Improving access to palliative care in Ontario
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 12 November 2016, the McMaster Health Forum convened a citizen panel on addressing health-system sustainability in Ontario. The purpose of the panel was to inform the efforts of the Ontario Medical Association in launching a discussion on the pressing challenges and future changes needed to guide Ontario’s health system towards sustainability. 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 (where possible) identifies the values underlying different positions.
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Summary of the panel

Participants identified five challenges related to addressing health-system sustainability in Ontario: 1) inconsistent access to health services; 2) lack of accountability for providing high-quality care; 3) insufficient attention paid to what helps keep people healthy; 4) limited access to reliable and easily understandable information on health and the health system; and 5) misalignment of the political system to support and achieve long-term change.

To help curb demand-side challenges to sustainability (element 1), participants emphasized the need for citizens to improve their levels of health literacy and to begin making healthier choices. Participants stressed that efforts to improve health literacy should focus on empowering individuals with demographic-specific education to support healthy decisions and to navigate the health system. Participants also expressed the need for increased use of technology and changes to their community environments to encourage healthy lifestyle behaviours. In discussing element 2 (ensure value for money by addressing challenges related to the supply of healthcare), participants identified three criteria that they thought should be met when making health-system decisions: 1) use a transparent process for decision-making and publicly communicate the steps taken to arrive at policy decisions; 2) use the best available evidence when making decisions about the health system and the programs, services or drugs provided within it; and 3) monitor and evaluate decisions to document whether the decision achieved the desired outcome. Finally, for enhancing approaches to leadership that support innovation and sustainability (element 3), participants supported the development of a non-partisan council made up of representatives from across the health system, including citizens, who would be tasked with ongoing monitoring and reporting on long-term health-system reforms.

When turning to potential barriers and facilitators to addressing health-system sustainability, participants identified two barriers: 1) lack of political will and current partisan approaches to politics limiting the likelihood for long-term policy reforms, which would require agreement and implementation across successive governments to take shape; and 2) current budgetary constraints at the provincial level and the lack of public support for increasing the tax base could limit the implementation of whole-system change. Participants however, identified increased debate and discussion about the health system as a potential window of opportunity for health-system sustainability to be made a priority in the next provincial election.
Discussing the problem: What are the most important challenges to addressing health-system sustainability in Ontario?

Panel participants began by reviewing the findings from the pre-circulated citizen brief, which highlighted what is known from research evidence about challenges that threaten the long-term sustainability of Ontario’s health system. In sharing their experiences accessing care in the health system and their opinions on what they thought could be improved, panel participants focused on five challenges related to addressing health-system sustainability in Ontario:

- inconsistent access to health services;
- lack of accountability for providing high-quality care;
- insufficient attention paid to what helps keep people healthy;
- limited access to reliable and easily understandable information on health and the health system; and
- misalignment of the political system to support and achieve long-term change.
Inconsistent access to health services

Participants discussed having a lack of consistent access to health services, expressing that it was often hard for them to get same- or next-day appointments when they or their children were sick. One participant discussed taking his children to walk-in clinics, because despite the long wait, “you know you’ll get seen. At the family doctor your appointment is five days out.”

Participants generally felt that they didn’t have the level of access to care that they would like, with those coming from rural communities expressing frustration with sometimes large discrepancies in access to care as compared to access for those living in better served areas of the province. For example, one participant compared his own access to care to that of his mother stating: “My mother is battling cancer and it is really hard for me to know that I have easy access to a doctor and great healthcare when my mother who lives two hours away from me is at a loss and is waiting three or four days just to see a family doctor.” Another participant expressed a similar challenge when they described having to reschedule appointments because the “roads weren’t safe enough to drive [from her community] to Belleville,” and questioned why care wasn’t available closer to home.

Box 1: Key features of the citizen panel

The citizen panel about addressing health-system sustainability 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 elements of a potentially comprehensive approach 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.
Several participants also remarked on how marginalized and transient populations and communities with high numbers of immigrants and refugees face additional challenges in accessing primary-care providers (e.g., for culturally appropriate care).

Despite these comments, participants, for the most part, understood that physical access to care is not always possible. However, they challenged the lack of acceptable technological alternatives that currently exist in the health system (e.g., corresponding with a physician or nurse practitioner over email) to enhance timely access.

In addition to access to primary care, participants also mentioned lengthy wait times for accessing specialists after a referral from their primary-care provider. Several participants described this as affecting all Ontarians regardless of whether one is from “a large city or a small community.”

Finally, two participants noted that the health system has little reserve capacity to address issues when they emerge. As one example, one participant described his grandfather not having access to an urgent surgical procedure because the surgeon was on vacation and there was no back-up while they were away. Another participant focused on the perceived shift of resources from her smaller rural community to a more urban setting, which was described as resulting in their community not having the capacity to respond to urgent issues locally.

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**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?** 12
- **Where were they from?** Urban (5) Sub-urban (3) Rural (4)
- **How old were they?**
  - 18-24 (4), 25-34 (2), 35-49 (2) 50-64 (1), 65 and older (3)
- **Were they men, or women?**
  - men (7) and women (5)
- **What was the income level of participants?**
  - 33% earned less than $20,000, 8% between $20,000 and $39,000, 25% between $40,000 and $59,000, 17% between $60,000 and $80,000, and 17% more than $80,000
- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panel
Lack of accountability for providing high-quality care

Participants discussed the lack of accountability for providing high-quality care in the system, including for what services are provided, where services are being delivered, and how providers and organizations are paid.

Participants generally felt there was a lack of accountability on the part of providers for delivering high-quality care that takes into consideration patient preferences. Many participants described feeling as though their family physicians were trying to rush their appointments, and several described a consistent focus on prescribing drugs rather than working with patients to support behavioural changes. Participants highlighted that as consumers they did not feel as though they had mechanisms available to them to question advice from their physicians.

Participants also described a lack of accountability for where care is being provided. Specifically, participants spoke to the challenge of health-workforce planning and physician choice over where they practice. Several participants, particularly those from rural communities, felt that there should be stronger rules dictating the distribution of professionals to ensure that there are sufficient levels of care in chronically underserved regions.

Finally, participants also suggested there was insufficient accountability for costs and payments made within the system. At the level of providers, participants questioned why there are not more requirements for physicians to prove that they are providing the services for which they are billing. While there was consensus among participants that their family physicians were not acting maliciously, they challenged the lack of required reporting and how payment structures incentivize providing higher volumes of care rather than quality care. At the organizational and system levels, participants highlighted what they viewed as a lack of accountability for costs and payments made between higher levels of the system, such as from the Ministry of Health and Long-Term Care to Local Health Integration Networks (LHINs) and then from the LHINs to community-level providers.
Insufficient attention paid to what helps keep patients healthy

Building off the discussion about provider accountability for delivering high-quality care, many participants shared that they felt the health system was too reactive and did not pay enough attention to interventions that could promote wellness and prevent disease.

In particular, participants remarked on how quickly they are provided with prescriptions by their physicians rather than working towards behaviour changes that could support an overall healthier lifestyle. For example, one participant shared his experience with his father, who he described as having been on Lipitor for the past 20 years, yet made very few changes to his diet and exercise over that period of time.

In highlighting this lack of attention paid to health-promoting activities, participants focused their discussion on the limited attention paid to nutrition and its impact on health. Several nutrition-related issues were raised, including the lack of education and awareness about preparing and eating nutritious food, limited awareness about the amount of salt and sugar in processed foods, and the lack of consistency in serving sizes and nutritional information on packaging. Participants also discussed structural factors such as the power of the salt and sugar industries, the marketing of junk food to children, and the inability of select populations (e.g., northern and less affluent areas) to access affordable and nutritious foods.

Limited access to reliable and easily understandable information on health and the health system

The final challenge that participants expressed was an uncertainty about where to find reliable sources of information. Participants felt uneasy about using Google to find health information, but felt that in many cases they did not know where to find more reliable sources, or how to evaluate information to determine whether or not it was credible. Participants explained that despite there “being a lot of information out there, it isn’t easy to digest.”

Expanding on this, participants also felt there was a lack of accountability on the part of the media for publishing information that is based on the best available evidence. Participants noted that while some citizens take the time to consult a number of sources, others may
read headlines and take them as facts, leading to a number of misconceptions regarding healthcare and the health system. One participant suggested that “there is an inherent mistrust of information professionals give you. People would rather believe what they read on Facebook.”

**Misalignment of the political system to support and achieve long-term change**

As an underlying reason for limited progress towards addressing health-system sustainability, participants pointed to the lack of alignment between the political system and long-term change. In particular, several participants discussed how politicians being elected to four-year terms means that there is often not enough time to develop a comprehensive plan, gain consensus on it and then implement the transformation before they have to begin campaigning for the next election. Participants emphasized that the political interest of being re-elected often leads politicians to focus on achieving ‘quick wins’ that can be used to campaign on, rather than developing long-term policy that may take time to result in tangible improvements. Moreover, one participant remarked about the lack of collaboration between politicians (e.g., across party lines), sectors, and health-system stakeholders, and with citizens.
Discussing the elements:

How can we address the problem?

After discussing their views and experiences related to the problem, participants were asked to reflect on three elements of a potentially comprehensive approach for ensuring health-system sustainability in Ontario:

1) engage patients and citizens to keep the health system sustainable by addressing demand-side drivers of change;
2) align features of the health system to achieve value for money by addressing supply-side drivers of change;
3) harness distributive leadership approaches that enable the system to innovate and move towards sustainability.

Several values-related themes emerged during the discussion about these elements, with three emerging across the three elements with some consistency:

• patient and citizen engagement (in their own care and in system-level decision making);
• evidence-based decision-making (in determining what services to fund); and
• transparency (in who is involved in decision-making and how decisions are made).
Element 1 – Engage patients and citizens to keep the health system sustainable by addressing demand-side drivers of change

Element 1 considers a range of approaches to alter the trajectory of the current demographics, built environment, socio-cultural environment and individual choices that contribute to the current strain on the health system. Broadly speaking, these include:

• enabling Ontarians to make healthier lifestyle decisions;
• promoting the establishment of healthier living and working environments;
• adopting and implementing appropriate ‘nudge’ policies that increase the likelihood that Ontarians choose healthy lifestyles;
• enhancing the health literacy of Ontarians and enabling informed care choices through the provision of information about health systems;
• supporting patient self-management and shared decision-making; and
• strengthening and supporting the role of patients’ families and carers, and increasing the role of patient peer-to-peer support.

Three values-related themes emerged during the discussion about element 1:
1) empower citizens with education to support healthy decisions and their efforts to navigate the health system;
2) embrace innovation and advances in technology; and
3) integrate citizens’ values and preferences when developing services that encourage healthy lifestyle behaviours.

Participants strongly agreed with many of the sub-elements that were presented as part of element 1, and affirmed the role that they as citizens felt they could play in curbing demand for the health system. Participants felt that when provided with easily accessible information and education they could be empowered to improve their levels of health literacy and to make healthier life choices.

Many participants supported the use of tailored education across the lifespan that is “framed in a way that each demographic can use and understand.” Two participants drew on the recent reforms to Ontario’s sexual education curriculum as a potential example of gradual learning that could be used for health more generally. Specific suggestions included increasing the requirements of health classes in elementary school, supporting the creation of cooking and nutrition classes in high schools and universities, providing parenting
courses in the community (e.g., to help parents foster a healthy lifestyle for their families), and running free courses on staying active while aging in seniors’ centres. Participants stressed that for empowerment strategies to work, information and education will have to be well promoted, easy to access and structured in a way that encourages active involvement.

Throughout the discussion, participants viewed technology and innovation as being an integral part of efforts to deliver health-promotion and disease-prevention interventions, as well as for engaging citizens. Several participants highlighted that marketing strategies used by private companies to promote their products (e.g., incentivizing consumers with free access to health apps and fitness trackers, or using social media platforms such as Snapchat and YouTube) could similarly be used for the public interest to promote healthy lifestyles (e.g., by providing health-related facts or skills through online cooking classes).

After hearing one participant discuss an approach used in his community for health promotion, other participants identified the need for interventions that could improve community design such as increasing walkability scores, ensuring safe play areas for children and adolescents, increasing the availability of grocery stores that provide healthy food, and providing tax credits to adults to engage in physical-activity programs. However, participants noted that changes to community design would need to take into consideration the values and preferences of those living in each community. As one participant explained: “It is about creating the kind of community where everyone is out because they feel safe and because things are within walking distance.”

**Box 3: Key messages about engaging patients and citizens to keep the health system sustainable by addressing demand-side drivers of change (element 1)**

- Empower citizens with information and education to increase health literacy and generate a greater understanding of health and the health system
- Support the adoption of innovation and technology in the development of health-promotion and disease-prevention initiatives and in educating consumers
- Promote patient and community centredness in developing health-promotion and disease-prevention interventions as well as in making any adjustments to the built environment
Element 2 – Align features of the health system to achieve value for money by addressing supply-side drivers of change

Element 2 focused on strengthening, and in some cases realigning, components of the health system to ensure greater value for money. This includes:

- organizational changes, such as:
  - ensuring that health system and organization decision-making processes are informed by the best available evidence; and
  - integrating routine assessments of system sustainability into all system-level decision-making processes;

- changes to financial arrangements, such as:
  - aligning funding and remuneration models with population-health outcomes and appropriate health-system performance measures that align with patient preferences and values; and
  - ensuring publicly funded programs, services and drugs take advantage of medical advances that offer ‘value-for-money,’ while identifying and disinvesting in those that are no longer cost-effective; and

- changes in how programs, services and drugs are delivered, such as:
  - improving the integration of programs and services that focus on promoting health and preventing illness, providing care to those who become sick, and supporting the ongoing management of conditions;
  - identifying the most promising models of care delivery that can help to ensure long-term system sustainability, given shifts in demographics, risk factors and burden of disease in the province; and
  - ensuring services are provided by the health professional(s) who have the most appropriate scope of practice, and who best align with the needs of the patient.

Three values-related themes emerged during the discussion about element 2:

- transparency in the decision-making process to foster trust in policy decisions;
- clearly communicate the process for decision-making and any subsequent decisions with the public; and
- support evidence-based decision-making in determining what programs, services or drugs should be publicly funded.
When asked how best to approach decision-making on funding programs, services or drugs and how providers should be remunerated, participants identified three criteria that they thought should be met when making health-system decisions:

1) use a transparent process for decision-making and publicly communicate the steps taken to arrive at policy decisions;
2) use the best available evidence when making decisions about the health system and the programs, services or drugs provided within it; and
3) monitor and evaluate decisions to document whether the decision achieved the desired outcome.

Participants generally felt that if decisions adhere to these three criteria they would be supported by the public. In outlining these criteria, participants stressed the importance of communication and public reporting, describing how they “felt uninformed” about how these decisions are currently made in the health system, and so often find themselves “untrusting” of policy decisions. Several other participants described how broad patient and citizen engagement would contribute to transparency and trustworthiness of decision-making processes, and that they are being made in the best interest of the public and not to appeal to certain stakeholders.

Interestingly, several participants expressed preferences about how the system should be financed, with some expressing support for using public and private financing in a two-tiered system as a way to improve access to medically necessary care. Those who supported a two-tiered system believed that citizens should be given the option to pay to receive the care they need if they can afford it, and thought that a second privately-financed tier of care would relieve some pressure from the public system and increase efficiency for all. Other participants were more skeptical however, with more becoming skeptical after hearing the concerns of some on the panel and clarification from the panel facilitator that research evidence does not necessarily support the notion that a two-tiered system would alleviate

Box 4: Key messages about aligning the health system to achieve value for money by addressing supply-side drivers of change (element 2)

- Ensure transparency in the decision-making process to foster trust in policy decisions
- Clearly communicate the process for decision-making and any subsequent decisions with the public
- Support evidence-based decision-making in determining what programs, services and drugs should be publicly funded
pressure on the public system. For example, one initially skeptical participant stated: “I just think there are consequences that we can’t even imagine. At the moment it is easy for us to talk about because changes always seem better, but I am not sure it will turn out that way.”

In addition to this discussion, one participant provided feedback on how he believed the health system should organize and remunerate providers, stating that “we need to prioritize the models that provide the best access and start to improve care in rural communities.” He further went on to express support for the use of incentives for return-of-service initiatives to retain providers in chronically underserved areas.
Element 3: Enhance approaches to leadership that support innovation and sustainability

The final element moved away from what strategies could help to ensure health-system sustainability to answering who should lead the process of change and how should it unfold. In particular, this element focuses on ways to engage all stakeholders in the process of change – including actors from the political (both elected officials and the civil servants supporting them), the managerial, professional and public levels – to gain broad support for change and a sense of ownership over reforms.

Three values-related themes emerged during the discussion on element 3:
• ensure transparency in communicating who is involved in decision-making for addressing health-system sustainability;
• promote accountability for reforms to address health-system sustainability; and
• foster citizen and stakeholder involvement in high-level decision-making in health-system reforms.

Participants expressed that in making broad changes to the health system they would appreciate knowing “who” was involved in decision-making and what the roles of different stakeholders were in the process of change. Participants called for increased transparency in who “is sitting at the table” and who they can hold accountable for the decisions that are made.

When asked who should be involved in developing and implementing reforms, participants overwhelmingly agreed that representatives should be included from all levels of the health system. Participants expanded on this idea suggesting that a representative council from across the health system be created to monitor and oversee long-term reform efforts in the health system.

Box 5: Key messages about enhancing approaches to leadership that support innovation and sustainability

• ensure transparency in communicating who is involved in decision-making to address health-system sustainability
• promote accountability for reforms to address health-system sustainability
• foster citizen and stakeholder involvement in high-level decision-making
Regardless of whether such a council were to be created, participants supported an increase in the amount, accessibility and availability of public reporting (particularly when provided by independent organizations) to keep decision-makers accountable.

Finally, participants expressed the desire for public officials and health-system decision-makers to engage in clear communication and dialogue with the public in efforts to gain their input into decisions, and to create a system for patients that represents citizens’ values and preferences.
Discussing the implementation considerations:
What are the potential barriers and facilitators to implement these options?

In deliberating about the three elements, participants also identified potential barriers and facilitators for efforts to address health-system sustainability in Ontario. Participants were generally optimistic about the possibility of change and identified two barriers and one facilitator to long-term whole-system reform. For barriers, participants believed that the lack of political will and current partisan approaches to politics limit the likelihood for long-term policy reforms, which would require agreement and implementation across successive governments to take shape. Similarly, participants believed that the current budgetary constraints at the provincial level and the lack of public support for increasing the tax base could limit the implementation of whole-system change.

Despite these two barriers, participants identified the increased debate and discussion about the health system as a potential window of opportunity for health-system sustainability to be made a priority in the next provincial election.

“We all have to take responsibility for change, the response will be slow but we have to get involved”
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Authors
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Michael G. Wilson, PhD, Assistant Director, McMaster Health Forum and Professor, McMaster University

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