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**Dialogue Summary:
Strengthening Care for People with Chronic Diseases in Ontario**

21 April 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.

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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 agree with the challenges presented in the evidence brief, which related to: 1) the high burden of chronic disease; 2) the challenges associated with providing care for chronic disease, particularly for those living with multiple chronic diseases; 3) the patient not always being put at the centre of care; 4) system features making it difficult to provide accessible, comprehensive, coordinated and continuing care; and 5) system planners, clinicians and patients lacking timely data and evidence. Participants also identified specific challenges related to care for people with multiple chronic diseases, including the lack of focus on patient goals as part of chronic-disease management, the complexity involved in supporting those with multiple chronic diseases, and the potential for some conditions to be de-emphasized or focused on to the exclusion of other conditions. Moreover, participants identified the lack of focus on prevention of chronic disease as a key challenge, indicating that efforts are often not proactive, focused on common risk factors or connected to supports for addressing the social determinants of health (e.g., income and housing).

Participants placed the most emphasis on activities related to putting the patient at the centre of care (element 1) and collecting and using data across all levels of the system to support and enhance chronic-disease prevention and management (element 3), rather than on convening chronic-disease councils to support chronic-disease prevention and management (element 2). However, in calling for a time-limited task force to spur action to strengthen chronic-disease prevention and management in the province, participants did not wholly reject the premise of element 2. To move forward with element 1, participants emphasized the need to: 1) communicate persuasively about the need for a culture shift to support a focus on helping patients achieve their goals; 2) pursue promising models of patient-centred care, scale up the models and approaches that seem to be working, align incentives to support scale-up, monitor implementation, evaluate impacts, and make needed adjustments over time; 3) make better use of existing venues in the community (e.g., pharmacies) where patients already spend time; and 4) recognize that patient diversity requires different approaches for different groups. For element 3, participants indicated that key activities will need to include designing or selecting a manageable number of performance metrics focused on the achievement of patient goals, removing the legal restrictions to sharing data across organizations and sectors, and finding ways to support data sharing and accelerating the move towards patient portals.

Participants agreed that the most important next step is to ‘kick start’ a culture shift and action towards strengthening care for people with chronic diseases, and that enabling this likely requires a time-limited task force (with patients and citizens in leadership roles) with a mandate to articulate a vision along with key policy changes needed to move towards that vision. Participants also emphasized three types of activities that would be needed to support the activities of a task force: 1) supporting innovation through a systematic approach (e.g., through a health-innovation fund) where promising ideas can be considered on a ‘level playing field;’ 2) fostering physician leadership and engagement to support needed innovation and change, combined with leadership from the system level to ensure that the vision is sustained and innovations are spread; and 3) collecting credible data and evidence about new models of care to identify those that are worthwhile to spread.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Dialogue participants generally agreed with the challenges presented in the evidence brief, which related to: 1) the high burden of chronic disease; 2) the challenges associated with providing care for chronic disease, particularly for those living with multiple chronic diseases; 3) the patient not always being put at the centre of care; 4) system features making it difficult to provide accessible, comprehensive, coordinated and continuing care; and 5) system planners, clinicians and patients lacking timely data and evidence to proactively prevent and manage chronic disease. Participants identified several additional challenges, which broadly related to challenges particular to care for people with multiple chronic diseases and the lack of proactive prevention of chronic disease. We describe the specific challenges that participants identified related to these two areas in turn below.

Challenges related to care for people with multiple chronic diseases

Participants identified three broad challenges related to care for people with multiple chronic diseases. First, participants noted the lack of focus on patient goals as part of chronic-disease management. As several participants pointed out, patients, caregivers and providers need help to anticipate and to achieve these goals, whereas current approaches are typically focused on specific chronic diseases, rather than on how to live well with multiple chronic diseases. As one participant stated, “unfortunately, our system has been focused on treating the disease and not the patient.” Another participant added that the attitudinal shift from managing a disease to helping patients achieve their goals (e.g., preparing their meals, better diet and engaging in preferred types of physical activity) as opposed to physiological indicators (e.g., lowering hemoglobin levels) is important but will not be easy.

As noted by several participants, the lack of focus on patient goals has led to there being few guidelines or patient materials on managing multiple chronic diseases, which leaves a significant gap that needs to be filled before progress can be made in strengthening care for chronic diseases. One participant specifically highlighted that this gap will be difficult to fill given that most research that

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 Ontario;
- 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 potentially comprehensive approach (among many) for addressing the problem;
- 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 potentially 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 elements 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.

could be used to develop such materials does not include those living with multiple chronic diseases.

The second challenge identified by participants relates to complexity involved in supporting those with multiple chronic diseases. Many participants indicated that the main challenges include those that have long been the focal point of efforts to strengthen the health system, including those related to:

- providing well resourced and connected primary and home and community care (e.g., needed home and community care is often only partially covered; those with complex conditions need support with coordinating care across providers, settings and sectors);
- supporting integrated specialty care (e.g., patients not receiving timely access to specialists; fragmented care between primary care and speciality care; scheduling/sequencing of hospital visits can make it difficult for patients and their families to manage their care; and telehealthcare often not being used to its full potential);
- access to and supports for appropriate medication use (e.g., many patients do not have access to prescription-drug coverage, which can limit access and adherence for those who lack the means to pay out-of-pocket; and communication between providers about medication management can be limited, which is a particularly important challenge for those prescribed several medications);
- supporting self-management (e.g., while self-management is an important part of chronic-disease prevention and management, patients and their families often lack the supports and education needed to manage their chronic disease with confidence);
- ensuring the system is sensitive to the needs of the most vulnerable, who typically also have a higher prevalence of chronic disease (e.g., Indigenous people, immigrants and refugees, those living in poverty and/or those with mental health and substance-use conditions); and
- supporting informal caregivers (e.g., while caregivers are an essential part of the system, their role is often not recognized and supported, and many also simultaneously manage their own chronic diseases).

Lastly, some participants highlighted that an important challenge to be aware of is the potential for some conditions to be de-emphasized or focused on to the exclusion of other conditions. For example, all participants agreed about and several emphasized the importance of promoting greater recognition that providing care to people with a complex condition (e.g., mental health and substance-use conditions or dementia) who also have other chronic diseases is particularly complex. As a result, these participants indicated that clinicians who have a limited amount of time with a patient and caregiver will inevitably have to allocate most of their focus to one condition, rather than being able to engage in a comprehensive and patient-centred visit. As one participant stated, “when someone has a mental illness, that becomes the focus of their care and their other chronic conditions become secondary.”

Lack of proactive prevention of chronic disease

Participants also all agreed with the findings of the citizen panel that there needs to be more focus on the prevention of chronic disease. In particular, participants emphasized that efforts in primary care are typically not proactive. For example, one participant highlighted that actions to prevent chronic disease are not at the forefront of the most recent proposal for transforming the health system into one that puts the needs of patients at its centre. Specifically, the participant indicated that the language in these most recent proposals are about services that would benefit those most in need, and therefore seems to focus on those who are already sick instead of preventing chronic disease in the first place.

Moreover, as part of proactive prevention efforts, participants indicated that a focus on common risk factors (e.g., tobacco use, regular exercise and a healthy diet) is often lacking. Several participants also indicated that prevention is too often framed as being about healthy behaviours, rather than also being focused on supports that can help address the social determinants of health (particularly for those with low incomes and/or in need of supportive housing). Emphasizing this point, one participant indicated that the social determinants of health, particularly poverty, turns something that is already challenging to deal with into a crisis because there is a lack of supports available to intervene quickly and comprehensively to prevent the onset of chronic disease or to prevent those with chronic diseases from becoming sicker.

DELIBERATION ABOUT ELEMENTS OF A COMPREHENSIVE POLICY AND PROGRAMMATIC APPROACH

Participants identified several considerations for moving forward with the three elements of a potentially comprehensive approach that were presented in the evidence brief, which we describe below.

Element 1 - Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care

Participants strongly agreed with the need to pursue changes that put the patient at the centre of care, and identified four considerations for championing the changes needed to achieve this goal. First, participants emphasized the need to communicate persuasively about the need for a culture shift away from care that takes a disease-focused approach to one that instead emphasizes helping patients achieve their goals. Participants viewed this shift as essential given the increasing number of people living with multiple chronic diseases, and the many challenges of providing care to them. Moreover, participants emphasized that such a shift needs to be operationalized carefully given resource constraints in the system.

The second consideration related to how to (carefully) approach operationalizing the changes needed as part of a culture shift. In general, participants indicated that the approach taken needs to include the following essential steps:

- identify and pursue promising models of patient-centred care (e.g., team-based care with a ‘most responsible’ care provider as well as patient navigators to ensure continuity and coordination of care for the most complex patients) and specific approaches that can be part of such models (e.g., decision aids, supports for self-management and personalized care plans);
- scale-up the models and approaches that seem to be working (e.g., e-consults and tele-homecare);
- align incentives to support scale-up (e.g., providing remuneration for clinicians to use e-consults); and
- monitor and evaluate implementation to be able to make needed adjustments over time.

One participant emphasized that as part of this approach, there needs to also be accountability for addressing patient goals, which requires that patients and families are followed by teams, are informed about their progress, and are clear about what they need going forward. Several other participants indicated that this process will need to accept that moving forward with new models does not require the ‘best’ evidence (e.g., randomized controlled trials or longitudinal studies), but can make use of the best available pragmatic data and evidence combined with monitoring and evaluating over time to determine what (if any) adjustments are needed, and whether further spread is warranted.

Third, several participants indicated that putting the patient at the centre of care needs to include efforts to make better use of existing venues in the community (e.g., pharmacies) where patients already spend time, as well as the providers in the community (e.g., pharmacists and EMS providers) with whom patients interact. For example, one participant indicated that there is a need to look at the full range of services in the community that could serve as points of access for delivery of care for patients and their families, and integrate them as part of the province’s shift towards a population-based approach.

Lastly, several participants called for recognizing that the diversity of patients requires different approaches for different groups. One participant suggested that one part of such tailoring needs to involve providing education and information that helps to direct people to what they need. Others noted the importance of developing personalized care plans to ensure care is attuned to the specific needs of patients and their families. Related to this, another participant noted that tailoring also means having to engage in an explicit discussion in the province about what should be included in the available ‘basket of services’ and what should not be, as this will determine the types of resources available to customize packages of care for patients and their families.

Element 2 - Convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management

Most dialogue participants agreed that chronic-disease councils are not what is needed to support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management. Many viewed this function as something that could be handled by leveraging existing structures and processes, including the Ministry of Health and Long-Term Care, Health Quality Ontario and the Local Health Integration Networks. However, one participant expressed skepticism about this view, and highlighted the lack of progress since release of a report in 2006 on the same topic as a reason for why a different approach such as chronic-disease councils might be needed.

While the idea of chronic-disease councils was rejected, participants acknowledged that there may be a need to consider a time-limited task force that could jump start a push towards the development of evidence-based tools that support the achievement of patient goals, as well as the development of an inventory of existing tools that are suitable across a range of chronic diseases and in primary care and home and community care. Some also pointed to the need to recognize that there are both some youth and many adults who may still have only one chronic condition and benefit from single-disease supports.

Element 3 - Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management

Participants indicated that collecting and using data across all levels of the system to support and enhance chronic-disease prevention and management (element 3) will need to include three types of activities. First, there was consensus about the need to design or select a manageable number of performance metrics that capture the achievement of patient goals. Several participants noted that this will also require ensuring that these metrics are used at the appropriate level (system, organization or provider) and that they are not used to penalize those organizations or providers who deal with sicker or more disadvantaged patients. One participant also emphasized that the measures should be collected at the community level to ensure care is adjusting to local needs over time, but that the infrastructure for data collection will be needed at the system level to ensure consistency of tracking across the province. Second, some noted the need to remove the legal restrictions to sharing data across organizations and sectors, and to find ways to support such sharing. However, a number of participants noted that such efforts should not underestimate privacy concerns given the current constraints of electronic record systems. Lastly, most agreed about the need to draw on successful examples of patient portals (e.g., MyChart at Sunnybrook) to accelerate their implementation and integration across the system (i.e., to avoid patients having to access multiple portals when they are receiving care from several providers in different settings), given that such resources are in strong demand from patients and their families to help them manage their care and health.

Considering the full array of elements

Participants placed the most emphasis on activities related to putting the patient at the centre of care (element 1) and collecting and using data across all levels of the system to support and enhance chronic-disease prevention and management (element 3), rather than on convening chronic-disease councils to support chronic-disease prevention and management (element 2). However, in calling for a time-limited task force to spur action to strengthen chronic-disease prevention and management in the province, participants did not wholly reject the premise of element 2. Indeed, as outlined below, this idea formed the key next step that participants identified as being needed.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Several barriers to implementation were identified by participants. First, some participants identified physician motivation to support change in the system as a potential barrier. Specifically, one participant noted that physicians in Ontario currently feel disrespected and disempowered, which makes it difficult to motivate them to support progress towards new ways of doing things. Several participants also identified political inertia as a key implementation barrier, with one participant indicating that spurring significant change is challenging because “policymakers won’t move because the risk aversion is too high and the policy cycle too short.” Another barrier identified was the perceived lack of innovation in the system, which one participant attributed to health-system funding “squashing innovation” (e.g., because doing things differently was seen as being penalized rather than rewarded), and another attributed to the bureaucratic approach to evaluation in the province. Lastly, some participants identified a lack of a cohesive patient voice as an important barrier, with one participant indicating that those living with chronic diseases (particularly those with multiple chronic diseases) do not have the strong voice needed to achieve ‘bottom-up’ change.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

Participants agreed that the most important next step to address these barriers is to ‘kick start’ a culture shift and action towards strengthening care for people with chronic diseases. There was general consensus that enabling such a culture shift may require a time-limited task force with a mandate to articulate a vision (e.g., where we need to move for supporting people with multiple chronic conditions) along with the key policy changes that will be needed to move towards that vision. While a task force was seen as a promising ‘top-down’ initiative, several participants emphasized the need for balance with ‘bottom-up’ approaches. Some suggested that this could be supported within the task-force model by ensuring patients and citizens are in leadership roles to ensure all of its activities are focused on patient goals, their values and preferences to drive the achievement of those goals, and that they are mobilized to support action. Several participants also indicated that while a task force can provide ‘top-down’ leadership, it would not be able to mandate action, so it would need to support ‘bottom-up’ action by inspiring teams to take action (e.g., by identifying leading performers to support implementation of best practices). Moreover, many participants indicated that such a balanced ‘top-down’ and ‘bottom-up’ approach would be helpful for bypassing political decision-making, particularly if it had strong patient and citizen engagement because, as one participant stated, it could provide a ‘pardon’ for subsequent governments to move forward with priorities based on evidence and patient/citizen values and preferences.

Participants also emphasized three types of activities that would be needed to support the activities of a task force, and more generally to support efforts to strengthen care for people with chronic diseases. First, several participants emphasized that innovation needs to be supported through a systematic approach, such as an arm’s-length health-innovation fund. Such an approach was suggested given that it would allow promising ideas to be considered on a ‘level playing field’ so that small groups such as Community Health Centres and Family Health Teams can engage in innovation, evaluation and scaling up in ways that larger organizations are often able to within existing budgets. Second, fostering physician leadership and engagement to support needed innovation and change, combined with leadership from the organizational and system level to ensure that the vision is sustained and innovations are spread, were identified by many as essential. For example, one participant indicated that strong multi-level leadership is essential to supporting change within complex adaptive systems. Lastly, there was consensus among participants about the need to collect credible data and evidence about new models of care to identify those that are worthwhile to spread. Several emphasized that approaches to measurement and evaluation will need to acknowledge that ‘full’ evaluation is not always needed, and instead a stepped approach is most appropriate, where there just needs to be enough results to be able to confidently take the next step in implementation. Moreover, some indicated that collecting credible data and evidence will require identifying and prioritizing a small number of outcomes that can be used as a gauge against whether goals are met, and, if goals are not met, be willing to ‘fold up’ the project and re-invest the funds in spreading the implementation of others that have met their goals.



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