

## Topic Overview

### Improving End-of-life Communication, Decision-making and Care in Ontario

#### Stakeholder Dialogue 11 September 2013

The McMaster Health Forum convened a stakeholder dialogue on the subject of improving end-of-life communication, decision-making and care in Ontario. With the support of the Ontario Medical Association and by McMaster University's Labarge Optimal Aging Initiative, the dialogue brought together 20 participants – one policymaker, six managers, seven healthcare professionals, three researchers, and three citizens – from across Canada to examine the problem, options for addressing it, and key implementation considerations.



The views expressed in the evidence brief and dialogue summary are the views of the authors and should not be taken to represent the views of the funders.

#### Deliberation about the problem

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.





Participants drawn from government, health, professional and research organizations gather during a McMaster Health Forum event on 11 September 2013

## Deliberation about an approach

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.

## Deliberation about next steps

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.

## Dialogue deliverables

To learn more about this topic, consult the [evidence brief](#) that was presented to participants before the dialogue, the [summary](#) of the dialogue, and [view or listen](#) to the [interviews](#) with dialogue participants. For an electronic copy of the evidence brief or dialogue summary, or to view or listen to the interviews, visit our website [www.mcmasterhealthforum.com](http://www.mcmasterhealthforum.com) and click on 'Products' along the sidebar, or for direct access to our YouTube and iTunes U channels, simply click on the icons below.



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