

Topic Overview

Improving End-of-life Communication and Decision-making in Ontario

Citizen panel
30 November 2013

The McMaster Health Forum convened a citizen panel on the subject of improving end-of-life communication and decision-making in Ontario. The panel was organized with the support of McMaster University's Labarge Optimal Aging Initiative and 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 panel brought together nine citizens from across Ontario to examine the problem, options for addressing it, and key implementation considerations.

Discussing the problem

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.



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, McMaster University, McMaster University's Labarge Optimal Aging Initiative, or the authors of the panel summary.





Nine citizens from across Ontario gather during a McMaster Health Forum event on 30 November 2013.

Discussing the options

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.

Discussing the implementation considerations

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.

To learn more about this topic, consult the [citizen brief](#) that was presented to participants before the panel and the [summary of the panel](#). For an electronic copy of the citizen brief or panel summary, visit our website www.mcmasterhealthforum.org and click on 'Products' along the sidebar.



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