

EVIDENCE >> INSIGHT >> ACTION

Strengthening Care for People with Chronic Diseases in Ontario

The McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at regional/provincial levels and at national levels, the Forum harnesses information, convenes stakeholders and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions and communicate the rationale for actions effectively.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-16 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panel on strengthening care for people with chronic diseases in Ontario.

This brief includes information on this topic, including what is known about:

- the underlying problem;
- three elements of a potentially comprehensive approach to address the problem; and
- potential barriers and facilitators to implement these elements.

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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Key Messages

What's the problem?

Several factors contribute to the challenge of strengthening care for people with chronic diseases in Ontario:

- the burden of chronic disease is high;
- the burden of chronic disease continues to grow and affects some groups more than others;
- care for people with chronic conditions is challenging;
- the patient is not always put at the centre of care;
- many system features make it difficult to provide accessible, comprehensive, coordinated and continuing care; and
- system planners, providers and patients lack timely data and evidence to proactively prevent and address chronic disease.

What do we know about elements of a potentially comprehensive approach for addressing the problem?

- **Element 1:** Prevent and manage chronic diseases by putting the patient at the centre of care
 - This could include activities related to:
 - ensuring all Ontarians receive the care they need when they need it (e.g., through different approaches to scheduling appointments, and using team-based models of care, secure email and telephone consultations);
 - supporting the engagement of patients in their care (including managing aspects of it); and
 - supporting seamless transitions between settings (e.g., using care coordinators and supporting effective communication between primary care and specialist care).
- **Element 2:** Convene clinical disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management
 - The councils could be co-chaired by experts with experience managing multiple chronic conditions and comprised of representatives from disease- and care and support-focused working groups.
 - The councils could provide clinical leadership, create evidence-based tools to support implementation of best practices across the province, and to inform care and support patient engagement.
- **Element 3:** Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management
 - This could include using information systems and electronic health records to identify and contact high-risk patients, decision-support systems for providers and patients, summarizing clinical performance to help practices/organizations assess and adjust their performance, and performance reporting across all levels of the system.

What implementation considerations need to be kept in mind?

- Barriers to implementing these elements might include: 1) resistance from citizens, providers and organizations to new ways of providing care; and 2) difficulty implementing infrastructure needed for strengthened data supports.
- Windows of opportunity for implementing these elements might include: 1) harnessing the increased attention being paid to strengthening patient-centred care; 2) drawing on momentum created by high-profile proposals to reform primary, home and community care; and 3) strengthening care for people with chronic diseases to meet larger health-system goals.

Questions for the citizen panel

>> We want to hear your views about a problem, three elements of a potentially comprehensive approach to addressing it, and how to address barriers to moving forward.

This brief was prepared to stimulate the discussion during the citizen panel. The views and experiences of citizens can make a significant contribution to finding the best ways to meet their needs. More specifically, the panel will provide an opportunity to explore the questions outlined in Box 1. Although we will be looking for common ground during these discussions, the goal of the panel is not to reach consensus, but to gather a range of perspectives on this topic.

Box 1: Questions for citizens

Questions related to the problem

- What challenges have you faced in accessing care for a chronic disease for you or a family member?
- What challenges do you see for providing care for:
 - the sickest Ontarians (e.g., those living with multiple chronic diseases);
 - those with some ongoing care needs for chronic diseases; and
 - those with no chronic conditions but who may need some care to prevent diseases

Questions related to the elements of a potentially comprehensive approach to address the problem

- Element 1 (Prevent and manage chronic diseases by putting the patient at the centre of care)
 - What would help you get the care you need when you need it?
 - What would be helpful to support you to: 1) take ownership of your health; and 2) to understand how to manage your own care?
 - What would help make your care seamless?
- Element 2 (Convene clinical disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management)
 - In what ways do you think patients should be engaged in the development of approaches to chronic-disease prevention and management?
- Element 3 (Provide data supports across all levels of the system to support chronic-disease prevention and management)
 - What types of data and information supports would be helpful for you to make informed decisions about your care and to manage chronic diseases for you or someone you provide care to?
 - What are your views about making patient information available to support providers' efforts to assess their performance related to chronic-disease prevention and management?

Question related to implementation considerations

- What do you see as the main challenges for achieving these expectations?

Box 2: Glossary

Chronic disease

A health problem requiring ongoing management over a period of years or decades (e.g., asthma, cancer, depression, diabetes and heart disease).(1)

Patient-centred care

“Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”(3)

Primary care

“Level of a health service system that provides entry into the system for all new needs and problems, provides person-focused (not disease-oriented) care over time, provides care for all but very uncommon or unusual conditions, and co-ordinates or integrates care provided elsewhere by others.”(5)

Home and community care

Services to help people receiving “care at home, rather than in a hospital or long-term care facility, and to live as independently as possible in the community. Home and community care is delivered by regulated health care professionals (e.g., nurses), non-regulated workers, volunteers, friends and family caregivers.”(8)

Self-management

“An individual’s ability to manage the symptoms, treatment, physical, psychosocial, and lifestyle changes inherent in living with a chronic condition.”(9) It empowers patients and prepares them to manage their health and healthcare.(10;11)

Electronic health record

“A complete health record under the custodianship of a health care provider(s) that holds all relevant health information about a person over their lifetime. This is often described as a person-centric health record, which can be used by many approved health care providers or health care organizations.”(13)

Multimorbidity

A term that refers to people living with multiple chronic health conditions



Taking on this challenge can result in better care for people with chronic diseases.

The context: Why is strengthening care for people with chronic diseases a priority in Ontario?

There is much attention being paid to how to strengthen patient-centred care in Ontario. This focus has come from several key stakeholders in the system,(14-16) including the Ontario Medical Association which commissioned this brief through its emphasis on “putting patients first.”(17)

Strengthening care for people with chronic diseases is critical for making progress towards the priority of patient-centred care because of:

- the growing burden of chronic disease in Ontario;
- the complexity of providing care for people with chronic conditions (particularly those living with multiple chronic conditions); and
- patients not always being put at the centre of care.

The focus for doing this has been on strengthening primary care (including better coordination between primary care and specialists), as well as home and community care in order to enhance patient experience, improve health outcomes and keep costs manageable.

What's needed to strengthen care for people with chronic diseases?

Systems of care can focus on symptoms (e.g., breathlessness), diseases (e.g., asthma or depression) or specific populations (e.g., frail elderly or people with multiple chronic conditions).(18) However, as discussed later in the section about the problem, the path to strengthening care for people with chronic conditions is more complex than this.

As a starting point, developing and executing a plan requires identifying the types of action needed, making the best use of resources available to take these actions, and having data to support their implementation, monitoring and evaluation.

What types of action are needed?

At least two types of action are needed. The first is to develop or enhance existing comprehensive disease-management approaches. Different diseases (e.g., cardiovascular disease, diabetes, mental health and addictions, cancer, asthma, etc.) need different approaches. However, actions are needed to support patient-centred, comprehensive and coordinated care management approaches that cut across diseases. This is especially important with an increasing number of 'high needs users' of the system who account for a high proportion of health-system costs (e.g., those living with multiple chronic health conditions and often in challenging social circumstances).

The second set of actions needed is to provide supports such as team-based care, helping patients manage certain parts of their care, and leadership. These steps could then lead to supports for pain management, wound care, crisis intervention, smoking cessation and end-of-life care.

Making the best of resources to take actions

Making the best use of the resources available means putting the patient at the centre of actions taken. It also means having different stakeholders working together across different parts of the system to prevent and manage chronic diseases. In terms of specific actions that could be taken, this could mean:

- helping patients adopt healthy lifestyles to prevent chronic disease and/or managing certain aspects of their care (with needed supports from providers)
- practices/organizations and providers helping their patients to prevent chronic disease, supporting them in managing their chronic diseases and providing needed care;
- coordinating delivery of care by practices/organizations and providers at the community level;
- deploying resources at the regional level; and
- supporting province-wide population-based prevention initiatives.

What data supports are needed to support these actions?

Having timely access to data (e.g., health information collected about individual patients during their medical visits that then has their names removed and is combined with the information of patients from across Ontario) is essential for supporting these actions. There are several ways that data can help support action as it can:

- 1) allow those who can take action (e.g., providers or the practices in which they work) to identify and reach out to high-risk patients to support prevention of chronic disease;
- 2) enable those who already have one or more chronic diseases to learn how to minimize the impact on their health and quality of life (e.g., by helping them to take action to manage their chronic disease);
- 3) support those who can take action to identify what's not working and continue to improve care for people with chronic diseases over time.

Data could be used in several ways as part of the third point above. At the system level, data supports could be used to measure, provide feedback and publicly report impacts on patient experiences, health outcomes and costs. It could also be used to identify practices which are different than others (for instance, where patients appear to receive care that isn't as high quality as others). This could be used to help providers to improve their practice, or understand why the patients differ (and what they might need to improve outcomes).

Benefits of strengthening care for people with chronic diseases

Evidence from systematic reviews (i.e., a synthesis of results from all the studies addressing a specific topic) has found several benefits for strengthening care for chronic diseases. For example, 27 reviews found that integrating care across settings (e.g., hospitals, primary care

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and care provided in the community) and between providers (e.g., between family physicians, specialists and other providers):

- reduced hospital admissions and re-admissions;
- improved the use of treatment guidelines to support delivery of appropriate care; and
- improved quality of life for patients.(19)

Box 3: The health system in Ontario

Key features of the health system

- Medical care provided in and with hospitals and by physicians is fully paid for as part of Ontario's publicly funded health system.
- Care and support provided by other healthcare providers such as nurses, physiotherapists, occupational therapists and dietitians are typically not paid for by the health system unless provided in a hospital or long-term care setting, or in the community through Family Health Teams, Community Health Centres and community and other designated clinics.
- Other healthcare and community services such as prescription drug coverage, community support services and long-term care homes may be partly paid for by the health system, but any remaining costs need to be paid by patients or their private insurance plans.
- Fourteen geographically defined Local Health Integration Networks (LHINs) have responsibility for the planning and funding of healthcare in their regions, and for ensuring that the different parts of the health system in their regions work together.
- The most recent estimates of the health workforce in Ontario indicate that for every 100,000 Ontarians there are 100 family physicians, 102 specialists, 699 registered nurses (including 14 nurse practitioners), 83 pharmacists, 48 physiotherapists and 38 occupational therapists.(4)
- 94% of Ontarians report having a primary-care provider,(6) and 25% of the population receive team-based care (Family Health Teams, community health centres, nurse-practitioner-led clinics and Aboriginal health access centres).(7)

Features most relevant to home and community care

- Fourteen Community Care Access Centres (CCACs) – one for each LHIN – have responsibility for connecting people with the care they need at home and in their community (although these have been proposed to be eliminated in the most recent proposal for strengthening patient-centred care in Ontario).
- 644 not-for-profit community support-service (CSS) agencies provide assistance to more than 800,000 community-dwelling Ontarians (including older adults, and people with a physical disability and/or mental health issue, and addictions). The assistance can include personal support (e.g., for household tasks, transportation, meals-on-wheels, supportive housing and adult day programs).(12)
- 75 community health centres (CHCs) serve approximately 500,000 people in Ontario with 250,000 of these accessing primary, home and community care services.

Features for specific populations (high-needs users of the health system)

- 69 Health Links (of an anticipated total of 90) support the delivery of integrated care for those with complex needs (typically those living with multiple chronic diseases).



80% of Ontarians over the age of 45 (roughly 3.7 million people) are living with a chronic condition (2)

The problem: Why is strengthening care for people with chronic diseases necessary but challenging?

Several factors contribute to the challenges related to strengthening care for chronic diseases in Ontario. These factors broadly relate to:

- the burden of chronic disease is high;
- the burden of chronic disease continues to grow and affects some groups more than others;
- care for people with chronic conditions is challenging;
- the patient is not always put at the centre of care;
- many additional system features make it difficult to provide accessible, comprehensive, coordinated and continuing care; and
- system planners, providers and patients lack timely data and evidence to proactively prevent and address chronic disease.

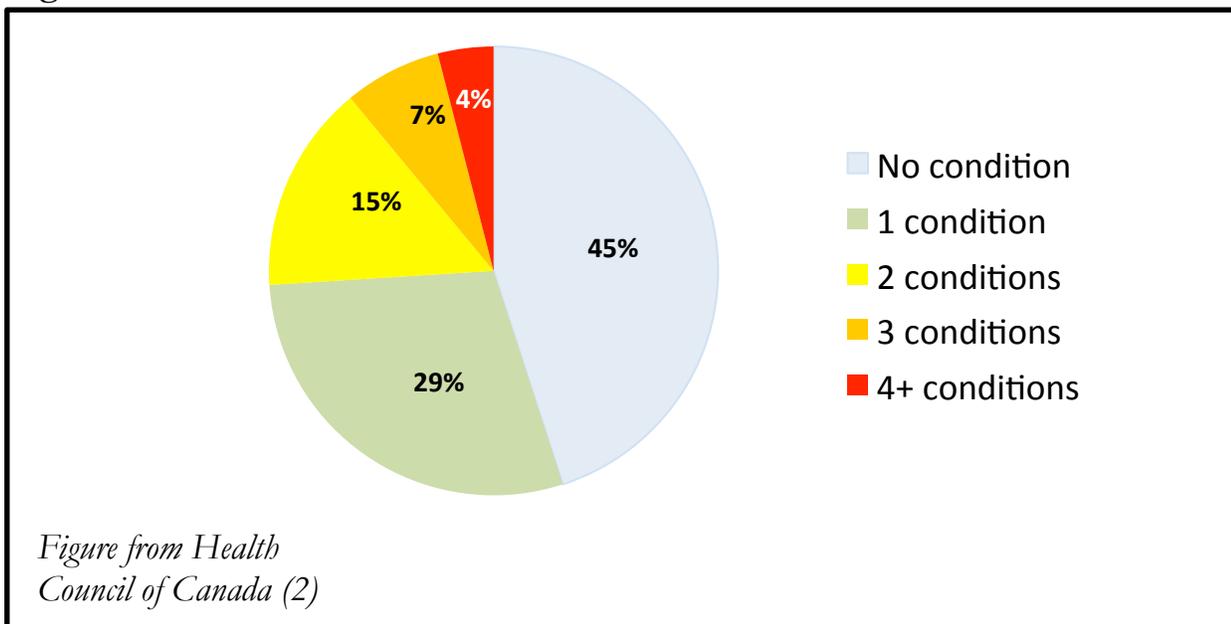
The burden of chronic disease is high

Many Ontarians are living with chronic diseases or provide care to friends, family and other members of their communities who need help managing their health issues. Data indicates that approximately:

- 38% of Canadians over the age of 20 have at least one chronic health condition;(20)
- 21% of Canadians are living with a major chronic condition (cancer, diabetes, cardiovascular disease, chronic respiratory diseases);(20)
- 15% of Canadians are living with two or more chronic health conditions;(20)
- 80% of Ontarians over the age of 45 (roughly 3.7 million people) are living with a chronic condition;(2) and
- 70% of those who are considered the sickest Canadians have two or more chronic health conditions. (2)

Chronic disease has an impact on people's ability to engage in daily life, reduces their mobility, and limits their ability to participate in social activities,(2) but worse, chronic disease has been associated with early death for people between the ages of 30 and 69.(2) In Ontario, chronic diseases were responsible for 79% of all deaths in 2007, led by cancer and cardiovascular disease (38% each).(21) Many forms of disability and early deaths are preventable if chronic conditions are identified and managed early.

Figure 1: Canadians with chronic health conditions



The burden of chronic disease continues to grow and affects some groups more than others

Disability and early deaths are preventable if chronic conditions are identified and managed early. However, the number of people living with chronic disease is increasing by 14% per year across Canada, and the number of deaths due attributed to it have steadily increased.(22) In Ontario the population is projected to increase to 16.9 million by 2031 with persons 65 and over making up 25% of the population. The combination of population growth and an aging population is expected to result in an increase in the burden of chronic disease in the province unless action is taken.(21)

This growing burden of chronic disease affects many groups, including:

- **older adults:** 75% of Ontarians over the age of 65 report having one or more of 11 chronic health conditions;(23)
- **women:** 14% of Canadian women have two or more chronic health conditions as compared to 11% of men (across all age groups);(24) and
- **economically vulnerable groups:** 40% of low-income Canadians have one or more chronic health conditions, compared to 27% of high-income Canadians.(2;24;25)

These statistics show that the problem is more concentrated in older adults and in the most vulnerable in our society (e.g., people with limited education, low incomes and/or living in rural communities).(2;24;25) The poorest Canadians are almost three times as likely as the highest-income Canadians to have multiple chronic health conditions.(24)

Care for people with chronic conditions is challenging

Lack of coordination makes it difficult to provide a population-level team-based approach that offers care and support for chronic diseases based on patient need. For example, the sickest Ontarians, such as those with multiple chronic health conditions, pose a significant and growing challenge for providing care that is coordinated and patient-centred. These sickest patients and their caregivers can be left to navigate the system where they have to see a family physician, set and attend appointments with several specialists in different settings, manage many medications, organize home-based care, and identify additional supports such as transportation that they may need.

Providing care for people with multiple chronic health conditions is particularly challenging because there are several potentially competing health outcomes, and many specialists may only focus on outcomes in one area.⁽²⁶⁾ For example, providers and patients must find a balance between improving nutrition, living situation, function, severity of symptoms, survival, and active life expectancy of a patient, as well as other health outcomes. Balancing these health outcomes highlights the need to ensure that patients and their caregivers are supported to prioritize these outcomes based on their values, needs and preferences. For example, what may be reasonable goals for a 30-year-old may not resonate for someone who is 85 and at-risk for becoming frail.

This also means that there are often several potentially competing treatments. All these treatments may overlap and interact, and physicians may not always agree on which treatment is most important. This creates uncertainty about benefits and harms of different treatments, and a risk of worsening one condition by treating another one.⁽²⁷⁾

In addition, healthcare providers and patients are often using medical guidelines (also known as ‘clinical practice guidelines’) to help them make decisions about appropriate care for specific health conditions. However, the majority of guidelines focus on single conditions (e.g., a guideline to treat asthma, a guideline to treat diabetes, a guideline to treat depression). With some exceptions from groups that are trying to overcome this issue,⁽²⁸⁾ these guidelines rarely address how to best integrate care for people with multiple chronic health conditions.⁽²⁹⁻³²⁾ The lack of appropriate multi-condition guidelines means that healthcare providers and patients often have to turn to several guidelines focused on single conditions and try to make sense of how best to proceed in an individual case, which can be burdensome for everyone involved.^(33;34)

The patient is not always put at the centre of care

A recent analysis of the performance of Ontario's health system found that 86% of adults indicated they were always or often involved in decisions about their healthcare.⁽⁶⁾ This level of involvement is average, and only marginally lower than the best-performing countries, such as the United Kingdom (87%) and New Zealand (88%).⁽⁶⁾

Even though patients report relatively high levels of involvement in their care, this does not measure whether they were working in partnership with their care provider, which is needed for patient-centred care. In addition to this, there are several ways in which the patient is not put at the centre of care. For example:

- health professionals don't always work together to get people the care they need,⁽³⁵⁾ despite this being important for improving patients' outcomes;⁽³⁶⁻⁴⁰⁾ and
- a lack of electronic health records (i.e., a system enabling healthcare providers to access health information about individual patients) means that all the information about a patient is typically not in one place.

Also, patients, families and caregivers often lack the supports they need to help them to make informed decisions about their health and how to manage their care needs, and are not always engaged in policy development about the health system. Without such supports and engagement opportunities, care may not be patient-centred. Also, policy developed to address health-system issues may not be based on citizens' values and preferences, or be flexible enough to accommodate those values and preferences.



Many system features make it difficult to provide accessible, comprehensive, coordinated and continuing care

There are many system-level challenges that will need to be addressed as part of efforts to strengthen care for people with chronic diseases. These challenges lie in how care is delivered and paid for, which we summarize in Tables 1 and 2 below.

Table 1. Challenges related to how care is delivered

Challenge	Example/description of the challenge
Fragmented care	<ul style="list-style-type: none"> • A patient with diabetes, multiple sclerosis and emphysema may need to seek care from a different doctor for each condition. • These various healthcare providers may be in different settings and may not effectively communicate with each other,(33;34) which increases the risks of medical errors and poor care coordination.(41)
Limited time with care providers	<ul style="list-style-type: none"> • Patients often only have 15 minutes with their doctor. • This is difficult when seeking care for multiple chronic conditions, and limits: <ul style="list-style-type: none"> ○ the provision of optimal care and supports for self-management; and ○ efforts to meaningfully engage patients in collaborative decision-making about their care.(42)
Heavy burden faced by patients and caregivers	<ul style="list-style-type: none"> • Patients with chronic diseases (especially those with multiple chronic conditions) have greater self-care needs, and may not be supported or able to manage these needs. • Older adults are also more likely to rely on informal and family caregivers to support them.(27) • The burden for patients and caregivers may take various forms, such as: <ul style="list-style-type: none"> ○ assisting patients with daily living activities; ○ managing multiple appointments with multiple healthcare professionals in multiple settings; or ○ helping patients follow multiple and complex drug regimens. • This heavy burden may generate great stress for these caregivers.(42)

Table 2. Challenges related to how care is paid for

Challenge	Example/description of the challenge
<p>Financial burden on patients and families</p>	<ul style="list-style-type: none"> • While the majority of care is publicly paid for, patients have to pay out-of-pocket for: <ul style="list-style-type: none"> ○ prescription drugs (e.g., almost one in 12 Ontarian aged 55 and over skipped medication because of cost);(6) and ○ many home and community supports such as rehabilitation therapy, nursing care, help with household activities, and transportation to and from medical appointments. • Coverage of these services can vary across Local Health Integration Networks (LHINs). • This makes it difficult for providers and organizations (e.g., Community Care Access Centres) to develop comprehensive and customized packages of care and services for people with chronic diseases that are based on their specific needs and their ability to pay.
<p>Caregivers can face a significant financial burden</p>	<ul style="list-style-type: none"> • It is estimated that there are more than two million unpaid caregivers in Canada. (43;44) • The estimated economic value of these contributions is in the range of \$25 billion.(45) • Those identified as either intensive caregivers and/or primary caregivers (as opposed to caregivers in general) are significantly less likely to be in the labour force as compared to non-caregivers.(46) • Financial support for informal and family caregivers remains limited.
<p>The way providers are paid does not always support prevention or care for people with complex needs</p>	<ul style="list-style-type: none"> • Payment systems are not always designed to keep people healthy or address the needs of those with complex conditions. For example: <ul style="list-style-type: none"> ○ most doctors are paid for each service provided separately (this is called a ‘fee-for-service’ model), which is not always conducive to supporting preventive care or integrated care for patients with chronic health conditions (especially those with multiple chronic disease);(33) and ○ most capitation contracts (i.e., providing a fixed amount to provide care for a patient each year) are only adjusted for age and sex and do not take into account medical complexity or other factors that could make patients sicker.
<p>Financial strain on the system</p>	<ul style="list-style-type: none"> • Care for chronic disease accounts for approximately 55% of direct health-system costs in Ontario (e.g., paying for tests and procedures), and also has an impact on indirect costs (e.g., because of lost economic productivity).(3) • The 5% of patients who have the most complex needs account for two-thirds of healthcare costs,(5) which points to a need to find more efficient ways to provide the care needed for those with complex care needs.

System planners, providers and patients lack timely data and evidence to proactively prevent and address chronic disease

Access to timely, up-to-date and easy to use data and evidence could help ensure that those who can take action in the system will make better-informed decisions about policies, programs and care. However, Ontario does not currently have strong systems in place to facilitate this, and/or those systems that are in place are not consistently used.

For example, system planners and policymakers do not always have the data they need to develop programs and policies. This stems from often having person-level data from the health system and other public systems (e.g. education), but not being able to use it (e.g., not being able to draw on information from electronic medical records) or link them in a way that can contribute to planning across sectors. This is essential to ensure that Ontarians with complex needs can be identified and then linked with the most appropriate services.

For providers this can mean that they are not able to draw on ‘real-time’ data about patients in their practice to identify those who may be at-risk for chronic disease, are receiving care recommended in guidelines, or are meeting treatment goals. It may also limit their ability to identify those at risk for becoming a ‘high-needs user’ of the health system so that they can reach out to them earlier to help manage their chronic diseases. However, the flip side of this is that many providers do have access to data about their practice relative to others in their group, their region or the province, but it is inconsistently used.

Lastly, in addition to a lack of electronic health records that put all of a patient’s health information in one place, patients also do not typically have access to their health information (e.g., through patient portals). Having access to their own health information could help patients set goals for their health, manage their own care and better engage in decisions about their care with their providers.



Taking a patient-centred approach to care for people with chronic disease can have many benefits, including increased access to specialists, better use of technology, improved coordination of care and reduced hospitalizations.

Elements of a potentially comprehensive approach to address the problem

>> To promote discussion about the pros and cons of potential solutions, we have selected three elements of a potentially comprehensive approach for strengthening care for people with chronic diseases in Ontario

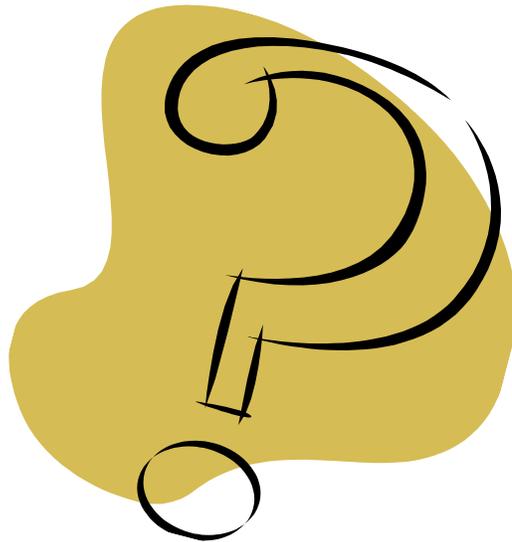
Many approaches could be used as a starting point for discussion. We have selected three elements of a potentially comprehensive approach for which we are seeking public input.

- 1) Prevent and manage chronic diseases by putting the patient at the centre of care.
- 2) Convene clinical disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management.
- 3) Collect and use data across all levels of the system to support chronic-disease prevention and management.

These approach elements should not be considered separately. Instead, each should be considered as contributing to a comprehensive approach to addressing the problem. New approach elements could also emerge during the discussions.

As you review the elements, please keep in mind the broader questions we posed at the start of this brief related to the three elements.

- Element 1
 - What would help you get the care you need when you need it?
 - What would be helpful to support you to: 1) take ownership of your health; and 2) to understand how to manage your own care?
 - What would help make your care seamless?
- Element 2
 - In what ways do you think patients should be engaged in the development of approaches to chronic-disease prevention and management?
- Element 3
 - What types of data and information supports would be helpful for you to make informed decisions about your care and to manage chronic diseases for you or someone you provide care to?



Element 1 – Prevent and manage chronic diseases by putting the patient at the centre of care

This element could focus on implementing components of patient-centred care models that broadly focus on:

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

In Table 3, we summarize the types of activities that could be included in each of these areas of focus. Several systematic reviews (and some key studies) have found that using models of patient-centred care have many benefits, including:

- increased access to specialists;
- improved patient and clinician experience;
- better use of technology;
- improved coordination of care;
- enhanced delivery of preventive services; and
- reduced hospitalizations and emergency department visits.(52;53;53-58)

Table 3. Types of activities that could be included in element 1

Area of focus	Types of activities
<p>Ensure patients receive care when they need it</p>	<ul style="list-style-type: none"> • Providing patient-driven scheduling to ensure timely access (i.e., access to same- or next-day appointments, with priority for those who need it most) • Using team-based models to provide same- or next-day access to care • Using secure email and telephone encounters to enhance access, and to prepare for, follow-up from, or substitute for in-person visits
<p>Engage patients in their care</p>	<ul style="list-style-type: none"> • Developing personalized care plans where patients and clinicians collaboratively develop a care plan to address the patients' health issues • Promoting the use of resources and providing skills development to help patients manage certain aspects of their care • Supporting shared decision-making with care providers (e.g., through decision aids) • Engaging patients in their care through shared use of electronic health records that allow for laboratory and radiology test results review, online medication review and refills, and provision of "after-visit summaries" (see element 3 for additional examples of how information technology can be used)
<p>Support seamless transitions between settings</p>	<ul style="list-style-type: none"> • Providing a single point of contact for the sickest patients who assume responsibility for ensuring patients are transitioned across providers, teams and settings • Having a central 'hub' to coordinate outreach and follow-up for discharges from hospital and emergency or urgent care visits • Ensuring effective communication between care providers

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

This element could include an oversight council led by experts with experience in managing multiple chronic conditions and be comprised of representatives from disease- and care and support-focused working groups, as well as citizens/patients.

The council could work collectively to:

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

We identified several systematic reviews relevant to the three activities listed above that could be included in this element.

Key findings from these reviews include:

- implementing regional collaborations to enhance the quality of surgical care has been found to significantly improve clinical outcomes (e.g., fewer surgical-site infections);(47)
- mixed or unclear evidence about whether partnerships between sectors (e.g., health systems, public health and community care),(48) or access to resources for chronic-disease prevention and management,(49) improve health outcomes;
- training of patients and their families, as well as healthcare professionals, was found to be an important component of successfully involving cancer patients and their families in research, policy, planning and practice;(50) and
- involving patients in the planning and development of healthcare plans has several benefits for:
 - patients (e.g., improved self-esteem)
 - providers and staff (e.g., rewarding experience)
 - processes for care (e.g., simplified appointment procedures); and
 - broader supports (e.g., improved transportation between sites).(51)

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

This element could include:

- 1) clinical information systems that use electronic health records to identify and contact high-risk patients, and more generally support chronic-disease prevention across all levels of the system.
- 2) systems to support decision-making by patients and providers;
- 3) providing a summary of clinical performance of healthcare at the practice/organizational level over a period of time to change health professional behaviour (typically called audit and feedback); and
- 4) performance reporting at the practice/organizational, sub-regional, LHIN and provincial level (e.g., how are individual hospitals performing).

We identified several systematic reviews relevant to the four activities listed above that could be included in this element.

Key findings from these reviews include:

- chronic care models that incorporate clinical information systems (i.e., systems such as electronic health records that organize patient and population data to facilitate more efficient care) as one of several components, have been found to improve the performance of healthcare practices, as well as health outcomes of patients;(59;60)
- systems to support decisions by providers such as computer-aided reminders have been found to achieve small improvements in physician behaviour (e.g., ordering proper medications, providing vaccinations when needed and ordering appropriate tests);(61)
- audit and feedback (i.e., a summary of clinical performance of healthcare over a period of time to change health professional behaviour) has been found to result in a 4-16% improvement in following clinical practice guidelines;(62)
- there is mixed evidence about whether public reporting has an impact on improving patient outcomes.(63-67)

Implementation considerations

It is important to consider what barriers we may face if we implement the proposed elements of a potentially comprehensive approach to address the problem. These barriers may affect different groups (for example, patients, citizens, healthcare providers), different healthcare organizations or the health system. While some barriers could be overcome, others could be so substantial that they force us to re-evaluate whether we should pursue that element. Some potential barriers to implementing the elements are summarized in Table 4.

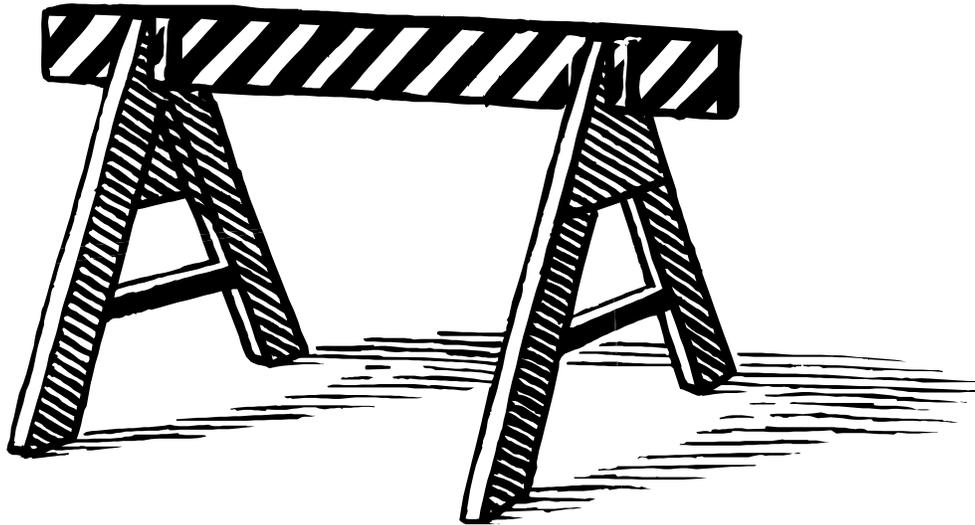


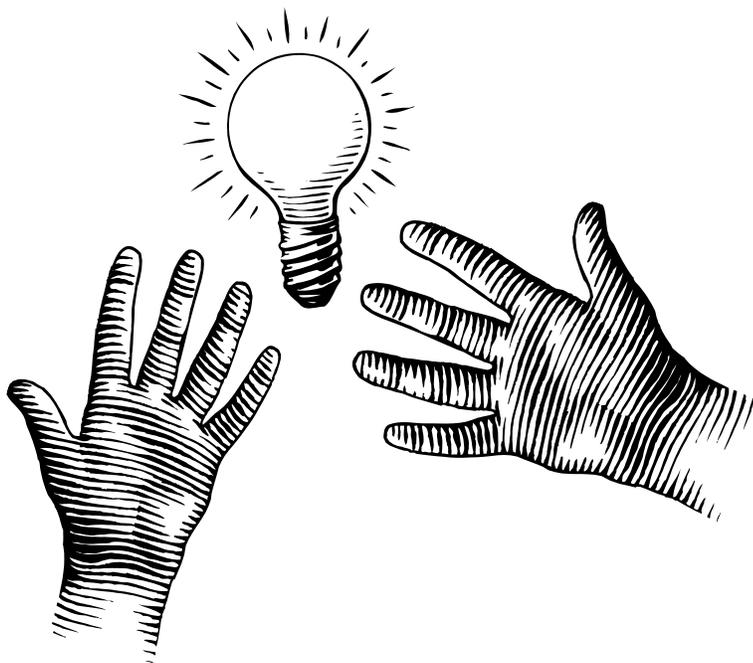
Table 4: Potential barriers to implementing the elements

Element	Description of potential barriers
<p>Element 1 – Prevent and manage chronic diseases by putting the patient at the centre of care</p>	<ul style="list-style-type: none"> • Citizens, healthcare providers, organizations and/or policymakers could view this as another different approach that requires investment, but doesn't lead to real change in the system. • Expectations from citizens for timely access may be difficult to balance against what is feasible given existing resources. • Healthcare providers may resist the idea of working in a model that ensures same- or next-day access to care. • Not all citizens may like the idea of being more involved in and responsible for their care. • Some healthcare providers may initially feel uncomfortable providing more responsibility to the patient for their care. • Healthcare providers may find it difficult to ensure outreach to all patients discharged from hospital or emergency departments without electronic health records that link care across providers and settings.
<p>Element 2 - Convene clinical disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management</p>	<ul style="list-style-type: none"> • Healthcare providers may see this as another commitment on top of managing already busy practices. • Some healthcare providers may not consistently follow the leadership and guidance from the clinical disease council. • Some patients and citizens may not feel sufficiently informed to properly contribute to citizen-engagement processes. • Citizens, healthcare providers, organizations and/or policymakers could view this and the other elements as another different approach that requires investment, but doesn't lead to real change in the system.
<p>Element 3 – Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management</p>	<ul style="list-style-type: none"> • Policymakers lack access to transparent performance measures of patient-centred outcomes (e.g., patient experience), which limits their ability to monitor progress of efforts to put the patient at the centre of care. • Some healthcare providers and organizations may lack the infrastructure needed to implement audit and feedback, or to support improvement based on existing audit and feedback systems. • Healthcare providers, organizations and policymakers will face significant challenges for implementing clinical information systems that can be integrated for use across all care settings and providers in the province. • Organizations and policymakers may be hesitant to implement performance reporting to avoid the potential for bad publicity.

The implementation of each of the three elements could also be influenced by the ability to take advantage of potential windows of opportunity. A window of opportunity could be, for example, a recent event that was highly publicized in the media, a crisis, a change in public opinion, or an upcoming election. A window of opportunity can facilitate the implementation of an element.

Examples of potential windows of opportunity relate to:

- **Harnessing increased attention:** Recently there has been much attention on strengthening patient-centred care in Ontario, which focuses on elements included in this brief. This attention could help support action towards strengthening care for people with chronic disease in Ontario.
- **Drawing on momentum created by high-profile proposals:** Recent high-profile proposals to reform primary, home and community care in Ontario, including the highly publicized proposal from the province to strengthen patient-centred care, emphasize many of the activities included in the element to put the patient at the centre of care.(14;68)
- **Meeting health-system goals:** Strengthening care for people with chronic disease through all three elements could help the province address each of the four goals in the province's action plan for the health system: 1) improving access; 2) connecting services; 3) support people and patients; and 4) protect the universal health system.(15)



Acknowledgments

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Conflict of interest

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Merit review

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