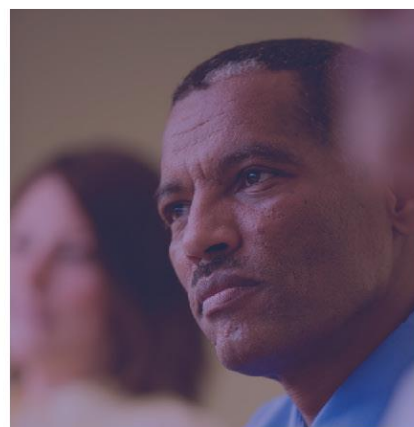


## IMPROVING END-OF-LIFE COMMUNICATION AND DECISION-MAKING IN ONTARIO



30 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 November 30, 2013, the McMaster Health Forum convened a citizen panel on how to improve end-of-life communication and decision-making 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. 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 identifies (where possible) the values underlying different positions.

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# Summary of the panel

Panel participants discussed the shortfalls in communicating wishes for end-of-life care and in making decisions about end-of-life care in Ontario, as well as the causes of these shortfalls. In particular they focused on four challenges: 1) few people engage in end-of-life conversations with their families and friends; 2) there are uncertainties about which healthcare professionals they could/should talk to; 3) ‘advance care planning’ is new to most people; and 4) there are risks of communication breakdowns.

After discussing the underlying problem, participants were invited to reflect on three options (among many) for improving end-of-life communication and decision-making in Ontario: improving public awareness about end-of-life care (option 1); engaging citizens in a province-wide dialogue to encourage open discussions about end-of-life care (option 2); and providing citizens with the information and tools they need to engage in advance care planning (option 3). Several values-related themes emerged during the discussion, which include: people-, family-, and community-centredness (awareness campaigns and a province-wide dialogue should be attuned to their needs and values); shared responsibility (to get the conversation going); collaboration (between the health system and other sectors to get the message out); privacy (someone’s wishes for end-of-life care are private and should not be debated in public); empowerment (access to information and tools about advance care planning); and credibility (of those who develop and endorse information and tools). When considering the full array of options, participants preferred options 1 and 3, but felt that option 3 should precede option 1.

When turning to potential barriers and facilitators to moving forward, participants argued for the need to use good branding in public awareness campaigns to ensure that professional associations, charities and other stakeholders come on board. In addition, participants generally agreed that prevailing views in the population are changing. They perceived that more people are gradually becoming comfortable about engaging in end-of-life conversations with their families and friends, in part due to the desire for greater control over the last stage of their life, and the desire to have peace of mind, but also because people are paying greater attention to quality of life, not just longevity.



“A lot of times things that crop up as problems are really nothing more than a failure to communicate.”

## **Discussing the problem:**

What are the most important challenges to improving end-of-life communication and decision-making in the province?

Panel participants began by reviewing the findings from the pre-circulated [citizen brief](#), which highlighted what is known about the problem – challenges in communicating wishes for end-of-life care and making decisions about end-of-life care in Ontario – and its causes. In particular they focused on four challenges, which gave them the opportunity to begin to articulate the values underlying their positions on this topic:

- few people engage in end-of-life conversations with their families and friends;
- there are uncertainties about which healthcare professionals they could/should talk to;
- ‘advance care planning’ is new to most people; and
- there are risks of communication breakdowns.

We review each of these challenges in turn below.

## Few people engage in end-of-life conversations with their families and friends

Panel participants generally agreed that few people engage in end-of-life conversations with their families and friends, which was a challenge identified in the citizen brief. Participants pointed out four underlying reasons for why people may shy away from such conversations: 1) people are in denial about death; 2) end-of-life (and end-of-life care more specifically) is a very personal issue and people may not be inclined to talk openly about it; 3) end-of-life conversations may generate fear among some people; and 4) certain ethno-cultural communities may be less inclined to talk openly about end-of-life issues. Each of these reasons is further discussed below.

First, participants pointed out that a lot of people are in denial about death. The source of such denial may vary from one individual to another. As one participant noted, many people are focused on the here and the now: “For them, it’s just not going to happen any time soon. I don’t have to deal with it right now, and if it happens, *c’est la vie*. Nobody cares in a sense.” A second participant agreed and mentioned that such denial is the reason why it’s particularly challenging to get young people to talk about these issues:

### **Box 1: Key features of the citizen panel**

The citizen panel about improving end-of-life communication and decision-making 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.



“The biggest barrier is getting people – not just old people, but young people – involved as well.” A third participant suggested that some people may also be in denial because they are not emotionally equipped to cope with the questions that end-of-life conversations may raise: “A lot of people can’t handle the questioning.”

Second, participants emphasized that end-of-life (and end-of-life care more specifically) is a very personal issue. Therefore, many people may simply be uncomfortable talking about it openly, even with their families and friends.

Third, participants emphasized that end-of-life conversations may generate different types of fear. For example, some people may shy away from end-of-life conversations out of fear that it may precipitate terrible events. As one participant noted, people are afraid to express their wishes for end-of-life care with their friends and families, especially when they are healthy: “We’re not going to talk about this or it will happen.” Others argued that people with life-limiting illnesses (as well as their friends and families) may be reluctant to engage in end-of-life conversations because it may signal that they are giving up hope. As one participant noted: “As long as there is hope, death isn’t an option. ... There’s no need to accept it until it is the only option, and I guess people have different degrees of what to consider an option.” A second participant argued that this fear of giving

## 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?**

9

- **Where were they from?**

Across the province of Ontario

- **How old were they?**

18-24 (3); 25-44 (2); 45-64 (3) and 65 and older (1)

- **Was there a balance between men and women?**

Men (6) and women (3)

- **What was the educational level of participants?**

11% completed elementary school, 22% completed community college, 11% completed technical school and 56% completed a bachelor’s degree/post-graduate training or professional degree

- **What was the work status of participants?**

11% self-employed, 67% working full-time, 11% unemployed, and 11% retired

- **What was the income level of participants?**

11% earned less than \$20,000, 22% between \$20,000 and \$40,000, 11% between \$40,000 and \$60,000, 33% more than \$60,000 and 22% preferred not to answer

- **How were they recruited?**

Selected based on explicit criteria from the AskingCanadians™ panel

up hope was partially fuelled by the media: “The media glorifies the fight: doing everything to fight the process [of dying]. ‘*He didn’t stop trying, he pushed, he’s a fighter*’ – this is why it’s hard for people to see that it’s not necessarily giving up as other people would see it.”

Lastly, a few participants emphasized that certain ethno-cultural communities deal with end-of-life in very different ways and may be less inclined to talk about it openly. As one participant noted: “In the Indian community, this topic is not discussed. If it happens you just deal with it.” Other participants agreed that it was a culturally sensitive topic and that it was a challenge to encourage end-of-life conversations given the multicultural landscape of Ontario.

## There are uncertainties about which healthcare professional they could or should talk to

Participants then turned to the second challenge discussed in the citizen brief: few people engage in end-of-life conversations with healthcare professionals. While participants generally agreed with this observation, they pointed out that most people are probably unsure about who they could or should talk to. Participants wondered who has the time to engage in such conversations (especially with healthy patients) and who has the expertise to discuss end-of-life care issues.

The discussion focused on the potential role of family physicians (what many citizens continue to call general practitioners or GPs), who are the first point of contact that most people have with the health system. Participants argued that family physicians (for the few who had access to them) were probably not in the best position to engage in end-of-life conversations. Three reasons emerged that may explain this perception: 1) several participants expressed that they do not have a good rapport with their family physician, or at least the kind of rapport that would allow such conversations to take place; 2) participants generally perceived that family physicians lack expertise in this area; and 3) participants seem generally more inclined to engage in conversations with healthcare providers who deliver end-of-life care. These reasons are discussed in turn below.

First, several participants expressed that they do not have a good rapport with their family physician. For instance, several participants mentioned that they rarely see their family physicians and have not developed a close enough relationship with them to facilitate end-of-life conversations. As one participant noted: “How often do you really see your doctor? It’s a personal issue, discussing [end-of-life care] wishes. They know my body, they know my health, but they are not involved in my life on a daily basis. So, I wouldn’t want them to



[play a role in end-of-life care decisions with me].” A second participant agreed: “I don’t think I have that type of rapport with my GP. People who see me on a regular basis know what my life entails. If you were to see a specialist for a chronic disease, it’s good to ask advice on how they feel treatment may or may not benefit you. At the end of the day, it’s your decision. So, I feel that you should talk to people involved in your day-to-day life.” Other participants also mentioned that the 10- or 15-minute appointments are not conducive to conversations on such a sensitive issue. As one participant noted: “You might have 10 minutes with your doctor. They don’t have time to listen to your story and advise you. It’s one after the other. They don’t have time. You can only bring up X number of things.”

Second, participants were also concerned that family physicians may not have enough experience to advise people on end-of-life care issues. As one participant noted: “What is the point or value in speaking with the GP if they don’t have experience with advanced [medical] specialties?” Nevertheless, some participants saw family physicians as a gateway to other specialists: “If they’re not ready to help you themselves, they can point you in the direction of those who can.”

Third, since the hospital is often the default option for end-of-life care, many participants believe that family physicians are not likely the ones who will deliver end-of-life care. Thus, they did not see the value of engaging in end-of-life conversations with them. As one participant noted: “[It’s] not likely to be your GP who sees you in the hospital and oversees your treatment. When you get diagnosed with these things, it’s the specialist I want to see and talk to about these things.” A second participant added: “The GP is in his office. He is never going to come to the hospital to look after me. So, I’m not sure if he’s the best one to talk about this.”

While participants were skeptical about the potential role of family physicians in end-of-life conversations, they clearly saw the value of engaging in conversations with healthcare providers with expertise in palliative and end-of-life care: “The specialist is aware of these things. He deals with them day in and day out.” However, they were still unsure who these healthcare providers should be.

## Advance care planning is new to most people

The third challenge that emerged during the discussion also resonated with a challenge listed in the citizen brief: most people are not aware of ‘advance care planning.’ Participants mentioned that people are increasingly aware of Power of Attorney for Personal Care, but were not aware there was a process called ‘advance care planning’ to encourage and support

reflection and discussion about their wishes for end-of-life care. Participants generally saw the value of advance care planning, but some saw its full potential when it was done concurrently with the Power of Attorney for Personal Care. As one participant noted, you may express your wishes for end-of-life care, but if you haven't appointed a substitute decision-maker, you may end up with the wrong person making decisions on your behalf. "It's a good idea making these arrangements before because you may be stuck with someone making these decisions who you don't want."

The idea that a person and his/her substitute decision-maker should be prepared to make difficult decisions, and be at peace with the decisions made, also emerged as an important reason to engage in advance care planning. "If you didn't talk about it to anyone, that person [the substitute decision-maker] may live with the guilt and anxiety. 'Did I make the right choice?'"

## There are risks of communication breakdowns

The fourth challenge that emerged from the discussion is that people are concerned about potential communication breakdowns. In other words, they are worried about the lack of availability (or knowledge) of existing advance care plans and expressed wishes for end-of-life care, which was another challenge listed in the citizen brief. One participant noted that healthcare providers and substitute decision-makers should follow any known wishes. "The issue is, how do we know?"

Several participants regretted that there was no system currently in place where advance care planning documents could be stored (e.g., an electronic health record). Such a system could be accessible to substitute decision-makers, but also could inform healthcare providers that a patient has expressed wishes for end-of-life care and appointed a substitute decision-maker. A few participants mentioned that something as simple as a sticker or code on the Ontario Health Insurance Plan (OHIP) card, similar to the one indicating consent to donate organs and tissues, could be of great value.

As the discussion about the problem was wrapping up, a participant summarized all challenges as essentially problems of communication. "A lot of times, things that crop up as problems are really nothing more than a failure to communicate. Once everyone's on the same page, it really sort of evaporates."



“It’s the brand and it’s the market. That’s how you’re going to get this awareness out there.”

## **Discussing the options:**

### How can we address the problem?

After discussing the challenges that reflect or contribute to shortfalls in end-of-life communication and decision-making in Ontario, participants discussed three options for making improvements:

- 1) improving public awareness about end-of-life care;
- 2) engaging citizens in a province-wide dialogue to encourage open discussions about end-of-life care; and
- 3) providing citizens with the information and tools they need to engage in advance care planning.

## **Option 1 – Improving public awareness about end-of-life care**

The discussion about the first option focused on ways to raise public awareness about end-of-life care, with a specific focus on social marketing campaigns. This option was originally selected because it could help raise awareness about the current gaps in end-of-life services, build commitment for addressing these gaps, and empower the public to advocate for change (for example, advocating for the development of a provincial end-of-life strategy).

Overall, this option particularly resonated with participants who saw public awareness campaigns as a promising way to address the fear and stigma associated with end-of-life conversations, but also to encourage people to engage in advance care planning. Three values-related themes emerged during the discussion that could guide how such public awareness campaigns are designed and delivered:

- people and family-centredness (campaigns that are attuned to their needs and values);
- shared responsibility (to get the conversation going); and
- collaboration (between the health system and other sectors to get the message out).

Participants generally believed that public awareness campaigns should be carefully designed in order to be attuned to the specific needs and values of people and their families. They emphasized that good branding was a key success factor for such public awareness campaigns, and worried that terms like ‘advance care planning’ and ‘end-of-life’ may not resonate with most people. They also emphasized the need for emotionally charged campaigns that are specifically designed for different target audiences (e.g., particular age groups, linguistic groups and ethno-cultural groups). As one participant noted: “It’s the brand and it’s the market. That’s how you’re going to get this awareness out there. Gotta come up with a brand that people will not cringe from and a marketing campaign that will sell.”

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

- Public awareness campaigns are a promising way to address the fear and stigma associated with end-of-life conversations, but also to encourage people to engage in advance care planning
- Three values-related themes emerged during the discussion that could guide how such public awareness campaigns are designed and delivered:
  - people and family-centredness (campaigns that are attuned to their needs and values);
  - shared responsibility (to get the conversation going); and
  - collaboration (between the health system and other sectors to get the message out).

For instance, campaigns targeting older adults should create a sense of urgency to engage in advance care planning, so that they are prepared to face the difficult decisions at the last stage of their lives, and also to protect their children/loved ones who may have to make these decisions on their behalf. As one participant illustrated, engaging in advance care planning on your death bed is like “calling to buy insurance for your house while it’s burning” - it needs to be done much sooner.

Participants also believed that public awareness campaigns should target a broad set of audiences since we have a shared responsibility to get the conversation going. They particularly emphasized the need to target younger audiences. This would encourage them to engage in conversations with their parents, but also have the long-term impact of changing social norms around end-of-life conversations. As one participant noted: “If you don’t get the younger generation involved, the information will die with the older generation and nothing will progress.” One participant also suggested that the campaign should shift people’s focus from the “later stage in life” to “anytime in life,” to emphasize that advance care planning may be needed anytime.

Lastly, participants discussed the need to increase collaboration between the health system and other sectors to expand the reach of such public awareness campaigns. Participants discussed the importance of relying on more traditional channels (e.g., pamphlets, ads, social media, websites) and venues where these campaigns could take place (e.g., walk-in clinics and patient consultation rooms in pharmacies). However, they suggested reaching out to less conventional partners who could amplify the reach of public awareness campaigns about advance care planning and end-of-life care (e.g., life-insurance companies, lawyers involved in completing their clients’ Power of Attorney for Personal Care and living wills, and funeral homes offering pre-planning for funerals). Participants argued that these potential partners are already dealing with matters related to life and death and they have access to a very large and diverse set of audiences. Having these partners distribute documentation and forms/templates for advance care planning was seen as a promising approach to raise awareness.

## **Option 2 – Engaging citizens in a province-wide dialogue to encourage open discussions about end-of-life care**

The discussion focused to a lesser extent on the second option, which examined how to engage citizens in a province-wide dialogue to encourage open discussions about end-of-life care. This option was originally selected to address the challenges associated with a ‘death-denying’ society that avoids thinking and talking about death. More specifically, it could help to raise awareness about end-of-life care issues, increase public understanding of end-of-life care issues, and ultimately make people feel comfortable talking about it.

Two values-related themes emerged during the discussion about option 2:

- privacy (someone’s wishes for end-of-life care are private and should not be debated in public); and
- community-centredness (awareness campaigns and dialogues should be attuned to the needs of particular ethno-cultural communities).

Participants held divergent views about the value of a province-wide dialogue to encourage open discussions about end-of-life care. On the one hand, some participants did not see the topic to be conducive to a vast public dialogue with thousands of Ontarians since it’s mostly dealing with personal and private matters (i.e., your wishes for end-of-life care), as opposed to a highly controversial policy issue such as major healthcare reforms, euthanasia, or medically-assisted death. As one participant noted: “It’s to help your family with these decisions. It’s not up for public debate. This is it. This is what I want and that’s it. As long as it’s within legal limitations, there’s no debate.” Therefore, public awareness campaigns targeting specific audiences were perceived as more promising to

### **Box 4: Key messages about engaging the public in a province-wide dialogue (option 2)**

- Two values-related themes emerged during the discussion about option 2:
  - privacy (someone’s wishes for end-of-life care are private and should not be debated in public); and
  - community-centredness (awareness campaigns and dialogues should be attuned to the needs of particular ethno-cultural communities).



encourage open discussions about end-of-life care among families and friends (option 1), rather than in public. As another participant noted: “Put [the message] out there and make everyone aware of it. They choose to talk about it or they don’t. End of story.”

On the other hand, a few participants saw the potential value of smaller and more focused dialogues in specific ethno-cultural communities to encourage open discussions about end-of-life care. Such community dialogues should be carefully designed and involve highly-respected people (or spokespersons) from these communities. As one participant noted, this could help “get the conversation started” in certain communities where end-of-life has traditionally been a taboo issue.

## **Option 3 – Providing citizens with the information and tools they need to engage in advance care planning**

The discussion about the third option examined the information and tools that citizens may need to engage in advance care planning. More specifically, this option could inform citizens about the legal aspects of advance care planning that are specific to Ontario (e.g., who can speak on their behalf when they are no longer capable to do so, and the link between advance care planning and consent to treatment). It could also provide citizens with simple tools to help them communicate and document their wishes for end-of-life care.

Two values-related themes emerged during the discussion about option 3:

- empowerment (access to information and tools about advance care planning); and
- credibility (of those who develop and endorse the information and tools).

Participants called for greater empowerment to ensure that people acquire the information and tools they need to engage meaningfully in advance care planning. Participants identified three types of tools that would be useful: 1) tools to learn about advance care planning (e.g., what it is, how to do it, and the legal considerations); 2) tools to complete an advance care plan (e.g., flexible templates that could be adapted to people’s needs); and 3) tools to communicate the advance care plan or make people aware of its existence (e.g., electronic registry, code on an OHIP card, a bracelet similar to the MedicAlert bracelet, and tear-off cards given to two other people to confirm that you have an advance care plan and have appointed a substitute decision-maker).

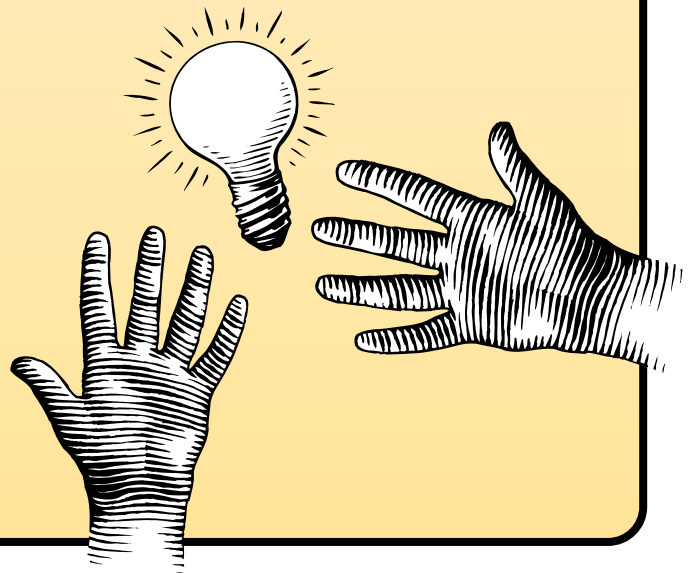
Participants then discussed the most effective ways to direct people's attention to them, but also to raise awareness of these tools among healthcare providers. Participants suggested using the same channels and venues proposed for the public awareness campaigns, with some notable exceptions, like the use of smartphone applications that could provide information about advance care planning, and could document, store and share advance care plans.

Participants emphasized that it was important to consider the public credibility of the organizations that would produce, or endorse, the information and tools. While some suggested that the tools should be produced and endorsed by disease-focused foundations or health professional organizations, others emphasized the need to have the “governmental stamp” to convey the message that they are valid and legitimate. Nevertheless, participants generally believed that these tools should be produced and endorsed by groups that are “broad-based, legitimate, popular, and not too controversial.”

Lastly, when considering the full array of options, participants emphasized that it would be important to sequence options 1 and 3 appropriately. These participants argued that it would be more fruitful to focus efforts on developing the information and tools that citizens may need to engage in advance care planning, before launching a public awareness campaign that could generate greater demand for the information and tools.

**Box 5: Key messages about providing the information and tools to engage in advance care planning (option 3)**

- Two values-related themes emerged during the discussion about option 3:
  - empowerment (access to information and tools about advance care planning); and
  - credibility (of those who develop and endorse the information and tools).
- Option 3 should precede option 1.





“Deliver it [the message about the importance of advance care planning and end-of-life care]. Keep it out there.”

## **Discussing the implementation considerations:**

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

After discussing the three options (among many) for improving end-of-life communication and decision-making in Ontario, participants examined potential barriers and facilitators for moving forward.

The discussion about the barriers generally focused on the stigma associated with end-of-life issues. As we try to mobilize various professional associations, charities and other stakeholders to launch a large-scale public awareness campaign about advance care planning and end-of-life care, some may be cautious about being associated with ‘death.’ However, several participants were confident that good branding could overcome this barrier.

When turning to the potential facilitators for moving forward, participants generally agreed that prevailing views in the population are changing. They perceived that more people are becoming comfortable with engaging in end-of-life conversations with their families and friends. Participants pointed out two factors in this change: 1) people want greater control over the last stage of their lives and peace of mind; and 2) people are paying greater attention to quality of life, not just longevity.

Participants generally agreed that end-of-life conversations were particularly important to have greater control over the last stage of their lives and to have peace of mind. By clearly expressing their wishes for end-of-life care, this could ensure that their wishes are carried out, and potentially avoid decisional conflicts among their loved ones if they become incapable of expressing their wishes. One participant noted the importance of having peace of mind that their wishes would be carried out. “It’s not that I think that I’m going to die this week or this month or this year. I know we’re all going to die and I know what I want my last days to be and my family knows what I want my last days to be, so I don’t think about it anymore. Life happens. I just flow through life and whatever comes comes, and when it’s over, it’s over. I’m at peace with that and if more people can get there, everyone would be a lot more comfortable.” Another participant further discussed the importance of avoiding decisional conflicts based on a recent personal experience. “I get how important these conversations are. Me and my mother have had these conversations. She’s 87 with cancer, but it’s a slippery slope. I have brothers and sisters, so that’s four different opinions as to what to do for mom, so let mom make the decision. You may agree/disagree with it, but this is what she wants, her choice.”

People are also increasingly thinking about the quality of life as opposed to strictly focusing on prolonging life. “You have to think about what you’re going to be like in that extra day.” Thus, this increased focus on quality of life is likely to encourage more end-of-life conversations.

## **Discussing how to move forward**

As the citizen panel concluded, participants emphasized again the importance of communicating with the public to raise awareness about advance care planning and end-of-life care. However, they were conscious about the considerable efforts necessary to achieve this. Therefore, they were enthusiastic to see the Ontario Medical Association and other organizations “with no axe to grind” that are willing to move this agenda forward. One participant urged them to pursue their communication efforts in the following way: “Deliver it [the message about the importance of advance care planning and end-of-life care]. Keep it out there.

# Acknowledgments

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## Conflict of interest

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