The McMaster Health Forum convened a citizen panel on the subject of improving access to palliative care 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 10 citizens from across the region covered by the Hamilton Niagara Haldimand Brant Local Health Integration Network to examine the problem, options for addressing it, and key implementation considerations. The purpose of the panel was to guide the efforts of the Ontario Medical Association and other provincial efforts in promoting the development of a provincial strategy to improve care at the end of life, including access to palliative care.

Discussing the problem

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.
Discussing the options

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.

Discussing the implementation considerations

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.

Panel deliverables

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.com and click on ‘Products’ along the sidebar.