McMaster
University

McMaster
HEALTH FORUM

PANEL SUMMARY

IMPROVING ACCESS TO PALLIATIVE CARE IN ONTARIO

16 NOVEMBER 2013

EVIDENCE >> INSIGHT >> ACTION

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 regional/provincial levels 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 views 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 summary

On 16 November 2013, the McMaster Health Forum convened a citizen panel on how to improve access to palliative care in Ontario. The purpose of the panel was to guide the efforts of the Ontario Medical Association in promoting the development of a provincial strategy to improve care at the end of life, including access to palliative care. This summary highlights the views and experiences of panel participants about:

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

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

Table of Contents

Summary of the panel

Panel participants began by reviewing the findings from the pre-circulated citizen brief, which highlighted what is known about the underlying problem – shortfalls in access to high-quality palliative care in Ontario – and its causes. They individually and collectively focused on six challenges in particular: 1) a lack of public awareness about what 'palliative care' is; 2) the stigma associated with the term 'palliative care'; 3) an aging population and its anticipated strain on the health system; 4) a lack of support for family and informal caregivers who provide palliative care at home; 5) the potential costs involved in accessing high-quality palliative care; and 6) a lack of public accountability for ensuring access to palliative care.

After discussing the challenges, participants were invited to reflect on three options (among many) for improving access to palliative care in Ontario. The idea of launching social-marketing campaigns about palliative care (option 1) strongly resonated with panel participants, many of whom had expressed concerns earlier in the discussion about the lack of public awareness about palliative care. Implementing health-system navigators (option 2) was generally new to most participants and generated a lot of interest as a way to alleviate the burden on the shoulders of patients and families, especially if the health-system navigators have broad knowledge of the health system, and the leadership and skills to advocate for them. Participants saw the value of engaging the public, both in the development of a provincial strategy (option 3), and_also for designing public-awareness campaigns. The discussion made clear the need to carefully sequence these options in the following order: options 2, 1 and 3. Participants pointed out that establishing health-system navigators was seen as crucial before launching public-awareness campaigns that could generate greater demands for palliative care. Participants also worried that it may be difficult to achieve meaningful and large-scale public engagement for the development of a provincial strategy, given the current lack of public awareness regarding palliative care.

When turning to potential barriers and facilitators to moving forward, participants focused on the need to nurture a grassroots movement that could raise awareness and create a sense of urgency for improving access to high-quality palliative care in the province. These efforts could contribute to creating the 'burning platform' necessary to advance this important agenda.

> "I didn't have the term 'palliative care' back then. Having had that experience before [i.e., participating in this citizen panel], it would have changed things."

Discussing the problem:

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

Panel participants began by reviewing the findings from the pre-circulated citizen brief, which highlighted what is known about the underlying problem – shortfalls in access to high-quality palliative care in Ontario – and its causes. They individually and collectively focused on six challenges in particular:

- a lack of public awareness about what 'palliative care' is;
- the stigma associated with the term 'palliative care';
- an aging population and its anticipated strain on the health system;
- a lack of support for family and informal caregivers who provide palliative care at home;
- the potential costs involved in accessing high-quality palliative care; and
- a lack of public accountability for ensuring access to palliative care.

We review each of these challenges in turn below.

A lack of public awareness about what 'palliative care' is

The discussion initially focused on the limited public awareness about what palliative care is, when it is appropriate, where it is provided, and by whom.

Many participants were surprised by the broad definition of palliative care provided in the citizen brief, which includes four components: pain management; symptom management; social, psychological, emotional and spiritual support; and caregiver support. Several participants shared the view that palliative care is perceived more narrowly by the public as a type of medical care focused on managing pain and symptoms.

Many participants were unaware that palliative care was appropriate soon after the diagnosis of a serious health condition, not just when someone is approaching death. Also, several participants indicated that prior to the citizen panel they perceived palliative care as a type of care that could only be provided in a limited number of settings like hospitals and nursing homes, and by a limited number of healthcare providers such as doctors. As one participant summarized it: "I was unaware that these options were out there."

Box 1: Key features of the citizen panel

The citizen panel about improving access to palliative care in Ontario had the following 11 features:

1. it addressed a high-priority issue in Ontario;
2. it provided an opportunity to discuss different features of the problem;
3. it provided an opportunity to discuss three options for addressing the problem;
4. it provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. it provided an opportunity to talk about who might do what differently;
6. it was informed by a pre-circulated, plain-language brief;
7. it involved a facilitator to assist with the discussions;
8. it brought together citizens affected by the problem or by future decisions related to the problem;
9. it aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. it aimed for open and frank discussions that will preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

Participants suggested that not knowing enough about palliative care was a fundamental obstacle to requesting and accessing it. One participant who provided care to a loved one with a terminal illness mentioned that, had he known then what he knows now, he would have requested palliative-care services: "I would have a slightly different perspective now. I didn't have the term 'palliative care' back then. Having had that experience before [i.e., participating in this citizen panel], it would have changed things."

The stigma associated with the term 'palliative care'

While discussing the lack of public awareness about palliative care, participants also talked about the stigma associated with the term palliative care, which is perceived as being strongly associated with death. A few participants argued that some might even fear that talking about palliative care (or requesting palliative-care services) might hasten death. As one participant emphasized, palliative care must be promoted and celebrated as a form of love, kindness and comfort offered to those in need, and thus it shouldn't be feared.

An aging population and its anticipated strain on the health system

The increasingly aging population (and its anticipated strain on the health system) was an important source of concern that many participants indicated had motivated them to join the citizen panel. Many panel participants were concerned about their aging relatives and their ability to have timely access to the high-quality care that they may need, especially in their last days, weeks or months of life (e.g., home support, caregiver support). Many participants expressed a particular concern that aging family members may be increasingly vulnerable because they are often too proud to ask for assistance. They also noted their worry that frail older adults are increasingly living alone with limited extended family, and they are thus at greater risk of being left on their own in times of need.

A lack of support for informal and family caregivers who provide palliative care at home

A third key challenge to improving access to palliative care was the lack of support currently offered to informal and family caregivers, especially those who provide palliative care at home. Several participants expressed the wish of dying at home, surrounded by their loved ones. These participants called for greater access to palliative care at home, especially in the context of highly publicized events where patients in nursing homes and other healthcare settings were neglected or received poor care. As one participant noted: “I had a lot of bad reports of nursing homes. I want to die at home with my family. I’d like to avoid that [going to a nursing home]. I’d like to see palliative care provided at home, or close to home.”

Another participant argued that many people have an idealized vision of palliative and end-of-life care at home, and often downplay (or ignore) the burden on informal and family caregivers: “Caregivers’ burden is important and they don’t know how much work this is. They often can’t afford it. It creates tensions. It’s worse than a newborn. It’s 24 hours a day, 7 days a week. It’s a stressful environment. There is a loss of dignity. Some caregivers are running out.” Another participant spoke of “family fractures” created by the stress and anxiety of providing palliative care at home.

Box 2: Profile of panel participants

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants:

- **How many participants?**
  10
- **Where were they from?**
  Region covered by the Hamilton Niagara Haldimand Brant Local Health Integration Network
- **How old were they?**
  18-24 (2), 25-44 (3), 45-64 (2), 65 and older (3)
- **Were they men, or women?**
  men (5) and women (5)
- **What was the educational level of participants?**
  10% completed elementary school, 40% completed high school, 20% completed community college, 10% completed technical school and 20% completed a bachelor’s degree/post-graduate training or professional degree
- **What was the work status of participants?**
  10% self-employed, 20% working full-time, 10% unemployed, 40% retired, 10% students, and 10% homemakers
- **What was the income level of participants?**
  30% earned less than $20,000, 40% between $20,000 and $40,000, 10% between $40,000 and $60,000, 10% between $60,000 and $80,000, and 10% more than $80,000
- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panel

The potential costs involved in accessing high-quality palliative care

A fourth key challenge to improving access to palliative care that emerged during the discussion was the economic burden for informal and family caregivers, especially the costs of palliative care associated with home-based services (e.g., medications, equipment and personal care services). One participant asked: "What if someone doesn't have the money or insurance?" A second participant also shared his concerns about the potential costs of palliative care: "I'm self-employed, so the financial issue is worrying. I don't work, I don't get paid."

Many participants agreed with the individual who noted that "everybody should be entitled to get it [palliative care]." However, some wondered to what extent access to palliative care, especially 'high-quality' palliative care, could be compromised if someone was lacking financial resources. A participant, who discussed the issue with a group of seniors before coming to the citizen panel, argued that the costs (either real or perceived) were a source of concern for many people: "I've asked a few senior people about access to palliative care and they said: 'we've heard of it, how much is it gonna cost?'." Other participants were concerned that, if access to high-quality and home-based palliative care was influence by someone's ability to pay, this could exacerbate health inequalities. One participant noted: "I would have thought that it would be harder to access for people from lower social classes." A second participant acknowledged that perception and added that "riches get you better care." A third participant worried that disadvantaged people may "die anonymously in hospitals" because they could not afford home-based, palliative-care services.

A lack of public accountability for ensuring access to palliative care

A fifth challenge that emerged during the discussion was a perceived lack of public accountability for ensuring access to palliative care. Although several participants praised the efforts by governments at various levels, some were skeptical about the government's commitment and capacity to sustain and bring about change. One participant noted: "The biggest challenge is that government is too slow. Every provincial government has made promises that they couldn't [keep] up with." A second participant noted that "funding is inconsistent" and "laws are always changing." A third participant suggested that while "certain groups of people benefit from [palliative care] policies and programs, these [seem to] fail a lot of people." Participants generally agreed with the need to have greater public accountability at the level of policymakers, health system managers and healthcare providers regarding access to palliative care in the province. As one participant put it: "Accountability is important [...] right from the bottom and at each level."

> “If you want to get the public behind something, you need to have a cause.”

Discussing the options:

How can we address the problem?

After discussing the challenges that together constitute the problem, participants were invited to reflect on three options (among many) for improving access to palliative care in Ontario:

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 can be pursued together or in sequence. A description of these options, along with a summary of the research evidence about them, was provided to participants in the citizen brief that was circulated before the event.

Option 1 – Improving public awareness about palliative care

The discussion about the first option focused on ways to raise public awareness about palliative care, with a specific focus on social-marketing campaigns. This option was originally selected because 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, build commitment for addressing these gaps, and empower the public to advocate for change.

Box 3: Key messages about improving public awareness (option 1)

What are the views of participants regarding this option?

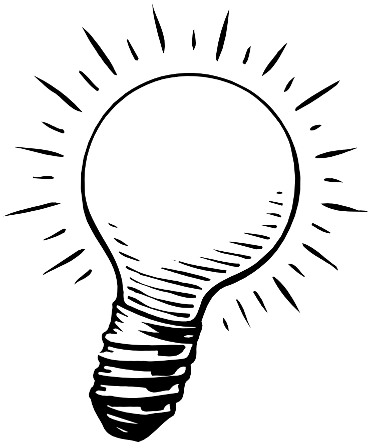
- Raising awareness on this topic will be challenging because the term 'palliative care' is complex and there is a stigma associated with it
- Many audiences could be targeted, but participants generally agreed that middle-aged adults who are likely to provide palliative care to their aging parents would be a key audience
- Many channels could be leveraged to raise awareness about palliative care (including those outside the health system and families with lived experience), but reaching the most vulnerable will be challenging
- Citizens may be more receptive to public-awareness campaigns led by authoritative and trustworthy voices (e.g., Ontario Medical Association, other healthcare provider associations, and grassroots movements)

This option strongly resonated with panel participants, many of whom had expressed concerns earlier in the discussion about the lack of public awareness about palliative care. Participants initially focused on the challenge of raising public awareness, especially for those who are not already affected by palliative-care-related problems. One participant mentioned that the general public may not be receptive to a public-awareness campaign if they are not affected by the problem and actively looking for information: "If I'm not looking for it [i.e., information on palliative care], I'm not going to find it." Other participants emphasized that the expression 'palliative care' may be hard to sell. For some, the expression 'palliative care' may not be familiar: "It doesn't mean anything to me… [It takes time to] absorb what the words mean." For others, the expression may be too strongly associated with death. Thus, a public-awareness campaign on palliative care would be "tricky" because you need to "remove the fear" or "stigma" attached to it. Some participants suggested that efforts to frame the message should focus on "help rather than death," that "palliative care is out there," or that it was important for people to be prepared for the "inevitable." As one participant noted, "you're not marketing death, you're marketing counsel."

Participants debated who should be the target audiences for such a public-awareness campaign, and what channels could be used to reach these audiences. Some participants argued that it could be relevant to target a younger audience to "teach them about their aging parents," [and grandparents]. However, some participants did not see the value of targeting younger audiences on this topic: "It's probably not the demographic group you want to reach. It's probably more those in their 30s and 40s." Most participants generally agreed about the value of targeting middle-aged adults who are likely to provide palliative care to their aging parents, and who could thus advocate for improving access to palliative care.

Participants mentioned many channels that could be leveraged to raise awareness about palliative care, such as advertising in social media, healthcare facilities, public places (e.g., shopping malls and bathroom stalls), and in announcements or advice from faith-based organizations, funeral and estate planners who are "already talking about death", and lawyers who prepare wills. Participants also mentioned that families who are affected by chronic health conditions and terminal illnesses, especially those benefiting from palliative care, could play a powerful role in raising public awareness.

One participant cautioned that not all channels may be effective in raising public awareness. For instance, this participant mentioned that fewer people are watching conventional television, and that people could easily skip ads on YouTube. This participant was also concerned about reaching the most vulnerable groups who may not have access to television or the Internet: "Realistically, we are lower incomes. We have basic commodities. What would be best to reach me?"



Lastly, the discussion focused on who should be leading such a public-awareness campaign. Some participants argued that the Ontario Medical Association and other healthcare-provider associations may be in a great position to launch such a campaign because they are perceived as authoritative and trustworthy. One participant noted the following: "We trust the doctors, not the politicians." A second participant agreed and added that family physicians were ideal to convey public-awareness messages: "[People] listen to their family doctors. They pay more attention to them."

Option 2 – Supporting patients and families to navigate the system

The discussion about the second option focused on what citizens would need in order to feel appropriately equipped to navigate the system, and especially on the value of health-system navigators (i.e., people who help patients and families in need of palliative care to access services, guide them through the health system, and help them overcome any barrier they may face). This option was originally selected to address the challenges of accessing care in a complex and fragmented health system. 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.

The concept of a health-system navigator was generally new to most participants and generated a lot of interest. As one participant noted: "I've never heard of system navigators… that's awesome." One participant saw the health-system navigator as crucial to alleviate the burden on the

Box 4: Key messages about providing support to navigate the system (option 2)

What are the views of participants regarding this option?

- The concept of a 'health-system navigator' is novel and participants could see its value in alleviating the burden on patients and families
- A health-system navigator should have certain 'qualities,' such as having a healthcare background to provide valid information and guidance, but also leadership skills to advocate for patients and families
- Various types of a navigation system could be helpful (e.g., face-to-face or online systems), but some citizens would feel more equipped if it is linked with Telehealth Ontario

shoulders of patients and families: “It’s hard for people to find the resources out there. Removing the stress of making that first step is important.”

Participants generally agreed that doctors and nurses are probably “too overworked” to take on this new role. They then discussed what skills such a navigator should have, or as one participant described as “the quality of the navigator.” Participants envisioned someone with “some health background” who could “sit down with them, talk to them, and help them” with valid information and guidance. A few participants also recommended someone with influence and leadership skills who could advocate for them.

The discussion then focused on how patients and families should be able to connect with a health-system navigator. Many envisioned the health-system navigator as offering services in a face-to-face setting. However, most participants were unaware if many healthcare organizations, and especially family practices, in the province currently offer a system navigation role. Other participants suggested that a health-system navigator role could be centralized and offered via telephone or the Internet. A few participants felt that they would be more equipped to navigate the system if the navigator role was linked to Telehealth Ontario (the free and confidential telephone service you can call to get health advice or general health information from registered nurses). A few other participants also mentioned that they would be comfortable with an online navigator. As one participant mentioned: “I would appreciate a system navigator online, for dummies, a basic website, [where you could indicate] your issue than here’s the contact. Something that I don’t need a PhD to understand.”

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

The discussion focused to a lesser extent on the third option, which examined the role that citizens could play in the development of a provincial strategy. This option was originally selected given the Ontario Medical Association's efforts to promote the development of a provincial end-of-life care strategy. Such a strategy could set a provincial vision as well as performance and accountability measures. Engaging the public could help to ensure that palliative-care policies and the organization of services are more closely aligned with the values, needs and preferences of patients and their informal/family caregivers.

A few participants saw the value of engaging the public, either for the development of a provincial strategy or for designing the public-awareness campaign. As one participant noted: "I'd like to see the real people talk about it." However, participants were unsure about the most effective mechanism to engage the public.

Box 5: Key messages about engaging the public in the development of a provincial strategy (option 3)

What are the views of participants regarding this option?

- There is value in engaging the public in developing a strategy or a public-awareness campaign, but participants were unsure about the most effective way to do this

Lastly, when considering the full array of options, participants emphasized that it would be important to sequence the three options appropriately. These participants argued that it would be more fruitful to first focus efforts on establishing a health-system navigator role where people can get information and guidance (option 2), before launching a public-awareness campaign that could generate greater demands for palliative care (option 1). In addition, participants also worried that it may be difficult to achieve meaningful and large-scale public engagement (option 3), given the current lack of public awareness regarding palliative care. As one participant emphasized: "If you want to get the public behind something, you need to have a cause…" This participant went further and argued that you need a cause that creates passion: "Unless it pertains to us, you're not going to get a real public response." In terms of sequencing, this means that option 2 likely needs to precede options 1 and 3.

"We have to face the reality that this could happen at any age [i.e., the need for palliative care]. We have to face it. It's inevitable."

Discussing implementation considerations:

What are the potential barriers and facilitators to implement these options?

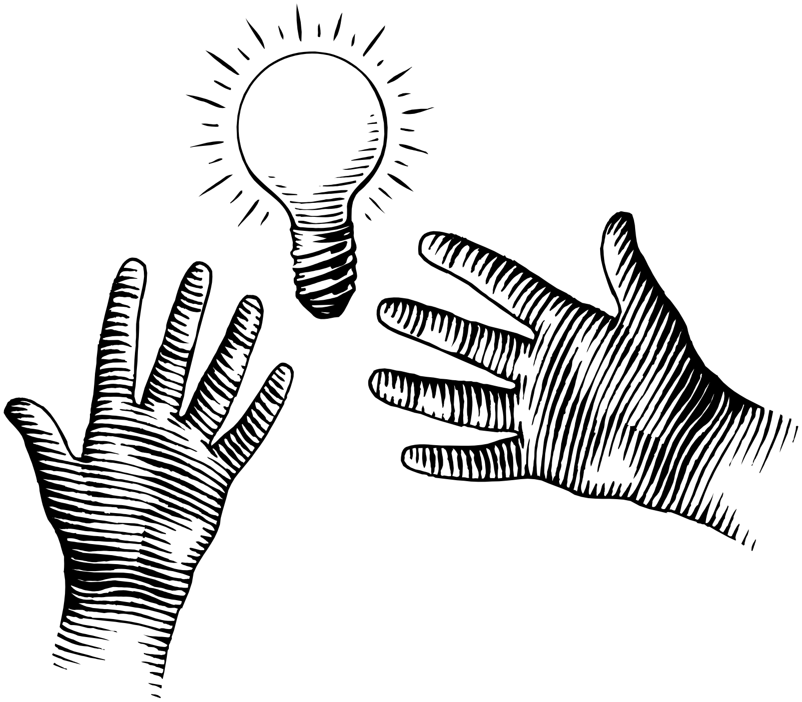
After discussing the three options (among many) for improving access to palliative care in Ontario, participants examined potential barriers and facilitators for moving forward.

The discussion generally focused on the lack of awareness as one of the most fundamental obstacle for moving forward (i.e., awareness about what palliative care is and about existing programs and services). Participants said that the citizen panel greatly enhanced their awareness about palliative care and nurtured a greater sense of urgency about the need to improve access to high-quality palliative care in Ontario. One participant expressed this in the following way: "We have to face the reality that this could happen at any age [i.e., the need for palliative care]. We have to face it. It's inevitable."

When turning to potential facilitators to moving forward, participants suggested that the experiences of two very popular grassroots movements could inspire us: Movember (the annual event involving the growing of moustaches during the month of November to raise awareness about men's health issues, such as prostate cancer) and Pink Ribbon (the campaign to raise awareness about breast cancer). Participants praised these two campaigns as being able to mobilize the public from all ages and all walks of life. Health system stakeholders involved in the palliative-care field should emulate these experiences or, as one participant suggested, they should rely on experts to better brand or sell 'palliative care': "There are clever marketing people who could get the word out there."

Conclusion

As the citizen panel concluded, participants expressed the need to create a 'burning platform' to advance this agenda and were enthusiastic that the Ontario Medical Association (OMA) was willing to play a greater role in addressing this problem. One participant urged the OMA to spearhead a public-awareness campaign: "Find someone in your organization to spearhead this. Don't wait for government. Don't make it a political thing. You have the brain power to do it. Then create the campaign, find the face for this campaign, and talk about it." Another participant agreed, but encouraged the OMA to do this in a collaborative way: "Do it. Get the word out. Doctors [shouldn't] be territorial about [this] stuff." Lastly, one participant was happy that this discussion generated a lot of ideas that could fuel a burning platform, but this participant invested a lot of hope in the capacity of the OMA to start the fire: "We have lay knowledge. You guys can start it.



Acknowledgments

Authors

François-Pierre Gauvin, PhD, Lead, Evidence Synthesis and Francophone Outreach, McMaster Health Forum
Julia Abelson, PhD, Faculty, McMaster Health Forum, and Professor, McMaster University
John N. Lavis, PhD, Director, McMaster Health Forum, and Professor, McMaster University
Camilla Tapp, Co-op Analyst, Marketing and Communications, McMaster Health Forum

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 goal of this initiative is to guide the efforts of the Ontario Medical Association and other provincial organizations to promote the development of a provincial end-of-life care strategy. The views expressed in the panel summary are the views of panel participants and should not be taken to represent the views of the Government of Ontario, Ontario Medical Association, McMaster University, McMaster University's Labarge Optimal Aging Initiative, or the authors of the panel summary.

Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the panel summary. The funder reviewed a draft panel summary, but the authors had final decision-making authority about what appeared in the panel summary.

Acknowledgements

The authors wish to thank the entire McMaster Health Forum team for support with project coordination, as well as for the production of this panel summary. We are especially grateful to all the participants of the citizen panel for sharing their views and experiences on this pressing health system issue.

Citation

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

ISSN

2368-2116 (Print)
2368-2124 (Online)

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