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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 10-14 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 February 1, 2014, the McMaster Health Forum convened a citizen panel on how to improve care and support for people with multiple chronic health conditions in Ontario. The purpose of the panel was to guide the efforts of policymakers, managers and professional leaders who make decisions about our health system. 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

Panel participants discussed the shortfalls in the care and support provided to people with multiple chronic health conditions in Ontario and the causes of these shortfalls. In particular they focused on five challenges: 1) an aging population with increasingly complex care needs; 2) fragmentation of care; 3) burden on informal/family caregivers; 4) lack of informational support; and 5) lack of focus on health promotion and disease prevention.

Participants reflected on three options (among many) for improving care and support for people with multiple chronic health conditions in Ontario: changing the way care is organized and delivered (option 1); supporting patients to engage in conversations with their healthcare providers (option 2); and supporting patients to manage their own care (option 3). Six values-related themes emerged throughout the discussion about these options, including: 1) patient- and caregiver-centredness (care and support must be attuned to the complex needs of people with multiple chronic health conditions, as well as the needs of their informal/family caregivers); 2) access (to reliable and timely information, as well as to coordination support); 3) collaboration (to mobilize all those who can provide needed support and services beyond what is provided by the health system); 4) solidarity (to ensure we do not leave the most vulnerable to fend for themselves); 5) empowerment (to equip people to engage in conversations with healthcare providers and manage their own care); and 6) trust (between patients and providers).

When turning to potential barriers and facilitators to moving forward, participants mostly emphasized the challenges associated with implementing new care models for people with multiple chronic health conditions (e.g., possible resistance from the provincial medical association), as well as the challenges associated with implementing a comprehensive and intersectoral approach to reduce the burden of chronic health conditions. Panel participants expressed a desire to move forward in three ways. First, they called for greater communication among healthcare providers as well as between healthcare providers and patients. Second, participants called for health-system stakeholders to “speed up the change” to implement new care models that are aligned with the needs of people with multiple chronic health conditions. Lastly, participants reiterated the need to invest more efforts in health promotion and disease prevention.



“Stress trickles through the whole family.”

Discussing the problem:

What are the most important challenges to improving care and support for people with multiple chronic health conditions?

Panel participants began by reviewing the findings from the pre-circulated **citizen brief**, which highlighted what is known about the underlying problem – shortfalls in the care and support provided to people with multiple chronic health conditions in Ontario – and their causes. In particular they focused on five challenges, which gave them the opportunity to begin to articulate the values underlying their positions on this topic:

- an aging population with increasingly complex care needs;
- fragmentation of care;
- burden on informal/family caregivers;
- lack of informational support; and
- lack of focus on health promotion and disease prevention.

We review each of these challenges in turn below.

An aging population with increasingly complex care needs

Panel participants initially focused on the challenge of designing a health system that could address the needs of an aging population with increasingly complex care needs. Several participants said that this concern was a source of motivation to attend the panel, and some noted they are increasingly struggling to care for and support aging parents and family members, many of whom are affected by chronic health conditions.

Participants generally agreed that the shifting demographic is putting severe strain on them and the health system. Some even worried that the health system could no longer provide optimal care and support. As one participant noted: “Everyone is living longer, but fewer doctors are there to help.”

Many participants called for long-lasting transformative changes to Ontario’s health system to address the complex needs of an aging population, and emphasized the need for these changes to align with their values and preferences. For example, despite widespread support among older adults to receive care at home whenever possible (and to die at home surrounded by their loved ones), the nursing home was perceived as the default option by many participants. As one participant noted: “We’re the only culture putting our parents in nursing homes....”

Box 1: Key features of the citizen panel

The citizen panel about improving care and support for people with multiple chronic health conditions 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 options 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 preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

Fragmentation of care

The second challenge given attention by participants was the fragmentation of care and the corresponding values expressed for a more holistic and patient-centred approach to care. As one participant noted, most doctors are specialized in one part of the body, and few are looking at the whole patient and all the problems together: “The ‘human being’ doesn't have a doctor.” A second participant added: “We need doctors who will take the time to get to know and care about patients.” Participants agreed on the need for a more holistic and patient-centred approach to care, especially for those who have multiple chronic health conditions. Such an approach would involve doctors and other health professionals seeing patients ‘as a whole’ and address all of their psychological, physical and social needs.

Panel participants noted that fragmentation of care appears to be exacerbated by the nature of current physician-patient relationships, which are not conducive to taking a holistic and patient-centred approach to each patient. Several participants described the current model as a ‘doctor-paper relationship’ rather than a ‘doctor-patient relationship.’ One participant observed that, “doctors often won’t see the patients, they will just talk to the nurses and then prescribe by writing on a paper.” Such relationships were viewed as having a negative impact

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?**
11
- **Where were they from?**
Region covered by the Hamilton Niagara Haldimand Brant Local Health Integration Network (southern Ontario)
- **How old were they?**
18-24 (2), 25-44 (4), 45-64 (3), 65 and older (2)
- **How many men and women?**
Men (6) and women (5)
- **What was the educational level of participants?**
9% completed high school, 27% completed community college, 27% completed technical school, 18% completed a bachelor’s degree/professional training, and 18% completed post-graduate training
- **What was the work status of participants?**
18% self-employed, 36% working full-time, 9% working part-time, 9% unemployed, 9% retired, 9% students, and 9% disabled
- **What was the income level of participants?**
36% earned less than \$20,000, 36% between \$20,000 and \$40,000, 18% between \$40,000 and \$60,000, and 9% more than \$80,000
- **How were they recruited?**
Selected based on explicit criteria from the AskingCanadians™ panel

on the continuity that is central to the care of patients with multiple chronic conditions.

Participants also expressed concern about the typical 15-minute appointments they have with their physicians, and the ‘one-issue-per-visit policy’ displayed in some family physicians’ waiting rooms, both of which can exacerbate the fragmentation of care. Participants generally agreed that such medical encounters were particularly challenging for those with multiple chronic health conditions. One participant also lamented the number of physicians that can become involved in care and the resulting duplication of medical testing: “Each doctor frequently re-orders tests done by the one before, duplicating work and causing more stress.”

Participants argued that current funding arrangements may also contribute to the fragmentation of care, particularly the fee-for-service remuneration model for physicians. In the same vein, they indicated that there was a lack of incentives in the current funding model for providing holistic and patient-centred care. As one participant said: “fee-for-service has superseded good care.”

Despite the relatively grim portrait offered by participants regarding the fragmentation of care, one participant actually described his care experience as very patient-centred and being coordinated by a pharmacist. This experience illustrates that there are promising efforts currently underway to provide more holistic and patient-centred care and to support greater collaboration between patients and healthcare providers.

Burden on informal/family caregivers

The third challenge raised by participants was the significant burden faced by informal/family caregivers. Several participants expressed concern about the stress associated with caring for and coordinating care for someone with multiple chronic health conditions. They pointed out that such stress can worsen the patient’s illnesses, the burden on informal/family caregivers, and even their families’ health: “Stress trickles through the whole family.”

Participants also emphasized that the psychosocial burden of living with multiple chronic health conditions and being an informal/family caregiver was sometimes made worse by the associated financial burden. They pointed out that many people couldn’t work as a result of suffering from (or providing care to someone with) multiple chronic health conditions. Others may struggle with taking time off work to attend (or accompany someone to)

multiple medical appointments. Participants were concerned that money-related stress can particularly hurt those who are the most underprivileged. One participant illustrated these equity concerns by saying: “Health has become a luxury for those who can afford it.”

Lack of informational support

Participants identified the lack of informational support for people with multiple chronic health conditions and their caregivers as a fourth challenge. Participants generally agreed that valid and comprehensive information can empower patients to manage their own care. However, they emphasized that people can easily become overwhelmed by the quantity of health-related information available about their multiple chronic health conditions (e.g., details about how to follow a complex drug regimen).

A few participants said that people with multiple chronic health conditions (and their informal/family caregivers) must be particularly proactive to gather and analyze health-related information, and also be alert in making sure multiple medications prescribed by different physicians do not interact. In addition, one participant argued that patients and informal/family caregivers must increasingly be educated and ‘tech-savvy’ in order to navigate the vast amount of health-related information available.

A few participants emphasized the asymmetry of information between patients and physicians. For example, they complained that their medical records were not easily accessible to them. As one participant noted: “Patients don’t own their [health records], the hospitals do. They hide some of it from patients.”

Lack of focus on health promotion and disease prevention

The fifth challenge raised by panel participants was a perceived lack of focus on health promotion and disease prevention to curb the burden of chronic health conditions.

Participants expressed concern that many of our behaviours, as well as the social, economic and physical environments in which we live, are not conducive to good health. Participants generally agreed that it was critical to invest more effort into health promotion and disease prevention, given shifting demographics and the increasing number of people with multiple chronic health conditions.



“Information is important, but timeliness of information is key...”

Discussing the options: How can we address the problem?

After discussing the challenges that reflect or contribute to shortfalls in the care and support provided to people with multiple chronic health conditions in Ontario, participants discussed three options for making improvements:

- 1) changing the way care is organized and delivered;
- 2) supporting patients to engage in conversations with their healthcare providers to prioritize amongst multiple and complex care needs; and
- 3) supporting patients to manage their own care.

Option 1 – Changing the way care is organized and delivered

The discussion about the first option focused on implementing models of care for patients with multiple chronic health conditions that could improve the patient experience and improve health. The Chronic Care Model was presented to participants to spur reflection about how care could be organized and delivered. Panel participants generally agreed that the Chronic Care Model was a viable model to improve how care is organized and delivered. The discussion focused in particular on four elements of the model -- self-management support, decision support, clinical information systems, and community

resources -- and to a lesser extent on the other two elements of the model (i.e., delivery system design and the broader health system).

Three values-related themes emerged during the discussion that should guide changes to the way care is organized and delivered. These values include:

- patient- and caregiver-centredness (in order to be attuned to the complex needs of people with multiple chronic health conditions, as well as the needs of informal/family caregivers);
- access (to reliable and timely information, and to coordination support); and
- collaboration (in order to mobilize all those who can provide needed support and services beyond what is provided by the health system).

Overall, participants emphasized a holistic and patient-centred approach to provide optimal care. Many participants agreed that the components of the Chronic Care Model could achieve this, while a few participants debated the extent to which the model was attuned to the complex needs of people with multiple chronic health conditions, especially those who suffer from mental health problems and addictions, or from Alzheimer's disease and other dementias. Participants were concerned that these individuals were most likely unable to contribute to managing their own conditions or to make informed decisions, which are two pillars of the Chronic Care Model. This was discussed as a growing problem with the aging population, as one participant pointed out: "With older people, [the problem is] the cognitive skills..."

Participants also called for the implementation of (long-awaited) electronic health records (a clinical

Box 3: Key messages about option 1

What are the views of participants regarding this option?

- The Chronic Care Model appears to be a viable model to improve how care is organized and delivered, but a few participants worried that some patients may be unable to contribute to managing their own health conditions or to make informed decisions.
- Three values-related themes emerged during the discussion about option 1:
 - patient- and family-centredness;
 - access (to reliable and timely information, and to coordination support); and
 - collaboration.

information system) and other e-health initiatives that could improve access to reliable and timely information regarding their own health, and could provide greater coordination support to navigate the complex health system.

Lastly, participants emphasized the need for greater collaboration to mobilize community resources outside the health system. They pointed to the key role that the charitable sector can play in providing needed support and services, such as informing and educating the public regarding chronic health conditions (e.g., educational seminars); supporting informal/family caregivers (with tools, resources and coaching) to navigate the complex legal system in order to provide care and support for someone with multiple chronic health conditions who is unable to self-manage or make informed decisions; and creating a ‘burning platform’ to advocate for policies to improve patient care, and defend the rights of patients and informal/family caregivers.

Option 2 – Supporting patients to engage in conversations with their healthcare providers to prioritize amongst multiple and complex care needs

The discussion about the second option focused on one particular element of the Chronic Care Model, namely decision support. More specifically, participants discussed how to support patients to engage in conversations with their healthcare providers to prioritize amongst their multiple and complex care needs, in a way that takes into account their values, needs and preferences.

Two values-related themes emerged during the discussion that should guide option 2: patient-centredness (which had already emerged during the discussion about option 1) and empowerment. First, panel participants generally agreed that greater ‘shared decision-making’ was a worthy endeavour, as it could lead to more patient-centred care attuned to the values, needs and preferences of patients. However, participants debated the feasibility of the idea for two main reasons. First, participants reiterated that many people with multiple chronic health conditions are unable to engage in conversations with their healthcare providers and to make informed decisions (e.g., people with mental health and addiction problems or with Alzheimer’s disease and other dementias). Second, participants indicated that time was a major issue. As one participant noted, meaningful conversations to prioritize amongst multiple and complex care needs require a significant amount of time,

which is lacking for most people: “Providers, patients, everyone lacks time.” So, while we should strive to achieve greater shared decision-making (and hence greater patient-centredness), several participants suggested that it may be difficult to do so on practical grounds.

Lastly, participants called for greater empowerment to ensure that people acquire the knowledge, tools and information they need to engage in conversations with their healthcare providers. They also emphasized that such empowerment could be achieved through health literacy interventions to inform and educate the public early in life about chronic health conditions. Such interventions could also equip them to navigate the complex health system both before and after the onset of multiple chronic health conditions.

Option 3 – Supporting patients to manage their own care

Another element of the Chronic Care Model -- self-management support -- was the focus of the third option. Four values-related themes emerged during this discussion, which include:

- solidarity;
- empowerment (which also emerged in option 2);

Box 4: Key messages about option 2

What are the views of participants regarding this option?

Two values-related themes emerged during the discussion about option 2:

- patient-centredness; and
- empowerment.
- Greater shared decision-making is a worthy endeavour, but participants debated its feasibility for two main reasons: some people may be unable to engage in the necessary conversations, and many lack the time to do so.
- Greater education early in life is necessary to equip people to engage in shared decision-making and to navigate the complex health system.

- trust; and
- access (to reliable and timely information and to coordination support, both of which emerged in option 1).

The idea of self-management generated mixed views. Some participants worried that putting greater emphasis on self-management could be perceived as a way for the health system to leave patients to fend for themselves. They worried that an emphasis on self-management could preclude solidarity with those vulnerable patients suffering from multiple chronic health conditions. However, other participants argued that self-management is about empowerment, not about leaving people on their own: “Self-managing is not about removing everybody else.”

Several participants noted the challenges associated with empowering patients to manage their own care, including physicians’ dominance in the system, the lack of trust (or mutual respect) between healthcare providers and patients, and the difficulties encountered in accessing the information necessary to engage in self-management. Overcoming these challenges can be exhausting, as one participant described: “Fighting all the time is where the real waste of energy is....”

Box 5: Key messages about option 3

What are the views of participants regarding this option?

Four values-related themes emerged during this discussion, which include:

- solidarity (towards those most vulnerable);
 - empowerment;
 - trust (between patients and healthcare providers); and
 - access (to reliable and timely information, and to coordination support).
- The idea of self-management generated mixed views. Some participants indicated that it could be perceived as a way for the health system to leave patients to fend for themselves, while others argued that it was about empowerment.
 - Participants noted several challenges associated with empowering patients to manage their own care (e.g., physicians’ dominance in the system and lack of trust).

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Participants also called for better tools to identify quickly those patients who are unable to manage their own care, and for greater legal support to informal/family caregivers who care for people who are unable to care for themselves.

For those with the capacity to manage their own care, panel participants emphasized the need to have greater access to relevant, accurate and timely health information. As one participant stated: “Information is important, but timeliness of information is key....” To achieve this, participants again called for the government to speed up the implementation of electronic health records and other e-health initiatives that could help people manage their own care. Several participants seemed exasperated by the slow progress on this front. As one participant noted: “We might be further along if we had that darn e-health system in place already.” They perceived such systems as essential to ensure better lines of communication and decision-making for patients and healthcare providers.

Lastly, a few participants expressed concern about informational overload. They argued that case managers are essential to support people who want to manage their own care. For instance, case managers can translate all of the technical information that may come from multiple healthcare providers, but also help to coordinate the care among multiple providers and help patients navigate the system.





“It's not just an issue of healthcare, but also of the workforce and the broader economy in general. People need income, benefits, time and freedom to make use of healthcare well.”

Discussing implementation considerations: What are the potential barriers and facilitators to implement these options?

After discussing the three options for improving care and support for people with multiple chronic health conditions in Ontario, participants examined potential barriers and facilitators to the options.

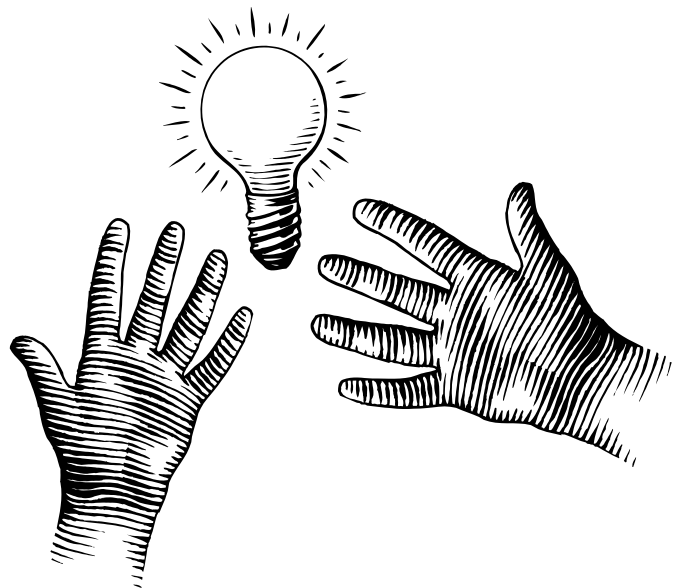
When discussing potential barriers, some panel participants were concerned that implementing new care models for people with multiple chronic health conditions may not be welcomed by the provincial medical association. Other participants were more concerned about the obstacles to implementing a comprehensive and intersectoral approach to curb the burden of chronic health conditions. One participant re-emphasized the multifaceted nature of the problem and that we should not focus strictly on its healthcare dimensions: “It’s not just an issue of healthcare, but also of the workforce and the broader economy in general. People need income, benefits, time and freedom to make use of healthcare well.” Another participant was also concerned that most health organizations that could play a significant role are disease specific (e.g., cancer societies, diabetes societies,

arthritis societies), and it may be more challenging for these organizations to provide optimal support for people with multiple chronic health conditions.

Participants then turned to key factors that could facilitate efforts to improve care and support for people with multiple chronic health conditions. They indicated that efforts would be facilitated if the Chronic Care Model was firmly grounded within Ontario's legal framework (e.g., Health Care Consent Act, Substitute Decisions Act, and Power of Attorney for Personal Care). They also expressed that getting the medical association on board could help to break down the silos in terms of communication and decision-making. Lastly, they argued that adopting a population health approach and encouraging greater collaboration could facilitate our efforts to tackle the problem. For instance, they called for the development of a comprehensive and intersectoral strategy that goes beyond healthcare to curb the burden of chronic health conditions.

Discussing how to move forward

Panel participants expressed a desire to move forward in three ways. First, they called for greater communication among healthcare providers as well as between healthcare providers and patients in order to provide optimal care and support for people with multiple chronic health conditions. Communication was perceived as fundamental in overcoming some of the current fragmentation in the system. Second, participants called for health-system stakeholders to “speed up the change” to implement new care models that are aligned with the needs of people with multiple chronic health conditions. Lastly, participants reiterated the need to invest more efforts in health promotion and disease prevention. They perceived the burden of chronic health conditions as “getting worse and worse” and were worried about strictly focusing on treating sickness. Instead, they argued that a comprehensive approach, which includes the promotion of good health and better choices, as well as the prevention of chronic health conditions, may be the only viable solution in the long run.



Acknowledgments

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Conflict of interest

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