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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 6 February 2016, the McMaster Health Forum convened a citizen panel on how to build a primary-care 'home' for every Ontarian. The purpose of the panel was to guide the efforts of the Ontario College of Family Physicians to promote the implementation of the patient's medical home model 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 five challenges related to building a primary-care 'home' for every Ontarian (and their experiences with primary care more generally): 1) lack of coordination and communication between primary-care providers, specialists and other care providers in a care team; 2) limited use of patient-friendly technology that is accessible to patients and their families; 3) difficulty accessing care when needed; 4) the system not always focusing on the perspective of the patient; and 5) the need for primary care to be more than just 'healthcare'. In addition to these challenges, one participant questioned if 'home' is the best way to describe these initiatives and suggested "healthcare hubs" instead. There was general agreement amongst the other participants about the confusion with terminology, as many felt 'home' has a special meaning separate from healthcare.

Participants reflected on three elements of a comprehensive approach to address the problem: ensure all Ontarians receive the care they need when they need it (element 1); put the patient at the centre of care (element 2); and ensure the full range of care is seamlessly linked across providers, teams and settings (element 3). Several values-related themes emerged during the discussion about these elements, with five emerging with some consistency: 1) access (e.g., using triage procedures to ensure the sickest patients are seen first and offering a range of appointment booking options); 2) competence/expertise (e.g., additional education and support to teach primary-care providers how to better communicate with patients); 3) trusting relationships between patients, doctors and other providers (e.g., making greater use of shared-decision making and nurse practitioners); 4) collaboration among patients, providers and organizations within the health system (e.g., team-based care and integration of primary, secondary and allied health providers); and 5) collaboration between the health system and other sectors (e.g., between health and education to integrate personal health decision-making into grade-school curricula).

When turning to potential barriers and facilitators to moving forward, participants focused on the need for incentives to encourage care providers, and especially physicians, to work more collaboratively with each other and patients, and to adopt new booking, referral and communication platforms. Participants identified integrated and accessible electronic health records as being critical for the effective implementation of many components of the elements.



Strengthening primary care is challenging and requires addressing many challenges, including lack of coordination, limited use of technology, difficulties in accessing care, the patient not always being put first, providing more than just 'healthcare'.

Discussing the problem:

Why is building a primary-care 'home' for every Ontarian necessary but challenging?

Panel participants began by reviewing the findings from the pre-circulated [citizen brief](#), which highlighted what is known about the underlying challenge (needing an approach that provides all Ontarians with timely access to primary care) and its causes. They individually and collectively focused on five challenges in particular:

- lack of coordination and communication between primary-care providers, specialists and other care providers in a care team;
- limited use of patient-friendly technology that is accessible to patients and their families;
- difficulty accessing care when needed;
- system not always focusing on the perspective of the patient; and
- primary care needs to be more than just 'healthcare'.

In addition to these challenges, one participant questioned if 'home' is the best way to describe these initiatives, and suggested "healthcare hubs" instead. There was general agreement amongst the other participants about the confusion with terminology, as many felt 'home' has a special meaning separate from healthcare.

Lack of coordination and communication between primary-care providers, specialists and other care providers in a care team

Participants primarily identified the issues of lack of coordination in the context of the lack of use of electronic health records (which was an important recurrent theme throughout the citizen panel), and in relation to specialist referral and prescription refill practices.

Participants expressed that the current use of electronic medical record systems across the province is not adequate to meet the needs of Ontarians. One participant described the way primary-care providers and specialists in the province use and share patient records as "antiquated", with many lamenting the fact that the province does not have interoperable electronic health records that allow for coordination across providers, teams and settings. One participant shared their frustration with having to wait to obtain an appointment with a particular specialist who only accepts referrals by mail.

Box 1: Key features of the citizen panel

The citizen panel about building a primary-care 'home' for every Ontarian 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 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.

The limitations of existing electronic health records systems were described as more than just an inconvenience, and were seen to have important implications for care. Several participants shared stories involving miscommunications between their primary-care provider, specialists and community-care providers. A common issue shared by participants was that their primary-care provider was not made aware of the outcomes of an interaction with other parts of the health system (e.g., a specialist appointment, emergency room visit, or walk-in clinic visit where tests were ordered). Having shared similar experiences, this led other participants to describe situations where they came to an appointment with their primary-care provider and were frustrated because the provider was unaware of another healthcare encounter the patient had, and did not receive any documentation (e.g., test results). This was especially frustrating for participants who had experiences accessing specialist care (which can take months from the time of referral) only to find that their primary-care provider was not provided with the specialist's assessment. Participants also described scenarios in which they attempted to explain what the specialist told them, which made them uncomfortable since they didn't possess the expertise needed to convey complex and comprehensive medical information.

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?**

13

- **Where were they from?**

Region covered by the Local Health Integration Network for Hamilton Niagara Haldimand Brant, Toronto Central, Central, Mississauga Halton, Waterloo Wellington, and South West

- **How old were they?**

18-24 (1), 25-44 (2), 45-60 (5), 65 and older (5)

- **Were they men or women?**

Men (6) and women (7)

- **Were they living in urban or suburban settings?**

Urban (8) and suburban (5)

- **Did they have access to a family physician?**

Did not have a family physician (4)

Have a family physician but are not enrolled in a Family Health Team (5)

Enrolled in a Family Health Team (4)

- **How many were living with a chronic condition?**

Living with one chronic condition (3)

Living with two chronic conditions (5)

Living with three chronic conditions (3)

Living with more than three chronic conditions (1)

- **How many were care providers to someone else living with one or more chronic conditions?**

Care provider to someone with one chronic condition (1)

Care provider to someone with three chronic conditions (3)

- **What was the income level of participants?** 15% earned less than \$20,000, 30% between \$20,000 and \$40,000, 7% between \$40,000 and \$60,000, 23% between \$60,000 and \$80,000, 15% more than \$80,000, and one preferred not to answer

- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panel

Building a Primary-Care 'Home' for Every Ontarian

While not having accessible electronic health records can be frustrating and delay timely access to care, several participants highlighted ways in which this can be especially problematic if a condition changes or worsens quickly. One participant shared an experience which involved a breakdown in communication between their primary-care provider and clinic staff, and a series of specialists. Delays in sharing test results and scheduling subsequent appointments resulted in a major health issue going undiagnosed, which quickly worsened until emergency surgery was required. The participant was especially disappointed with their primary-care provider and their staff, but acknowledged the quick response of the specialist who intervened. This participant also shared another experience of caring for a family member who was terminally ill and had been discharged from hospital to receive palliative care at home. The participant was told to take over-the-counter analgesics following discharge from hospital, but the family member's condition worsened once at home and they developed severe pain. The participant recounted not being able to reach the primary-care provider, and nobody at a walk-in clinic or hospital would intervene. Due to a lack of effective communication and accessible health providers, the individual's condition could not be verified and additional pain management was not offered in a timely manner.

Several participants had experiences receiving care, or overseeing the care of family members, in their homes from a Community Care Access Centre (CCAC). Participants had varying levels of satisfaction with the way services were organized and provided. One participant described an experience of caring for a family member that was marred by communication issues between themselves, the primary-care provider, and the CCAC. Another participant expressed high satisfaction with the quality of care provided to their family member by a CCAC, which organized nursing services, personal support workers, and meals-on-wheels. A third participant added that while they had also received great care, they said such an experience seems to depend on the kind of health issue being managed and where you live. Other participants indicated that some areas of the province seem to have sufficient resources in terms of available care providers, or have more clients than they can manage, which make the work of CCACs more challenging.

Finally, several participants questioned specialist referral and prescription refill practices in Ontario. Participants took issue with the requirement for subsequent referrals in cases where they had already been seen by a specialist (e.g., endocrinologist or dermatologist) and then needed to be followed indefinitely. One participant described a situation in which they missed the cut-off to rebook themselves to see the specialist by two weeks, then had to make an appointment with their primary-care provider to start the referral process again,

despite needing to be seen for a chronic issue. Collectively, participants agreed that this type of referral system makes the delivery of care in a timely manner difficult, and was seen as adding unnecessary costs. Participants also discussed limits on prescription refills for drugs that need to be taken for extended periods of time (e.g., giving a 30-day dose of a drug, with three refills, which has to be taken every day for the foreseeable future). One participant expressed frustration with having to book appointments to get refills for a drug they need to take for the rest of their life. Participants described inconsistencies between providers, and noted that some providers are willing to extend refills by phone or fax, while others insist on in-person visits. One participant said they had not seen their primary-care provider in years, but their pharmacist receives approval for refills of their medication without question.

Limited use of patient-friendly technology that is accessible to patients and their families

In addition to limiting communication between primary-care providers, specialists and other providers, participants indicated that the limited use of technology also results in patients having limited access to their health records if they need to produce them when they have not automatically been shared between providers. Many participants expressed frustration about not having access to their own health records, and felt they should be stored in a way that would make them accessible to both patients and providers. One participant suggested all health records should be stored in a centralized archive where they can be accessed for permitted purposes.

Several participants indicated that it can be time consuming and costly to obtain and move health records between providers. This was especially true for those with multiple chronic conditions who may have multiple records kept by different providers in different sites. One participant who had experienced a series of complex health issues expressed frustration with having to spend thousands of dollars to transfer health records that came at a per-page cost. These expenses can also be high for patients requesting files for multiple family members.

One of the participants expressed confusion about why primary-care providers are not able to make better use of standard communication and retention practices that are commonly used in other sectors like banking (e.g., electronic communication and sending reminders by

email or post). The participant and others said that without technology-enabled communication, it will be difficult to improve patient experience.

Difficulty accessing care when needed

The majority of participants had experienced challenges with accessing primary care for themselves or for members of their families. This was discussed by participants in two ways: 1) issues related to accessing care from an established primary-care provider in a timely manner (e.g., being able to book an appointment that same week); or 2) finding a primary-care provider who is taking patients in their area.

Participants discussed what they think are reasonable expectations in terms of timely access to a care provider. One participant strongly felt that patients should be seen within 24 to 48 hours. Another participant explained that expecting 24-hour access for primary care might be unrealistic and could overburden the system. Others felt that access can be improved without overburdening the system through the use of alternative communication and care-delivery formats like email and telephone. Participants expressed that care includes being able to tell a trained person about their symptoms without an in-person appointment. For example, participants described wanting to be able to call their primary-care provider's office to speak with a trained healthcare provider (who does not necessarily need to be a physician) and ask if they think a medical issue merits booking an immediate appointment, a future appointment, or whether they can try to manage the situation themselves. Several participants emphatically supported the greater use of nurse practitioners in primary care to conduct assessments and manage routine issues. Generally, participants felt the use of technology and granting greater responsibilities to nurse practitioners would do much to address current access problems in the system.

Participants also expressed frustration with what they perceived to be gatekeepers, primarily non-medically trained clerical staff, who restrict access to timely care through appointment booking practices that are not meeting the needs of patients. Many participants shared experiences of having to book appointments by phone (often waiting to call at the exact moment the clinic opens), and having patients scheduled in the order they call, or the order in which they arrive for walk-ins, instead of based on medical needs. There was consensus among participants that there should be a triage process whereby a qualified person (e.g., a licensed nurse) assesses the severity of a patient's health issues and determines who should be seen in what order (see the elements section for more details about this proposed solution). Without this, participants expressed concern that non-medically trained staff are

making decisions which affect patients' health, which they viewed as inappropriate. However, one participant defended the gatekeeper role and said there has to be limits on patient access to providers. Thus, a tension emerged between ensuring timely care for everyone who wants it, and preventing misuse of the system.

Several of the participants described having very positive long-term relationships with a primary-care provider which ended when their provider retired or moved to another area. These participants experienced challenges finding a new primary-care provider, when other local providers are not accepting new patients. Some of the participants had been through multiple primary-care providers within the last few years because of providers retiring or relocating. Participants who had been with the same provider for years, in some cases decades, were surprised by challenges accessing new providers. One participant described having been interviewed and assessed for suitability before being accepted into a practice that closed the same year, and having the same experience at the next practice which also ended up closing. Being without a primary-care provider created barriers to accessing specialist care for some participants. This issue was especially pertinent for one participant who has to receive regular specialist medical assessments to maintain their employment certification.

Participants also discussed the issue of enrolment eligibility requirements in the context of access and equity for some groups. A participant shared that their entire family had the same primary-care provider until the practice recently closed. One of their family members who is living with a chronic condition has had difficulty finding another provider. The participant expressed concern that some primary-care providers are refusing to take on patients with complex medical needs and especially those who require pain management (e.g., narcotics). Another participant shared their experience of feeling ignored during multiple emergency room visits because of what they perceived to be healthcare providers assuming they were trying to obtain narcotics for non-medical uses (or 'drug seeking'). This same participant was eventually diagnosed with a chronic condition and provided pain management, but not until the condition worsened and required hospitalization.

Another participant raised the issue of transitioning between pediatric and general primary care, and expressed concerns that adult care settings may not have appropriate expertise and protocols for working with youth. As a result, the participant indicated that young adults can fall between the cracks when transitioning to different care providers.

Lastly, where someone lives in the province was identified as an important factor for determining whether they can find a care provider, with many participants noting additional challenges for those who reside outside of the Greater Toronto Area. A participant who provides care to elderly family members described challenges finding primary-care providers who are accepting patients, and has resorted to travelling long distances to Toronto to ensure continuity of care. Other participants indicated that they were not able to find another primary-care provider in their area and now rely on walk-in clinics. While walk-in clinics were seen as an effective option by some participants, especially those who could access ones with advanced capabilities (e.g., on-site blood testing and imaging), other participants expressed concern that walk-ins are not effective options for more serious issues and for people living with greater medical complexity (e.g., older adults). One participant described a different experience. Instead of challenges accessing primary care, they complained about being invited for repeat physical examinations several times a year by their primary-care provider. They felt this was unnecessary considering their age and excellent health, and that it was a poor use of time and resources. They opted instead to use walk-ins when they had an issue.

The system does not always focus on the perspective of the patient

Several participants raised concerns about the ability of primary care to integrate patients' needs and perspectives. Specifically, participants questioned whether physicians are being trained to listen to patients and engage in mutual decision-making. A participant shared a story about a period in which they lived with chronic pain that reduced their mobility and resulted in missed work days. They recounted the steps they had taken to discuss their concerns with their primary-care provider, and even identified what they believed was the source of the issue. However, the provider dismissed the patient's interpretation and recommended subsequent treatments that did not alleviate their pain or improve functioning. The participant believed their provider failed to listen to how the issue was affecting their quality of life, and disregarded the knowledge they shared about their own body. The primary-care provider eventually relented and provided the specialist referral the participant had been requesting. This participant subsequently had surgery and made a full recovery, but felt the process took much longer than it should have. The participant further stressed that physicians need to be more empathetic towards patients' needs and beliefs about their health.

Another participant who had less success navigating the system expressed frustration with what they described as years of inadequate care and being sent from one specialist to another while their health continued to decline. “I don’t know where I fell through the cracks, but I just did. I know I’m not alone in this, that’s for sure.” This feeling of frustration was shared by several other participants who believed care providers had not considered their needs and preferences in the past.

Participants also agreed that patients typically have to advocate for themselves and their loved ones to prevent “falling through the cracks.” Several participants talked about the importance of patients being empowered to manage their conditions. However, a concern was raised that “most patients don’t have a clue what’s available to them ... they just take what they’re given.” This was seen as limiting a patient’s ability to advocate for themselves and engage in health-seeking behaviours. Although participants felt care providers need to do more to understand their perspectives and needs, many stressed that it is also important for patients to understand physicians’ needs. They are “running a business” and have costs they need to cover (e.g., staffing and other overhead), and they have other patients who need them, all of which influences how much time they can spend with each patient.

Primary care needs to be more than just ‘healthcare’

A theme that came up several times throughout the day is that primary care needs to be more than ‘healthcare’. One participant reminisced about when general practitioners used to make house-calls. Instead of just treating the patient’s presenting medical issue, they also assessed the patient’s home environment to identify any social or environmental factors that might influence their health or create barriers to recovery (e.g., poor sanitation, stairs in the home, living alone, etc.). Another participant indicated that going beyond ‘healthcare’ also means taking action to address the “social determinants of health” (e.g., income, social status, social support networks, education, employment and working conditions, social and physical environments, personal health practices and coping skills, healthy child development, gender and culture). The same participant emphasized the importance of mental health, and highlighted the benefits of informal community supports to decrease isolation as an important mental health intervention. This was supported by another participant who explained that physicians often underestimate the mental health component of living with an illness, especially for people who are unable to work as a result of their condition.

Participants described not having consistently received health promotion and prevention messaging from their providers that they could have used to make informed decisions about their health. Overall, this led some participants to question whether general practitioners and family physicians are being trained in holistic approaches to health and wellness that consider the range of factors that might influence a patient's health, ability to engage in health-seeking, and whether they benefit from prescribed treatments. One participant expressed that preventing chronic disease is especially important in the context of Ontario's aging population, but that everyone can benefit from more preventive services offered by nurses and other allied health professionals (e.g., dietitians and physiotherapists) to empower patients to "learn to stay healthy so we don't use resources that those who are seriously ill need."

Participants also identified a number of factors in primary care which are currently creating barriers to patients (and their care providers) receiving care in the home and through community supports. Participants identified the lack of supports offered to family and other unpaid caregivers who may not be equipped to provide the types of care patients need when formal care providers are not on site. A participant expressed gratitude for having an extended family who provides care and support to each other, but also raised concerns that care providers make assumptions about what the family is able and competent to do (e.g., technical expertise administering medications), and that informal care providers may be managing their own health issues and have personal limitations that prevent them from engaging in certain activities (e.g., expecting one elderly person to move another). Participants further identified the lack of respite services, transportation services, and programs to decrease isolation and improve mental health as needing to be addressed.

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 that could be used to build a primary-care 'home' for every Ontarian, that were outlined in the citizen brief. These elements included:

1. ensuring all Ontarians receive the care they need when they need it;
2. putting the patient at the centre of care; and

3. ensuring the full range of care is seamlessly linked across providers, teams and settings.

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

1. access (e.g., using triage procedures to ensure the sickest patients are seen first and offering a range of appointment booking options);
2. competence/expertise (e.g., additional education and support to teach primary-care providers how to better communicate with patients);
3. trusting relationships between patients, doctors and other providers (e.g., making greater use of shared decision-making and nurse practitioners);
4. collaboration among patients, providers and organizations within the health system (e.g., team-based care and integration of primary, secondary and allied health providers); and
5. collaboration between the health system and other sectors (e.g., between health and education to integrate personal health decision-making into primary and secondary school curricula).

We describe below these five 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 examined ways to ensure all Ontarians receive the care they need when they need it, which was described in the citizen brief as possibly consisting of:

1. patient-driven scheduling to ensure timely access (i.e., access to same- or next-day appointment, with priority for those who need it most);
2. team-based models that provide same- or next-day access to care for all Ontarians, with those who are sickest seeing a physician, those who are healthy and need routine care seeing another team member (e.g., a nurse practitioner), and those seeking after-hours care being linked to an available team member; and
3. secure email and telephone encounters to enhance access to, prepare for, follow-up from, or substitute for in-person visits.

Building a Primary-Care 'Home' for Every Ontarian

Seven values-related themes emerged that participants felt were important for guiding efforts to ensure all Ontarians receive the care they need when they need it:

- access (to the range of available services in a timely manner);
- choice (about care formats and ways of booking appointments and interacting with care providers);
- competence/expertise (recognizing the skills held by non-physician members of healthcare teams);
- collaboration among patients, providers and organizations within the health system (by offering team-based care and integrated records);
- accountability (in terms of ensuring patients are able to access care somewhere when their primary-care provider is not available);
- innovation (in terms of implementing new care-delivery formats using technology); and
- empowerment (in terms of educating patients to make informed decisions).

Participants valued access and discussed the importance of receiving care in a timely fashion to address health issues before they worsen. One participant explained that care should be provided “when the patient needs it” and “in a timely fashion,” and called for the development of benchmarks for measuring timely access. However, this same participant stressed that benchmarks should be realistic and balance need and urgency. Accountability was also valued with several participants expressing agreement with the notion that care providers should be doing more to facilitate access. One participant suggested primary-care providers, and/or their staff, should be responsible for identifying alternatives if they cannot see a patient in a reasonable timeframe (e.g., walk-in clinics that are open in the area). Introducing such a requirement was seen as a way of reducing unnecessary emergency room visits and saving the system money.

Furthermore, participants valued access for those most in need. Participants expressed preferences for appointments to be made based on need, and that those with more urgent medical issues should be seen first. For example, an urgent issue (e.g., where someone is experiencing acute pain) should be scheduled for the same day, while less urgent issues (e.g., chest congestion) could be scheduled for later. This was described as an important strategy to identify and diagnose medical issues quickly (before they progress), and to potentially reduce unnecessary emergency room visits by patients who feel they have nowhere else to turn.

Participants further valued having a choice over how they access their provider and book appointments. Participants discussed the respective benefits of a range of appointment-booking options, including same day and advance scheduling. One participant explained that their primary-care provider now only offers same-day scheduling, and it has worked very well with their flexible schedule which allows them to take whatever slot is available. However, this same participant acknowledged the importance of having more than one option since same-day appointments may not be appropriate for everyone (e.g., people who work during the day, or people with mobility issues who may have to plan travel in advance). In terms of when patients should be seen, participants overwhelmingly felt that triage (the sorting and ordering of patients based on the severity of their presenting health issue) is acceptable as long as the criteria used and timeframes are communicated to patients.

A preference for improving the availability of team-based care models was also expressed, with participants valuing collaboration. One participant expressed considerable satisfaction with the care they received at a high-capacity team-based setting which has over 40 physicians (general practitioners and specialists), nurse practitioners, physiotherapists, psychologists and other allied health professionals. Two participants shared stories of how a team-based model was able to catch, treat and stop the progression of a chronic condition. Participants further valued the competence of nurse practitioners, and many stated they would be comfortable receiving care from them instead of a physician for a range of health issues. One participant

Box 3: Key messages about ensuring all Ontarians receive the care they need when they need it (element 1)

Seven values-related themes emerged that participants felt were important for guiding efforts to ensure all Ontarians receive the care they need when they need it:

- access (to the range of available services in a timely manner);
- choice (about care formats and ways of booking appointments and interacting with care providers);
- competence/expertise (recognizing the skills held by non-physician members of healthcare teams);
- collaboration among patients, providers and organizations within the health system (by offering team-based care and integrated records);
- accountability (in terms of ensuring patients are able to access care somewhere when their primary-care provider is not available);
- innovation (in terms of implementing new care-delivery formats using technology); and
- empowerment (in terms of educating.

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expressed a preference for seeing a nurse practitioner, saying “when it comes to day-to-day things [nurse practitioners] have more experience than physicians.”

Regardless of whether a team-based approach is used, participants valued having access to ‘one-stop shops’ that are able to provide comprehensive care without requiring patients to travel (e.g., seeing a primary-care provider, a specialist, and getting blood work done at the same site). One participant shared their positive experience with receiving care at a clinic that has an on-site lab for bloodwork and imaging centre for X-rays. Recognizing that this may not be feasible everywhere in the province, participants identified the need to use interoperable health records to improve the integration of existing health services across the province by having their files easily accessible to care providers at different sites.

Participants valued innovation in care delivery through telecare (including the use of various combinations of technology such as videoconferencing and the use of remote diagnostic sensors and monitors) and telehealth (which in Ontario provides confidential advice from a nurse about whether to handle a problem yourself, visit your doctor or nurse practitioner, go to a clinic, contact a community service, or go to a hospital emergency room). Telecare was seen as a cost-effective way to reach Ontarians who live in rural, remote and isolated parts of the province where it is not be feasible to provide on-site team-based care. In contrast, telehealth was seen as a cost-effective strategy for providing all Ontarians with access to a care provider in a timely manner, and for possibly reducing unnecessary emergency room visits. However, one participant raised concerns about access (e.g., in terms of the technology required for telecare) and about the potential to miss issues that can only be caught through an in-person physical exam.

Finally, participants valued empowerment and reiterated the need for better education to advise Ontarians about what constitutes a health emergency (i.e., an issue that needs immediate medical attention) and how to manage their own health for routine issues. Or as one participant expressed: “We need to take responsibility for our healthcare.”

Element 2 – Put the patient at the centre of care

The discussion about the second element examined ways to put the patient at the centre of care, which was described in the citizen brief as possibly consisting of:

1. personalized care plans based on patient goals;
2. supports for self-management and shared decision-making between care providers and patients; and
3. electronic health records to engage patients in managing their care.

Four values-related themes emerged that participants felt were important for guiding efforts to ensure all Ontarians are put at the centre of care:

- continuously improving quality (in terms of doing more to know about what's happening with an individual patient's health and making better use of technology);
- competence/expertise (in terms of care providers being aware of all of the options available to patients);
- trusting relationships (solidarity) between patients and doctors, among many others (between care providers and also between providers and patients in terms of non-judgment, engagement, and shared decision-making); and
- empowerment (in terms of care providers giving patients tools and resources).

Participants valued having care providers who continuously improve quality by being patient-centred and adopting new technology. One participant argued that “patient-centred care needs to be defined with each patient” in ways that recognize their individual needs and goals. Participants expressed strong preferences for having care providers who make efforts to be knowledgeable about their patients' health (e.g., following up with specialists to find out the results of appointments). To support this, participants called for the greater use of technology by providers (within primary-care and between primary-care and specialist-care providers) to enable them to share patient medical information.

Participants further expressed preferences for providers to adopt patient-friendly information technology (e.g., using secured email or having access to a ‘patient portal’ in the form of a secured website they can log in to). This was seen as important for enabling patients to communicate with providers and access test results without having to make an in-person appointment. One participant who receives their results by email explained that it increases efficiency and reduces their anxiety because “not knowing what's going on can be really stressful.” Participants generally liked the idea of being able to book appointments

online, and being able to receive updates from their care providers (e.g., changes to clinic hours). However, one participant worried about the potential for miscommunications over email and preferred telephone exchanges which would still be efficient, but provide the opportunity to ask questions and clarify information with the care provider.

Participants valued competence and expertise within a patient-centred approach, and expressed preferences for their primary-care providers to be knowledgeable about the range of care options available, and to be willing to discuss them. Participants liked the idea of having a most responsible care provider (who oversees and directs their care) with whom they can build a trusting relationship over time. While competence was very important, participants also strongly valued having a trusting relationship with their care provider, and expressed that the two often go hand-in-hand. Moreover, some participants expressed preferences for wanting to engage in shared decision-making about their care plans and to be treated in a non-judgmental manner (e.g., not being stigmatized for using narcotics to manage their chronic pain).

Finally, participants valued empowerment and wanted access to health education and information to help them make informed decisions about their care, and work in partnership with their care providers. One way that participants identified for enabling this at a population level was through the health and education systems working closely together to integrate more health and wellness related material into the standard school curriculum (e.g., in health class and in other courses). Participants expressed that more comprehensive health education could better prepare young people to manage their routine care needs (e.g., not going to the emergency room for a low-grade fever) and eventually communicate more effectively with their primary-care providers about more complex needs.

Box 4: Key messages about putting the patient at the centre of care (element 2)

Four values-related themes emerged that participants felt were important for guiding efforts to ensure all Ontarians are put at the centre of care:

- continuously improving quality (in terms of doing more to know about what's happening with an individual patient's health and making better use of technology);
- competence/expertise (in terms of care providers being aware of all of the options available to patients);
- trusting relationships (solidarity) between patients and doctors, among many others (between care providers and also between providers and patients in terms of non-judgment, engagement, and shared decision-making); and
- empowerment (in terms of care providers giving patients tools and resources)

Element 3 – Ensure the full range of care is seamlessly linked across providers, teams and settings

The discussion about the third element examined ways to ensure the full range of care is seamlessly linked across providers, teams and settings, which was described in the citizen brief as possibly consisting of:

1. care coordinators for the sickest patients to help with transitions across providers, teams and settings
2. outreach and follow-up for discharges from hospitals and emergency departments; and
3. effective communication between care providers.

Four values-related themes emerged that participants felt were important for guiding efforts to ensure the full range of care is seamlessly linked across providers, teams and settings:

- excellent patient and family experience (in terms of prioritizing those most in need);
- collaboration among patients, providers and organizations within the health system (in terms of sharing and making use of patient health records);
- fairness (in terms of ensuring the full range of care, including care from allied health providers, is available for those who need it, and having equitable access to providers across the province); and
- collaboration between the health system and other sectors (in terms of improving transportation to and from care sites).

Participants valued having an excellent patient experience for themselves, their families, and for other people living in their communities. Although participants wanted excellent care for everyone, many recognized that some Ontarians need the “next level” of care coordination (e.g., the elderly and those living with multiple chronic health conditions). Most agreed that these patients should be prioritized during triage, and need additional coordination support to ensure they access needed specialist care. In combination with this, participants emphasized that care coordinators could help support access to the broader range of programs and services that these priority groups may need (e.g., efforts to reduce isolation and depression as a way to improve seniors’ health and wellness and reduce medical costs). Towards enabling all of this “next level” of care, participants further valued collaboration and expressed strong preferences for having their medical information shared between providers, teams and settings through the system-wide implementation of interoperable electronic health records.

Fairness was valued in terms of ensuring the full range of care is available and organized in a way that makes it available to all who need it. Specifically, participants recognized that many Ontarians are not able to afford care from allied health providers or the cost of essential treatments and medications. One participant noted that physiotherapy is only covered for people under the age of 18 and over the age of 65. Participants felt that covering physiotherapy throughout the lifespan could support people who are managing chronic health issues and/or recovering from injuries to remain in the workforce. Another participant noted that dental care is only covered under extreme circumstances, or for people receiving social assistance, but that many low-income people do not have adequate coverage. Finally, participants agreed that a provincially sponsored pharmaceutical program is needed by all Ontarians to lessen the growing burden of medication costs.

Fairness was further valued in how physicians are recruited and retained. Participants identified the need for incentives to recruit physicians to practice in underserved areas of the province to ensure equitable access to primary care.

Alternately, participants suggested applying penalties to those physicians who are trained in the province but leave without practising. One participant expressed concerns that physicians are benefiting from Ontario's excellent medical schools and education subsidies, but are not practicing in the province. Another participant expressed concerns about the number of physicians concentrated in urban centres, saying "we need more doctors and not in the city." Overall, participants called for more to be done to retain physicians and encourage them to work in under-resourced areas.

Box 5: Key messages about ensuring the full range of care is seamlessly linked across providers, teams and settings (element 3)

Four values-related themes emerged that participants felt were important for guiding efforts to ensure the full range of care is seamlessly linked across providers, teams and settings:

- excellent patient experience (patient, family, and community-centered) (in terms of prioritizing those most in need);
- collaboration among patients, providers and organizations within the health system (in terms of sharing and making use of patient health records);
- fairness (in terms of ensuring the full range of care, including care from allied health providers, is available for those who need it, and having equitable access to providers across the province); and
- collaboration between the health system and other sectors (in terms of improving transportation to and from care sites).

Finally, participants valued collaboration between the health system and other sectors. Participants expressed preferences for investing in public infrastructure, and especially public transportation, to improve access to healthcare providers. Some described challenges they experienced getting to appointments because they live in suburban and rural areas where providers may not be close to where they live. For example, for those who do not drive and live in areas with limited public transportation, getting to medical appointments through taxis results in significant out-of-pocket costs. Some participants pointed out that volunteer programs exist to provide transportation for people living with some conditions (e.g., cancer) to certain kinds of appointments (e.g., chemotherapy). They also noted that few services exist to transport the public to routine care appointments or between multiple appointments. This was seen as a particularly significant barrier to care for those who need ongoing care from multiple providers working in different settings that are often not close to where they live.

Discussing the implementation considerations:

What are the potential barriers and facilitators to implement these elements?

Throughout the deliberations, participants discussed potential barriers and facilitators to implementing the three elements of a potentially comprehensive approach for building a primary-care 'home' for every Ontarian. One participant shared that, in their view, building a primary-care 'home' for every Ontarian is an important goal, but they worried about the feasibility of aligning all of the factors needed to ensure success. Other participants felt the 'home' model was achievable and identified examples of primary-care providers who are already using aspects of the model. For example, some primary-care providers are already engaging in a mix of activities to:

- be proactive about ensuring their patients receive the care they need when they need it (e.g., short waits for appointments and following up with specialists);
- work in team-based care models and provide 'one-stop shopping' for care;
- support shared decision-making with patients; and
- use alternative ways of communicating with patients (e.g., email and telephone) and for scheduling appointments.

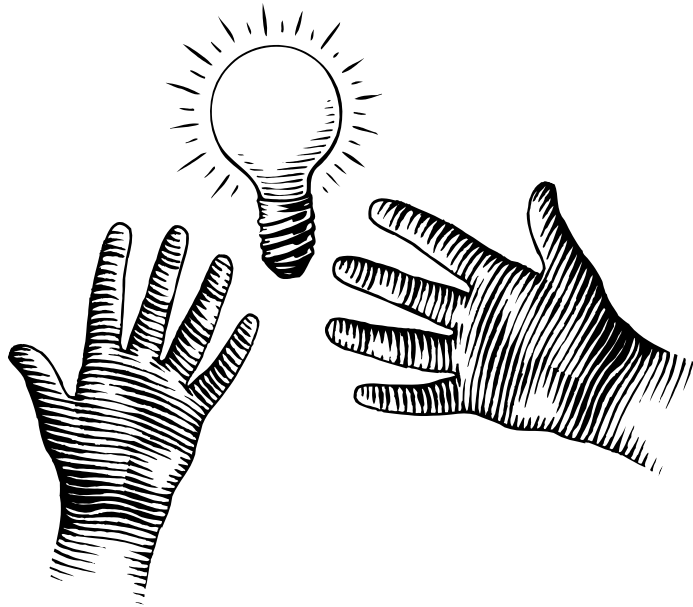
Given this, participants generally agreed that while aspects of the 'home' model are already being used across the province, they need to be integrated and implemented in a way that reaches all Ontarians. However, some participants worried that primary-care providers working in "traditional" models are unlikely to change their practices without a combination of incentives, education and requirements from their governing bodies and the province.

While consensus emerged about the need for the use of team-based care models and an increased role for nurse practitioners, some participants warned that increased responsibility needs to come with increased authority. Specifically, one participant said "the idea [of using nurse practitioners] is wonderful" but, in their view, "some lack confidence to go ahead and do something." The role was seen by participants as less beneficial if nurse practitioners just defer to physicians. Moreover, participants argued that nurse practitioners need to be

empowered by the health system to make care decisions and advocate for patients. Another participant suggested there should be public education campaigns to alert patients to the benefits of using nurse practitioners. Similarly, telehealth (also staffed by registered nurses) was seen as a great resource, but which should be doing more to empower Ontarians (although some took issue with the tendency for telehealth to refer callers to the emergency room because of fears about liability).

Lastly, participants identified a number of challenges related to the province being able to implement interoperable electronic health records. For example, some wondered whether integration of records can be achieved considering the logistical challenges of working across multiple systems (e.g., between individual practices, and across the province). While some participants viewed these challenges as insurmountable, others pointed out that access and integration has been achieved in other sectors (e.g., banks have developed ways of communicating with each other) and that it will just be a matter of time and whether the province is willing to invest in the process.

The deliberations wrapped up with the optimistic view of one participant: “To me, we live in the best country in the world, we just need to tweak our healthcare and improve it.”



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