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**Dialogue Summary:  
Improving End-of-life Communication, Decision-making and Care in Ontario**

11 September 2013

#### McMaster Health Forum

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

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#### Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. One of the two funders reviewed a draft dialogue summary but the authors had final decision-making authority about what appeared in the dialogue summary.

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#### Dialogue

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## SUMMARY OF THE DIALOGUE

Dialogue participants generally agreed that too few people in Ontario engage in advance care planning discussions with their families, substitute decision-makers and healthcare providers. They also agreed about the lack of timely access to high-quality palliative care for many people in the province. Participants discussed the underlying causes of the problem, with several emphasizing a deeply rooted culture of not talking about death and others emphasizing the lack of accountability among healthcare providers and health system leaders to patients and families. A few dialogue participants also emphasized equity considerations, particularly for the remote, vulnerable, marginalized and culturally and/or linguistically diverse populations who face significant barriers to high-quality end-of-life communication, decision-making and care. Dialogue participants held different views about whether a ‘burning platform’ already exists for addressing challenges in end-of-life communication, decision-making and care, or whether one can be created through public engagement. In addition, they held different views about the value of combining – in the same public dialogue – end-of-life communication and decision-making (e.g., advance care planning) and access to palliative care.

Dialogue participants generally supported three potential elements of a comprehensive approach to address the problem, although they focused more on better aligning health system arrangements to support end-of-life communication, decision-making and care (element 1), and on educating, training and supporting healthcare providers in end-of-life communication, decision-making and care (element 2), compared to strengthening citizens’ capacity to engage in communication and decision-making about end-of-life care (element 3). They expressed different views about sequencing. A few participants were worried that public dialogue could generate greater demands for advance care planning and access to palliative care than the current system could handle. These participants argued for building capacity among healthcare providers before engaging in a larger public dialogue. Other participants disagreed and emphasized the need to pursue all three elements at the same time in order to bring about change.

Many dialogue participants committed to: increasing awareness of the importance of end-of-life communication, decision-making and care among their target audience and with the public; increasing the dissemination of information, training opportunities and dialogue within their own constituencies; and aligning messages, nurturing synergies and avoiding duplication among the Ontario Medical Association and other stakeholder groups for which it is a ‘front burner issue’. Dialogue participants also identified concrete steps that they could take depending on the nature of their organizations and/or roles, such as identifying gaps or lack of progress in the action items from the 2011 Declaration of Partnership and Commitment to Action, and developing a fulsome strategy that fills the gaps and spurs progress.

## SUMMARIES OF THE FOUR DELIBERATIONS

### DELIBERATION ABOUT THE PROBLEM

Dialogue participants expressed broad agreement with the five manifestations of, or contributors to, the problem described in the evidence brief: 1) many die each year in Ontario and many more are affected by these deaths; 2) few people engage in conversations about end-of-life issues; 3) current programs and services may not be fully aligned with Ontarians' needs and preferences; 4) current health system arrangements may limit capacity to improve the situation; and 5) many agreed upon courses of action, while promising, have not yet been fully implemented.

In particular, participants generally agreed that too few people in Ontario engage in advance care planning discussion with their families, substitute decision-makers and healthcare providers. One participant noted that there was also little discussion about goals of care, and no system in place to ensure that patients and their families engage in these conversations: "As a palliative care physician ... most of my patients have no idea what advance care planning is, nobody talked with them about this.... Communication is the most important thing, but it's not happening." Another participant pointed out a lack of awareness and knowledge among the public and healthcare providers regarding advance care planning and how to engage in such difficult conversations.

Participants also generally agreed about the lack of timely access to high-quality palliative care for many people in the province. One participant pointed out that there is a patchwork of palliative care services with very little integration, a lot of overlap and significant gaps. A second participant noted that while staff of some clinical departments embrace palliative care, staff in other departments in the same organization never consult with the palliative care team. A third participant argued that it was unacceptable that the health system was currently unable to provide palliative care to 70% of those in need: "Nobody would accept this [unmet need] in another area of healthcare." While some participants mentioned the need to draw lessons from the progress made in palliative care for cancer, one participant argued that there were misperceptions "that we got it right in cancer care." This participant pointed out that performance indicators from this sector suggest that 52% of patients in cancer care are still dying in hospitals, many are still visiting emergency

#### **Box 1: Background to the stakeholder dialogue**

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

- 1) it addressed an issue currently being faced in Ontario;
- 2) it focused on different features of the problem, including (where possible) how it affects particular groups;
- 3) it focused on three elements (among many) for addressing the policy issue;
- 4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three elements of a potentially comprehensive approach for addressing the problem, and key implementation considerations;
- 5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible options for addressing it;
- 6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
- 7) it ensured fair representation among policymakers, stakeholders and researchers;
- 8) it engaged a facilitator to assist with the deliberations;
- 9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"; and
- 10) it did not aim for consensus.

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

departments, and some are still only being referred to palliative care services in the last few weeks of life, if at all. Another participant suggested that one of the key features of the problem is that healthcare providers feel ill-prepared to address the palliative care needs of their patients, and that there is no standardized curriculum to prepare them: “They don’t remember lectures on palliative care. It’s learned on the fly. [They] feel uncomfortable doing it. Education is a very important aspect of the access issue.” One participant was particularly worried given the current trend of ‘downloading’ palliative care to primary care and the community: “Do they have resources to deal with it? The trend is worrisome [given recent] surveys show[ing] that primary care physicians do not see this as part of the curriculum.”

Dialogue participants discussed the underlying causes of the problem. Several participants emphasized that a deeply rooted culture of not talking about death was at the root of the problem (and that changing the culture would be key in any efforts to improve end-of-life communication, decision-making and care). As an indication of our culture of ignoring end-of-life issues, one participant cited the most recent report card from the Canadian Medical Association (CMA), which revealed that, when presented with three priorities in seniors’ health care, 63% selected home and community care and only 12% prioritized end-of-life care. A second participant highlighted the need to normalize end-of-life conversations and to nurture a culture shift: “We don’t really talk about it.... The big challenge is to initiate this culture change among the population and providers.” A third participant argued that this culture shift could be facilitated or triggered by engaging various partners from outside the health sector, such as employers, community organizations, the education system, service clubs and faith-based groups. This individual made the point that changing the culture is not the sole responsibility of healthcare providers: “It’s not just a healthcare issue. It’s a social and public health issue. Society has moved away from death. We need to bring other partners together to deal with this. How do we educate and prepare our kids.” A fourth participant agreed, emphasizing that end-of-life conversations need to start much earlier: “The critical care unit is a bad place for discussing end-of-life care.” A fifth participant reminded the group that system-level changes are often driven by public demands, meaning that changing this culture would likely be needed to spur the sorts of changes that are needed.

Other participants emphasized the lack of accountability among healthcare providers and health system leaders to patients and families for high-quality end-of-life communication, decision-making and care. One participant noted that there are significant challenges in dealing with many regulated professions and organizations in a context characterized by many system-level barriers to coordination and by a lack of clear accountability for coordination. A few participants agreed that the lack of ‘ownership’ of the problem constituted an important challenge. One participant noted, for instance, that primary care was taking ownership of the chronic disease problem, but that: “Nobody is accountable for the quality of end-of-life care.”

A few dialogue participants also emphasized equity considerations, particularly for the remote, vulnerable, marginalized and culturally and/or linguistically diverse populations who face significant barriers to high-quality end-of-life communication, decision-making and care. One participant suggested that there is no equity across the province in end-of-life care: “Those lucky enough to get services receive excellent care.” A second participant noted that there was not only a lack of equity based on geography, but also based on type of disease (e.g., palliative care for those living with dementia) and patient population (e.g., the pediatric population). This participant suggested that it has been historically easier for cancer patients to access palliative care, since the illness trajectories are usually better known, but that access has remained challenging for patients with other diseases. A third participant noted that more than 180 languages and dialects are spoken in the Toronto area, which constitutes a significant barrier to meaningful end-of-life conversations and increases the risk of miscommunication.

Dialogue participants held different views about whether a ‘burning platform’ already exists for addressing challenges in end-of-life communication, decision-making and care, or whether one can be created through public engagement. One participant suggested that there is a ‘tsunami’ in the making: “We have a demographic bulge. We are not prepared to deal with the aging baby boomer population.” A second

participant argued that it was “a slow burn issue that could turn into a flash fire.” Other participants pointed out that medically assisted death, an issue beyond the scope of the current dialogue, should not be neglected and could have important consequences for efforts to improve end-of-life communication, decision-making and care. One participant observed that “bill 52 [Quebec’s proposed act respecting end-of-life care, which will open the door to medically assisted death] ... is a huge burning platform. It’s also coming from the west [of the country]. It’s a perfect end-of-life storm. It’s the perfect time to have these discussions.” Another participant agreed and mentioned that society was going to make a decision on this controversial issue: “We need to be prepared for it.” However, one participant expressed concerns that the public may not be sufficiently informed to engage in a dialogue about such a complex issue. Another participant argued that the current dialogue around assisted suicide was taking much-needed attention away from a dialogue on access to high-quality palliative care, which this individual argued is really about improving quality of life.

In addition, participants held different views about the value of combining – in the same public dialogue – end-of-life communication and decision-making (e.g., advance care planning and goals-of-care discussions) and access to palliative care. One group of participants suggested that it would be more fruitful to separate the two conversations. One such participant indicated that one of the biggest issues is that most people do not understand the differences between advance care planning and palliative and end-of-life care. A second participant agreed. “It’s easier to talk about [it separately]. [Addressing advance care planning first] will open up the conversation for the next issue: palliative care.” A third participant echoed this point, suggesting that the public will not press for timely access to high-quality, integrated palliative care unless it is first informed about advance care planning. However, another group of participants disagreed with separating the two conversations. As one participant noted, “in the real world, they are related.” Another participant emphasized the need to use the expression ‘palliative approach,’ which includes both communication and decision-making and therefore makes it impossible to separate the two conversations.

## **DELIBERATION ABOUT ELEMENTS OF AN APPROACH TO ADDRESS THE PROBLEM**

Dialogue participants generally supported three potential elements of a comprehensive approach to address the problem, although they focused more on better aligning health system arrangements to support end-of-life communication, decision-making and care (element 1) and on educating, training and supporting healthcare providers in end-of-life communication, decision-making and care (element 2), compared to strengthening citizens’ capacity to engage in communication and decision-making about end-of-life care (element 3).

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

The deliberation about the first element initially focused on the need for a provincial strategy to improve end-of-life communication, decision-making and care. Participants generally agreed that the 2011 Declaration of Partnership and Commitment to Action could form the nucleus of a strategy and be a good vehicle to move the agenda forward. One participant noted that this collaborative initiative was the beginning of a strategy, but that they have not yet tackled everything in the declaration. A second participant agreed that the declaration was an excellent starting point, but argued that there was a need for fine-tuning: “There has been some stumbling on the implementation. Some of the language is open to interpretation.... There is a wide range of how things are being interpreted and a lack of clarity about where the accountability lies.” Several participants suggested that there was also a need for an expansion of focus beyond palliative care, which was quite comprehensively addressed by the declaration, to include a fuller engagement with end-of-life communication and decision-making. Another participant noted that, while the declaration is helpful, the power of a formal provincial end-of-life strategy should not be underestimated, in part because it illustrates the government’s commitment to tackle an issue systematically.

Several dialogue participants indicated that work on a strategy and on issues that might be addressed in the strategy (or in the declaration) would ideally be supported by developing performance indicators and a single point of contact for end-of-life communication, decision-making and care within the Ministry of Health and Long-Term Care. As one participant noted, there are currently regional palliative care leads who are external to the ministry, but no one who could bring together all the various parts of the ministry that touch on end-of-life communication, decision-making and care. Another participant argued that only someone at the ministry could bridge the conversation about end-of-life communication and decision-making with the conversation about access to palliative care.

Furthermore, several dialogue participants focused on the need to establish a coordinated approach to scaling up best practices in governance, financial and delivery arrangements for end-of-life communication, decision-making and care. These participants noted that there are examples of excellence that need to be spread across the system. For example, some nurse practitioners working for Community Care Access Centres (CCACs) are working collaboratively with palliative care teams despite their reporting relationship (to organizations that have a resource-allocation role). Under a different model, some system navigators working collaboratively with palliative care teams are accountable to patients and not to organizations with a resource-allocation role. These two examples of a coordinated approach could, in the view of a few dialogue participants, be helpfully adopted across the system in whatever combination makes sense given regional and sub-regional differences. As one participant noted, we need to build on existing strengths *and* find local solutions.

The deliberation then turned to the need for an information system – a key health system arrangement – that links patient information, plans of treatment and goals-of-care records to assist with transitions from one setting to another. A few participants lamented that health records are not shared across providers and settings. One participant noted that healthcare organizations are using different software for their electronic health records and some are still using paper charts. A second participant highlighted that some patients can have as many as five health records, and that the situation can be even more complex for non-cancer patients, particularly patients with multimorbidity. A third participant emphasized the importance of an integrated health information system and the potential value of virtual teams of care that use such a system: “Technology can be an incredible enabler.” A fourth participant agreed, noting that people are now far more open to new forms of communications. A fifth participant reminded the group that we have heard calls for and promises of an integrated health information system for many years now, suggesting that progress in addressing end-of-life issues should not be tied to the delivery of such a system.

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

The deliberation about the second element of an approach to address the problem focused on how to get (in the language of some) or how to enable (in the language of others) healthcare providers to engage in end-of-life communication and decision-making with their patients. One participant referred to the ‘Decision-Making for the End-of-Life’ policy from the College of Physicians and Surgeons of Ontario: “The policy is there from the regulated bodies and yet it is not happening. The information is out there, but the physicians are not doing it.” This participant suggested that there is a lack of knowledge on the part of healthcare providers, but also a lack of levers to move them (or assist them in moving) to act on this knowledge. A number of participants spoke to the use of both ‘carrots and sticks’ (e.g., incentives and regulations), but one participant expressed concern about the use of ‘sticks’ to bring about change: “Stick approaches work poorly.”

Participants generally agreed about the importance of educating and training providers both to facilitate communication and decision-making (e.g., advance care planning and goals-of-care discussions), and in the palliative approach (including multidisciplinary and shared-care approaches). For physicians, several participants suggested encouraging them to take advantage of mandatory continuing professional development and existing fee codes to support their end-of-life work, while others encouraged subsidizing

the creation and use of high-quality continuing professional development materials for which providers can receive continuing-education credits. For other primary-level providers, participants also suggested encouraging them to take advantage of healthcare organizations' continuing-professional-development programs (e.g., building capacity of volunteers in long-term care to promote advance care planning).

A few participants agreed about the need to appoint a task force to ensure that synergies and complementarities exist in the core competencies that have been established for relevant disciplines involved in end-of-life communication, decision-making and care. One participant argued that there was a need for greater standardization in the education and training: "It is highly variable across the 17 [medical] schools in the country. It needs to be standardized. Giving lectures and webinars is not enough. The palliative care approach is a 'use it or lose it' kind of thing. If you only do it once a year, you will not be comfortable, you will stop and refer."

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

The deliberation about the third element focused on engaging citizens in a provincial dialogue to normalize end-of-life conversations in general, and spur them to complete advanced care plans in particular. One participant argued that it was essential to do this and much more: "Given what we are trying to achieve, we need to take a step back, we need to engage them in every step of the way. We need to engage them in every component on the strategy, including the terminology."

Participants suggested various ways to facilitate or trigger such public dialogue. One participant noted that it could be possible to take advantage of national town halls being organized by the CMA. Other participants suggested building on existing campaigns, like Speak Up and Speak Up Ontario!, in planning provincial advertising campaigns, ideally as a partnership among physician, nurse and hospital associations and governments, among others. A few participants suggested encouraging Ontario's Local Health Integration Networks to support regional and sub-regional dialogues as part of their public-engagement responsibilities. Several participants suggested adapting (where needed) existing Ontario-specific materials to ensure that advance care plans are not seen as synonymous with palliative care, and supporting the organization(s) that make available such materials. Lastly, two participants highlighted the need to ensure that all of these efforts are attentive to where citizens' awareness and knowledge are currently lacking, and to the cultural and linguistic differences among citizens.

### **Considering the full array of options**

Dialogue participants generally supported the three potential elements of a comprehensive approach to address the problem, but they expressed different views about sequencing. A few participants were worried that public dialogue could generate greater demands for advance care planning and access to palliative care than the current system could handle. These participants argued for building capacity among healthcare providers before engaging in a larger public dialogue. One participant expressed concerns: "I worry of the human resources issue. What if we are very successful at this and cannot meet the increased demand for palliative care? It's a concern that things must happen in the right order." Another participant elaborated on this point: "Engaging the public is great if there is a burning platform. I'm not entirely sure there is. I think you need to develop the capacity, before you create the demand for it." Other participants disagreed and emphasized the need to pursue all three elements at the same time in order to bring about change: "We need to start all three, but some will be bearing fruit sooner."

## **DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS**

In discussing the main barriers to implementing the three elements of a potentially comprehensive approach to improving end-of-life communication, decision-making and care in Ontario, dialogue participants sometimes reiterated points made in earlier deliberations. For instance, participants generally agreed that society may be reluctant to engage in end-of-life conversations because of cultural norms. Some participants focused on the challenge of developing a shared vision for end-of-life communication, decision-making and care at the system level, while others expressed concern about the ‘change fatigue’ in certain parts of the health system, including in primary care. A few participants pointed out that how the issue is framed may constitute a barrier, noting that (depending on the language used) some members of the public and some stakeholders may perceive ‘end-of-life care’ as ‘code’ for medically assisted death, or that the underlying motivations are financial. One participant emphasized the need to carefully frame the message in a positive manner: “We need to say that it is about quality and doing what is right for patients.” However, that participant acknowledged that even with such positive framing there may still be suspicion, concluding: “We need to be vigilant about our language and messaging.” A second participant agreed: “The resources issue is taboo .... If we want to derail the whole thing, then for sure you put this front and centre. Before everybody is up to speed on this issue, we should not go down the resources route.” However, a few participants believed that we should not shy away from the resources issue. One participant noted: “I agree that most of it is about quality, but it’s also about resources. I understand the political risks of doing this.” These participants emphasized the need to develop a business case around the resources issue, with one pointing out the initiative of the CMA to mirror the Choosing Wisely campaign that is underway in the United States to encourage physicians, patients and other health-system stakeholders to think and talk about medical tests and procedures that may be unnecessary and, in some instances, harmful. Another participant agreed and emphasized that such a campaign should not be about overall cost savings to the system, but rather about realigning resources to provide the best care for all and to ensure equity: “We need to show the public that it is about re-investing, rather than the overall saving piece.”

Participants then turned to potential windows of opportunity for improving end-of-life communication, decision-making and care. Participants generally agreed with the need to build on the 2011 declaration and the strong engagement from various health system stakeholders, including the Local Health Integration Networks. One participant noted: “The declaration has a lot of support and may expand to [include] advance care planning.” A second participant was cautious about relying exclusively on the existing declaration: “There is strength in the declaration model, which is flexible, but there is a risk of too much variation across regions and sub-regions.” Other participants noted that the upcoming negotiations to establish the next Physician Services Agreement will begin no later than December 2013. They noted that these negotiations will target a variety of service areas for enhancement and investment, and could be conducive to raising end-of-life communication, decision-making and care higher on the governmental agenda.

Participants had mixed views about the effects of the upcoming decision in the Rasouli case (i.e., the Supreme Court ruling about who has the ultimate say regarding the withdrawal of life support in Ontario) and Bill 52 (i.e., Quebec’s proposed legislation that addresses medically assisted death). Some saw these events as opportunities to discuss advance care planning and end-of-life care, while others argued that doing so could have potentially negative consequences that could derail future public dialogue. One participant was worried that people will see these as ‘pathways to euthanasia’. A second participant emphasized that the current public discourse is not entirely useful and constructive: “They may confuse the message[s].” A third participant was uncertain about the potential impact of the Rasouli case: “Cases like the Rasouli cases are difficult.... They make terrible laws because they are outliers. It’s gonna be a tough one.”

## **DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES**

When the focus of deliberation turned to next steps for different constituencies, many dialogue participants committed to:

- 1) increasing awareness of the importance of end-of-life communication, decision-making and care among their target audiences and, through public awareness or social-marketing campaigns, with the public;
- 2) increasing the dissemination of information, training opportunities and dialogue within their own constituencies; and
- 3) aligning messages, nurturing synergies and avoiding duplication among the Ontario Medical Association and other stakeholder groups for which it is a ‘front burner issue.’

Dialogue participants also identified concrete steps that they could take depending on the nature of their organizations and/or roles, including:

- 1) identifying gaps or lack of progress in the action items from the 2011 Declaration of Partnership and Commitment to Action, and developing a fulsome strategy that fills the gaps and spurs progress;
- 2) developing performance indicators for the declaration/strategy and a single point of contact for end-of-life communication, decision-making and care within the Ministry of Health and Long-Term Care;
- 3) engaging the ministry in a dialogue about what examples of excellence are worth scaling up across the province;
- 4) exploring how to integrate advance care planning and a palliative-care approach into institutional-accreditation and professional-certification standards;
- 5) embedding end-of-life concepts (e.g., advance care planning) in existing programs and services in order to facilitate a culture shift;
- 6) reviewing the curricula of medical schools across the province to explore what is currently being done and what could be improved; and
- 7) building the capacity of the legal system to engage meaningfully in end-of-life communication, decision-making and care (e.g., finding funding opportunities to develop or use toolkits).



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