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**Dialogue Summary:
Strengthening Care for Frail Older Adults in Canada**

12 October 2016

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.

Authors

Kerry Waddell, M.Sc., Co-Lead, Evidence Synthesis, McMaster Health Forum

Michael G. Wilson, PhD, Assistant Director, McMaster Health Forum, and Assistant Professor, McMaster University

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funders reviewed a draft dialogue summary, but the authors had final decision-making authority about what appeared in the dialogue summary.

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Dialogue

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SUMMARY OF THE DIALOGUE

Dialogue participants generally agreed with the problem as presented in the brief, which related to challenges in defining and diagnosing frailty, that it affects some Canadians more than others, the complex needs of frail older adults leading to care that is fragmented, and the significant support required from caregivers. They also agreed that while more attention is being placed on frailty and on care for older adults, a number of challenges still remain. Building on this, participants focused on the problem as it relates to four challenges: 1) the health system is not aligned to the needs of frail adults and caregivers; 2) evidence is often not helpful or not sufficient to spur change; 3) no one owns the issue of strengthening care for frail older adults; and 4) there is inadequate recognition of caregivers as a value-added resource to the health system.

Participants generally agreed with the three elements of a potentially comprehensive approach to addressing the problem that were presented in the evidence brief, but identified several considerations for moving forward with them. For element 1 (engaging in efforts to prevent frailty or prevent the onset for those who are 'pre-frail'), participants indicated that increased integration with public health was necessary, and that broader population-focused interventions are needed to make cities more 'age friendly' and to provide education to promote healthy aging throughout one's lifespan. For element 2 (managing challenges faced by frail older adults), participants identified the need for new models of care that are more patient-centred, suggesting specifically the adoption of intermediate care options (i.e., care in the community beyond the scope of primary care, but designed to avoid admission to hospital or long-term care). In discussing this element participants also supported increased patient engagement and the adoption of technology that can both help to coordinate care across health professionals for frail adults and their caregivers. For element 3, all participants agreed that the current level of supports available for caregivers across the country was insufficient. Participants generally agreed that there should be more communication directed to caregivers to help them self-identify and seek support, however, they had mixed views on what supports should be made available. Participants also agreed that caregivers would benefit from technology that could assist them in providing care.

Participants identified four types of activities and considerations that need to be the focus moving forward: 1) engaging the public in discussions on their expectations for primary care, and for home and community care for frail older adults; 2) continuing to support and invest in research on frailty, particularly for assessing patient-relevant outcomes for interventions to prevent and manage frailty and support caregivers; 3) create better alignment between the programs and services needed by frail older adults and their caregivers, and the broader health-system arrangements that are needed to support patient-centred and coordinated delivery of those programs and services; and 4) encourage home-care programs to assess caregivers' needs (not just those of patients), and develop valid support choices that can be made widely available to caregivers.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Participants were enthusiastic about discussing ways in which care can be strengthened for frail older adults across Canada, and in discussing the problem, many participants echoed the challenges presented in the brief, which included:

- frailty is challenging to define and diagnose;
- frailty affects some Canadians more than others;
- frail older adults have complex needs which often leads to care that is fragmented; and
- frail older adults require significant support from informal caregivers.

Building on these, however, participants focused on four additional factors in conceptualizing the problem. We discuss these in detail below.

The health system is not aligned in a way that addresses the needs of frail adults and their caregivers

Participants identified that our current health system is not structured in a way that supports frail older adults or their caregivers, and identified a number of dimensions of this challenge. The prominent challenge identified is the insufficient amount of home and community care available in the system. Participants expressed that provincial and territorial health systems in Canada “were designed to fund hospitals and physicians,” and that the system continues to prioritize these aspects over home and community care. While participants noted that the current federal government has committed to improve funding for home care, another participant was quick to point out that when divided among the population the new commitment added a little under \$40 per person.

Participants also highlighted that the health workforce is missing core competencies that are needed to provide comprehensive geriatric care and address issues along the full continuum of aging. Participants noted that there have been some efforts to increase the education and skills that providers have for addressing the needs of frail older adults, including courses in the medical curriculum on aging and geriatrics. Despite these advancements, some participants indicated that while the system is educating new providers, it is not training or updating the skills of practising physicians to meet the needs of frail older adults or their

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

- 1) it addressed an issue currently being faced in Canada;
- 2) it focused on different features of the problem, including (where possible) how it affects particular groups;
- 3) it focused on three elements of a comprehensive approach (among many) for addressing the policy issue;
- 4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three elements of a comprehensive approach for addressing the problem, and key implementation considerations;
- 5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible options for addressing it;
- 6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
- 7) it ensured fair representation among policymakers, stakeholders and researchers;
- 8) it engaged a facilitator to assist with the deliberations;
- 9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: “Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed”; and
- 10) it did not aim for consensus.

We did not aim for consensus because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health-system leaders typically need to engage elected officials, boards of directors and others on detailed commitments.

Participants’ views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

caregivers. Moreover, participants also pointed out that the health system has moved away from encouraging general skills to instead emphasize specialties and specialist providers. Highlighting the latter point, one participant noted that “the system right now is enthralled with ‘-ologists’ and it has missed out on the more general understanding and complimentary set of skills that can support these older adults.” The same participant continued by discussing how primary care needs to play a larger role than it currently does, noting that these professionals (both physicians and nurses) are best suited to take a broader view of the needs of patients and their caregivers.

In focusing on primary care, participants mentioned that the ideal model for caring for frail older adults was undoubtedly an interprofessional team-based approach that provides coordination across providers and settings to address the complex needs of these patients and their caregivers. However, many participants expressed frustration with the long-standing difficulty in implementing these types of care models, which several attributed to the structure of incentives in the health system, particularly the challenges that fee-for-service arrangements pose. One participant noted that “we have figured out how to fund for quality and volume, but there is no mechanism to fund teams to deliver care.” Participants emphasized that it isn’t sufficient to rely on providers’ goodwill to coordinate care, and instead the system will need to be reoriented to support this kind of care, particularly when engaging different health professionals across the health and social care spectrum who are all paid in a variety of different ways. However, some participants noted that this is not a new challenge and is one that has been historically very difficult to change.

Finally, participants discussed that the emphasis on measuring health-system processes rather than on patient-relevant outcomes (including patient and caregiver satisfaction) that provide more meaningful information in evaluations of interventions and pathways of care restricts the understanding of the needs of frail older adults. Participants further emphasized that evaluations should be more inclusive of patient and caregiver voices to ensure the right questions are being asked and the right outcomes are being assessed.

Evidence is often not helpful or sufficient to spur change

Deliberations about the role of evidence to support change initially echoed the challenge outlined in the evidence brief related to the difficulty in defining frailty. Participants highlighted the uncertainty of the literature around what frailty is, and therefore who could actually be ‘diagnosed’ or identified as frail makes pursuing changes to the health system very difficult. Related to this, participants identified two challenges that relate to evidence that were not included in the evidence brief. The first was the inherent bias towards a medical perspective in the literature. One participant discussed how because of the rigour associated with and subsequently the emphasis placed on randomized control trials within much of the medical literature, the evidence used to inform efforts to support frail older adults and their caregivers tends to disproportionately draw on these types of studies. However, participants further noted that due to the pressures within the medical profession to publish high volumes of research, that the literature from this perspective is more common than research from a broader social-science perspective, which has much to offer in terms of informing efforts to strengthen care for frail older adults and their caregivers. One participant explained this by stating: “We have a tendency to view things that are not written as a randomized control trial as low quality, but it is important to remember that while it is a necessary component, it is by no means sufficient. To design a system change, we have to bring in our experience of the real world.”

The second challenge participants found with the existing body of literature was a tendency for the evidence to focus on specific interventions, with very little of it relating to system-level changes that could support frail older adults and their caregivers. Participants emphasized that this limitation contributes to difficulties for policymakers to make evidence-informed decisions about how to reorganize health-system arrangements.

No one owns the issue of strengthening care for frail older adults

Building from the challenges identified above, participants discussed how without supportive evidence and a common understanding of the problem it is difficult to create a compelling case for change. Participants pointed out that even among the dialogue participants who had a specific interest in the topic, there was a wide array of views about what frailty is, the challenges faced and the solutions needed to bring about meaningful change.

Adding to this challenge, several participants noted the lack of a champion for the issue of strengthening care for frail older adults. While participants noted that there are some advocating for change for improving care for older adults and greater coordination of care more generally, few seem to be speaking out about the challenges that frailty will pose in the future, and the changes that will be needed in not only the health system, but in other sectors such as education, infrastructure and finance to comprehensively address the issues at a population level. Without a champion to take ownership of the issue, participants emphasized that creating a burning platform for change and subsequently moving away from the status quo will be extremely difficult. Participants mentioned how this was evident in the lack of priority placed on and political action taken towards strengthening care for frail older adults and their caregivers.

Inadequate recognition of caregivers as a value-added resource to the health system, and the health challenges they face in their role

Finally, participants focused on the pressure placed on caregivers to supplement gaps in home care. One participant highlighted that “we often view caregivers only as a labour resource rather than as a knowledge resource who can contribute to the planning and care of the patient.” Participants emphasized that caregivers are not brought into the care process or considered as part of the care team, despite their critical importance for providing support, and managing and providing care for frail older adults.

This statement further sparked a discussion among the group about the supports that are available to assist caregivers. Some participants mentioned how the current system does not provide help to caregivers in a way that addresses the many health challenges they also face, and instead only provides assistance to them in relation to their caregiving role. For example, many of the services available for caregivers focus on building capacity through education, but neglect their need for health and social services. One participant felt that this is reflected in the way in which we view caregivers, by indicating that “we need to think about their role and how we actually see them in the system – are they cost savers, care partners or a client who has their own rights and needs?” The participant continued by stressing that she believed any efforts designed to take some of the burden off caregivers should reflect this change in view of caregivers as clients with their own set of needs.

Other dialogue participants discussed how there has not been enough thought put into the types of supports that are needed to provide meaningful assistance to caregivers. For example, a number of participants discussed how formal home-care services will only provide personal care, but that this is not really what the patient or the caregiver needs. One participant mentioned that it is not the personal care that burdens caregivers, but rather other aspects such as meal preparation, shopping for food and other household items, doing dishes and cleaning their home. In addition, another participant highlighted the insufficiencies of providing tax credits particularly for rural and low-income Canadians given that they don’t confer much benefit for those with little to no income.

DELIBERATION ABOUT POLICY AND PROGRAMMATIC ELEMENTS

Participants agreed that the broad elements of an approach to strengthening care for frail older adults will need to focus on preventing frailty or the onset of it for those who are ‘pre-frail’ (element 1), manage the many health challenges faced by frail older adults (element 2), and support caregivers in their efforts to prevent, delay the onset of and manage the burden of frailty (element 3). However, in deliberating about the elements, participants identified alternative framings that could be considered. In distilling the thoughts of many participants during the deliberations, one participant indicated (and many agreed) that the elements could be more helpfully reframed by focusing on function, which would translate into maintaining function for as long as possible (element 1), preventing functional decline (element 2) and protecting caregivers’ functional capacity (element 3). With this reframing in mind, we provide a description of dialogue participants’ views and perspectives about each of the elements.

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

While participants all agreed that more preventive interventions need to be available, the majority of participants’ views about what is needed differed from the sub-elements that were presented in the evidence brief. Participants felt particularly strongly that increasing screening to identify those who are frail or ‘pre-frail’ was a poor use of resources and would prove ineffective. Many of the participants cited literature that does not support the use of screening, and instead, participants emphasized the need to move away from targeted approaches towards population-focused interventions that “shift the curve” of functional decline to keep people healthier for longer. Participants suggested that this must include interventions much earlier in life to keep those in their 30s, 40s and 50s healthy. Several participants suggested that it is during this time of life that many habits that contribute to functional decline are set in motion, and which therefore determine how early and quickly individuals develop deficits in their health.

In thinking about interventions that could prevent frailty or its onset for those who are pre-frail, participants strongly supported two ideas. The first was the notion that both within and beyond the health system there needs to be more discussion about aging, and specifically about what a healthy aging trajectory looks like and how it can be supported. One participant mentioned how “there are so many resources put into financial planning for your older years, but nothing in terms of health planning.” Participants felt it was important that more people are aware of what to expect as they age, and how to prevent many of the common diseases or disabilities that may lead to symptoms of frailty. The second idea for interventions that was deliberated on at length was a focus on changes to the built environment that could help to prevent some of the incidents that lead or increase the likelihood of becoming frail, including the adoption of the healthy aging cities initiative. As one participant shared, these types of interventions can be quite simple (e.g., reducing the height of steps to make it easier for older adults to climb stairs or increasing the time intervals for crossing the street), but have far-reaching impacts (e.g., preventing falls and making it easier for older adults to remain in their homes, and making communities more accessible for older adults to live in).

While most of the participants agreed that a population approach to “shift the curve” of functional decline is needed, others questioned how far the curve could actually be shifted, and felt that placing all of the resources on population-level interventions was problematic, and that a more nuanced approach could be the better way forward. While no consensus was reached either about what interventions or what populations should be prioritized, participants did agree that since frailty is the result of interactions between an individual’s health, social and physical environments, interventions used need to be sufficiently complex to address each of these components. Participants stressed that this should include considering non-medical settings for efforts to prevent frailty (or functional decline more generally) and “looking at health strategies rather than healthcare strategies.”

Element 2 – Managing challenges faced by frail older adults

In discussing element 2, participants generally supported providing more integrated and person-centred care for frail older adults, recognizing that the complex needs of these individuals requires a coordinated, team-based approach that engages patients and their caregivers in the process of care. Many participants emphasized that such team-based approaches to care need to be grounded in community-level care, rather than taking acute-focused care pathways and applying them to care delivered in the community. Indeed, many indicated that it will be critical that home and community care become a funding priority for each the federal, provincial and territorial governments. However, some participants questioned the use of the ‘hospital-at-home’ model, which they felt to be a process that takes care pathways from the hospital and moves them to the patient’s, home thereby leading to a replication of problematic pathways of care and a lack of interprofessional communication, in a similar way to current care in hospitals.

While some participants focused on the best models of care to support frail older adults, other participants focused on additional supports that could help in their care. In particular, one participant spoke to the role that technology can play in creating person-centred care and in engaging patients. They discussed its ability to change modes of practice, its ability to “assist in the process of monitoring patients remotely, to run tests and to connect people together, both patients and professionals.” Some participants pointed out that many frail older adults or their caregivers (many of whom may also be older) may not feel comfortable with the use of technology, but others suggested that it was inevitable for technology to be embraced and critical for the development of patient-centred care.

Participants overwhelmingly agreed that there is a need to acknowledge the patient and their caregivers in the process of care and allow for their participation in care planning. One participant in particular highlighted that they did not think the system was sufficiently respectful of the ability of frail adults to make decisions for themselves. The participant described this by saying “we have to recognize that it doesn’t work that the system limits the decision-making of patients because of their age and their condition. We have to respect the capacity of frail older adults to understand options and trust that they will choose the most appropriate pathway.” As pointed out in element 3, many participants also emphasized the need for caregivers to be meaningfully engaged in the care team and decision-making.

In discussing safe transitions in care, participants brought up the idea of intermediate care to provide an alternative for those who require less resources than in a hospital setting, but more than what home care can provide. Participants were quick to begin referring to literature from the U.K. where intermediate care has been previously tried, and warned against the potential for these institutions to become ‘mini-hospitals’ rather than transition points. Some participants saw the potential for intermediate care to reduce the number of older adults in alternative levels of care, which they highlighted as a long-standing issue that has been difficult to address in many provinces. Other participants, however, emphasized the potential for an intermediate level to keep frail patients away from the intensive care unit where their outcomes can become worse. After discussing this model, participants generally agreed that there are a number of innovative practices that exist outside of Canada, and that intermediate care models should be considered as an approach that could be used to strengthen care for frail older adults.

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

While discussing each of the three elements, participants consistently brought up challenges of how best to support caregivers. At the outset of deliberations, there was much focus on whether and how caregivers and their contributions are valued in the system. Participants noted that caregivers are too often defined by their relationship to the patient as opposed to having their own health-related challenges that need to be recognized in processes of care. This included participants noting how the title of this element frames the caregiver by their role and responsibility in taking care of the patient. Instead, participants suggested the element be re-framed to be focused on ‘caring for the caregiver.’

One participant indicated that challenges self-identifying with the caregiver title may limit some individuals who are providing care to frail adults from accessing supports that have been designed for them. In discussing the role of caregivers, another participant mentioned that the system does not sufficiently recognize the benefits of being a caregiver, and instead of focusing on how caregiving can be a burden, the system “should also play up its ability to improve our relationships and compassion and its role in strengthening our moral fabric.”

While participants agreed that current supports in the health system for caregivers are insufficient, they expressed mixed views about the best solutions to address this lack of support. Some participants believed that solutions should focus on increasing funding for and implementing reforms of primary-care, home-care and long-term care sectors in the country, given that the over-burdening of caregivers is a symptom of important gaps in needed care from these sectors. Other participants, however, felt that caregiving was a process that some individuals would engage in regardless of what primary, home and community care services are available, with one participant stating: “There is something about the role people define themselves in and what they feel their obligations are regardless of how many resources you provide, and this comes from the human aspect – no matter how much money I have my mother would have continued to play the role of caregiver to her husband.”

Those participants who agreed with this viewpoint felt that supports should be designed for caregivers that are attuned to the reality of their roles. Participants discussed financial and technological supports as two approaches that should be considered to help care for caregivers. In terms of financial supports, participants had mixed opinions on whether caregivers should be provided with a caregiving salary, with some viewing this as an important gesture to recognize the work these individuals do, while others were concerned that this may incentivize caregivers to stay out of the workforce. Greater levels of convergence were found for alternative types of funding supports including personal home-care budgets where some of the funds could be allocated to caregivers in their role of caring for and supporting frail older adults. Others suggested changing currently non-refundable tax credits to be refundable in the future. All participants agreed that the federal compassion care benefit did not provide adequate protection from economic or job loss.

As for element 2, participants emphasized the important role that technology could play in supporting caregivers. One participant recognized that the technological supports that are currently funded in the health system are those that support the independence of the patient, and that technologies that could assist caregivers are often excluded. The participant gave examples such as self-washing toilet seats that could help to take away many of the injury-causing work and strain that happens in caregiving. While participants recognized that technologies for caregivers would not be a panacea, they suggested that the development of a block grant for caregivers that could support them in purchasing these simple technologies could be a straight-forward policy to design and implement.

Considering the full array of options

Participants generally agreed about the need for each of the elements, though in many cases were divided on the specific sub-elements of them. Overall, participants affirmed the need for preventive programs, but suggested broader interventions that could be used to shift the entire population curve to improve health and reduce functional decline rather than targeting select risk factors. Across all three elements, participants emphasized the need for greater citizen and patient engagement, increased recognition of the intersections between health and social services, patient-centred models of care, prioritization of funding for home and community care services, and a shift in the way the health system views caregivers to be more inclusive of their roles as partners in care.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Participants identified three implementation considerations related to strengthening care for frail older adults. First, participants identified professional organizations as being a key barrier to change. Participants felt that professional organizations are often hesitant about changes in scopes of practice and working closely in teams (both of which participants thought were necessary to implement patient-centred models of care) for fear of reducing their autonomy in the system. Second, and related to the first consideration, participants discussed how, in the current political environment, making changes to professional funding models would be extremely difficult. Participants described the current fee-for-service arrangement as not being conducive to providing the type of patient-centred and coordinated care that is needed for frail older adults. In particular, participants thought that any change towards value-based payments or shifts towards capitation would be met with resistance from health professionals and associations. However, without a change in the incentives that exist in the health system, participants felt it would be challenging to strengthen care in a way that is aligned with the elements discussed throughout the dialogue. Finally, participants identified the current federal/provincial funding negotiations as a window of opportunity both to create dedicated funding for home and community care, and as a possible entry point to bring awareness to the issue of frailty across government.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

In the last deliberation about next steps, most participants agreed with one individual who suggested that a positive starting point would be to develop a clear understanding of public expectations for providing care for frail older adults. The participant suggested that this kind of conversation can help to define what kinds of supports should be developed and how the system should be changed. The participant saw engaging citizens early in the process of change as a critical next step to strengthening care for frail older adults.

Second, building off one of the challenges and implementation considerations, participants noted the need to continue to support and invest in further research on frailty that uses patient-relevant outcomes to evaluate interventions at the level of programs and services, but also system-level intervention. Such evaluations were seen as essential for strengthening care for frail older adults at the programmatic level (e.g., in determining what practical supports can be most helpful for frail older adults and their caregivers) and at the system level (e.g., to support the implementation of patient-centred and coordinated models of care). Participants felt that in using this evidence they could be more effective in collectively defining a problem and championing efforts to implement solutions.

Third, participants felt that in order to support lasting changes, better alignment is needed between the programs and services that are needed to care for frail older adults and their caregivers, and the broader health-system arrangements that are needed to support patient-centred and coordinated delivery of those programs and services. Participants discussed that this likely requires increased promotion of team-based care,

new funding arrangements including capitation and incentives for coordination, as well as greater system and professional adoption of technological tools for coordination of care and monitoring patients at home.

Finally, participants agreed that home-care programs should be encouraged to provide assessments for caregiver needs in addition to those of patients, and then use those assessments to develop a plan for how to best support caregivers using the resources and programs available. Participants suggested that moving forward with this would require a 'menu' of supports that could be used to help meet the needs of caregivers. Some specifically suggested that such a 'menu' could include direct funding to support caregivers in their role, personal home-care budgets or caregiver friendly work-place policies. Importantly, participants stressed that those designing these supports need to do a better job of considering "what the caregiver values, their role and how an individual who is providing care can be included as a partner in the design of supports and system changes," or as one participant put it "rebalance the status between caregivers and 'cure'-givers."



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HEALTH FORUM

>> Contact us

McMaster Health Forum
1280 Main St. West, MML-417
Hamilton, ON Canada L8S 4L6
Tel: +1.905.525.9140 x 22121
Email: mhf@mcmaster.ca

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