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## *Strengthening Care for Frail Older Adults in Canada*

### 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 13 August 2016, the McMaster Health Forum convened a citizen panel on how to strengthen care for frail older adults in Canada. The purpose of the panel was to guide efforts to strengthen care for frail older adults in Canada. 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 strengthening care for people with frailty in Ontario: 1) the complexity of frailty makes it challenging for all involved to understand, identify and manage; 2) frail older adults and those at-risk for frailty are not always proactively identified and linked with services they need; 3) lack of centralized information for patients and providers to support coordinated care and self-management; 4) caregivers face many challenges and have few supports available to them; and 5) lack of collective governance perpetuates fragmentation in the system.

Participants were supportive of greater access to activities that would help to prevent frailty or the onset of frailty for those who are ‘pre-frail’ (element 1) with a strong preference for increased information and media campaigns on frailty and healthy active aging. In deliberating how best to manage the burden of frailty (element 2), participants emphasized the importance of communication with providers who are equipped with the necessary skills to care for complex patients. Participants discussed at length the important role that caregivers play in supporting the care of frail older adults, and emphasized the need for caregiver-specific social and financial supports. Several values-related themes emerged during the discussion about these elements, with three emerging with some consistency: 1) collaboration (in delivering care for patients, and through the increased sharing of information, particularly for referrals to and coordination of care with specialists); 2) empowerment (of patients to seek care and manage their health, of caregivers with needed tools to assist managing the care of family members and friends, and of patients and caregivers in having access to needed health information); and 3) credibility (of information for patients and caregivers, of providers with the necessary training, and of resources to manage complex patients).

Throughout the deliberations, participants viewed several factors as important for implementation: 1) increased collaboration between providers and across settings of care to better manage the needs of frail older adults; 2) increased consistency across communities and provinces in the services available and standards that these services should meet; and 3) enhanced accountability to ensure that any reforms are successfully implemented as designed.



Strengthening care for frail older adults requires addressing many challenges, including the complexity of frailty, the need for outreach services to frail older adults, the lack of centralized information for patients and providers, and the social and economic burden placed on caregivers.

## **Discussing the problem:** Why is strengthening care for frail older adults necessary but challenging?

Panel participants agreed that with increasing numbers of older adults in the country, strengthening care for frail older adults is an important and growing issue across Canada. In sharing their personal experiences as both individuals at-risk of one day becoming frail, and as caregivers for friends and family who are managing symptoms of frailty and its interactions with other chronic conditions, participants individually and collectively focused on five challenges:

- the complexity of frailty makes it challenging for all involved to understand, identify and manage;
- frail older adults and those at-risk for frailty are not always proactively identified and linked with services they need;
- lack of centralized information for patients and providers to support coordinated care and self-management;
- caregivers face many challenges and have few supports available to them; and
- lack of collective governance perpetuates fragmentation in the system.

## The complexity of frailty makes it challenging for all involved to understand, identify and manage

Participants recognized the challenge in defining and diagnosing frailty, acknowledging that symptoms of frailty look very different between people, and that they often interact with chronic diseases or other health deficits. Many participants agreed that this makes it challenging to identify early symptoms of frailty in themselves or in friends and family members. Participants noted that the complexity of frailty also makes it difficult to know how to communicate to clinicians the symptoms or challenges that they face.

Participants agreed that the complex nature of frailty not only limits the ability of individuals to recognize that they (or those they care for) require care and support, but also the ability of health professionals to identify frailty in their patients. Most agreed that a key part of the struggle to identify frail adults is that unlike most other health conditions, it lacks a discrete 'diagnosis' given the complex interplay of physical, social and emotional factors that can contribute to frailty. While participants recognized this limitation, many felt that clinicians also did not have access to the necessary tools or competencies that could be used to identify those who are frail, or to monitor at-risk patients.

### **Box 1: Key features of the citizen panel**

The citizen panel about strengthening care for frail older adults in Ontario had the following 11 features:

- 1) it addressed a high-priority issue in Canada;
- 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.

Finally, participants discussed the broader implications of the complex nature of frailty. In particular, several participants expressed that inconsistent definitions or understandings of frailty can restrict public conversation on frailty and aging, which was something that all participants agreed is lacking, but urgently needed.

## Frail older adults and those at-risk for frailty are not always proactively identified and linked with services they need

Building on the challenges of defining and diagnosing frailty, many participants generally agreed that frail older adults living in the community and those at-risk for becoming frail are not always proactively identified. As a result, many participants pointed out that that many frail or ‘pre-frail’ older adults and their caregivers are not linked with the services they need.

Most attributed the lack of proactive identification to the challenges in ‘diagnosing’ frailty, and patients and physicians failing to recognize early warning signs, which results in missing possible opportunities to intervene and avoid further declines in health. Several participants identified that many frail individuals may not be aware that they should seek care, or may resist seeking care for fear of losing independence, despite

### 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?**  
16
- **Where were they from?**  
Region covered by Toronto and the Greater Toronto Area, Niagara-on-the-Lake, Kingston, Waterloo, Winnipeg, Montreal and Halifax.
- **How old were they?**  
18-24 (0), 25-44 (2), 45-60 (5), 65 and older (9)
- **Were they men, or women?**  
Men (7) and women (9)
- **Were they living in urban or suburban settings?**  
Urban (8), suburban (6) and rural (2)
- **How many were living with a chronic condition?**  
Living with one chronic condition (6)  
Living with two chronic conditions (5)  
Living with three chronic conditions (2)  
Living with more than three chronic conditions (2)
- **How many were providing care or support to a frail older adult?**  
To someone who is currently frail (1)  
To someone who will likely be frail in the near future (2)  
To someone who is frail with one chronic condition (1)  
To someone who is frail with two or more chronic conditions (1)  
Not a care provider (4)
- **What was the income level of participants?** 6% earned less than \$20,000, 13% between \$20,000 and \$40,000, 6% between \$40,000 and \$60,000, 19% between \$60,000 and \$80,000, 37% earned more than \$80,000, and 19% preferred not to answer.
- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panel

being, as one participant described, “one small incident away from becoming frail.”

Participants also discussed that individuals may face stigma in seeking care and, as a result, may resist sharing challenges they are having for fear of being a burden on their social-support systems. For example, one participant mentioned that their father “would speak and listen to anyone but his own kids” when it came to his health.

There was general agreement among participants that many older adults see their clinician only after significant decline in their health. Participants indicated that proactively receiving care for symptoms of frailty before they progressed was important, and suggested that clinicians should be closely monitoring patients for signs of deterioration. Participants further identified that these services are especially needed for individuals living in social isolation and those in rural and remote communities, who may be further removed from either a clinician or social group that could recommend seeking care.

## Lack of centralized information for patients and providers to support coordinated care and self-management

Participants discussed the lack of consistently available information in two primary ways:

- limited availability of citizen-friendly information about frailty and when and where to seek care; and
- absence of medical health records that can be shared between providers as well as with patients and/or caregivers.

Without an accurate diagnosis or definition of frailty, participants discussed how they often turned to online resources for assistance in diagnosing symptoms or for recommendations on where to seek care. Participants overwhelmingly agreed that there is a lack of easily accessible, user-friendly information available, and expressed frustration with not knowing what internet resources could be trusted as reliable sources of health information. They further emphasized that even before you start looking for resources there are no public campaigns or media efforts to attract attention to frailty or health deficits in aging. One participant questioned why programs such as ‘Participation’ had not been started for frailty. There was general agreement that this type of proactive communication was necessary to keep the burden of frailty from growing.



Further, participants felt strongly that medical information is not collected or used effectively, including not being accessible to caregivers. Participants discussed how, in the absence of an electronic health record, caring and coordinating care for patients with complex needs is challenging. Moreover, others indicated that this leaves caregivers to navigate a complex system without the information they need and without coordinated support from the clinicians providing care. One participant explained that they “felt like [they] were running around a maze in the dark” while trying to navigate and coordinate services for their mother.

Building on this, several participants specifically expressed frustration about not having easy access to the medical records and medical documentation of the people they care for, noting that this limits their ability to manage the care of their family members or friends. Numerous participants shared their experience of caring for a parent and how not having access to important health information led to misunderstandings between patient, clinician and caregiver over what instructions were provided.

While the need for electronic health records was agreed on, some participants acknowledged the challenges of achieving interoperability between medical record systems to make them consistently available within a province and across the country. Some specifically noted that the slow pace of change was largely attributable to privacy considerations, which are important to address before implementation.

## Caregivers face many challenges and have few supports available to them

Many of the participants indicated that they are or were previously caregivers for a frail older adult, and shared the difficulties they face or have faced in providing care for family and friends. One participant described it as “an extremely unappreciated job” with very few supports available. The participant further expressed that the supports that do exist often require out-of-pocket payment and/or are not sufficiently flexible to caregivers’ schedules and needs.

Similarly, many described having to be advocates or champions for the people who they were providing care for, and that this role was extremely challenging given that most were unfamiliar with navigating the health system. However, many also indicated that caregivers typically do not know what to expect in terms of commitment and progression of disease

when they begin providing care. These participants added that this uncertainty can cause stress and difficulty coping.

Lastly, participants shared that as caregivers they faced challenges communicating with health professionals, finding that information often got lost between the providers and the patient before it could get to the caregiver. A number of participants recounted barriers they faced in working in a legal 'grey zone', where information about the patient was not always offered by physicians in efforts to prioritize patient confidentiality. Several participants expressed that they would appreciate being provided with more information regarding the many legal challenges of caregiving, and what they were entitled to as a patient's power of attorney.

## Lack of collective governance perpetuates fragmentation in the system

One participant expressed that they felt there was a lack of collaboration both within and between federal, provincial and municipal governments to address the needs of older adults. Once mentioned, other participants agreed and elaborated on this problem, discussing how the lack of collaboration within and between systems has created uncertainty regarding the division of responsibilities between levels of government, and where to turn for information or services. As a result, participants lamented that without such collaboration, the fragmented approach to care seems likely to persist.

# Discussing the elements of an approach to address the problem

After discussing their views and experiences related to the problem, participants were asked to reflect on three elements of a potentially comprehensive approach for strengthening care for older adults in Canada. These elements included:

- 1) engaging in efforts to prevent frailty or the onset for those who are ‘pre-frail’;
- 2) managing the burden of frailty for older adults; and
- 3) supporting caregivers in their efforts to prevent, delay the onset of and manage the burden of frailty.

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

- collaboration (in delivering care for patients and through the increased sharing of information, particularly for referrals to and coordination of care across providers);
- empowerment (of patients to seek care and manage their health, of caregivers with needed tools and education to assist managing the care of family members and friends, and of patients and caregivers through having access to needed health information); and
- credibility (of reliable information for patients and caregivers, of providers with the necessary training and resources to manage complex patients).

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

## **Element 1** – Engaging in efforts to prevent frailty or prevent the onset of those who are ‘pre-frail’.

The discussion about the first element focused on preventing or delaying the onset of frailty among older adults. As described in the citizen brief, this approach could include:

- using data and screening tools to proactively identify those at risk for frailty;
- providing information and supports in different settings (e.g., seniors’ residences, healthcare facilities) for approaches that promote healthy aging and prevent frailty;
- using physical and occupational therapy to improve strength and functioning; and
- enhancing home-based care and support (e.g., transportation) to help older adults live at home for as long as possible.

Four values-related themes emerged that participants felt were important for preventing frailty or preventing the onset for those who are ‘pre-frail’:

- access (to credible information, to regular geriatric assessments and to services and interventions that will help to delay the onset or progression of frailty);
- empowerment (of patients and their caregivers with information and education to manage their health);
- collaboration between the health system and other sectors (so that efforts to prevent the onset of frailty take into account additional social factors); and
- equity (to ensure all older adults have access to services regardless of ability to pay).

In valuing access, participants expressed preferences for having easy-to-find information and services that promote better health and prevent the onset of frailty. As part of this, participants called for increased media attention on frailty and aging. In particular, suggestions were made for public service announcements similar to the ‘Participation’ campaign that could draw attention to early symptoms, and for places where individuals can seek help or community programs that help to promote strength and well-being among older adults. Participants expressed the importance of these campaigns targeting not only older adults, but younger generations as well to inform future decisions and promote ongoing awareness. Participants suggested that such efforts could be achieved in several ways, including targeted campaigns in community newspapers, embedded health-promoting messages and activities as part of programming in local organizations (e.g., the Lions Club), and recruiting high school students for required community service contributions (e.g., by having them learn from and help frail adults). One participant discussed the importance of

this information being citizen- and age-friendly, ensuring that the media portrayal of aging is positive and works to avoid stigma.

Participants valued the availability information, as many felt it empowered them as caregivers and as future older adults to become involved in their care earlier on.

In discussing available tools and approaches to identify symptoms of frailty, participants acknowledged the limitations of current screening tools. Given the limitations in these approaches, participants expressed a desire to instead have better access to geriatric assessments and ongoing monitoring of their health, to avoid possible incidents and promote early intervention. They supported continued efforts to develop screening tools and assessments that can be used by general practitioners.

Participants discussed the need for better access to health-promotion and disease-prevention services. One participant described current services for frail adults as a “patch-work” and went on to explain that they are inconsistently accessible between geographic areas. Given this, participants called for increased flexibility and affordability for inclusive community programs such as swimming and exercise classes, with one participant expressing that “seniors can accept their limitations if they have a zest for life and feel included in the community.” In calling for better access to programs and services, participants expressed the need for a gatekeeper or ‘responsible provider’ who could provide individuals and caregivers with the referrals and information they require. However, participants expressed frustration with the need to pay out-of-pocket for select services such as physiotherapy and occupational therapy, and expressed the importance of having these services equally available and affordable to all Canadians regardless of where they live or their ability to pay.

Finally, participants expressed that newly developed or enhanced information and services (e.g., media campaigns or physical activity programs) take into consideration additional

**Box 3: Key messages about engaging in efforts to prevent the onset of those who are ‘pre-frail’ (element 1)**

Four values-related themes emerged that participants felt were important for engaging people in efforts to prevent the onset of those who are ‘pre-frail’.

- Access (to credible information, assessments and services);
- Empowerment (of patients and caregivers);
- Collaboration between the health system and other sectors; and
- Equity (in access to and availability of services).

factors outside of the health system that contribute to an individual's risk of becoming frail. Participants mentioned the importance of considering transportation, fees and equipment required when planning for these services, in order to remove potential access barriers.

## **Element 2** – Managing the burden of frailty for older adults

The discussion about the second element focused on helping frail older adults manage the burden of frailty on their lives. This could include making care more integrated and 'person-centred', which the citizen brief described as:

- ensuring patients receive care when they need it;
- supporting the engagement of patients and their caregivers in their care; and
- supporting seamless transitions between settings.

Three value-related themes emerged that participants felt were important for guiding efforts to manage the burden of frailty:

- trusting relationships between patients, providers and organizations within the health system (to encourage frequent communication between providers and between patients and providers)
- competence (of providers to manage complex needs); and
- collaboration between health systems and other actors (to encourage a holistic view of patients).

Just as in element 1, participants expressed the need for clear communication and information from providers as well as more supports in knowing where and when to seek care. One participant reiterated how important it is for any information provided to patients or caregivers to be 'user-friendly' for older adults (e.g., available both online and in hard copy, delivered by a trusted and reliable source and are easy to understand).

Participants also valued a trusting relationship with providers who are able to engage and communicate clearly with patients and their caregivers. Many participants recounted the challenges they have had in the past, both as caregivers and as patients, and many highlighted not having sufficient time with clinicians to clearly articulate their questions and concerns. Sufficient time with clinicians was also highlighted as particularly important given the need for clinicians to have a holistic perspective of the patient (i.e., taking into account factors other than just health symptoms), and to provide information and referrals tailored to an individual's personal resources and unique circumstances.

Towards this goal, participants suggested changes to the competencies and skills that providers have to ensure they are sufficiently trained to deliver care to older adults. Participants discussed how clinicians are now expected to manage more complex patients and that their skills need to adapt to this change. To do this, participants thought team-based models of care should be prioritized for those who would most benefit from them, and that concerted efforts should be made to improve coordination between providers and settings of care. In discussing team-based models, participants shared their experiences with accessing care through models such as Family Health Teams and Community Health Centres in Ontario, and indicated a strong preference for models that provide ‘one-stop shopping’. Participants suggested that coordination could be further enhanced between providers through the development and use of interactive electronic health records.

**Box 4: Key messages about managing the burden of frailty for older adults (element 2)**

Three values-related themes emerged that participants felt were important for guiding efforts to manage the burden of frailty.

- Trust (in the relationship between patients, providers and caregivers)
- Competencies (such that providers are trained to better manage complex conditions)
- Collaboration between health systems and other health sectors (to connect patients with care beyond the health sector that takes into consideration their unique needs)

### **Element 3** – Supporting caregivers in their efforts to prevent, delay the onset of and manage the burden of frailty

The discussion about the third element examined ways to support caregivers in their efforts to delay the onset of and manage the burden of frailty, which was described in the citizen brief as possibly consisting of efforts to:

- address the economic security of caregivers through financial programs (e.g., flexible work arrangements or tax deductions for caregivers);
- engage caregivers in decision-making about how care and support is organized to ensure it is appropriate for their needs; and
- provide education and supports to reduce caregiver burden and to help them cope and build resilience.

Two values-related themes emerged that participants felt were important for guiding efforts to support and enhance the experience of caregivers of frail older adults:

- patient- and caregiver-centred care (to ensure services are designed to meet the unique needs of both the patient and the caregiver); and
- empowerment and appreciation (to ensure caregivers have the necessary information to provide care and feel appreciated for the work they do).

As previously mentioned, the majority of participants indicated that they had been caregivers or that they anticipate being caregivers in the near future. Participants expressed the many challenges faced in finding services and supports, with one participant saying that “almost everything is designed to help the person in need, and it feels like there is very little consideration for the person who is supporting them.” This participant further articulated that the right kinds of supports would go a long way in easing the burden of caring for family members and friends.



Participants discussed how the first step in providing supports is ensuring the right information is available to empower caregivers to manage the needs of the family and friends who they support. This includes what they can expect in providing care, how symptoms or diseases will likely progress, and basic information on what services exist and how to navigate the health system. One participant mentioned the development of caregiver classes or caregiver workshops on different subjects, which many subsequently agreed would be a helpful resource. Participants further added that meeting and discussing caregiving with others in similar situations would provide some social support and the opportunity to learn from the experiences of others who have encountered similar challenges.

**Box 5: Key messages about supporting caregivers in their efforts to prevent, delay the onset of and manage the burden of frailty (element 3)**

Two values-related themes emerged that participants felt were important to provide support to caregivers managing the care of older adults.

- Patient- and caregiver-centred care (such that services are designed to support and acknowledge the needs of caregivers as well as those of patients)
- Empowerment and appreciation (to empower caregivers with the necessary information and skills to effectively manage care as well as formally acknowledging their work through social and financial supports)

While the literature found mixed evidence for the benefits of respite care, participants overwhelmingly supported its increased use across Canada, with one expressing that even a two-day vacation “made a huge difference.” Participants noted that these services should be widely advertised and sufficiently flexible to meet the broad array of caregiver needs.

The financial burden of caregiving was also discussed with many participants expressing the challenge of taking time off work and being able to afford equipment, and that even small financial relief could help. Participants suggested the implementation and advertising of select tax exemptions and tax credits for caregivers and the resources they may use in the process of managing care. As another example of an approach to providing financial relief, one participant recommended initiatives to help offset expenses for medical equipment and transportation often incurred by caregivers.

Finally, participants recognized that these changes may take time to implement and suggested in the short term that caregivers could be equipped with select resources to help

them better manage care. Specific suggestions included emergency response kits to place on the refrigerator, medication and appointment log books, and guides to health and social services such as an Ontario guide to programs and services for seniors.

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

Participants discussed three important factors to consider when planning and implementing reforms. First, participants indicated that ensuring collaboration between providers and across settings should be an essential part of the approach taken to strengthen care for frail older adults and those with other complex needs. Second, several participants called for an increased level of consistency and standards in programming across the country. Noting that while population needs may differ between communities, all Canadians should have access to relatively similar services and quality of care. As one participant stated: “I should be able to move to a different community or province without interrupting my care.” Finally, participants indicated that there should be a focus on increased levels of accountability for reforms to ensure that any reforms are successfully implemented as designed.

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

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