‘navigate’ the health system.

Navigating the healthcare system is a challenge in many sectors. As a provincial report stated: “There are still too many instances where patients don’t know how to access the care they need, don’t know what services are available or are waiting in hospitals until home care or long-term care are available.”(44)

This situation is also true in palliative care. For example, patients and families requiring palliative care will often move from one healthcare provider to another and from one setting to another. They are at risk of ‘getting lost’ in a system that is not fully integrated, which may have important health consequences. A fragmented system also “duplicates efforts, wastes everyone’s time and increases costs.”(45)

One way to improve these transitions could be to introduce ‘health system navigators’ (also known as ‘transition coaches’). A health system navigator is a person who helps patients and families in need of palliative care to access services, guides them through the health system, and helps them overcome barriers they may face. Many people could play this role, including healthcare professionals, trained volunteers or peers (e.g., people from the same culture or community). Navigation programs can also be delivered online.(45)

Health system navigators have knowledge about local services and the broader health system. They also have the capacity to adapt to the changing (and complex) needs of patients and families. They provide constant guidance to patients and families independently of the location of care.

Health system navigation programs have often focused on people with cancer. However, a few recent programs have been established to support specific underserved populations or cultural groups. For example, a program was established for the Chinese-Canadian community in Toronto.(45)

We found two systematic reviews examining the effectiveness of health system navigators. The first is a recent and medium-quality review that examined navigator models relevant to chronic disease management for older adults. The authors found benefits for integrated and coordinated care guided by a navigator, using a variety of interventions such as care plans and treatment goals. A care plan is an agreement between you and your healthcare providers to help you manage your health on a day-to-day basis, with clear and achievable goals. The authors also found that health system navigators could improve satisfaction for both patients and healthcare providers, as well as improve the patients' quality-of-life and functionality.(46)

The second review is an older and low-quality review that examined the effectiveness of navigation programs for cancer patients. The authors found some evidence that navigation programs can increase participation in cancer screening and adherence to follow-up care after the detection of an abnormality.(47)

While health system navigators appear promising, a recent public consultation revealed that Ontarians have mixed feelings about them.(45) Some saw health system navigators as a solution to a system that is poorly organized and integrated. Those who liked the option of navigators suggested that it could be helpful to the following groups: those with very complex care needs; those who may be unable to advocate for themselves; those with limited geographic access to services; and those with communication barriers, language or otherwise.(45)

On the other hand, some saw health system navigators as a “Band-Aid solution” that could create even more levels of bureaucracy. Therefore, they suggested that efforts should be dedicated to improving existing communication and coordination among healthcare providers.(45)

## **Option 3** – Engaging the public in the development of a provincial strategy

The third option aims to create a process for engaging the public and other stakeholders in developing a provincial strategy for end-of-life care. This strategy could set a provincial vision, as well as performance and accountability measures.

Engaging the public could help to ensure that the voices of citizens and those of informal/family caregivers are heard and reflected in the planning and governance of the health system. It could also help to ensure that palliative and end-of-life policies, and the organization of services, are more closely aligned with the values, needs and preferences of patients and their informal/family caregivers.

We found six systematic reviews examining different strategies to engage the public. There is limited evidence about the effectiveness of different types of methods to engage the public in developing healthcare policies,(48-50) in defining priorities and in allocating resources.(51)

However, three reviews found that methods allowing informed discussion among citizens (instead of more traditional methods like surveys and focus groups) can enhance their awareness and understanding about an issue, and also increase their competence for future public engagement activities.(49;52;53)

A recent and medium-quality review concluded that the implementation of a public engagement process can be influenced by many factors. Two key factors are the degree of commitment of the organization putting the process in place, and the types of issues that will be discussed (for instance, some issues are more complex or contentious than others).(53)

## Option 1 – Improving public awareness about palliative care

### Summary of what is known about social marketing campaigns

- Social marketing campaigns can be effective to:
  - encourage voluntary health behaviour change;(42;43) and
  - bring about changes in the environment in which we live and in public policies.(43)
- Shorter social marketing campaigns generally achieved larger impacts.(42)
- Online social marketing campaigns have similar effects to sophisticated print campaigns, but have the advantages of reaching more people and lower costs.(42)
- No systematic review identified negative consequences of social marketing campaigns.

## Option 2 – Supporting patients and families to navigate the system

### Summary of what is known about health system navigators

- Health system navigators appear promising to provide integrated and coordinated care, using a variety of interventions such as care plans and treatment goals.(46)
- Health system navigators could improve:
  - satisfaction for both patients and healthcare providers;(46)
  - the patients' quality-of-life and functionality;(46)
  - participation in cancer screening;(47) and
  - adherence to follow-up care after the detection of an abnormality.(47)
- No systematic review identified negative consequences of health system navigators.

## Option 3 – Engaging the public in the development of a provincial strategy

### Summary of what is known about public engagement

- There is limited evidence about the effectiveness of different types of methods to engage the public in developing healthcare policies,(48-50) in defining priorities and in allocating resources.(51)
- Methods allowing informed discussion among citizens (in contrast with more traditional methods like surveys and focus groups) can:
  - enhance their awareness and understanding about an issue; and
  - increase their competence for future public engagement activities.(49;52;53)
- No systematic review identified negative consequences of public engagement.

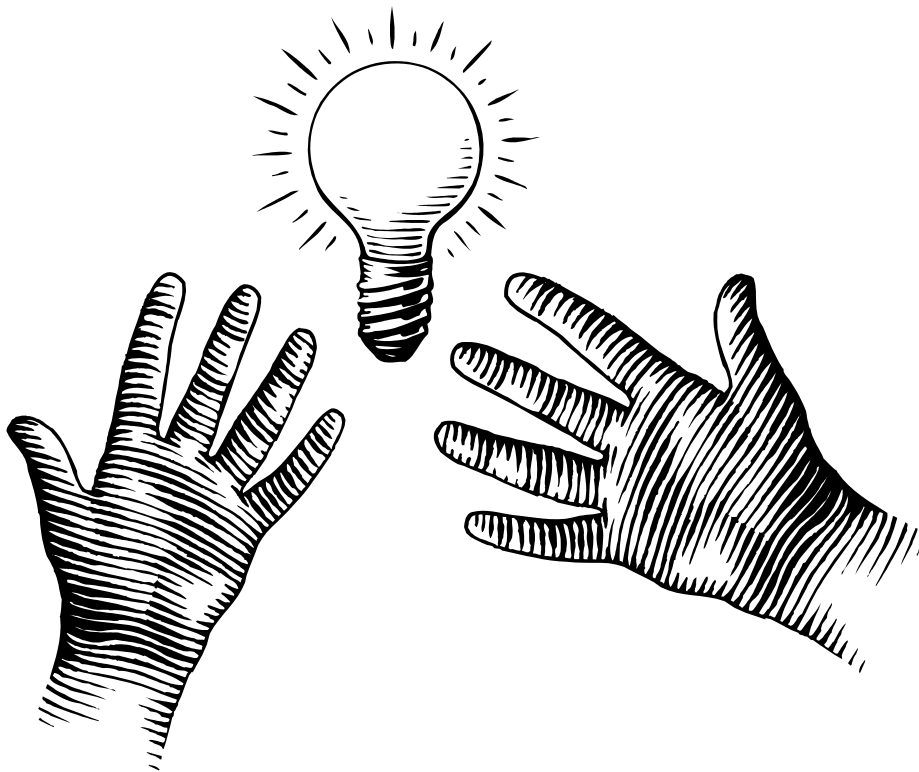


# Implementation considerations

It is important to consider what barriers we may face if we implement the proposed options. These barriers may affect different groups (e.g., patients, citizens, healthcare providers), different healthcare organizations or the health system. While some barriers could be overcome, others could be so substantial that they force us to re-evaluate whether we should pursue that option.

The implementation of each of the three options could also be influenced by the ability to take advantage of potential windows of opportunity. A window of opportunity could be, for example, a recent event that was highly publicized in the media, a crisis, a change in public opinion, or an upcoming election. A window of opportunity can facilitate the implementation of an option.

A list of potential barriers and windows of opportunity for implementing the three options is provided on the following page. This table is provided to spur reflection about some of the considerations that may influence choices about an optimal way forward. We have identified the barriers and windows of opportunity from a range of sources (not just the research literature) and we have not rank ordered them in any way.



### Option 1 – Improving public awareness about palliative care

Barriers	Windows of opportunity
<ul style="list-style-type: none"> <li>• It may be difficult to develop social marketing campaigns that are tailored to the various ethno-cultural communities in the province.</li> <li>• It may be difficult to ensure that a social marketing campaign reaches all those who could benefit, including hard-to-reach groups (e.g., people with limited reading skills or limited access to mass media).</li> </ul>	<ul style="list-style-type: none"> <li>• There is an opportunity to build on past and ongoing initiatives led by the Canadian Hospice Palliative Care Association, such as:               <ul style="list-style-type: none"> <li>○ National Hospice Palliative Care Week (the first week of May each year);</li> <li>○ National Caregiver Day (April 5<sup>th</sup> each year); and</li> <li>○ the Living Lessons initiative [<a href="http://www.living-lessons.org">www.living-lessons.org</a>], an awareness campaign designed to provide tools and resources to patients, families, caregivers, volunteers and healthcare providers.</li> </ul> </li> <li>• There is also an opportunity to build on an international awareness campaign: World Hospice Palliative Care Day [<a href="http://www.worldday.org">www.worldday.org</a>] (second Saturday of October each year)</li> </ul>

### Option 2 – Supporting patients and families to navigate the system

Barriers	Windows of opportunity
<ul style="list-style-type: none"> <li>• Some healthcare providers may be resistant to this new role as it requires a work culture of teamwork.(45)</li> <li>• Health system navigators may have limited capacity to encourage cooperation (particularly when they are peer navigators).(45)</li> </ul>	<ul style="list-style-type: none"> <li>• The government of Ontario released an action plan for healthcare in 2012, which identified the need to improve patient transition from one setting to another as a government priority.(44)</li> <li>• The Local Health Integration Networks and many other healthcare organizations are committed to improving transitions of care.</li> </ul>

### Option 3 – Engaging the public in the development of a provincial strategy

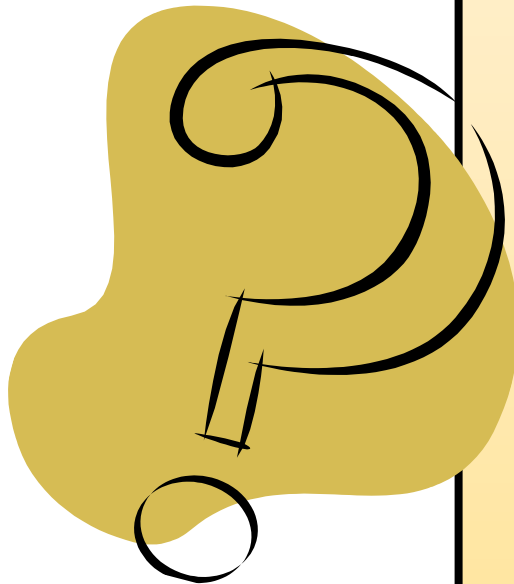
Barriers	Windows of opportunity
<ul style="list-style-type: none"> <li>• Some citizens may be frustrated by past citizen-engagement efforts which have not meaningfully influenced policies, programs and services.</li> <li>• Some individuals and organizations may try to broaden the issue to contentious moral and legal issues (e.g., assisted suicide, euthanasia), or to frame 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).</li> </ul>	<ul style="list-style-type: none"> <li>• 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.(54)</li> <li>• There is an opportunity to build on past and ongoing initiatives that have brought together numerous organizations to develop common visions, guiding principles, and tangible actions to improve access to palliative care.(11)</li> </ul>

# Questions for the citizen panel

>> We want to hear your views about the problem, the three options for addressing it, and how we can move forward.

This brief was prepared to stimulate the discussion during the citizen panel. The views, experiences and knowledge of citizens can make a great contribution in finding viable solutions to the problem.

More specifically, the panel will provide an opportunity to explore the following questions outlined in the box on the right. Although we will be looking for common ground during these discussions, the goal of the panel is not to reach consensus, but to gather a range of perspectives on this topic.



>> What are the most important challenges faced for improving access to palliative care in the province?

>> What are your views about the three proposed options?

**Option 1** – How can we raise public awareness about palliative care and its broader role in chronic disease management?

**Option 2** – What would citizens need to feel appropriately equipped to navigate the system?

**Option 3** – What role could citizens play in the development of a provincial strategy and how would they do that?

>> What are potential barriers and windows of opportunity to implement these three options?

# Acknowledgments

## Authors

François-Pierre Gauvin, PhD, Lead, Evidence Synthesis and Francophone Outreach, McMaster Health Forum  
Julia Abelson, PhD, Adjunct Faculty, McMaster Health Forum, and Professor, McMaster University  
John N. Lavis, MD, PhD, Director, McMaster Health Forum, and Professor, McMaster University

## Funding

The citizen brief and the citizen panel it was prepared to inform were funded by McMaster University's Labarge Optimal Aging Initiative and by the Government of Ontario (through a Ministry of Health and Long-Term Care Health System Research Fund grant entitled Harnessing Evidence and Values for Health System Excellence). The McMaster Health Forum receives both financial and in-kind support from McMaster University. The views expressed in the citizen brief are the views of the authors and should not be taken to represent the views of the Government of Ontario, McMaster University, or McMaster University's Labarge Optimal Aging Initiative.

## Conflict of interest

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

## Merit review

The citizen brief was reviewed by a small number of citizens, other stakeholders, policymakers and researchers in order to ensure its relevance and rigour.

## Acknowledgements

The authors wish to thank Amanda Chen for assistance with reviewing the research evidence about the options, Sue Johnston for assistance with editing, Julia Olesiak for graphic design and photography, and Julie Baird for formatting of this brief. We are grateful to Steering Committee members and merit reviewers for providing feedback on previous drafts of this brief. We are especially grateful to Michael Wilson for his insightful comments and suggestions. The views expressed in this brief should not be taken to represent the views of these individuals.

## Citation

Gauvin FP, Abelson J, Lavis JN. Citizen Brief: Improving Access to Palliative Care in Ontario. Hamilton, Canada: McMaster Health Forum, 16 November 2013.

## ISSN

2292-2326 (Print)

2292-2334 (Online)

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