McMaster University

McMaster HEALTH FORUM

MEETING THE FUTURE HOME AND COMMUNITY CARE NEEDS OF OLDER ADULTS IN ONTARIO

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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 August 20, 2014, the McMaster Health Forum convened a citizen panel on meeting the future home and community care needs of older adults in Ontario. The input from the citizen panel will guide the efforts of policymakers, managers and professional leaders who make decisions about our health system. It will also be used by the Ontario Association of Community Care Access Centres (OACCAC) in their continued efforts to provide optimal home and community care to older adults in Ontario. 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 challenges related to meeting the future home and community care needs of older adults in Ontario. During the deliberations, the following five challenges were consistently raised: 1) caregiving is essential but challenging, and inconsistently or inadequately supported; 2) home and community supports often do not provide what's needed to allow older adults to stay at home; 3) most people don't know about available services, and those who do often face challenges in accessing them; 4) electronic health records and e-health initiatives are long overdue; and 5) a lack of planning at the individual and system levels.

Participants reflected on three options (among many) for designing a system that meets the home and community care needs of three groups: 1) older adults who make it to 85 in good health (option 1); 2) older adults who have two or more chronic health conditions but still enjoy a good quality of life (option 2); and 3) older adults who are socially isolated and suffering from many chronic health conditions (option 3). Several values-related themes emerged throughout the discussion about these options, including: fairness (in terms of access to affordable home and community care, to coordination support, and to personal health information); patient-centredness (home and community care attuned to the specific needs of patients); empowerment (through information sharing and work opportunities); population-health orientation (a system designed to promote active lifestyles and maintain good health); collaboration (between the health system and other sectors, as well as among providers and citizens); competence (of volunteers and personal health workers); and solidarity (involving socially isolated and vulnerable older adults).

When turning to potential barriers to address the future home and community care needs of older adults in Ontario, participants focused on two key barriers to overcome: one financial (i.e., financial sustainability of the system to provide the full range of home and community care needed) and one attitudinal (i.e., people relying too heavily on the government to bring about change). Panel participants also suggested two strategies that could be used as facilitators to change: involving the mass media to raise public awareness about the issue and developing an intersectoral strategy.

"This is a problem we have now and it's going to get worse."

Discussing the problem:

What are the most important challenges to meeting the future home and community care needs of older adults in the province?

Panel participants began by reviewing the findings from the pre-circulated citizen brief, which highlighted what is known about the underlying challenges related to meeting the future home and community care needs of older adults in Ontario. They individually and collectively focused on five challenges:

- caregiving is essential but challenging, and inconsistently or inadequately supported;
- home and community supports often do not provide what's needed to allow older adults to stay at home;
- most people don't know about available services, and those who do often face challenges in accessing them;
- electronic health records and e-health initiatives are long overdue; and
- long-term planning at the individual and system levels is limited.

We review each of these challenges in turn below.

Caregiving is essential but challenging, and not consistently or adequately supported

Participants highlighted the importance of caregiving and the key role that informal/family caregivers must play in caring for (and advocating on behalf of) family members, friends and neighbours who are in need of home and community care. However, participants generally agreed that caregiving can pose several challenges to those who provide care and those who receive care, as well as to other family members or friends. In addition, they agreed that caregivers are inconsistently or inadequately supported.

Challenges of caregiving

Many participants pointed out that caregiving can create serious tensions. For example, several noted that some older adults feel like a burden on their spouses or children, while others refuse to obtain more formalized home and community care and supports despite their caregivers feeling overwhelmed. Some participants noted the difficulties in caring for someone who faces significant challenges that are not easily managed in home or community settings (e.g., dementia), or for those who have 'given up.'

Box 1: Key features of the citizen panel

The citizen panel about meeting the future home and community care needs of older adults 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 will preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

Several participants emphasized that such tensions make it difficult for many to deal with the emotional, physical and economic burden of caregiving at home. Participants were particularly concerned about the mental and overall health of informal/family caregivers and the lack of attention paid to their health. For example, several participants specifically raised the concern that caregiving often leads to burnout, and one participant emphasized the emotional toll from watching a loved one fall ill and decline in health.

Participants also worried that shifting demographics (i.e., an aging population as well as increasingly aging caregivers) and changing family structures (i.e., the decline of the nuclear family, the increasing number of older adults living alone with limited or no family support) could worsen the situation. Some participants also spoke of a generational gap and argued that younger generations might be less willing to provide care to their aging parents than older generations (e.g., because of family, work and cultural circumstances). These participants were concerned that this generational gap may reduce the caregiving support available, which will place further strain on already limited home and community supports. As one participant indicated: "This is a problem we have now and it's going to get worse."

Inconsistent or inadequate support for caregivers

Many participants emphasized that informal and family caregivers are not consistently or adequately supported, which places limits on their ability to provide or advocate for needed home and community supports. Some participants mentioned that services that are available are very helpful, but limited in scope. For example, they indicated that three or four hours of home and community care per week are not enough for those requiring near constant support, especially those with multiple chronic health conditions or complex conditions such as dementia. Other participants noted a lack of respite care for informal/family caregivers, as well as needs assessments that can be used to tailor services for both patients and their informal/family caregivers.

Several participants indicated that there was a need for more personal support workers (PSWs), but indicated that these health workers are often not prioritized for investment in the current health system. One participant said that "PSWs are the rock of the system, but are paid minimum wage." Participants generally agreed and claimed that personal support workers deserved to be paid much more, which could entice more people into working in such a critical role for the system. Building on this, one participant argued that the priorities of the health system are generally backwards. This participant said that "we don't have a healthcare system, we have a sickness system, and the system needs to be turned on its head!"

Lastly, several participants indicated that informal/family caregivers are often left out of the provider/patient relationship. When healthcare providers connect with their patients, they do not always directly communicate as well with informal/family caregiver(s) who are more likely to be the most knowledgeable about the patient's needs. A few participants added that this is sometimes the result of older adults refusing to have their caregivers go to their appointments and accept assistance, and/or physicians not allowing additional people in the room for privacy concerns. As a result of not engaging more actively with informal/family caregivers, many important aspects of older adults' needs can be ignored, resulting in significant gaps in needed supports.

Home and community supports often do not provide what's needed to allow older adults to stay at home

Participants generally acknowledged that receiving care at home reflects the desire and expectation of many older adults. However, to stay at home, older adults need to have a broad range of supports available that can be used to address their particular needs (including help with the general upkeep of a home and assistance with minor repairs). Yet, many

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?**
  14
- **Where were they from?**
  From across the province of Ontario
- **How old were they?**
  45-64 (4), 65 and older (10)
- **Were they men, or women?**
  Men (5) and women (9)
- **What was the educational level of participants?**
  7% completed high school, 21% completed community college, 64% completed a bachelor's degree/professional training, and 7% completed post-graduate training
- **What was the work status of participants?**
  21% self-employed, 7% working part-time, and 71% retired
- **What was the income level of participants?**
  7% earned less than $20,000, 29% between $20,000 and $40,000, 21% between $40,000 and $60,000, 7% between $60,000 and $80,000, 7% more than $80,000, and 29% preferred not to answer
- **How were they recruited?**
  Participants were selected based on explicit criteria from the AskingCanadians™ and the clients of Community Care Access Centres

participants indicated that these supports are typically not available, only minimally available (e.g., for three to four hours per week) and/or require payment. As a result, participants noted that caregivers end up having to take care of the home as well as the person. Such gaps in home and community care were viewed as resulting not only in the overall needs of older adults not being met, but also caregiver burnout.

A few participants also worried that keeping older adults at home could increase social isolation for both older adults and their caregivers. Specifically, some indicated that staying at home can result in a lack of human contact and lead to serious depression, which were seen as issues that are not typically addressed proactively through currently available home and community supports.

Most people don't know about available services, and those who do often face challenges in accessing them

The third set of challenges raised by participants was the lack of awareness about home and community care services currently available. Participants generally agreed that efforts to raise awareness (e.g., through education or advertising) about home and community care are limited. Participants indicated that accessing services is currently more of a "learn as you go" experience rather than having everything clearly spelled out in one place and in a way that makes it clear who can access what and where. They also pointed out that technology is not harnessed in a way that lets people know what they could access in a given situation or context.

In addition, participants indicated that those who are aware of the availability of these services often face challenges in accessing them. All participants were in agreement that citizens should be entitled to the same care and support regardless of where they live or who they are. Yet, participants recognized the existence of important barriers to accessing home and community services, especially linguistic, cultural, financial and geographic (i.e., people living in rural versus urban areas). As one participant said: "We need to deal with the issue of providing healthcare that is accessible to all." Several participants indicated that without informal/family caregivers willing to be strong advocates and capable of playing this role, many older adults will not access the types of home and community care services needed even if they are available to them.

Electronic health records and e-health initiatives are long overdue

There was a general frustration among participants that it has taken so long to develop and implement electronic health records and other e-health initiatives. One participant talked about the critical importance of such a system by indicating that "the objective is noble and it is a building block for any system that works effectively, by allowing easy access to patient data." Participants generally agreed that the lack of a central resource for each individual makes coordination and system navigation much more challenging. Another participant expressed a wish for "a central computerized system where everything is focused in one spot." A few participants spoke about local initiatives (e.g., the InfoWell patient portal offering personalized health information and tools, as well as links to community programs) as examples of initiatives that should be scaled up at the provincial level.

Long-term planning at the individual and system levels is limited

Participants indicated that there was a lack of planning at both the individual and system levels regarding the future home and community care needs of older adults. At the individual level, many participants said that older adults are often more preoccupied with their financial situation than their health, but there is a need to attend to both. Some participants indicated that they were concerned that their ability to pay could become a limiting factor for accessing important home and community care services. They emphasized that older adults are now living much longer than what they had planned for financially.

Participants also agreed that there has been a lack of proactive short-, medium- and long-term planning at the system level. One participant argued that long-term planning can be particularly challenging given that the care needs of older adults may be changing with every generation, and that we are likely facing a temporary situation given that baby boomers are aging. Participants were also concerned about the affordability of home and community care services at the system level. While some participants worried about how the province could possibly afford to provide all the services that are needed to meet the future needs of older adults, others argued that the financial resources were available but needed to be reallocated. For example, one participant stated that "we [the province] actually have more money than we realize, but it's not being allocated in the ways that it should be."

"We need to get beyond the nuclear family to the 'chosen family'."

Discussing the options:

How can we address the problem?

After discussing the challenges that together constitute the problem and its causes, participants were invited to reflect on three options (among many) for meeting the future home and community care needs of older adults in Ontario:

1) designing a system that meets the needs of older adults who make it to 85 in good health;
2) designing a system that meets the needs of older adults who have two or more chronic health conditions but still enjoy a good quality of life; and
3) designing a system that meets the needs of older adults who are socially isolated and suffering from many chronic health conditions.

The three options can be pursued together or in sequence. A description of these options, along with a summary of the research evidence about them, was provided to participants in the citizen brief that was circulated before the event.

Option 1 – Designing a system that meets the needs of older adults who make it to 85 in good health

Participants generally agreed that people who make it to 85 in good health do not need a lot of formalized home and community care services, and are likely not in contact with Community Care Access Centres (in contrast with the populations described under options 2 and 3 who are more likely to use the services they offer). Nevertheless, participants noted that this population likely needs periodic support to help them with health issues that may arise, and/or to engage in activities that promote good health.

Five values-related themes emerged during the discussion that were identified as being important for guiding home and community care for this population:

- fairness (in terms of access to affordable home and community care);
- patient-centredness;
- empowerment (through information sharing and work opportunities);
- population-health orientation (a system designed to promote active lifestyles and maintain good health); and
- collaboration (between the health system and other sectors).

Box 3: Key messages about designing a system that meets the need of older adults who make it to 85 in good health (option 1)

- This population may need periodic support to help them with health issues that may arise, and/or to engage in activities that promote good health.

- Five values-related themes emerged during the discussion:
  - fairness (in terms of access to affordable home and community care);
  - patient-centredness;
  - empowerment (through information sharing and work opportunities);
  - population-health orientation (a system designed to promote active lifestyles and maintain good health); and
  - collaboration (between the health system and other sectors).

Overall, participants emphasized the need to ensure fairness in terms of access to home and community care programs, services and supports. These should be accessible in different ways based on an individual's comfort zone or specific preferences, such as online, over the phone or in-person, and directly or through

their family doctor. Participants also expressed concerns about ensuring the affordability of home and community care, both at the individual level and at the system level.

Participants also emphasized that home and community care should be patient-centred. They indicated that care should be attuned to the specific needs of each individual, which included linguistic and cultural needs.

There was also broad-based support for a system that empowers both older adults and their caregivers. One possible approach that was identified to achieve this was to support public awareness campaigns about existing home and community care services that are available. Participants suggested that available services (e.g., home maintenance, house work, etc.) should be advertised and promoted so that people know what they can access. This was noted as being especially important for services that are subsidized and can be accessed by those who might not otherwise be able to afford them. Some participants also supported the idea of a centralized information network (or 'one stop-shop') that can provide information about what services are available, and link people with the support they need. Others suggested 'piggy-backing' on common dissemination mechanisms that could reach almost everyone (e.g., hydro bills, tax bills, etc.) as a way of broadly increasing awareness of what is available. In addition, participants indicated that older adults may become socially isolated as time goes by. They emphasized the need to encourage opportunities for older adults to re-engage in the labour market for those who are healthy and still want to work. This was seen as a way to maintain social engagement while supplementing their income.

Participants also highlighted the importance of having a system that values the health of the population. They called for healthcare providers to be more proactive in supporting initiatives to promote active lifestyles and maintain good health.

Participants supported greater collaboration to ensure that the health system was fully integrated within and beyond healthcare. Such collaboration would ensure that the full array of social determinants of health is considered. For instance, participants emphasized the need for safe and affordable housing to meet the needs of older adults. They also pointed out that home maintenance should be more readily available in order to maintain older adults in a healthy home.

Option 2 – Designing a system that meets the needs of older adults who have two or more chronic health conditions but still enjoy a good quality of life

Participants generally agreed that optimally designing a system that meets the needs of populations for both this and the third option is crucial, because getting the system right for those with the most complex care needs likely means that it will work well for the rest.

Three values-related themes emerged during the discussion that were identified as being important for guiding home and community care for this population:

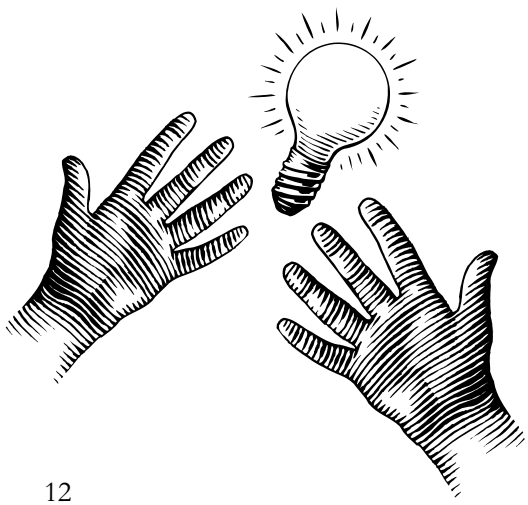
- fairness (in terms of access to coordination support and to personal health information);
- collaboration (among providers and citizens); and
- competence (of volunteers and personal health workers).

Participants emphasized that everybody should have timely access to coordination support and to their personal health information. Participants pointed out the need for patient navigators who could make referrals to and coordinate the full spectrum of services needed by older adults with multiple chronic health conditions. They also said that electronic health records and other e-health initiatives would be critical in facilitating the work of patient navigators, by ensuring the portability of patients' health information from one health provider to another.

Participants then discussed the need to improve collaboration among healthcare providers. Most participants agreed about the need to provide more team-based care to people who have multiple chronic health conditions, which would include a wide range of providers (pharmacists, practical nurses, etc.). While agreeing about the need for team-based care models, some participants emphasized that all care teams should have a clear primary contact for patients.

Participants also indicated that there is a need for greater collaboration among citizens in general. They emphasized the need to harness the energy of volunteers, particularly older adults helping each other. They supported the idea of a tax credit for those who volunteer extensively as a way to promote and reward the collaborative work being done and provide them with needed financial support.

Other participants emphasized that what's most important is having volunteers who have the experience to provide care for those with complex care needs (e.g., helping older adults with activities of daily living and/or medication assistance). Some expressed concern that volunteers (as well as personal health workers) currently do not have enough training to deal with more complex issues, such as Parkinson's disease, dementia, and multiple chronic health conditions.



Box 4: Key messages about designing a system that meets the needs of older adults who have two or more chronic health conditions but still enjoy a good quality of life (option 2)

- Three values-related themes emerged during the discussion:
  - fairness (in terms of access to coordination support and to personal health information);
  - collaboration (among providers and citizens); and
  - competence (of volunteers and personal health workers).

- Patient navigators are needed to make referrals to and coordinate the full spectrum of services, and their work could be facilitated by electronic health records and other e-health initiatives.

- There is a need to have greater team-based care involving a wide range of providers (pharmacists, practical nurses, etc.), but a primary contact is necessary among each team.

- The energy of volunteers should be harnessed, but such volunteers should be trained to deal with older adults with complex care needs.

Option 3 – Designing a system that meets the needs of older adults who are socially isolated and suffering from many chronic health conditions

Participants generally agreed that it was this group – older adults who are socially isolated and suffering from many chronic conditions – that is most likely to need support from Community Care Access Centres. During the discussion, solidarity emerged as the main value-related theme that should guide home and community care for this population.

Specifically, participants generally agreed that the system should promote strong and compassionate relationships with socially isolated and vulnerable older adults. Participants discussed strategies to address isolation, varying from a 'buddy system' (i.e., two people who are able to monitor and help each other), home visiting, regular telephone contact and the use of advocates/coaches. Such mechanisms were identified as being helpful to support ongoing contact, rapidly identify older adults who are in need as well as to engage hard-to-reach populations.

Participants debated about the value of encouraging this group to stay at home, especially if they are not socially engaged and have no siblings or extended family. One participant encouraged a redefinition of the traditional family for older adults, and especially those who are socially isolated, saying "we need to get beyond the nuclear family to the chosen family." That participant argued that older adults must be able to redefine their family based not on biological bounds, but instead on language, values and/or culture. She also encouraged the development (and promotion) of assisted living facilities that are adapted for people from different linguistic and ethnocultural backgrounds, which would provide a rich and dynamic environment that could re-engage older adults socially.

While participants generally agreed that all three populations needed informal/family caregivers who could play the role of advocates to get the care they need (and who can follow through with each person through the stages of their life), they said that it was particularly true for those who are socially isolated and thus, the most vulnerable.

Box 5: Key messages about designing a system that meets the needs of older adults who are socially isolated and suffering from many chronic health conditions (option 3)

- Solidarity emerged as the main value-related theme during the discussion.
- The system should promote strong and compassionate relationships with this population.
- Various strategies could be used to address isolation, such as a 'buddy system,' home visiting, regular telephone contact and the use of advocates/coaches.
- Assisted living facilities that are adapted to people from different linguistic and ethnocultural backgrounds would provide a rich and dynamic environment that could re-engage older adults socially.
- This group particularly needs informal/family caregivers who can play the role of advocates to get the care they need.

"One is only one voice, 14 voices are stronger and 400 even stronger."

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

After discussing the three options (among many) for meeting the future home and community care needs of older adults in Ontario, participants examined potential barriers and facilitators for moving forward.

Participants identified two key barriers to overcome in order to move forward: one financial and one attitudinal. First, participants debated about whether funding was lacking to provide the full range of home and community supports that are needed to allow older adults to live at home for as long as possible. In doing so, participants generally agreed that a reflection is required to assess "where the money is going," how it is currently being allocated, and to ensure that the fee structure is tied to quality of care provided and the health of the population being served. Second, participants discussed the view held by some that too many people rely on the government to bring about change. Instead, several argued that creating change is really about an "us" mentality and being able to move forward together.

Panel participants also suggested two strategies that could be used as facilitators to change: 1) involving the mass media to raise public awareness about the issue; and 2) developing an intersectoral strategy. Participants generally agreed about the need to shed more light on the issue of meeting the future home and community care needs of older adults, and suggested involving the mass media in a large-scale public awareness campaign. One participant emphasized the need to mobilize the public on this issue in order to create a 'burning platform' by stating that "one is only one voice, 14 voices are stronger and 400 even stronger." Participants also said that the development of an intersectoral strategy was necessary to meet the future home and community care needs of older adults in the province. Some noted that the government does have a role in addressing the issue, but that implementation also requires enhancing the engagement of communities, organizations and charities (within and beyond the traditional healthcare boundaries) that can have a real impact on top of what the government is doing.

Discussing how to move forward

As the citizen panel concluded, participants expressed various wishes for home and community care in Ontario. First, the health system should be driven by compassion in order to provide the home and community care needed to those most in need. Second, the health system should be more proactive to seek older adults and informal/family caregivers in need. Participants emphasized that those who are unaware of current services available, socially isolated, or incapable of advocating for themselves, will never seek help. Third, the health system should shift its focus from a sickness to a wellness system that keeps people living healthy lives at home and in the community whenever possible. As one participant noted: "[We need to] invest more money into the community instead of shoving people into hospitals." Lastly, there is a need to speed up change. Participants expressed a sense of urgency to establish e-health initiatives, as well as one-stop-shopping services and referrals to what people need. As one participant pointed out: "[We] need to implement now because 10 years from now is too late."

Acknowledgments

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Conflict of interest

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