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## 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 10-16 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 15 October 2016, the McMaster Health Forum convened a citizen panel on enhancing access to patient-centred primary care in Ontario. The purpose of the panel was to guide efforts to enhance access to patient-centred primary care in Ontario. This summary highlights the views and experiences of panel participants about:

- the underlying problem;
- three possible elements to address the problem; and
- potential barriers and facilitators to implement these elements.

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

Panel participants identified four challenges related to enhancing access to patient-centred primary care in Ontario: 1) patients have inconsistent access to primary-care providers (e.g., primary-care practices not accepting new patients and providing care when needed); 2) primary care does not comprehensively address patients' needs (e.g., challenges accessing needed services in the home and community-care sector); 3) individuals are not always accountable for their own health (e.g., lack of responsibility for engaging in unhealthy behaviours); and 4) technology is adopted slowly, and is inconsistently implemented across primary-care settings (e.g., inconsistent use of interoperable electronic health records to share information between providers).

Participants were supportive of efforts that would ensure all Ontarians receive the care they need, when they need it (element 1) with a strong preference for improving the timeliness of care by having nurse practitioners act as their primary-care provider. Participants were also vocal in asking for increased coordination between their primary-care provider and any specialists they see. In deliberating about how to put the patient at the centre of care (element 2), participants emphasized the importance of education to help patients manage their own care. However, participants had mixed opinions about how to make the system accountable to meeting patient expectations (element 3), but most emphasized the need to develop measurements that reflect citizen values and preferences, and to use them as part of public reporting to enhance accountability. Several values-related themes emerged during the discussion about these elements, with three emerging with some consistency: 1) collaboration (in delivering care for patients, and through the increased sharing of information, particularly for referrals to and coordination of care with specialists); 2) education (of patients to seek care and manage their health); and 3) citizens' values and preferences (in the development of new models of care and in determining what measures should be used to evaluate primary care).

Throughout the deliberations, participants highlighted two factors as the most important for implementation: 1) moving forward with the implementation of electronic health records to support coordination across the system, and personal health records to help patients be more informed about their care and to take a more active role in it; and 2) improving the level of citizen engagement in planning and implementing patient-centred primary-care reforms.



Enhancing access to patient-centred primary care in Ontario requires addressing many challenges, including enhancing access, comprehensively addressing patients' needs, enhancing individuals' accountability for their health and increasing the pace of technology adoption.

## **Discussing the problem:** Why is enhancing access to patient-centred primary care necessary but challenging?

While the majority of panel participants had positive views related to Ontario's health system, most indicated that changes are needed to ensure that they are able to access primary care when they need it. Given the changing health needs of the population (e.g., growing numbers of people living with chronic conditions) and with primary care playing an increasingly large role in managing these health needs, participants agreed that developing new models of patient-centred primary care is an important and growing challenge across the province. In sharing their personal experiences and those of their friends and family with primary care, participants individually and collectively focused on four key challenges:

- patients have inconsistent access to primary-care providers;
- primary care does not comprehensively address patients' needs;
- individuals are not always accountable for their own health; and
- technology is adopted slowly, and is inconsistently implemented across primary-care settings.

## Patients have inconsistent access to primary-care providers

Throughout the deliberations about the problem, participants consistently raised challenges they had in accessing primary care. Only two participants expressed that they never experienced problems accessing a family physician when needed. Some participants spoke of the challenges they had in registering with a primary-care practice, with a common issue being that primary-care providers in their communities were not accepting patients. These participants expressed frustration with the current mechanisms available to help them to find a primary-care provider (e.g., HealthCare Connect as identified by one participant). Several also expressed that it seems unfair that registering with a primary-care practice seems to often be determined by social relationships, including family and friends who can connect you to a family physician and practice. Other participants noted that while they did not face barriers registering with a primary-care provider, they had challenges getting timely access to same- or next-day appointments with their physician when they or their family members were sick, as well as to appointments within a week or more for less urgent issues.

One challenge identified that often occurs because of a lack of access to primary care is the need to seek care in less-than-optimal settings. Several participants described seeking care at the emergency room as well as repeatedly visiting walk-in clinics rather than waiting until they could be seen by their own provider. While participants were quick to admit that this was not their preferred place to receive care and that they valued the coordination and familiarity they have with their primary-care provider, participants felt in many circumstances they did not have another option, particularly when care was needed outside of regular hours (i.e., evenings and weekends). Moreover, many participants indicated that while not optimal, walk-in clinics are an essential safety net in the primary-care sector given that many people lack access to primary care, particularly transitory and marginalized populations who often depend on this infrastructure to receive services.

## Primary care does not comprehensively address patients' needs

Participants emphasized that current models of primary care do not comprehensively meet their needs, with several participants expressing this concern in very different ways. For example, participants discussed that in addition to having challenges accessing primary care, they were frustrated with the lack of access to complementary services, such as those provided through the home and community-care sector. Several participants lamented the lack of access to publicly-financed physiotherapy, occupational therapy and dietary

counselling (with a small number of participants also noting the lack of access to complementary and alternative medicine), which they deemed to often be ‘medically necessary.’ Some participants also emphasized the lack of available supports from other sectors that often intersect with the health system, including social services that can provide assistance with disability claims or access to income supports. In general, participants felt that without embedding these complementary supports as part of primary care, the services they were receiving were limited and did not reflect a comprehensive approach to care.

Also, two participants shared stories of primary-care practices not being sufficiently family-oriented, as they registered some members of their families but not others. Participants noted that having the same physician for their entire family was important to them, both for convenience and to ensure familiarity of the physician with the entire family (e.g., with parents and their children).

Other participants discussed this challenge in relation to the continued fragmentation and lack of interprofessional team-based primary-care practices in the province. While some participants were extremely pleased with the care they had received, others questioned why team-based care is available in select areas in the province, but not in their communities. Participants felt that these models of care would enable better access to a primary-care provider when they need it and result in fewer gaps in care when they are referred to other providers.

Finally, participants expressed frustration with the limited time their family physicians had to spend with them. In particular, participants took issue with what they described as the “one issue per appointment rule,” which when combined with an average 15-minute appointment, means insufficient time to express their concerns or ask their primary-care provider questions. In discussing this issue, one participant described having had the same physician for 20 years, and that when the practice was smaller, they had a better relationship with the physician. However, the participant said that now their physician “is having trouble knowing their patients, and when I go in the nurse comes up and says ‘two issues, that’s it’ ... and she [the physician] doesn’t remember my history or my family anymore.”

Participants also expressed concerns that this focus on single issues and short appointments does not allow the physician to comprehensively address their needs or to understand how they intersect with other social, emotional or environmental challenges. For example, one participant discussed his brother’s post-radiation care for leukemia, and described that in referring him to a specialist the practical issues of transportation or expected assistance to

get to and from appointments was never discussed. The participant stressed that acknowledging the intersections between health and other sectors is critical for providing patients with the best possible primary care and avoiding the need to seek care in sub-optimal settings.

## Individuals are not always accountable for their own health

Many participants indicated that in addition to health-system decision-makers and healthcare professionals, patients and citizens also need to be accountable for addressing the challenges faced for enhancing patient-centred primary care. For example, one participant stated “there is no accountability on the patient to take care of themselves.” While this participant and others tempered this statement by emphasizing that patients can only manage some aspects of their care, and that many aspects of their health are out of their control (e.g., as determined by broader determinants of health), there was general agreement that citizens need to be more engaged and increasingly accountable for their own health.

One participant explained the need for increased patient accountability by saying: “What people don’t seem to understand is that you don’t just go to the hospital, they bandage you up and send you home to rest anymore. There is a lot more that comes home

### **Box 1: 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?**  
13
- **Where were they from?**  
Region covered by Toronto and the greater Toronto area, Hamilton, Haldimand, Brant, Mississauga, Halton, and Sault Ste, Marie
- **How old were they?**  
18-24 (1), 25-34 (2), 35-49 (3), 50-64 (5) 65 and older (2)
- **Were they men, or women?**  
Men (7) and women (6)
- **Were they living in urban or suburban settings?**  
Urban (5), suburban (4) and rural (4)
- **How many were living with multiple chronic health conditions?**  
Yes (5) No (8)
- **How many were living with mental health or substance-use problems?**  
Yes (4) No (9)
- **What was the income level of participants?** 15% earned less than \$20,000, 31% between \$20,000 and \$39,999, 38% between \$40,000 and \$59,999, 8% between \$60,000 and \$79,000, 8% earned more than \$80,000.
- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panel

with you.” The participant built on this statement by discussing the challenge he felt in balancing his expectation that people care for themselves while also respecting many social and structural factors (e.g., low socio-economic status, geographic location and lack of education) that account for engaging in unhealthy behaviours, and/or that contribute to not adhering to medical advice.

Other participants added to the deliberation by explaining that while they felt expectations in the health system had evolved to support increased patient accountability, they did not believe that the necessary efforts to ensure people are knowledgeable about their behaviours had been implemented in parallel. One participant indicated that he did not feel primary-care providers or the health system more broadly provide education or opportunities for engagement that support awareness and empowerment to take control of one’s health and healthcare.

## Technology is adopted slowly, and is inconsistently implemented across primary-care settings

While participants understood the reality that their physician would not always be available, they questioned why technology has not been adopted that could help to maintain continuity of care between providers (e.g., electronic health records that share information with their family physician after having to seek care outside of their regular primary-care clinic) or to provide access (e.g., through email) to care when primary-care providers were unavailable (i.e., to prevent seeking care in less-than-optimal settings).

In particular, participants questioned why interoperable electronic health records have been inconsistently implemented with different levels of interconnectivity across the province. Participants expressed that they would be more willing to trade continuity of care received through an appointment with their most-responsible care provider to obtain more timely care from a different provider, if their information and health history were easily shared. Many expressed that this easy exchange of information is often not possible because of the lack of interoperable health records, which leads to many patients having to repeat their ‘patient story.’ In addition to electronic health records, participants also expressed some frustration with the current technology available for after-hours telephone consultations. While one participant was a large supporter of Telehealth, others felt it served to delay their trip to the emergency room and found the advice often unhelpful.



Citizens' values  
and preferences for  
enhancing patient-  
centred primary  
care in Ontario

## **Discussing the elements of an approach to 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 enhancing access to patient-centred primary care in Ontario:

- 1) ensure all Ontarians receive the care they need, when they need it;
- 2) put the patient at the centre of care; and
- 3) make the system accountable to meeting patient expectations.

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

- collaboration (in delivering care for patients, and through the increased sharing of information, particularly for referrals to and coordination of care with specialists);
- education (of patients to seek care and manage their health); and
- citizens' values and preferences (in the development of new models of care and in determining what measures should be used to evaluate primary care).

We describe below these three values as they relate to the three elements, along with other values that emerged during the deliberations.

## **Element 1** – Ensure all Ontarians receive the care they need, when they need it

The discussion about the first element focused on providing timely access to care, providing access to a most responsible care provider, and delivering care using teams of providers. As described in the citizen brief, this approach could include:

- providing flexible appointment scheduling (i.e., access to same- or next-day appointments for those with urgent needs, and appointments within a reasonable period of time for those with less urgent needs);
- using a team-based approach to care, where patients see their most responsible care provider (e.g., their family physician) whenever possible, with follow-up when this is not possible in urgent cases;
- expanding the mechanisms through which primary-care providers and patients, families and caregivers can interact (e.g., smart phone apps that support self-management through secure telephone and email consultations); and
- providing access to culturally and linguistically appropriate care.

Three values-related themes emerged that participants felt were important for ensuring all Ontarians receive the care they need, when they need it:

- timely access (to a most responsible care provider when needed);
- coordination/continuity (between all involved in providing care); and
- citizens' values and preferences (in how patients would prefer to contact their most responsible care provider).

In valuing access, participants expressed preferences for being able to reliably see their most responsible provider within a reasonable amount of time. However, participants held different opinions in what they considered a reasonable amount of time. All participants agreed that at some points they will need same- and next-day access, especially when they or their family members are sick. They agreed that this could likely be achieved by providers having blocks of time set aside each day for patients who need same- or next-day appointments. When the issue is not emergent, some participants expressed that they would be happy to wait up to a week if they have a secured date and time for an appointment.

When asked about who should be their most responsible care provider, participants unanimously agreed that it did not have to be a physician, and expressed that they valued continuity (e.g., seeing the same provider) and having timely access to them. Participants

also supported efforts to make better use of an expanded skill set of nurse practitioners and pharmacists if it meant they had easier access to care and more time to share their questions and concerns.

Participants also discussed the use of technology in primary care and expressed some frustration with the sluggish rate of adoption. Participants expressed that a key part of addressing this frustration would be wide-spread implementation of interoperable electronic health records, given the view that these could help to provide the coordination between health professionals that participants value. Select participants noted that in situations where their most responsible health provider is not available, they would feel comfortable seeking care from another professional so long as that provider had access to their health information. Expanding on the idea of technology, some participants also expressed a desire for technology-enabled access including patient portals (see more about this in element 2 below), online scheduling with their primary-care providers, and the ability to email or use the phone to discuss health concerns.

Participants also recognized that these changes in technology may not reflect the preferences of all Ontarians, particularly older adults who may be more accustomed to traditional models of care. To reflect this diversity, participants thought it was important that citizens are provided with choices that reflect their values and preferences for how to receive care (i.e., whether they are comfortable with a telephone conversation, brief email interaction or a face-to-face visit).

**Box 2: Key messages about ensuring all Ontarians receive the care they need, when they need it (element 1)**

Three values-related themes emerged that participants felt were important for ensuring all Ontarians receive the care they need, when they need it:

- access (to a primary care provider when needed);
- coordination/continuity (between all involved in providing care); and
- citizens' values and preferences (are considered with respect to how patients would prefer to contact their most responsible care provider).

## **Element 2 – Put the patient at the centre of care**

The discussion about the second element focused on providing patient-centred care, delivering care using teams of providers, providing comprehensive care, ensuring continuity of care and using medical records. As described in the citizen brief, this could include:

- creating personalized care plans where patients and clinicians collaboratively develop a plan to address the patient's health issues;
- promoting self-management resources;
- supporting shared decision-making with care providers (e.g., through decision aids);
- engaging patients, families and caregivers in care by providing access to personal health records (sometimes called patient portals) that allow for laboratory-test results review, online medication refills, provision of after-visit summaries, and informational supports that help patients, families and caregivers manage care;
- engaging care coordinators for the sickest patients who assume responsibility for ensuring patients are transitioned across providers, teams and settings; and
- ensuring effective communication between care providers (e.g., after discharge from hospital and urgent-care visits).

Four value-related themes emerged that participants felt were important for guiding efforts to put the patient at the centre of care:

- education (of patients and family members to help in managing their illness);
- trusting relationships between patients, providers and organizations within the health system (to encourage frequent communication between providers and between patients and providers);
- competence/expertise (of providers to provide comprehensive care, including for those with complex needs); and
- innovation/information (for adopting technologies that can assist in coordinating providers and helping patients to manage their own care).

In deliberations about element 2, participants discussed what features of primary care would help them take ownership of their own health and manage their own care. Participants expressed the need for more education on risk factors and diseases, both to stay healthy and prevent disease, and following diagnosis of a disease. One participant gave the example of diabetes given the need to empower people to engage in healthy behaviours to prevent it, but also to help those with diabetes to monitor it and manage their medications. Select participants felt that an important part of providing care is to allocate sufficient time for learning, asking questions and for follow-up discussions with care providers. Other suggestions from participants related to education include the need to provide reliable online health-related information and forums, information pamphlets in primary-care offices, and the development and promotion of YouTube videos on select topics. Other participants who favoured more traditional models of education felt that it should be taught in schools and built into curricula to instil a sense of personal responsibility at a young age.

**Box 3: Key messages about putting the patient at the centre of care (element 2)**

Four value-related themes emerged that participants felt were important for guiding efforts to put the patient at the centre of care:

- education (of patients and family members to help in managing their illness);
- trusting relationships between patients, providers and organizations within the health system (to encourage frequent communication between providers and between patients and providers);
- competence/expertise (of providers to provide comprehensive care, including for those with complex needs); and
- innovation/information (adopting technologies that can assist in coordinating providers and helping patients to manage their own care).

Participants also valued a trusting relationship with providers who engage and communicate clearly with patients in a way that helps them to manage their own health. Participants expressed that they wanted sufficient time with their primary-care providers to clearly articulate their questions and concerns. Participants also expressed the desire to seek second opinions or the perspectives of other types of providers, believing that this could effectively be done through teams of providers, preferably in one location. If the co-location of inter-professional teams is not possible, participants indicated that referrals to specialists would work well on the condition that there is seamless communication of information between their most responsible care provider and the specialists that they are referred to.

Participants were also extremely supportive of the idea of providing care for select conditions (e.g., low-back pain, depression or end-of-life care) using teams of providers with expertise in those conditions, but with those teams coordinating with their primary-care provider. However, they continued to reiterate that for these services to be effective and valued by patients they would need to be integrated with other parts of the health system (e.g., through sharing of information).

Finally, as for element 1, participants discussed the role of technology in enabling them to manage their own care. Participants had mixed views about whether they should be provided access to their electronic health records (or a patient portal). While almost all participants valued having more information on their own health, some participants were concerned that having access to the file could produce worry or fear among other citizens. The majority of participants, however, were comfortable with sharing some degree of information through a patient portal, but felt that if implemented, primary-care providers should be required to assist patients in understanding and interpreting the information they are given.

## **Element 3 – Make the system accountable to meeting patient expectations**

The discussion about the third element focused on ways to address the pillars of patient-centred primary care: supporting education, training and research; evaluating and encouraging ongoing improvement; and ensuring strong internal and external supports. This was described in the citizen brief as possibly consisting of efforts to:

- engage citizens and stakeholders in identifying what should be measured to determine if the system is meeting patient expectations;
- use an evaluation plan to determine if changes to the system have an impact and what additional changes might be needed; and
- report publicly on the performance of the system at the practice/organizational, community, regional and provincial levels.

Five values-related themes emerged that participants felt were important for making the system accountable to meeting patient expectations:

- information (on how primary care and primary-care providers perform);
- citizens' values and preferences (should be reflected in the development of measures and indicators used in evaluating performance);
- accountability (of providers and organizations for the quality of care being delivered);
- independence (of organizations responsible for evaluating and reporting on primary care); and
- choice (through the use of evaluations to determine what providers to seek care from).

Participants had mixed views about whether publicly reporting on primary care would be useful. While some participants were enthusiastic to know how primary care and their providers were performing, others felt that they “can judge how [their] doctor is doing on my [their] own.” Those who expressed more enthusiasm about measuring performance were keen to know about other consumers' ratings of satisfaction. In addition, one participant mentioned how she felt that the system was reporting on indicators that “make the system look good, but instead we should be reporting more on outcomes.” Participants also felt that decision-makers should engage citizens prior to determining what to measure to ensure that those selected are relevant and resonate with the public.

While not all participants were enthusiastic about the development of measurements for primary care, all participants did agree that wait times for referrals to specialists should be publicly reported and be easily accessible for citizens. Participants valued the information on how long they could expect to wait and wanted the ability to choose (based on the wait-time information provided) where to be referred.

All participants, including those who were less supportive of the development of primary-care metrics, agreed that if measurements were to be developed they should be reported on publicly and in ways that citizens could interpret and understand. Participants felt that this would help to keep providers and organizations accountable for the quality of care they are delivering.

Participants were again divided on what level reporting should take place. The majority of participants felt that the practice/organization level would be too focused for reporting and felt it could be met with a negative reaction from providers. Participants were split on whether they wanted reporting at the community or regional level (i.e., at the level of Local Health Integration Networks), with some expressing concerns that in rural areas of the province, a regional perspective may not be sufficiently representative of the experience in towns and villages. Participants did however, unanimously agree that any measurement and reporting should be done by a trusted independent organization such as the Ontario or patient ombudsman.

**Box 4: Key messages about making the system accountable to meeting patient expectations (element 3)**

Five values-related themes emerged that participants felt were important for making the system accountable to meeting patient expectations:

- information (on how primary care and primary-care providers perform);
- citizens' values and preferences (should be reflected in the development of measures and indicators used in evaluating performance);
- accountability (of providers and organizations for the quality of care being delivered);
- independence (of organizations responsible for evaluating and reporting on primary care); and
- choice (through the use of evaluations to determine what providers to seek care from).

## **Discussing implementation considerations:** What are the potential barriers and facilitators to implement these elements?

Participants discussed two important factors to consider when planning and implementing reforms. First, participants emphasized the need to move forward with the implementation of electronic health records in efforts to support coordination of information across the system. As a whole, participants agreed that in a sustainable health system there was a greater role for technology than had currently been explored. Building on this, participants also identified the need to develop personal health records to help patients be more informed about their care and to take a more active role in it. Second, several participants called for an increased level of citizen engagement in planning and implementing patient-centred primary care, with one participant stating: “The system is really out of touch with the person on the ground when it comes to healthcare ... [decision-makers] don’t understand citizens’ values or needs.”

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### Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the panel summary, and that they had final decision-making authority about what appeared in the panel summary.

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