





### STRENGTHENING CARE FOR PEOPLE WITH CHRONIC DISEASES IN ONTARIO





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### Strengthening Care for People with Chronic Diseases in Ontario

### McMaster Health Forum

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### 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 2 April 2016, the McMaster Health Forum convened a citizen panel on how to strengthen care for people living with chronic diseases in Ontario. The purpose of the panel was to guide the work of the Ontario Medical Association to support efforts to strengthen care for people with chronic diseases in Ontario. 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 four challenges related to strengthening care for people with chronic diseases in Ontario: 1) patients and their families are not always put at the centre of care; 2) home and community supports that are needed to manage chronic diseases are not available or accessible to those who need them; 3) limited collection, use and sharing of medical information using patient-friendly technology to make the information accessible to patients and their families, as well as to all of their care providers; and 4) proactive prevention of chronic diseases is not prioritized.

Participants were supportive of the activities outlined in the citizen brief for putting the patient at the centre of care (element 1) and, with strong privacy protections in place, for collecting and using data to support and enhance chronic-disease prevention and management (element 3). However, participants were skeptical about the value of convening chronic-disease councils to support chronic-disease prevention and management (element 2), given their view that it may not be good value for money spent. Several values-related themes emerged during the discussion about these elements, with four emerging with some consistency: 1) collaboration (in delivering care for patients, and through the increased sharing of information, particularly for referrals to and coordination with specialists); 2) empowerment (of patients with tools in place to assist in managing care, of patients and citizens to take lead roles in the councils, and of patients through having access to their own health information); 3) accountability (for systems leaders and care providers, and in terms of having strong mechanisms for public accountability and a clear mandate); and 4) trust (in the providers collecting and using personal information and in the system storing personal information, and supported by having open lines of communication).

Participants viewed several factors as important for implementation: 1) ensuring collaboration between primary, acute, and home and community care; 2) emphasizing prevention of chronic disease within primary care; 3) using interoperable electronic health records to provide patients and their families with access to their health information and to support patient-centred care; and 4) political will and increased funding to support change.



Strengthening care for people with chronic diseases requires addressing many challenges, including lack of patientcentred care, home and community supports not always being available to those who need them, limited use of patient-friendly technology, and limited priority placed on proactive prevention of chronic disease.

# **Discussing the problem**: Why is strengthening care for people with chronic diseases necessary but challenging?

Panel participants agreed that chronic disease is an important and growing issue in Ontario. In sharing their personal experiences as both patients who are managing one or more chronic diseases and as care providers to friends and family who are managing chronic diseases, participants individually and collectively focused on four challenges in particular:

- patients and their families are not always put at the centre of care;
- home and community supports that are needed to manage chronic diseases are not available or accessible to those who need them;
- limited collection, use and sharing of medical information using patient-friendly technology to make the information accessible to patients and their families, as well to all of their care providers; and
- proactive prevention of chronic diseases is not prioritized.

# Patients and their families are not always put at the centre of care

Participants agreed strongly that patients and their families are not always put at the centre of care. For example, one participant expressed that "the system is designed to put the doctor first [but] doctors need to realize the patients are first." Many participants agreed with this sentiment and several shared examples of care providers dismissing their health concerns only to later find that they had a chronic disease that was having a significant impact on their health and quality of life. One participant described an experience which they characterized as "demeaning" where they were "treated like a number" and told their symptoms were all in their head. The participant pointed out that they subsequently required emergency surgery for their condition that had gone undiagnosed due to this experience with their care provider.

All participants emphasized that these types of experiences often result from a lack of communication and coordination between clinicians and patients, as well as between clinicians and the parts of the system in which they work (e.g., between primary,

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

The citizen panel about strengthening care for people with chronic diseases in Ontario had the following 11 features:

- 1. it addressed a high-priority issue in Ontario;
- 2. it provided an opportunity to discuss different features of the problem;
- 3. it provided an opportunity to discuss three elements for addressing the problem;
- 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, plainlanguage brief;
- 7. it involved a facilitator to assist with the discussions;
- it brought together citizens affected by the problem or by future decisions related to the problem;
- 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.

acute, and home and community care). Several participants indicated that challenges with communication and coordination stems from there not being a 'most responsible provider' who is aware of and coordinates all parts of a patient's care plan. One participant attributed this to the lack of accountability among providers saying that "no doctor wants to be the team leader and be responsible for taking the lead ... there needs to be a structure and sense of responsibility." As well, several participants identified what they perceived to be

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battles over "turf" between specialists who refuse to share or redirect patients even when they are at capacity. This was seen as creating a situation in which the patient is not put first and, in many instances, seriously delaying care.

Related to challenges with communication and coordination, participants also expressed frustration with the lack of interoperable electronic health records. Many described situations in which they have met with multiple clinicians with none being aware of what the others had prescribed or recommended. One participant shared challenges they have experienced with managing multiple drug prescriptions and complications which resulted from individual providers prescribing without having access to the patient's record to see what else they were taking, and assess possible multi-drug interactions. This participant stated that "with having different chronic diseases, I've found that one doctor doesn't know what the other doctors do." In general, participants expressed that not having interoperable health records makes it difficult to communicate and share information between providers, and patients are often left confused and lacking clear answers, and possibly at risk of complications.

**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?
  13
- Where were they from?

Region covered by the Hamilton Niagara Haldimand Brant, Central, Central West, Mississauga Halton, Champlain, Erie St. Clair, and South West Local Health Integration Networks

- How old were they? 18-24 (1), 25-44 (2), 45-60 (5), 65 and older (5)
- Were they men, or women? Men (8) and women (5)
- Were they living in urban or suburban settings? Urban (6), suburban (5) and rural (2)
- How many were living with a chronic condition? Living with one chronic condition (4) Living with two chronic conditions (1) Living with three chronic conditions (0) Living with more than three chronic conditions (4)
- How many were care providers to someone else living with one or more chronic conditions? Care provider to someone with one chronic condition (0) Care provider to someone with two or more chronic conditions (4)

Several participants also indicated that

chronic-disease management is not always sensitive to each individual's unique circumstances. Some shared examples of providers making assumptions about a patient's

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ability (or the ability of their informal caregiver) to manage care plans, and were provided with very limited instruction despite needing such supports. As well, many participants emphasized that while people living in poverty have higher rates of chronic disease than those with higher incomes, they also are less likely to have access to the full range of care providers given the financial barriers they face. For example, some participants pointed out that services that are not publicly funded (e.g., physiotherapy and dental services) are often recommended but not accessible due to inability to pay. In addition, other participants pointed out that many are not able to afford to pay for prescription drugs and, as a result, do not take prescribed medications. One participant stated that taken together, this all means that a "whole-person approach" is not being used when caring for people with chronic diseases.

# Home and community supports that are needed to manage chronic diseases are not available or accessible to those who need them

Many participants indicated that, in their experience, existing structures that provide home and community supports to manage chronic disease (e.g., homecare support for activities of daily living, accessible transportation to and from medical appointments, and supportive/accessible housing) are not meeting the needs of those living with chronic diseases in the Ontario. While participants valued the support provided by Community Care Access Centres (CCACs), with many having benefited directly, they also identified gaps in coverage for needed home and community care. One participant shared that they live alone and face challenges caring for themselves due to their chronic diseases, but are not eligible to receive support from a CCAC. As well, participants identified the lack of transportation in general, and assistive transportation in particular, as an important issue. One participant identified a critical gap in terms of transportation for people with complex medical needs and limited mobility, saying "there is no one to help the patient out of the house and to and from the appointment."

Several often interrelated reasons were identified by panel participants to explain the lack of availability and accessibility of home and community supports. Key reasons identified by participants for this included:

- inadequate public funding (e.g., to provide services that are needed as part of comprehensive chronic-disease management);
- patients and families not being able to afford the out-of-pocket costs for accessing services that are not publicly covered; and

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• variability of what is accessible in different communities across the province. Related to the variability in access to services, participants specifically identified rural and remote regions as having fewer care providers, less funding for chronic-disease prevention, and limited infrastructure to support getting to and from appointments.

### Limited collection, use and sharing of medical information using patient-friendly technology to make the information accessible to patients and their families, as well as to all of their care providers

Participants felt strongly that medical information is not collected or used in an effective manner in the province, nor is it accessible to patients, their families and their care providers. Several participants expressed frustration about not having access to their own medical records that would allow them to be proactive in managing their chronic disease, and to be full partners with their care providers. One participant stated that "when you keep information from me, I can't find the right solution."

However, perspectives about the need for patient access to medical records varied, with some expressing significant concern about privacy of health information. Several participants were aware of recent high profile data breaches at hospitals in the form of inappropriate accessing of information and of data being lost or misplaced. Several participants also questioned whether it is appropriate for patients to access their own records considering they are unlikely to be qualified to interpret the information, which could result in patient anxiety or patients changing their own care plans.

### Proactive prevention of chronic diseases is not prioritized

Most participants agreed that there is a lack of focus on proactive chronic-disease prevention in primary care and that, without it, the burden of chronic disease will continue to grow in Ontario. Participants generally felt that prevention is more cost-effective than treatment, or as one participant stated, "prevention is cheaper than putting out fires after."

Some participants attributed this lack of focus on prevention to what they viewed as limited training and/or time for clinicians to engage in proactive health promotion and prevention (e.g., for nutritional advice and supports to engage in a healthy lifestyle). In terms of training, participants shared examples of care providers giving them outdated information

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(especially about nutrition) and failing to account for patients' holistic care needs. One participant explained that clinicians "treat the body like it's a machine, but they're not interested in how the different parts affect each other and the whole."

The challenge of health literacy was also mentioned by some participants as a barrier to citizens identifying reliable and understandable information. For example, participants indicated that they often turn to the internet to find information, but admitted struggling to make sense of health-related information and its applicability to them. One participant specifically described bringing information to their physician, who then often spent their appointment time explaining the limitations and inaccuracies (e.g., using a single study to suggest a change in care plan).

Finally, several participants emphasized that an important part of the challenge for preventing chronic disease is what they saw as diminished personal accountability for healthy behaviour among individuals. One participant held strong views on the matter and stated that "personal accountability is not a popular idea anymore. Nobody wants to pay for anything and be inconvenienced in any way." However, others maintained that prevention is a structural issue. For example, one participant emphasized that, in their view, the major challenge is the lack of collaboration between primary care and public health to address issues of poverty and access. Other participants noted that structural factors put those living in poverty at higher risk for chronic disease given the barriers they face for engaging in healthy behaviours, including healthy eating and exercise.

# 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 that could be used to strengthen care for people with chronic diseases in Ontario, which were outlined in the citizen brief. These elements are:

- 1. support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care;
- 2. convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management; and
- 3. collect and use data across all levels of the system to support and enhance chronicdisease prevention and management.

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

- collaboration (in delivering care for patients, and through the increased sharing of information, particularly for referrals to and coordination with specialists);
- empowerment (of patients with tools in place to assist in managing care, of patients and citizens to take lead roles in the councils, and of patients through having access to their own health information);
- accountability (strong mechanisms for public accountability exist and a clear mandate is present, and of systems leaders and care providers); and
- trust (in the providers collecting and using personal information and in the system storing personal information, and supported by having open lines of communication).

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

# **Element 1** – Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care.

The discussion about the first element focused on components of patient-centred care models, and participants agreed about the importance of all the components which broadly focus on:

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

Four values-related themes emerged that participants felt were important for ensuring patients are supported to prevent and manage chronic diseases by putting them at the centre of care:

- access (to the care they need when they need it, to disease prevention and health promotion services, and to patient-friendly technology);
- empowerment (of patients with tools in place to assist in managing care);
- collaboration among patients, providers and organizations (in delivering care for patients); and
- trusting relationships between patients and providers (in having open lines of communication).

In valuing access, participants expressed preferences for receiving the care they need when they need it, disease prevention and health promotion services, and for having access to patient-friendly technology.

In terms of getting the care they need when they need it, participants called for greater use of personalized care plans that support patients and their families to manage chronic diseases. One participant shared how much they appreciated receiving a resource following a family member's surgery that included a comprehensive care guide and a log book to track appointments, and document instructions and recommendations from clinicians. In addition to individualized care plans, participants identified the need for care coordinators or patient advocates who are responsible for coordinating care for those with complex chronic conditions. One participant stated: "If we're going to put the patient at the centre of things, a patient may be elderly and living at home and may need a personal healthcare coordinator to facilitate care and follow-up with results." While participants generally agreed with the need for a care coordinator, they differed over whether the coordinator should be an existing member of a care team (e.g., a physician or nurse) or someone independent who could be more objective and challenge the care team if needed.

In calling for a greater focus on the prevention of chronic diseases and access to health promotion and prevention programming and services, several participants challenged the current emphasis on access to specialist care for chronic diseases. For example, one participant stated: "We don't need more specialists, we need more prevention." Towards achieving this, several participants suggested there will need to be a shift in the system to prioritize prevention, as well as a combination of corresponding incentives and accountability measures to encourage care providers to work in a prevention model.

Box 3: Key messages about supporting patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care (element 1)

Four values-related themes emerged that participants felt were important for ensuring patients are supported to prevent and manage chronic diseases by putting them at the centre of care:

- access (to disease prevention and health promotion services);
- empowerment (of patients with tools in place to assist in managing care);
- collaboration among patients, providers and organizations (in delivering care for patients); and
- trusting relationships between patients and providers (in having open lines of communication).

Another value which emerged in relation to access was empowerment for patients by ensuring tools are in place to assist them in managing their own care. Participants generally favoured the idea of patients and their informal caregivers being able to engage with their care team by telephone and email to address questions or concerns, and to avoid unnecessary appointments (particularly in areas which require patients to travel long distances to appointments). One participant called for accessible on-line booking options that would allow patients to make appointments. This participant also suggested that such a system could include features that allow patients to indicate their perceived level of need (e.g., urgent), which could then be used to prompt providers to call the patient to assess whether the issue is in fact an emergency. However, several participants warned that not everyone is able to access and use technology in the same way, which could create new barriers for some groups.

Participants also valued collaboration among patients, providers and organizations, and expressed preferences to receive care through team-based approaches. One participant said:

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"there is a need for good effective care, but to achieve that you need a good productive, open, honest relationship, based on a team effort ..." across primary, acute, and home and community care. Another participant suggested that improving collaboration can be achieved using existing resources, and provided an example of bringing a team of specialists from a large urban centre to a rural centre periodically to see patients. Between visits from the specialists, local family physicians monitor patients' needs and communicate with the specialists remotely, which avoids patients having to make many long-distance trips to see different specialists.

As part of further enhancing collaboration, participants expressed a strong preference for having a 'most-responsible provider' to lead the team and oversee coordination between the various providers involved in managing a patient's chronic disease(s). Several participants identified nurse practitioners as possibly filling this role, because of their ability to provide primary care as well as having time to provide health promotion and prevention services.

Finally, participants valued trusting relationships between patients and providers, and expressed preferences for having open lines of communication with their care providers. Participants identified the need for some care providers to move beyond the traditional expert model, which one participant characterized as involving a "we know what's best for you" attitude. Specifically, some identified the need for more opportunities to discuss their needs openly with providers, but with the recognition that physicians may not be available, several participants reiterated the possibilities of harnessing nurse practitioners as a way to create trusting relationships between patients and teams.

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

The discussion about the second element examined the development of an oversight council led by experts with experience in managing multiple chronic conditions, and comprised of representatives from disease- and care and support-focused working groups, as well as patients and citizens. The citizen brief described that the role of the council could be to:

- provide clinical leadership for chronic-disease prevention and management for the province;
- engage in creating evidence-based tools and other supports; and
- support patient/citizen engagement in the development of approaches to chronic-disease prevention and management.

Five values-related themes emerged that participants felt were important for guiding efforts to ensure comprehensive and coordinated approaches to chronic-disease prevention and management:

- accountability (strong mechanisms for public accountability exist and a clear mandate is present);
- efficiency (should provide good value for money);
- expertise (among the individuals sitting on disease councils);
- empowerment (of patients and citizens to take lead roles in the councils); and
- fairness (among the individuals chosen to participate in the councils).

Participants had mixed reactions to element 2 with respect to their expressed values of accountability and efficiency. Some expressed that a chronic-disease council could be an opportunity for a strong mandate to develop and support the implementation of best practices and spread innovation. In contrast, others feared it would result in more administration and ultimately not be "good value for money." One participant said the idea raised "red flags", and that it sounded like another level of bureaucracy. However, another participant disagreed and emphasized the potential for long-term savings from increased efficiency that the councils could help achieve. Specifically, this participant indicated that they thought "…it's a good idea because in the long run it will be more cost-effective if they

can generate a model that could be used across the province to prevent duplication – it will save time and money."

In valuing expertise, fairness and empowerment in the context of the development of a chronic-disease council, participants shared strong preferences for transparent processes for identifying and appointing 'experts' to sit on the councils. However, participants debated what constitutes an expert, with one participant stating "I would rather have a patient who has been through it than a doctor who has had the school version of the issue." While the expertise of clinicians was acknowledged and deemed a necessary part of a chronicdisease council, participants strongly emphasized that there should be meaningful roles for patients and citizens in all activities of the council. Several participants also strongly endorsed the need for the patients and citizens engaged in the council to be diverse in terms of gender, age, socioeconomic

Box 4: Key messages about convening chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management (element 2)

Five values-related themes emerged that participants felt were important for convening councils to oversee the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management:

- accountability (strong mechanisms for public accountability exist and a clear mandate is present);
- efficiency (should provide good value for money);
- expertise (among the individuals sitting on disease councils);
- empowerment (of patients and citizens to take lead roles in the council); and
- fairness (among the individuals chosen to participate in the councils).

status, ethno-cultural background, and lived experience with the full range of chronic diseases and geography (i.e., to ensure regional differences are considered). Towards supporting engagement, participants suggested the need for appropriate compensation to be provided to ensure that patients and citizens do not face barriers to participating on the council.

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

The discussion about the third element examined ways to collect and use data across all levels of the system to support and enhance chronic-disease prevention and management, which was described in the citizen brief as possibly consisting of:

- clinical information systems that use electronic health records to identify and contact high-risk patients, and more generally support chronic-disease prevention across the system;
- decision-support systems at the provider and patient level;
- audit and feedback at the practice/organizational level; and
- performance reporting at the practice/organizational, community, regional and provincial levels.

Five values-related themes emerged that participants felt were important for guiding efforts to support and enhance chronic-disease prevention and management:

- collaboration between patients and providers (through the increased sharing of information, particularly for referrals to and coordination with specialists);
- empowerment (of patients through having access to their own health information);
- trust (in the providers collecting and using personal information and in the system storing personal information);
- privacy (of patients and their personal information); and
- accountability (of systems leaders and care providers)

Participants valued collaboration, and identified strong preferences for the increased sharing of information between patients and providers, particularly for referrals to and coordination with specialists. As one participant suggested: "Maybe the solution is a well-oiled medical system where everyone communicates with each other." The collection of data from and enhanced availability of patient health records were described as ways to improve care and improve efficiency in the system. However, participants further valued their privacy and trust, and expressed strong preferences for wanting their information safeguarded. To protect their privacy, participants expressed the need to only give relevant providers access to their information, and for measures to be taken at the system level to ensure their information is stored and used properly. Some participants noted that privacy concerns could be partially addressed by having a patient's most responsible provider be accountable for assigning who should have access to the patient's health records.

Participants further valued empowerment and expressed preferences for having access to their own health information. Most liked the idea of patient portals as a mechanism for empowering patients, provided that appropriate data privacy and security is in place. One participant shared a positive experience using a service that allows patients to access their test results and share them as needed. However, there were differences in opinion about the kinds of information that should be made available, with some identifying possible issues with patients interpreting their own test results (e.g., anxiety about not knowing what the results mean). One participant was concerned that the availability of information could result in too much responsibility on patients, and said that "it shouldn't be on me to explain my issues. Doctors should be doing the work."

Lastly, participants valued accountability and expressed the need for quality and performance monitoring at the provider and practice/organizational level, as well as at the system level. For providers and practices/organizations, some participants supported the idea of using audit and feedback to improve the quality of care. However, some questioned whether physicians and practices/organizations would be comfortable with what was seen as an approach that would call into question the quality and appropriateness of Box 5: Key messages about collecting and using data across all levels of the system to support and enhance chronic-disease prevention and management (element 3)

Four values-related themes emerged that participants felt were important for guiding efforts to use data across all levels of the system to support and enhance chronic-disease prevention and management:

- collaboration between patients and providers (through the increased sharing of information, particularly for referrals to and coordination with specialists);
- empowerment (of patients through having access to their own health information);
- privacy (of patients and their personal information);
- trust (in the providers collecting and using personal information and in the system storing personal information; and
- accountability (of systems leaders and care providers).

the care they provide. One participant questioned whether there is an effective mechanism that could be used to improve the compliance of doctors who are monitored. Others identified the potential of using approaches that would allow patients to anonymously rate physicians and practices/organizations (e.g., hospitals). One participant warned that performance should not be assessed based on the views of a few disgruntled people, but rather based on data at the population level. At the system level, some participants supported the idea of performance reporting as being important for ensuring accountability, but some indicated that it would only be worthwhile if the data and evidence used to generate the reports is trustworthy and comprehensive. Also at the system level, some participants expressed the need for better collection and use of data and evidence within the health system (i.e., primary, acute, and home and community care) and across other sectors, including public health and education. For collecting data, one participant identified examples of cohort studies that include data about health, mental health, and social factors such as income, education and region, conducted on some diseases, and being used to inform policy. This participant further suggested this should be done for all chronic diseases and the information should be better integrated to give a more accurate picture of the complexity of chronic diseases, especially since many people live with more than one chronic disease.

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

When turning to implementation considerations, participants identified four factors as important. First, all participants indicated that ensuring collaboration between primary, acute, and home and community care will need to be an essential part of implementing approaches to strengthen care for people with chronic diseases. Some participants pointed to existing models such as Family Health Teams that can be looked to for how to spread collaborative practices to the rest of the province. Second, several participants emphasized the need for more focus on prevention of chronic disease as part of primary care. Third, participants indicated that it will be difficult to achieve widespread patient empowerment without implementation of interoperable electronic health records that provide patients and their families with access to their health information. Lastly, some participants indicated that implementing the elements will require political will combined with increased funding to support the changes needed to strengthen care for people with chronic diseases in Ontario.

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