

EVIDENCE >> INSIGHT >> ACTION

**Evidence Brief:
Strengthening Care for People with Chronic Diseases in Ontario**

21 April 2016

McMaster Health Forum

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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Funding

The evidence brief and the stakeholder dialogue it was prepared to inform were funded by the Ontario Medical Association. The McMaster Health Forum receives both financial and in-kind support from McMaster University. The views expressed in the evidence brief are the views of the authors and should not be taken to represent the views of the Ontario Medical Association or McMaster University.

Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the evidence brief. The funders played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the evidence brief.

Merit review

The evidence brief was reviewed by a small number of policymakers, stakeholders and researchers in order to ensure its scientific rigour and system relevance.

Acknowledgments

The authors wish to thank [insert name] for assistance with summarizing systematic reviews. We are grateful to Steering Committee members (Barb LeBlanc, Nancy Dale, Nadia Daniell-Colarossi and Tatiana Jevremovic) and merit reviewers (Gail Czukar, Kaiyan Fu and Therese Stukel) for providing feedback on previous drafts of the brief. The views expressed in the evidence brief should not be taken to represent the views of these individuals.

Citation

Wilson MG, Lavis JN, Moat, KA, Guta A. Evidence Brief: Strengthening Care for People with Chronic Diseases in Ontario. Hamilton, Canada: McMaster Health Forum, 21 April 2016.

Product registration numbers

ISSN 1925-2242 (print)

ISSN 1925-2250 (online)

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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, 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 as a result of a lack of coordination and limited engagement of patients and citizens;
 - many system features make it difficult to provide accessible, comprehensive, coordinated and continuing care; and
 - system planners, clinicians and patients lack access to timely data and evidence to proactively prevent and manage chronic disease.

What do we know (from systematic reviews) about three viable elements of a potentially comprehensive approach to address the problem?

- Element 1 – Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care
 - This element might include activities related to: ensuring all Ontarians receive the care they need, when they need it; supporting the engagement of patients in their care; and ensuring the full range of care is seamlessly linked across clinicians, teams and settings.
 - We identified four systematic reviews that evaluated models of patient-centred care (e.g., team-based care, self-management supports, coordination between teams and settings, and use of technology to enhance access to care). The models were found to improve patient and clinician experiences, increase access to specialists, lead to better use of technology, improve coordination of care, enhance delivery of preventive services, and reduce hospitalizations and emergency department visits.
 - Several systematic reviews found benefits for specific approaches that could be used as part of a patient-centred care model, including advanced access scheduling, team-based models that provide same- or next-day care, secure email and telephone encounters, personalized care plans, self-management supports, decision aids to support shared decision-making, electronic health records to improve quality of care, care coordinators with clinical skills, and better discharge planning.
- Element 2 – Convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management
 - This element could include both chronic-disease councils and an oversight council led by experts with experience in managing multiple chronic conditions, which could work collectively to provide clinical leadership for chronic-disease prevention and management, create and support the use of evidence-based tools, and support patient engagement in the development of these approaches.
 - We found systematic reviews that identified benefits for regional collaborations (e.g., surgical communities of practice), engaging stakeholders in the creation of evidence-based tools, and citizen/patient-engagement processes.
- Element 3 – Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management
 - This element might include clinical information systems (that support chronic-disease prevention across the system by identifying and contacting high-risk patients), decision-support systems for patients and clinicians, audit and feedback at the practice/organizational level, and performance reporting.
 - We identified systematic reviews that found benefits for using clinical information systems as part of chronic-care models, decision-support systems for patients (e.g., patient portals) and providers (e.g., computerized reminders/prompts), and audit and feedback, but mixed effects for performance reporting.

What implementation considerations need to be kept in mind?

- Barriers to implementation might include: 1) the scale of the redesign of the health system, given redesign is more difficult than simply adding new 'ingredients'; 2) lack of interest, capacity and/or incentives for citizens/patients, providers and organizations to adopt new ways of doing things; and 3) the need for investments in infrastructure that would be needed for strengthened data supports.
- Windows of opportunity might include: 1) harnessing the increased attention being paid to strengthening patient-centred care; and 2) drawing on momentum created by high-profile proposals to reform primary, home and community care.

REPORT

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,(1-3) including the Ontario Medical Association, which commissioned this brief (and the stakeholder dialogue it was prepared to inform) to inform its focus on “putting patients first.”(4)

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, as well as the complexity of providing accessible, comprehensive, coordinated and continuing care for people with chronic conditions (particularly those living with multiple chronic conditions). Indeed, as identified in many systematic reviews, engaging in activities to strengthen care for chronic diseases can contribute to strengthening the health system more generally. For example, 27 reviews found that integrating care across settings (e.g., hospitals, primary care and care provided in the community) and among clinicians (e.g., among family physicians, specialists and other clinicians):

- 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.(15)

Perhaps the best example of how care for chronic disease has been systematically strengthened is with cancer care. Specifically, in Ontario, cancer has been organized as its own integrated sub-system, where Cancer Care Ontario is responsible for planning, funding and coordinating cancer care across the province.(5) However, strengthening care for people with chronic disease requires going beyond this, and focusing on integrated efforts to provide care for chronic diseases, as well as for conditions that are common to many diseases.

To this end, the most recent focus for strengthening care for people living with chronic diseases has been on strengthening primary care (including better coordination between primary and acute care, and across settings), as well as home and community care, in order to improve outcomes across the Triple Aim of enhancing the patient experience, improving health outcomes, and keeping per capita costs manageable.(2)

Given the focus on putting patients first by making care in the province more patient-centred and strengthening care for people with chronic disease, there is a clear ‘window of

Box 1: Background to the evidence brief

This evidence brief mobilizes both global and local research evidence about a problem, three elements of a potentially comprehensive approach for addressing the problem, and key implementation considerations. Whenever possible, the evidence brief summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The evidence brief does not contain recommendations, which would have required the authors of the brief to make judgments based on their personal values and preferences, and which could pre-empt important deliberations about whose values and preferences matter in making such judgments.

The preparation of the evidence brief involved five steps:

- 1) convening a Steering Committee comprised of representatives of the partner organization and the McMaster Health Forum;
- 2) developing and refining the terms of reference for an evidence brief, particularly the framing of the problem and three viable elements of a potentially comprehensive approach for addressing it, in consultation with the Steering Committee and a number of key informants, and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
- 3) identifying, selecting, appraising and synthesizing relevant research evidence about the problem, approach elements and implementation considerations;
- 4) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence; and
- 5) finalizing the evidence brief based on the input of several merit reviewers.

The three elements of a potentially comprehensive approach could be pursued simultaneously or in a sequenced way, and each element could be given greater or lesser attention relative to the others.

The evidence brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants’ views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is 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. A second goal of the stakeholder dialogue is 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.

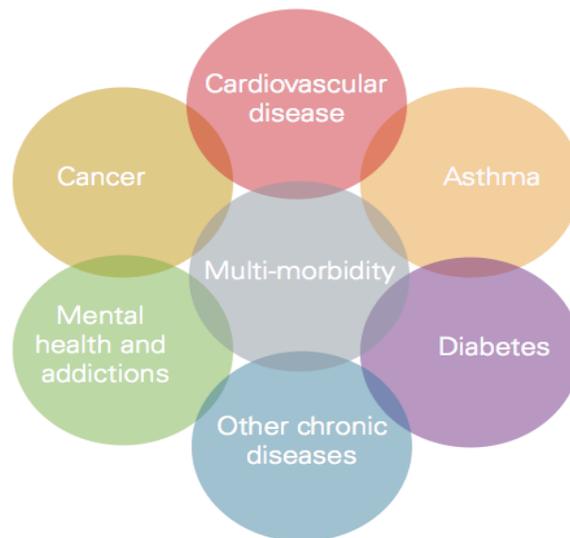
opportunity' for evidence-informed action. Supporting such action requires developing a plan that makes the best use of available resources, taking actions to execute the plan, and having data to support implementation, monitoring and evaluation.

Developing a plan to making the best use of available resources, means putting the patient at the centre of actions taken and having different stakeholders working collaboratively across different parts of the system to prevent and manage chronic diseases in a way that provides accessible, comprehensive, coordinated and continuing care for all Ontarians. Key components of a plan could include:

- patients adopting healthy lifestyles to prevent chronic disease and/or managing certain aspects of their care (with needed supports and in collaboration with providers);
- practices/organizations and providers empowering 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;
- planning and deploying resources at the regional level; and
- supporting province-wide population-based prevention initiatives.

Executing a plan will require at least two types of action, with one focused on diseases and the other on conditions that are common to many diseases. First, developing comprehensive disease-management approaches will require having approaches for different chronic diseases, such as cancer, cardiovascular disease, asthma, diabetes, mental health and addictions, and others. However, as portrayed in Figure 1, actions to develop approaches for specific diseases will need to also account for how to manage people with multi-morbidity (i.e., people living with multiple chronic diseases). This is especially important with the large number of 'high needs users' of the system who account for a high proportion of health-system costs (e.g., many of whom are those living with multiple chronic diseases). It is also especially important in the context of mental health and addictions, which are often not included in the discourse on chronic disease and, as a result, their unique features are not always included in approaches to strengthening care for chronic diseases.

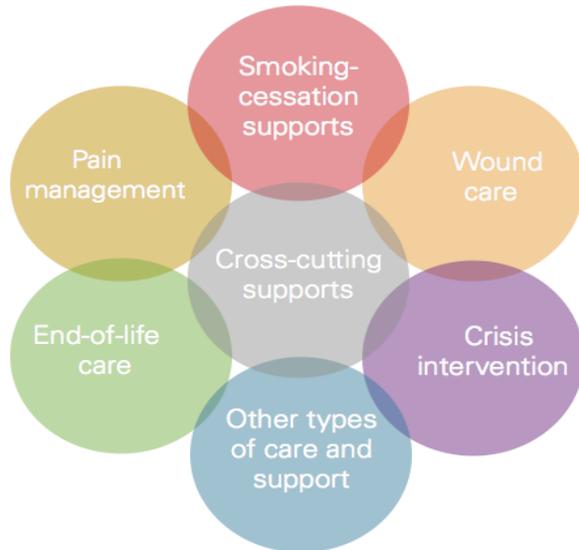
Figure 1: Developing comprehensive disease-management approaches for specific diseases and for multi-morbidity



The second type of action focuses on conditions that are common to many diseases, such as those outlined in Figure 2 (e.g., pain management, smoking cessation, wound care, crisis intervention, and end-of-life care, as well as other types of care and support), which often need to be addressed as part of care for many different chronic diseases. An important part of developing such approaches will be to ensure that cross-cutting

supports (e.g., interprofessional practice, self-management supports, and leadership) are available to support these actions.

Figure 2: Developing comprehensive approaches to manage conditions or issues that cut across diseases



Having timely access to anonymized and aggregated data is essential for supporting these actions. There are several ways that data supports can help support action as they can:

- enable patients who already have one or more chronic diseases to improve their quality of life and prevent disease progression or reduce its impact (e.g., by helping them to take action to manage their chronic diseases);
- allow clinicians and practices/organizations to identify and reach out to high-risk patients to support the prevention of chronic disease; and
- support system planners to identify what’s not working, and to improve care for chronic diseases over time.

Data could be used in several ways as part of the third point above. For example, at the system level, data supports could be used to measure, provide feedback and publicly report impacts on patient experiences, health outcomes and per capita costs. It could also be used to identify practices that are different from others (for instance, where patients appear to receive care that isn’t as high quality as elsewhere). This could be used to help clinicians within these practices to improve care, or understand whether and how their patients differ (and what they might need to improve outcomes).

Box 2: Equity considerations

A problem may disproportionately affect some groups in society. The benefits, harms and costs of elements of a potentially comprehensive approach to address a problem may vary across groups. Implementation considerations may also vary across groups.

One way to identify groups warranting particular attention is to use “PROGRESS,” which is an acronym formed by the first letters of the following eight ways that can be used to describe groups†:

- place of residence (e.g., rural and remote populations);
- race/ethnicity/culture (e.g., First Nations and Inuit populations, immigrant populations and linguistic minority populations);
- occupation or labour-market experiences more generally (e.g., those in “precarious work” arrangements);
- gender;
- religion;
- educational level (e.g., health literacy);
- socio-economic status (e.g., economically disadvantaged populations); and
- social capital/social exclusion.

The evidence brief strives to address all Ontarians, but (where possible) it also gives particular attention to:

- people of low socioeconomic status; and
- people living with multiple chronic conditions.

Many other groups warrant serious consideration as well, and a similar approach could be adopted for any of them.

† The PROGRESS framework was developed by Tim Evans and Hilary Brown (Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. *Injury Control and Safety Promotion* 2003;10(1-2): 11–12). It is being tested by the Cochrane Collaboration Health Equity Field as a means of evaluating the impact of interventions on health equity.

Overview of contextual factors related to strengthening care for people living with chronic diseases in Ontario

There are several features of the health system, other sectors that intersect with the health system, as well as features of specific populations affected by chronic disease that are important to take into account in the context of strengthening care for people living with chronic diseases in Ontario. We provide a summary of these factors below to assist with interpreting the information presented about the problem, three elements of a potentially comprehensive approach for addressing the problem, and implementation considerations.

Features of the health system relevant to providing chronic-disease prevention and management

- Medically necessary care for eligible Ontario residents that is provided in hospitals and by physicians is fully paid for as part of Ontario's publicly funded health system.
- Care and support provided by other clinicians such as nurses (including nurse practitioners), 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 as coordinated through Family Health Teams, Community Health Centres, Community Care Access Centres, and other designated clinics.
- Other healthcare and community services such as prescription drug coverage, community support services and long-term care homes may be wholly, partly or not paid for by the government, and any remaining costs need to be paid by patients, families, or their private insurance plans.
- Fourteen geographically defined Local Health Integration Networks (LHINs) have responsibility for the planning, funding and integration of healthcare in their regions, and for ensuring that the different parts of the health system in their regions work together (although they do not currently have oversight of physician, drug and public health budgets).
- The most recent estimates of the health workforce in Ontario indicate that for every 100,000 Ontarians there are approximately 100 family physicians, 102 specialists, 699 registered nurses (including 14 nurse practitioners), 83 pharmacists, 48 physiotherapists and 38 occupational therapists,(6) and of the 28,422 physicians in the province, 51% are specialists, with the majority (99%) practising in urban centres.(7)
- In primary care, the Ontario health workforce currently provides 94% of Ontarians with a primary-care provider (as reported by patients).(8)
- Primary care can be accessed by Ontarians in several ways, including through team-based models that currently reach 25% of the population through 184 Family Health Teams, 105 community health centres, 26 nurse practitioner-led clinics,(9) and 10 Aboriginal Health Access Centres, and through other primary-care models including family physicians working in solo practice or in Family Health Organizations (n=434), Family Health Groups (n=227) and Family Health Networks (n=24).(6)
- A range of mechanisms to access care for chronic diseases are available in the acute-care sector and include: urgent care centres; specialty programs in more than 60 areas (e.g., internal medicine specialties such as cardiology, and surgical specialties such as orthopedics, as well as anesthesia, obstetrics and gynecology, pediatrics, psychiatry, radiology, and laboratory medicine); and complex continuing care.(7)

Features of other sectors that intersect with the health system that are relevant to providing chronic-disease prevention and management

- Fourteen Community Care Access Centres (CCACs) – one for each LHIN – have responsibility for determining need for home and community care, and then connecting people with the care they need (although the most recent proposal for strengthening patient-centred care in Ontario has suggested that CCAC functions could be absorbed into LHINs).
- Home and community care can be delivered through many points of contact, including: 733 not-for-profit community support-service agencies that provide assistance (including personal support for household tasks, transportation, meals, supportive housing and adult day programs) to more than 800,000 community-dwelling Ontarians (including older adults, and people with a physical disability and/or mental health and

addiction issues); 487 mental health and addiction organizations; 245 diabetes education centres; and 55 emergency medical service organizations.(10)

- The 36 public health units, which are typically linked to municipal government, are not aligned with the boundaries of the LHINs (although the recent discussion paper from the province for strengthening patient-centred care proposes placing their budgets in the LHINs). The public health units provide a range of health-promotion and disease-prevention programs, including those that inform the public about healthy lifestyles, provide communicable disease control (e.g., education in STDs/AIDS, immunization and food inspection), and support healthy growth and development (e.g., parenting education, health education for all age groups, and selected screening services).(11)

Features of specific populations affected by chronic disease (either in terms of burden of disease and/or access to care to support chronic-disease prevention and management)

- Health Links (69 of an anticipated total of 90) support the delivery of integrated care for those with complex needs, which is typically people living with four or more chronic diseases and who comprise roughly 5% of the population.
- The 10 Aboriginal Health Access Centres provide community-led, primary healthcare, including many services related to chronic-disease prevention and management, as well as a combination of traditional healing, primary care, cultural programs, health-promotion programs, community-development initiatives, and social-support services to First Nations, Métis and Inuit communities.(12)
- Rural-Northern Physician Group Agreements support one to seven physicians per location to serve rural and northern communities with a nurse-staffed, after-hours Telephone Health Advisory Service for enrolled patients seeking care for a range of issues, including chronic diseases.(13)

THE PROBLEM

Substantial investments have resulted in progress towards strengthening care for chronic diseases in Ontario (e.g., through the implementation of Health Links), but many challenges still remain. These challenges broadly relate to:

- the burden of chronic disease is high, 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 as a result of a lack of coordination and limited engagement of patients and citizens;
- many system features make it difficult to provide accessible, comprehensive, coordinated and continuing care; and
- system planners, clinicians and patients lack access to timely data and evidence to proactively prevent and manage chronic disease.

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

Many Ontarians are living with chronic diseases or provide care to family, friends and other members of their communities who need help managing their chronic diseases. Data indicate that approximately 80% of Ontarians over the age of 45 (roughly 3.7 million people) are living with a chronic condition.⁽¹⁴⁾ Moreover, data from across Canada indicate that approximately:

- 70% of those who are considered the sickest Canadians (people with chronic conditions who described their health as fair or poor) have two or more chronic health conditions;⁽¹⁴⁾
- 38% of Canadians over the age of 20 have at least one chronic health condition;⁽¹⁵⁾
- 21% of Canadians are living with a major chronic condition (cancer, diabetes, cardiovascular disease, chronic respiratory diseases);⁽¹⁵⁾ and
- 15% of Canadians are living with two or more chronic health conditions.⁽¹⁵⁾

Many groups are affected by chronic diseases, including:

- older adults: 75% of Ontarians over the age of 65 report having one or more of 11 chronic health conditions;⁽¹⁶⁾
- younger adults: 12% of younger adults in Canada have three or more chronic health conditions;⁽¹⁷⁾
- women: 14% of Canadian women have two or more chronic health conditions as compared to 11% of men (across all age groups);⁽¹⁷⁾ and
- economically vulnerable groups: 40% of low-income Canadians have one or more chronic health conditions, compared to 27% of high-income Canadians.^(14;17;18)

Chronic disease affects peoples' mobility, and their ability to engage in daily life and participate in social activities.⁽¹⁴⁾ In addition, living with chronic disease has been associated with early death for people over the age of 30.⁽¹⁴⁾ In Ontario, chronic diseases were responsible for 79% of all deaths in 2007 (led by cancer at 38%, and cardiovascular disease at 38%).⁽¹⁹⁾ While disability and early deaths are preventable if chronic conditions are identified and managed early, the number of people living with chronic disease is increasing by 14% per year across Canada, and the proportion of deaths attributed to it has been steadily increasing.⁽²⁰⁾ In Ontario the population is projected to increase to 16.9 million by 2031, with persons 65 and over making up

Box 3: Mobilizing research evidence about the problem

The available research evidence about the problem was sought from a range of published and “grey” research literature sources. Published literature that provided a comparative dimension to an understanding of the problem was sought using three health services research “hedges” in MedLine, namely those for appropriateness, processes and outcomes of care (which increase the chances of us identifying administrative database studies and community surveys). Published literature that provided insights into alternative ways of framing the problem was sought using a fourth hedge in MedLine, namely the one for qualitative research. Grey literature was sought by reviewing the websites of a number of Canadian and international organizations, such as Health Quality Ontario, the Institute for Clinical Evaluative Sciences, and the Canadian Institute for Health Information.

Priority was given to research evidence that was published more recently, that was locally applicable (in the sense of having been conducted in Canada), and that took equity considerations into account.

25% of the population. The combination of population growth, an aging population and continued exposure to various risk factors is projected to increase the burden of chronic disease in the province unless action is taken.(19) The burden of chronic disease is also made more significant given the bi-directional relationship between mental illness and chronic disease. Specifically, people living with a serious mental illness are at higher risk of developing a chronic disease, and people who are living with a chronic physical condition are twice as likely to experience depression and anxiety.(21) This leads to high patient burden and makes caring for people with chronic disease complex (as discussed in the following section).

Care for people with chronic conditions is challenging

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 a system in which 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 goals,(22) and many specialists may only focus on goals in one area. For example, providers and patients must find a balance among improving nutrition, living situation, function, symptom burden, survival, life expectancy of a patient, and other health goals. Patients and their caregivers must also be supported to prioritize these goals based on their needs, values and preferences (e.g., what may be reasonable for a 30-year-old may not be reasonable for someone who is 85 and at risk for becoming frail). This also means that there are often several potentially competing treatments, and these treatments may interact, which can create uncertainty about the benefits and harms of different treatments, and a risk of worsening one condition by treating another one.(23)

In addition, clinicians and patients are often using clinical 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,(24) these guidelines rarely address how to optimally integrate care for people with multiple chronic health conditions.(25-28) The lack of availability 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 (e.g., primary-care providers such as family physicians may have to balance recommendations from several specialists), which can be burdensome for everyone involved.(29;30)

The patient is not always put at the centre of care as a result of a lack of coordination and limited engagement of patients and citizens

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.(8) This level of involvement is comparable to the best-performing countries, such as in the United Kingdom (87%) and New Zealand (88%).(8)

However, existing measures of patient-reported involvement in their care do not include a measure that reflects the full concept of patient-centred care, which the Institute for Patient- and Family-Centered Care defines as "...an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families."(31) The same institute further describes four core concepts of patient-centred care:

- 1) respect and dignity (i.e., providers listening to and respecting patient and family perspectives and choices, with their knowledge, values and beliefs incorporated into care planning and delivery);
- 2) information sharing (i.e., communicating and sharing timely, complete, unbiased and accurate information with patients and their families to support them to participate in care and decision-making);

- 3) participation (i.e., encouraging and supporting patients and their families to participate in care and decision-making in ways they are comfortable with); and
- 4) collaboration (i.e., healthcare providers and system leaders collaborating with patients and their families “in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care”).(31)

There are at least three ways in which the patient is not put at the centre of care. First, a lack of interprofessional collaboration limits the health system’s capacity to deliver better coordinated and integrated care. Interprofessional collaboration has been argued to be key to delivering better coordinated and integrated care, and may improve patients’ outcomes.(32-36) However, such collaboration and partnership with patients in planning their care and making decisions occurs relatively infrequently in primary- and community-care settings,(37) and between primary and speciality care given that transitions between these settings are particularly challenging.(38)

Second, a lack of comprehensive information and communication-technology infrastructure limits the health system’s capacity to deliver better coordinated and integrated care, and to deliver information to patients in an understandable and timely way. While the health system does have widespread use of electronic medical records within primary-care practices, and the ability to monitor care using administrative databases, the health system currently lacks interoperable electronic health records. Without interoperable electronic health records, it is difficult to provide coordinated care (including monitoring along the full continuum of care) between different care providers, such as family physicians, nurse practitioners, pharmacists and specialists, and across settings, such as primary care, acute care, and home and community care (as well as within large organizations such as hospitals where specialists often have to access several databases to get all the information they need about a patient). In addition, without interoperable electronic health records, it is difficult to monitor and evaluate the chronic-disease care delivered to populations.

Lastly, despite broad recognition about the need to empower patients to take on a greater role in managing their own care and in determining how the system should be designed to make sure it works for them,(39) patients, families and caregivers often lack the supports they need to engage in these types of activities. Without such supports and engagement opportunities, care may not be patient-centred. Also, policy developed to address macro- and micro-level health system issues may not be based on citizens’ values and preferences, or be flexible enough to accommodate an array of values and preferences. For example, a recent paper about the future of public involvement in health policy states that “public involvement is valued in theory, but too frequently sacrificed upon an altar of pragmatism: getting the public involved is considered too complex, too time consuming, too costly and its benefits too nebulous.”(40)

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

There are several challenges related to health system delivery, financial and governance arrangements that make it difficult to provide accessible, comprehensive, coordinated and continuing care. We summarize these challenges in Table 1.

Table 1: Summary of system features that make it difficult to provide accessible, comprehensive, coordinated and continuing care

Level of the system	Challenge	Example/description of the challenge(s)
Delivery	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 communicate effectively with each other,(29;30) which increases the risks of medical error 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, which is difficult when seeking care for multiple chronic conditions, and limits the provision of optimal care and supports for self-management, as well as constrains the ability of clinicians 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 diseases) 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.(23) • 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; and ○ helping patients follow multiple and complex drug regimens. • This heavy burden may generate stress and other health issues (e.g., depression) for these caregivers.(42)
	Limited training or supports for clinicians to address complex needs	<ul style="list-style-type: none"> • Most physicians feel they are not well prepared to manage the care of patients with complex needs, including being able to coordinate care and communication with other providers of and settings for care (e.g., hospital- and home-based care).(43) • A core challenge for implementing new models is that there is generally no training, support and/or coaching (e.g., practice coaching or practice facilitation) (44;45) for physicians and their teams to support them to transition to working in a new model.
Financial	Financial burden on patients and families	<ul style="list-style-type: none"> • While the majority of care is paid for publicly, patients may have to pay out-of-pocket for: <ul style="list-style-type: none"> ○ prescription drugs (e.g., almost one in 12 Ontarians aged 55 and over skipped medication because of cost);(8) 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 some services can vary across Local Health Integration Networks (LHINs). • Differences in ability to pay 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.
	Financial burden on caregivers	<ul style="list-style-type: none"> • 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)

		<ul style="list-style-type: none"> • Financial support for informal and family caregivers remains limited.
	<p>Payment systems for providers are not always designed to support multi-problem visits (as required by those with complex conditions) or to support preventive care visits</p>	<ul style="list-style-type: none"> • Most doctors are paid for each service provided separately (i.e., ‘fee-for-service’), which is not always conducive to supporting preventive care or integrated care for patients with chronic health conditions (especially those with multiple chronic disease).(29) • 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, and they also allow for physicians to opt out of taking on the most complex patients who seek frequent care.
	<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.
Governance	<p>Lack of accountability in some parts of the system</p>	<ul style="list-style-type: none"> • Formal plans for ongoing quality improvement based on data and evidence is a requirement only for interprofessional, team-based primary-care organizations in Ontario (not other primary-care organizations), but some lack resources to do this well, and this is not required (or supported) for those working in other models such as solo practice.
	<p>Lack of inter-sectoral collaboration</p>	<ul style="list-style-type: none"> • Public health services are disconnected from the rest of the health system, and population health is not a consistent part of health-system planning, which makes it challenging to address ‘upstream’ factors that keep people healthier for longer.(1)

System planners, clinicians and patients lack access to timely data and evidence to proactively prevent and manage chronic disease

While there are examples of frameworks that are being used as a starting point to enhance healthcare quality and health-system performance in Ontario,(8;47) there is a general need for better access to timely, up-to-date and easy to use data and evidence to help ensure that those who can take action in the system will make well-informed decisions about policies, programs and care. But, Ontario does not currently have strong systems in place to facilitate this, and 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 the data (e.g., not being able to draw on information from electronic medical records) or to link data in a way that can contribute to planning across sectors.

For clinicians 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, those who are receiving care recommended in guidelines, or those who are meeting treatment goals. It may also limit providers’ 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 disease(s). The flip side of this is that many clinicians 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 be supported to engage in decisions about their care with their providers.

Additional equity-related observations about the problem

Ensuring timely, coordinated and integrated care is important for people living with chronic diseases because it results in better health outcomes for individuals and populations, can help diminish the impacts of health inequities and reduce total costs for the healthcare system.(8;48) However, access to care (and hence patient-level health outcomes) is influenced by a number of system-level factors, such as the availability and distribution of care (e.g., primary and specialist care, as well as home and community care), medical factors (e.g., having multiple chronic conditions), and social factors (e.g., being part of a socially and/or economically marginalized group, like Indigenous peoples, recent immigrants and those living in poverty).(8;49;50)

Like all Canadians, Ontarians who live in poverty (or have ‘low socioeconomic status’) are at greater risk of developing chronic diseases (e.g., because of more limited access to nutritious food, exercise and health screenings, or work-related challenges including precarious/stressful work, unemployment or balancing/managing multiple jobs),(51) and experience a greater burden of illness than more affluent Canadians (e.g., higher rates of hospitalization).(52;53) In Ontario, the prevalence of five or more chronic conditions was significantly higher among older adults in the poorest neighborhoods (18.2%) compared to the wealthiest,(14.3%), with the poorest having a 2.5% increase in premature mortality. Across Canada, the prevalence of psychological distress, select mental disorders or substance dependence is 13% for low-income persons (37% higher than for those not identified as low-income).(54) Also, as noted earlier, there is a bi-directional relationship between mental illness and chronic disease, as people living with a serious mental illness are at higher risk of developing a chronic disease, and people who are living with a chronic physical condition are twice as likely to experience depression and anxiety.(21) Ontario (matched only by Nova Scotia) had the highest age-standardized utilization rates of health services for mental illness from 1996/1997 to 2009/2010, with especially high use among youth and older adults.(55)

Ontarians who are living with multiple chronic conditions may experience a range of barriers to accessing the care they need. For example, a recent study in Ontario found that as the number of chronic conditions increased from one-to-three to four or more, the odds of experiencing difficulty accessing specialist care increased from 2.2 to 3.8 compared to those with no chronic conditions.(56) The study further identified immigration status, education level and living in a rural setting as other important indicators of difficulties for accessing specialist care.(56)

In addition to rural and urban differences, further differences have been identified within the same city based on neighbourhood, with significantly reduced access for linguistic minorities.(49) Age is also a factor in determining the type and amount of care people living with chronic conditions receive, with an Ontario study based on data from the Institute for Clinical Evaluative Sciences (ICES) reporting that adults between the ages of 20 and 44 living with six or more diseases had 10 primary healthcare and 10 specialist visits per year, compared to those aged 85 years and older with six or more diseases who had more primary healthcare visits at 11 per year, but only four specialist visits in the same period.(57)

In a recent report about what Canadian physicians can do to help mitigate the effects of the social determinants of health on their patients, those interviewed identified “linking patients with supportive community programs and services” as the number one intervention to address health equity issues. This was understood to help with managing social and economic needs, and with adherence to treatment plans. The study further identified the importance of “interdisciplinary team-based practice settings” and having “a relationship with community services and programs” as important areas for intervention.(58) Physicians identified improved training, interdisciplinary team-based practice, and relationships with community services and programs as the top three facilitators.(58) In terms of potential action items for practice, they identified the need for the “development/consolidation and dissemination of plain language resources for patients on chronic disease management”.(58)

Citizens’ views about key challenges related to strengthening care for people with chronic diseases in Ontario

During a citizen panel convened on 2 April 2016, 16 ethnoculturally and socioeconomically diverse citizens were provided a streamlined version of this evidence brief written in lay language (details about the recruitment and approach to convening the panel are available in the panel summary, which can be downloaded from the McMaster Health Forum website).(59) During the deliberation about the problem, citizens were asked to share what they view as the key challenges related to strengthening care for chronic diseases in Ontario. To prompt discussion, citizens were asked to consider challenges they have faced in accessing care for a chronic disease for themselves or a family member, and what specific challenges might arise for the sickest patients, those with some ongoing care needs, and those with no chronic conditions but who may need periodic preventive care. We summarize the key challenges identified by citizens in Table 2.

Table 2: Summary of citizens' views about challenges

Challenge	Description
<p>Patients and their families are not always put at the centre of care</p>	<ul style="list-style-type: none"> • All participants emphasized that the lack of communication and coordination between clinicians and the parts of the system in which they work (e.g., between family physicians in primary care and specialists in acute-care settings), and between sectors (e.g., between primary, acute and home and community care) means that patients are not put at the centre of care. • Several participants indicated that the lack of communication and coordination stems from: 1) there often not being a ‘most responsible provider’ who is aware of and coordinates all parts of a patient’s care plan; and 2) the lack of interoperable electronic health records (which participants expressed frustration about given situations in which they have met with multiple clinicians with none being aware of what the others had prescribed or recommended). • Several participants indicated that chronic-disease management is not always sensitive to each individual’s unique circumstances (including their ability to self-manage parts of their care and to pay for services that are not publicly covered) which, as one participant stated, means that a “whole-person approach” is not being taken in care for chronic diseases.
<p>Home and community supports that are needed to manage chronic diseases are not available or accessible to those who need them</p>	<ul style="list-style-type: none"> • Many participants indicated that, in their experience, existing structures that provide home and community supports to manage chronic disease (e.g., home care 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 province. • Several often interrelated reasons for this were identified by panel participants, including inadequate public funding, patients and families not being able to afford the out-of-pocket costs for accessing services that are not publicly covered, and the variability of what is accessible in different communities across the province.
<p>Limited collection, use and sharing of medical information using patient-friendly technology to make the information accessible to patients and their families</p>	<ul style="list-style-type: none"> • Several participants expressed frustration about not having access to their own medical records that would allow them to be full partners with their care providers in their own care. • However, perspectives about the need for patient access to medical records varied, with some expressing significant concern about privacy of health information and the ability of patients to interpret the information made available to them (and the potential for anxiety that could result from, for example, not knowing what test results mean).
<p>Proactive prevention of chronic diseases is not prioritized</p>	<ul style="list-style-type: none"> • Most participants agreed that there is a lack of focus on proactive chronic-disease prevention in primary care and, without it, the burden of chronic disease will continue to grow in the province. • Some participants attributed this lack of focus on what they viewed as limited training and/or time for clinicians to engage in proactive prevention (e.g., for nutritional advice and supports to engage in a healthy lifestyle). • Several participants also 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. • The challenge of health literacy was also mentioned by some participants as a barrier to citizens identifying reliable and understandable information.

THREE ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH FOR ADDRESSING THE PROBLEM

Many approaches could be selected as a starting point for deliberations about strengthening care for people with chronic diseases in Ontario. To promote discussion about the pros and cons of potentially viable approaches, we have selected three elements of a potentially comprehensive approach. The three elements were developed and refined through consultation with the Steering Committee and key informants who we interviewed during the development of this evidence brief. The 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 chronic-disease prevention and management.

The elements could be pursued separately or simultaneously, or components could be drawn from each element to create a new (fourth) element. They are presented separately to foster deliberations about their respective components, the relative importance or priority of each, their interconnectedness and potential of or need for sequencing, and their feasibility.

The principal focus in this section is on what is known about these elements based on findings from systematic reviews. We present the findings from systematic reviews along with an appraisal of whether their methodological quality (using the AMSTAR tool) (60) is high (scores of 8 or higher out of a possible 11), medium (scores of 4-7) or low (scores less than 4) (see the appendix for more details about the quality-appraisal process). We also highlight whether they were conducted recently, which we define as the search being conducted within the last five years. In the next section, the focus turns to the barriers to adopting and implementing these elements, and to possible implementation strategies to address the barriers.

Box 4: Mobilizing research evidence about elements of a potentially comprehensive approach for addressing the problem

The available research evidence about elements of a potentially comprehensive approach for addressing the problem was sought primarily from Health Systems Evidence (www.healthsystemsevidence.org), which is a continuously updated database containing more than 5,000 systematic reviews and more than 2,400 economic evaluations of delivery, financial and governance arrangements within health systems. The reviews and economic evaluations were identified by searching the database for reviews addressing features of each of the approach elements and sub-elements.

The authors' conclusions were extracted from the reviews whenever possible. Some reviews contained no studies despite an exhaustive search (i.e., they were "empty" reviews), while others concluded that there was substantial uncertainty about the element based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the reviews' quality, the local applicability of the reviews' findings, equity considerations, and relevance to the issue. (See the appendices for a complete description of these assessments.)

Being aware of what is not known can be as important as being aware of what is known. When faced with an empty review, substantial uncertainty, or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an element could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a review that was published many years ago, an updating of the review could be commissioned if time allows.

No additional research evidence was sought beyond what was included in the systematic review. Those interested in pursuing a particular element may want to search for a more detailed description of the element or for additional research evidence about the element.

Citizens’ values and preferences related to the elements

To inform the citizen panel convened in April 2016, we included the same three elements of a potentially comprehensive approach to address the problem in the citizen brief that participants reviewed and used as a jumping-off point for their deliberations. During the deliberations, we identified several values and preferences from citizens in relation to these elements, which we summarize in Table 3.

Table 3: Citizens’ values and preferences related to the three elements

Element	Values expressed	Preferences for how to implement the element
<p>Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care</p>	<ul style="list-style-type: none"> • Access (to disease prevention and health promotion services) • Collaboration among patients, providers and organizations (in delivering care for patients) • Trusting relationships between patients and providers (supported by having open lines of communication) • Empowerment (of patients with tools in place to assist in managing care) 	<ul style="list-style-type: none"> • All participants agreed about the importance of all of the components of element 1, and participants provided specific examples of supports they believed would be most helpful to ensure the system aligns with their values, including: <ul style="list-style-type: none"> ○ a focus on prevention of chronic disease; ○ using skilled staff to help determine whether and how urgent the need is for an appointment with a physician or nurse practitioner, combined with alternative approaches to scheduling appointments (e.g., online scheduling); ○ team-based care where there is a ‘most responsible provider’ leading the team and coordination between the various providers involved in managing a patient’s chronic disease(s); ○ personalized care plans that support patients (and their caregivers) to manage chronic diseases (which could include log-books that track appointments and the recommendations made by clinicians during the appointments); ○ care coordinators or patient advocates who are responsible for coordinating care for those with complex chronic conditions; ○ nurse practitioners taking on a larger role for helping to manage chronic diseases; and ○ the use of telephone and email to address questions or concerns from patients and their caregivers to avoid unnecessary appointments (particularly in areas which require patients to travel long distances to appointments).
<p>Convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and</p>	<ul style="list-style-type: none"> • Accountability (strong mechanisms for public accountability exist and a clear mandate is present) • Efficiency (should provide good value for money) • Expertise (in the individuals sitting on disease councils) • Empowerment (of 	<ul style="list-style-type: none"> • Participants had mixed reactions to element 2 with respect to their expressed values of accountability and efficiency, with some expressing that it was an opportunity for a strong mandate to develop and support the implementation of best practices and spread innovation, while others feared it would result in more administration and ultimately not be “good value for money”. • Related to the values expressed, all participants agreed that if such councils were to be implemented that: 1) the process for identifying and appointing ‘experts’ to sit on the council should be transparent; 2) there should be a

management	<p>patients and citizens to take lead roles in the council)</p> <ul style="list-style-type: none"> • Fairness (in the individuals chosen to participate in the councils) 	<p>meaningful role for patients and citizens in all activities of the council; 3) the patients and citizens engaged should be diverse (e.g., in terms of socioeconomic status, ethno-cultural background, regional representation from across the province, and lived experience); and 4) appropriate compensation should be provided to ensure that patients and citizens do not face barriers to participating on the council.</p>
Collect and use data across all levels of the system to support chronic-disease prevention and management	<ul style="list-style-type: none"> • 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) 	<ul style="list-style-type: none"> • Participants were generally supportive of increased use of data and coordinated information sharing among professionals as a way to promote collaboration and patient empowerment. • Most liked the idea of patient portals as a mechanism for empowering patients, provided that appropriate data privacy and security is in place. • Some noted that privacy concerns could at least 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. • Some participants supported the idea of using audit and feedback to improve the quality of care, but some questioned whether physicians would be comfortable with what was seen as an approach that would call into question the quality and appropriateness of the care they provide. • Participants generally supported the idea of performance reporting in the system, but some emphasized the need to ensure the data and evidence used is trustworthy and comprehensive (with one participant indicating that performance should not be assessed based on the views of a few disgruntled people, but rather based on data at the population level).

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

This element could focus on implementing components of a patient-centred model that broadly focuses on:

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

There are many activities that could be included as part the above components of a patient-centred model, and we have summarized them in Table 4.

Table 4: Activities that could be included as components of a patient-centred model for chronic disease

Sub-element	Types of activities that could be included
Ensure all Ontarians receive the care they need, when they need it	<ul style="list-style-type: none"> • Providing patient-driven scheduling to ensure timely access (i.e., access to same- or next-day appointment, with priority for those who need it most) • Using team-based models differently to maximize capacity and effectiveness • Using secure email and telephone encounters to enhance access, and to prepare for, follow-up from, or substitute in-person visits
Support the engagement of patients in their care	<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 self-management resources; • Facilitating supported decision-making with care providers (e.g., through decision aids); and • 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”
Ensure the full range of care is seamlessly linked across providers, teams and settings	<ul style="list-style-type: none"> • Providing a single point of contact (e.g, a care coordinator) to provide system navigation using reliable and accurate information systems to conduct planned outreach for chronic care or preventive care, as well as help the sickest patients know what programs and services are available for them to access, and to assume responsibility for ensuring they are transitioned across providers, teams and settings • Having a central ‘hub’ coordinate outreach and follow-up for discharges from hospital and emergency or urgent care visits • Ensuring effective communication between care providers

Several systematic reviews and studies have found that engaging in these types of activities that are aligned with the Chronic Care Model,(61) to build models of patient-centred care (such as those delivered through Kaiser Permanente and Group Health Cooperative in the United States), have many benefits for people living with chronic diseases, including:

- increased access to specialists;
- improved patient and clinician experience;
- better use of technology (e.g., high rates of use of technologies such as secure electronic message threads and telephone calls to prepare patients for visits; use of shared electronic health records, including electronic communication for keeping patients engaged, maintaining continuity of care, and improving access; and electronic records and communication being used as decision-support tools to help providers deliver care);
- improved coordination of care (e.g., patient-perceived level of care coordination);

- enhanced delivery of preventive services; and
- reduced hospitalizations and emergency department visits.(16;17;17-22)

In addition to these key findings, we summarize in Table 5 the benefits, harms and costs identified from systematic reviews that we included related to the activities outlined above. For those who want more detail about the findings contained in Table 5 (or obtain citations for the reviews), Appendix 1a provides a fuller description of the findings from the reviews, and Appendix 1b provides detailed information about each review.

Table 5: Key findings from systematic reviews relevant to Element 1 – Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care (table adapted from an evidence brief focused on enhancing primary care) (62)

Sub-element	Key findings from systematic reviews
Ensure all Ontarians receive the care they need, when they need it	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • Advance access scheduling which shifts away from pre-arranged schedules to an open schedule where patients are offered an appointment with their physician on the day they call or at the time of their choosing (within 24 hours if desired), has been found to reduce wait times and no-show rates, but effects on patient satisfaction were mixed.(63) • Patients and clinicians report improved healthcare access, greater satisfaction and enhanced quality of healthcare in the family health team model.(36) • Models of care that use a collaborative team-based approach for people with mental health conditions improve mental and physical quality of life and social role functions when delivered for different disorders and in different settings.(64) • Telemedicine, as compared to face-to-face care or just consultation over the phone, achieves similar health outcomes, and can improve the management of some chronic conditions such as diabetes, but evidence about its costs and acceptability to patients and providers is uncertain.(65) <p><i>Harms</i></p> <ul style="list-style-type: none"> • Advance access scheduling has not been associated with any specific harms, but may leave patients with chronic conditions lost to follow-up in an advanced access system.(63) • Telemedicine technology has been associated with technical difficulties in the form of failed data transmission and/or video-conferencing, including monitoring systems which did not alert care providers or transmit their responses.(65) <p><i>Costs</i></p> <ul style="list-style-type: none"> • Economic evaluations have found that: <ul style="list-style-type: none"> ○ a patient-centred medical home serving seniors had significantly greater quality outcomes without significant cost differences as compared to usual care;(66) ○ eTools (electronic tools for health information exchange and health technologies) for people with diabetes showed cost per patient in the usual care group of \$30,226 CAD and \$29,889 CAD in the intervention group with an incremental cost per patient of -\$337 CAD in the intervention group and 0.006 improvement in quality-adjusted life years (QALYs);(67) ○ specialized nursing practice (patients treated by a nurse practitioner) for people with diabetes showed costs per patient of \$30,142 (CAD) as compared to \$30,226 in the usual care group of patients treated by a general practitioner (GP) (an incremental decrease of \$84 and increase in QALYs per patient of 0.003);(67) ○ enhanced specialized nursing practice (patients treated by a nurse practitioner plus a GP) for people with diabetes showed costs per patients of \$30,210 (CAD) as compared to \$30,226 in the usual care group of patients treated by a GP (an incremental decrease of \$15 and increase in QALYs per patient of 0.040); and

	<ul style="list-style-type: none"> ○ enhanced specialized nursing practice (patients treated by a nurse practitioner plus a GP) for people with coronary artery disease showed costs per patient of \$101,855 (CAD) as compared to \$111,611 in the usual care group of patients treated by a GP (an incremental decrease of \$9,757 and increase in QALYs per patient of 0.018);(67) ○ a face-to-face treatment program compared with a telephone-based treatment program for patients with generalized osteoarthritis cost less (€708);(68) ○ a program serving adults living in a rural community receiving primary healthcare and emergency services from a team with an on-site nurse practitioner and paramedics as well as an off-site family physician produced decreased total health and social utilization costs from year one (median \$3,085.75 USD) to year three (median \$1,918.54 USD);(69) ○ GP and nurse-led telephone triage resulted in modest cost savings (with slightly more savings for GP-led triage) compared to usual care where patients were managed following the standard protocols for their practice;(70) and • off-site collaborative care using telephone consultation was both more effective and cost-effective as compared to in-person care for depression.(71)
<p>Support the engagement of patients in their care</p>	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • Personalized care planning has been found to improve some indicators of physical and psychological health status, as well as patients’ ability to manage their condition.(72) • Approaches to self-management: <ul style="list-style-type: none"> ○ can include interventions “designed to develop the abilities of patients to undertake management of health conditions through education, training and support to develop patient knowledge, skills or psychological and social resources”; ○ can be delivered individually or in groups, face-to-face or remotely, and by professionals or peers; and ○ have been found to reduce health service utilization without negatively affecting patient health.(73) • While approaches to supporting shared decision-making have been found to have limited effects on patient participation/engagement in primary care and on health outcomes,(74;75) they have been shown to improve knowledge, participation, decisional conflict, self-efficacy and satisfaction.(76-78) • Decision aids (materials that help individuals and/or their caregivers make decisions about their healthcare) have been found to be helpful because they: <ul style="list-style-type: none"> ○ increase knowledge about healthcare options;(79-82) ○ encourage consumer involvement;(82) ○ support realistic perception of outcomes and risk;(80;82-85) ○ reduce decision-related conflict;(82) ○ increase patient-practitioner communication;(82) and ○ support professionals to provide information and counselling about available choices.(79) • Electronic health records have been found to improve the quality of healthcare by allowing providers to make more efficient use of time and adhere to guidelines, as well as to reduce medication errors and adverse drug events for patients (none of the studies in the review focused specifically on providing patients access to their medical records).(86) <p><i>Harms</i></p> <ul style="list-style-type: none"> • Interventions that promote personalized risk communication for informed decision-making about screening tests (e.g., mammography, colorectal cancer screening, etc.) could be harmful for high-risk patients if they are not introduced and explained carefully (while not addressed in the review, this could also occur if results are made available online for patients but not explained).(80) <p><i>Costs</i></p> <ul style="list-style-type: none"> • Systematic reviews and economic evaluations found that: <ul style="list-style-type: none"> ○ it is unclear whether limited cost savings resulting from personalized care planning

	<p>justifies the expense of the model;(72)</p> <ul style="list-style-type: none"> ○ both paper and computer-based decision aid tools to support women’s decision-making in pregnancy and birth are cost-effective;(79) ○ a web-based decision aid for parents deciding about MMR vaccination resulted in the highest vaccine uptake with National Health Service (NHS) costs for the aid being £35.06 compared to a leaflet at £42.23 and usual care at £42.23;(87) and <ul style="list-style-type: none"> • mobile phone supported self-monitoring of asthma showed similar health outcomes and health costs to those receiving paper-based monitoring, but the group receiving support through a mobile phone cost more overall because of the need to use an electronic monitoring service (£69 per person), resulting in total higher costs (£315 versus £245).(88)
<p>Ensure the full range of care is seamlessly linked across providers, teams and settings</p>	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • Approaches used to improve coordination of care throughout the system significantly reduce the number of people with chronic conditions (except for those with mental illness) being admitted to hospital, as well as emergency department visits for older adults.(89) • System navigators are a relatively new approach to link people with complex conditions to the care they need, so there is a lack of evidence to determine if they are helpful for supporting transitions between different settings.(90) • Creating tailored discharge plans for patients reduces how long they stay in hospital and the likelihood that they will be readmitted.(91) • 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 functioning of healthcare practices, as well as health outcomes of patients.(92;93) <p><i>Harms</i></p> <ul style="list-style-type: none"> • None identified. <p><i>Costs</i></p> <ul style="list-style-type: none"> • Systematic reviews and economic evaluations found that: <ul style="list-style-type: none"> ○ five of nine studies of navigation programs to support chronically ill older adults through healthcare transitions reported positive economic outcomes (including average savings of \$1,000 per participant in the intervention group in one study based on the cost difference between emergency room and outpatient visits);(90) ○ there is moderate evidence for a beneficial effect of 33 comprehensive care programs for patients with multiple chronic conditions, with incremental savings for the intervention groups ranging from \$204 per patient per year in one Canadian study, to \$12,260 per patient per year in a study in the United States;(93) ○ discharge planning for people with congestive heart failure was found to cost \$100,353 (CAD) as compared to \$101,080 for those receiving usual care (an incremental decrease of \$728 and an increase in quality adjusted life years per patient of 0.072);(67) ○ in-home care for people with congestive heart failure was found to cost \$90,415 (CAD) per patient as compared to \$101,080 per patient in the usual care group (an incremental decrease of \$10,665 and an increase in quality adjusted life years per patient of 0.111);(67) and • 15 care -oordination programs serving fee-for-service Medicare patients (primarily with congestive heart failure, coronary artery disease and diabetes) did not generate net savings.(94)

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

This element could include both chronic-disease councils (e.g., one for every major chronic disease) and 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 patients/citizens.

The chronic-disease councils and the oversight 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; and
- support patient/citizen engagement in the development of approaches to chronic-disease prevention and management.

We provide a brief overview of each sub-element below, and a summary of the key findings from the synthesized research evidence is provided in Table 6. For those who want more detail about the findings contained in Table 6 (or obtain citations for the reviews), Appendix 2a provides a full description of the findings from the reviews and Appendix 2b provides detailed information about each review.

While no reviews were identified that focused specifically on what is known about expert disease councils for improvements in chronic-disease management, one recent high-quality review,(95) and two older medium-quality reviews (96;97) were identified that focused on how a range of collaborative approaches to planning and coordination influenced health outcomes and quality of care. These reviews are mostly relevant to the functions of the oversight council and not chronic-disease councils. However, the latter could draw on the experience of how cancer has been organized in Ontario, which as mentioned earlier, operates as its own integrated sub-system.(5) It could also draw on the experience of the Strategic Clinical Networks that have been implemented in Alberta.(98) These networks have been created around specific diseases (e.g., cancer, cardiovascular disease and mental health and addictions), populations with specific health and wellness considerations (e.g., maternal and newborn health and seniors health) and areas where care is delivered (e.g., critical care, emergency settings and surgery). Each network is tasked with reshaping care within and across these areas by supporting patient-centred approaches (e.g., through developing and implementing decision aids), supporting local examples of good care and sharing those examples across the province, and using data and research evidence to support all of their activities (e.g., by supporting the development and/or implementation of clinical guidelines).

In terms of findings from systematic reviews, a recent, high-quality review assessed the influence of collaboration across sectors on a number of social determinants of health, and the limited evidence included in it suggested that collaboration had little to no effect on the social determinants of health and health equity.(95) One of the older medium-quality reviews assessed the impact of organizational partnerships in public health on health outcomes and health inequalities.(97) The authors concluded that there was little evidence available to suggest any health benefits associated with public-health partnerships, and even in instances where improvements in health outcomes were observed, the evidence was not strong enough to link these improvements to the existence of partnerships. However, the authors did find one potential benefit of partnerships: they help to increase the profile of the issue(s) upon which the partnership is based on local policy agendas.

The second older medium-quality review focused on the influence of regional surgical care collaborations (which took the form of communities of practice) on health outcomes.(96) The review found that regional collaborations resulted in a number of positive health outcomes (e.g. decreased mortality rates, reduced duration of post-operative intubations and fewer surgical site infections), as well as quality improvements. The review also found that there were a number of critical factors associated with the success of communities of practice, including: 1) trust among health professionals and institutions; 2) the availability of good quality data; 3) commitment among participating institutions; and 4) adequate infrastructure and methodological support for

quality management. This review also suggested that strong clinical leadership – which relates directly to the first sub-element of element 2 – contributed to ensuring successful communities of practice. We also identified another study that, while not a review, also pointed to the importance of clinical leadership in successful communities of practice. Specifically, the study suggested that the methodological centrepiece of stakeholder-engagement processes is entering into collaboration with a collective willingness to participate, and placing emphasis on the need to draw on the strengths of each member while respecting their unique positions and expertise.(99)

In addition to a recent medium-quality review (100) and a recent low-quality review (101) we identified (see following paragraph) that address the second sub-element (engage in creating evidence-based tools and other supports), several existing initiatives could be used as a guide. For example, the Program in Evidence-Based Care through Cancer Care Ontario develops guidelines for the full continuum of cancer care, including prevention, screening, diagnostic assessment, treatment, palliative care and survivorship.(102) Also, the work to develop care pathways through Quality-Based Procedures,(103) could be harnessed as part of efforts to develop guidance for chronic-disease prevention and management.

The recent medium-quality review focused on engaging stakeholders in developing and conducting systematic reviews to support evidence-based decision-making, and found a number of benefits to doing so, including: 1) identifying and prioritizing topics for research; 2) providing pragmatic feedback on the research protocol; 3) aiding in recruitment of research participants; 4) helping the researchers understand the research subject's perspective, ensuring that findings are interpreted with the end user in mind and that final products are readable and accessible; and 5) facilitating wider dissemination and uptake of research findings.(100) The authors also found that the greatest benefits of engaging stakeholders in the development and conduct of reviews were realized during stages related to refining the research topic(s) and developing the research approach, whereas the biggest challenges were related to time and resources, researcher skills for stakeholder engagement, finding the right people, balancing multiple inputs, and understanding the best/most appropriate time in the review process to engage different types of stakeholders.(100) The recent low-quality review focused on engaging stakeholders in research prioritization more generally (i.e. not only as it relates to systematic reviews), and identified several important components of the process that ought to be considered, including:

- engaging stakeholders early in the research process;
- being attentive to relationship building between researchers and stakeholders;
- establishing credibility with stakeholders by delivering high-quality project products;
- using multiple methods for engagement;
- allowing the appropriate amount of time for the engagement of all relevant stakeholder groups;
- documenting all input;
- employing a skilled facilitator for all group discussions;
- planning strategies for managing disruptive or dominating stakeholders;
- beginning prioritization processes with a streamlined list of topics;
- conducting icebreaking sessions during in-person activities;
- providing easy-to-understand informational materials at the beginning of engagement and before meetings; and
- offering opportunities for clarification.(101)

In addition to the findings summarized in Table 6 about citizen-engagement processes,(104-111) the reviews also noted that:

- citizen engagement in healthcare could mean engaging consumers of healthcare services, community members and/or the public in general, as well as specific sub-groups that are involved in or affected by a particular issue (e.g., people from culturally and linguistically diverse backgrounds);(109)
- the underlying goal of citizen engagement is to obtain public opinion (including from under-represented individuals and groups) to provide insight into social values and ethical principles for consideration in public decisions;(105)

- common tasks in citizen engagement include developing policy directions, recommendations and tools, and priority setting for resource allocation;(105;110)
- when adapting citizen-engagement processes (e.g., citizen juries) for specific aims, special attention should be paid to recruitment, independent oversight by a steering committee, duration of the jury, moderation, and respect for volunteer participants;(110)
- strategies that can be used for citizen engagement vary in their goals, scope of activities and methods used,(109) and processes need to be adapted to the context of the policy issue;(104)
- citizen engagement can be helpful for improving dissemination of information and processes for developing interventions, as well as for enhancing awareness and understanding among citizens;(106;111) and
- training of patients and their families, as well as healthcare professionals, is an important component of successfully involving patients and their families in research, policy, planning and practice.(108)

Table 6: Key findings from systematic reviews relevant to Element 2 – Convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management

Sub-element	Key findings from systematic reviews
Provide clinical leadership for chronic-disease prevention and management for the province	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • One recent high-quality review found that collaboration had little to no effect on the social determinants of health and health equity.(95) • One older medium-quality review found little evidence to suggest that partnerships in public health could improve health outcomes and equity, but did find that they may help raise the profile of issues on local policy agendas.(97) • Another older medium-quality review found that regional collaborations in surgical care resulted in significant improvements in health outcomes (e.g., fewer surgical-site infections) and in quality of care, and that strong clinical leadership was a key contributing factor to successful communities of practice.(96) <p><i>Harms</i></p> <ul style="list-style-type: none"> • None identified <p><i>Costs</i></p> <ul style="list-style-type: none"> • None identified
Engage in creating evidence-based tools and other supports	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • A recent medium-quality review found that the main benefits of stakeholder engagement in developing and conducting systematic reviews (as an example of contributing to the creation of evidence-based tools) include: identifying and prioritizing topics for research; providing pragmatic feedback on the research protocol; aiding in recruitment of research participants; helping the researchers understand the research subject’s perspective; ensuring that findings are interpreted with the end user in mind and that final products are readable and accessible; and facilitating wider dissemination and uptake of research findings.(100) • The same review noted that stakeholder engagement in the topic refinement and research development phase of conducting a systematic review was identified as the point where stakeholder engagement yielded the greatest benefit.(100) <p><i>Harms</i></p> <ul style="list-style-type: none"> • A recent medium-quality review indicated that the biggest challenges of engaging stakeholders in the development and conduct of systematic

	<p>reviews include time and resources, researcher skills for stakeholder engagement, finding the right people, balancing multiple inputs, and understanding the best/most appropriate time in the review process to engage different types of stakeholders.(100)</p> <p><i>Costs</i></p> <ul style="list-style-type: none"> • None identified
<p>Patient- and citizen-engagement processes</p>	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • 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 and access for people with disabilities).(107) • Citizen engagement can be helpful for improving dissemination of information and processes for developing interventions, as well as for enhancing awareness and understanding among citizens.(106;111) <p><i>Costs</i></p> <ul style="list-style-type: none"> • An older low-quality review found that costs related to public-engagement activities are rarely reported, but noted that well-structured processes range from tens of thousands of dollars to \$1 million or more.(112) • While not explicitly providing information about costs, an older medium-quality review noted that, in general, effective patient involvement requires both personnel and financial commitments.(108)

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:

- 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.

We provide a brief overview of each sub-element below, and a summary of the key findings from the synthesized research evidence is provided in Table 7. For those who want more detail about the findings contained in Table 7 (or obtain citations for the reviews), Appendix 3a provides a full description of the findings from the reviews and Appendix 3b provides detailed information about each review.

We identified two recent medium-quality reviews related to clinical information systems. Both reviews found that the use of clinical information systems (i.e., systems such as electronic health records that organize patient and population data to facilitate more efficient care) included as part of chronic-care models improved the performance of healthcare practices, as well as health outcomes of patients.(92;113)

As an example of a decision-support system for patients (in addition to decision aids which we outlined as part of element 1), we found a recent low-quality systematic review that assessed patient and provider attitudes related to the use of patient portals,(114) such as MyChart that is made available to patients at Sunnybrook Health Sciences Centre.(115) The systematic review found mixed attitudes from patients and their providers regarding the use of patient portals to manage their chronic diseases, with the most positive attributes of portals being enhanced communication between patients and providers, and the most negative perceptions being security concerns and lack of user-friendliness.(114)

In addition to the findings in Table 7 about decision-support systems and audit and feedback, it has been found that the absolute effects of provider-targeted interventions such as these range from 2-12%.(116) Therefore, to maximize the effects of such interventions, it is important to diagnose the underlying cause of the problem that needs to be addressed, select an intervention best suited to address the identified barriers to behaviour change, and iteratively refine and tailor the intervention(s) in a way that maximizes impact. For example, the recent high-quality review we identified about audit and feedback found an average absolute improvement of 4.3%. However, the review also found that more than 16% absolute improvement is observed when baseline performance is low and/or when key intervention features are incorporated (e.g., when feedback is provided more than once, when it includes both explicit targets and an action plan, when the source of feedback is a supervisor or colleague, and when it is delivered both verbally and in a written form).(117)

Lastly, we identified five reviews related to the sub-element focused on performance reporting. Overall, the evidence was mixed, with one relatively recent medium-quality review suggesting that public reporting could lead to improvements in performance and patient outcomes,(118) and three other reviews – one recent, one older medium-quality review, and one recent low-quality review – reporting either mixed or limited evidence.(119-121) However, despite the mixed evidence, it was suggested that targeting providers and managers with reports was a better strategy since they had the power to change things,(121) and that the following elements are needed in a public reporting strategy: 1) clear objectives that include accountability and quality improvement; 2) targets that include healthcare organizations; 3) report content that is transparent and comprehensive; 4) information provided in easy-to-use formats; and 5) wide distribution of reports using a variety of approaches.(122)

Table 7: Key findings from systematic reviews relevant to Element 3 – Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management

Sub-element	Key findings from systematic reviews
<p>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</p>	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • Two recent medium-quality systematic reviews that evaluated 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.(92;113) <p><i>Harms</i></p> <ul style="list-style-type: none"> • None identified <p><i>Costs</i></p> <ul style="list-style-type: none"> • None identified
<p>Decision-support systems at the provider and patient level</p>	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • In addition to the clinical information systems outlined above that are delivered as part of chronic-care models, an older high-quality review found that decision-support systems 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).(123) <p><i>Harms</i></p> <ul style="list-style-type: none"> • None identified <p><i>Costs</i></p> <ul style="list-style-type: none"> • The costs associated with implementing interventions to support provider behaviour change can vary substantially, but decision-support systems such as computer-aided reminders can be implemented as part of existing electronic medical records.
<p>Audit and feedback at the practice/organizational level</p>	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • A recent high-quality systematic review found that audit and feedback is effective for changing health professional behaviour with a median absolute improvement of 4.3%, and more than 16% absolute improvement is observed when baseline performance is low and/or when key intervention features are incorporated.(117) <p><i>Harms</i></p> <ul style="list-style-type: none"> • None identified <p><i>Costs</i></p> <ul style="list-style-type: none"> • The resources required to deliver audit and feedback include data abstraction, analysis and dissemination costs.
<p>Performance reporting at the practice/organizational, sub-regional, LHIN and provincial level</p>	<p><i>Benefits</i></p> <ul style="list-style-type: none"> • There is mixed evidence about whether public reporting has an impact on improving patient outcomes.(118-122) <p><i>Harms</i></p> <ul style="list-style-type: none"> • None identified <p><i>Costs</i></p> <ul style="list-style-type: none"> • None identified

Additional equity-related observations about the three elements

Several equity-related observations can be made in relation to the three elements of a potentially comprehensive approach for those of low socioeconomic status and people living with multiple chronic conditions. One important consideration is health literacy, given it has been found that 60% of adults and 88% of seniors are not health literate, which means they have difficulty accessing, understanding, evaluating and communicating health information.⁽¹²⁴⁾ People with lower income and education, as well several other groups (e.g., people over the age of 65, recent immigrants, those with limited cognitive capacities, and those who are not proficient in English), are particularly likely to have low health literacy.^(125;126) This has implications for each of the elements as it will need to be considered in the context of supporting self-management and shared decision-making (element 1), patient/citizen engagement in the development of approaches to chronic-disease prevention and management (element 2), and patient-information portals or decision support systems (element 3). While this is an important challenge to overcome, seven studies included in a recent high-quality systematic review compared the effects of interventions between high- and low-literacy groups, and the results indicated that shared decision-making interventions appeared to benefit disadvantaged groups more than groups with higher literacy, education and socio-economic status.⁽⁷⁶⁾ Therefore, while health literacy poses a challenge, efforts such as these can be harnessed to ensure meaningful patient/citizen participation in their care, and in program and policy development.

There are at least two additional equity considerations to take into account in relation to elements 1 and 2. For element 1, it will be important to ensure components of a patient-centred approach are supportive of providing access to those who most need it (e.g., those living with multiple chronic health conditions). In addition to the components outlined for element 1 in Table 4, this likely also means providing remuneration that supports physicians and other healthcare professionals to spend the time needed with the sickest patients, and to ensure the care they need is coordinated across other providers, teams and settings. Element 2 emphasizes the need for citizen engagement, but such engagement needs to be reflective of those who are involved in and affected by the issue (particularly those who are likely to be disproportionately affected by it, such as those living with multiple chronic health conditions).

IMPLEMENTATION CONSIDERATIONS

A number of barriers might hinder implementation of the three elements of a potentially comprehensive approach to strengthening care for people with chronic diseases in Ontario, which needs to be factored into any decision about whether and how to pursue any given element (Table 8). While potential barriers exist at the levels of patients/citizens, care providers, organizations and systems, the most important barriers might include: 1) the scale of the redesign of the health system, given redesign is more difficult than simply adding new ‘ingredients’; 2) lack of interest, capacity and/or incentives for citizens/patients, providers and organizations to adopt new ways of doing things; and 3) the need for investments in infrastructure that would be needed for strengthened data supports.

Table 8: Potential barriers to implementing the elements

Levels	Element 1 – Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care	Element 2 – Convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management	Element 3 – Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management
Patient/citizens	<p>Expectations from citizens for timely access may be difficult to balance against what is feasible given existing resources</p> <p>Not all citizens may like the idea of being more involved in and responsible for their care</p>	<p>Some patients and citizens may not feel sufficiently informed to properly contribute to citizen-engagement processes</p> <p>Participants in the citizen panel indicated that the council may lack legitimacy if patients and citizens engaged in the council are not reflective of the diversity of the province (e.g., in terms of socioeconomic status, ethno-cultural background, regional representation from within the province, and lived experience)</p>	<p>Not all citizens may be interested in having to access health information and/or manage their care using online resources</p> <p>Several participants in the citizen panel cited significant concerns about privacy of health information and the ability of patients to interpret the information made available to them as concerns they had with this element.</p>
Care provider	<p>Healthcare providers may have difficulty moving to proactive management from reactive responses</p> <p>Some healthcare providers may initially feel uncomfortable providing more responsibility to the patient for their care</p> <p>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>	<p>Healthcare providers may see this as another commitment on top of managing already busy practices, which may lead to limited ‘buy-in’ and long-term commitment (particularly if impacts are initially seen as minor)</p> <p>Some healthcare providers may not consistently follow the guidance from the chronic-disease councils</p>	<p>Some healthcare providers and organizations may lack the infrastructure needed to implement audit and feedback</p> <p>Healthcare providers, organizations and policymakers will face significant challenges for implementing clinical information systems that can be integrated for use across all providers and care settings in the province</p>
Organization	<p>Organizations may initially find it difficult to change how they</p>	<p>Managers in organizations could view this and the other elements</p>	<p>Some healthcare providers and organizations may lack the</p>

	schedule appointments, and be hesitant to invest in hiring care coordinators without knowing if their costs will be recovered	as another different approach that requires investment, but doesn't lead to real change in the system	infrastructure needed to implement audit and feedback Organizations and policymakers may be hesitant to implement performance reporting to avoid the potential for bad publicity
System	Policymakers (as well as care providers and organizations) will face significant challenges for implementing clinical information systems that can be integrated for use across all care settings and providers in the province	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	Policymakers lack access to transparent performance measures of patient-centred outcomes, which limits their ability to monitor progress of efforts to put the patient at the centre of care Organizations and policymakers may be hesitant to implement performance reporting to avoid the potential for bad publicity

On the other hand, a number of potential windows of opportunity could be capitalized upon (Table 9), which also need to be factored into any decision about whether and how to pursue one or more of the approach elements. These potential windows of opportunity 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 chronic diseases to meet larger health-system goals.

Table 9: Potential windows of opportunity for implementing the elements

Type	Element 1 – Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care	Element 2 – Convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management	Element 3 – Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management
General	Strengthening care for chronic diseases in a way that incorporates components similar to those outlined in the three elements could help the province address its system-level goals of: 1) improving access; 2) connecting services; 3) supporting people and patients; and 4) protecting the universal health system.(2) Difficult economic times, such as those presently faced in the province, sometimes force the development of innovative policy approaches to be able to make tough decisions.		
Element-specific	Recently there has been much attention on strengthening patient-centred care in Ontario, including a highly publicized proposal from the province in this area.(1) This attention could help support action towards deploying resources in the province in a way that strengthens care for chronic diseases in Ontario.	The public is increasingly wanting to have a voice in processes to inform decisions that affect them, and there are increasingly better mechanisms in place to do this.	The issue of data integration across the province is something getting attention at the provincial level with a series of citizen panels having been recently convened on this topic at the request of the Ontario Ministry of Health and Long-Term Care.(127) A task force has recently been convened with a focus on optimizing clinical practice in Ontario using data and evidence, which could act as a steward for many of the activities in this element.

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APPENDICES

The following tables provide detailed information about the systematic reviews identified for each element. There are two tables provided for each element with the first providing a more detailed summary of key findings than what was provided in Tables 5-7 in the evidence brief. Each row in the second table for each element corresponds to a particular systematic review and the reviews are organized by sub-element (first column). The focus of the review is described in the second column. Key findings from the review that relate to the element are listed in the third column, while the fourth column records the last year the literature was searched as part of the review.

The fifth column presents a rating of the overall quality of the review. The quality of each review has been assessed using AMSTAR (A Measurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial, or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered “high scores.” A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8.

The last three columns convey information about the utility of the review in terms of local applicability, applicability concerning prioritized groups, and issue applicability. The third-from-last column notes the proportion of studies that were conducted in Canada, while the second-from-last column shows the proportion of studies included in the review that deal explicitly with one of the prioritized groups. The last column indicates the review’s issue applicability in terms of the proportion of studies focused on chronic disease. Similarly, for each economic evaluation and costing study, the last three columns note whether the country focus is Canada, if it deals explicitly with one of the prioritized groups, and if it focuses on primary care.

All of the information provided in the appendix tables was taken into account by the evidence brief’s authors in compiling Tables 5-7 in the main text of the brief.

Appendix 1a: Summary of key findings from systematic reviews relevant to Element 1 – Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> • Ensure all Ontarians receive the care they need, when they need it <ul style="list-style-type: none"> ○ High- and medium-quality reviews found that: <ul style="list-style-type: none"> ▪ advance access scheduling which shifts away from pre-arranged schedules to an open schedule where patients are offered an appointment on the day they call or at the time of their choosing (usually within 24 hours), has been found to reduce wait times and no-show rates, but effects on patient satisfaction were mixed;(63) ▪ models of care that use a collaborative team-based approach for people with mental health conditions improve mental and physical quality of life and social role functions when delivered for different disorders and in different settings;(64) and ▪ telemedicine, as compared to usual face-to-face care or just consultation over the phone, achieves similar health outcomes, and can improve the management of some chronic conditions such as diabetes, but evidence about its costs and acceptability to patients and providers is uncertain.(65) • Support the engagement of patients in their care <ul style="list-style-type: none"> ○ Shared decision-making <ul style="list-style-type: none"> ▪ One high-quality review found clinically significant effects for shared decision-making interventions in three of 21 included studies.(75) ▪ One high-quality review found moderate positive effects of shared decision-making interventions on knowledge, participation, decisional conflict and self-efficacy of disadvantaged populations, and indicated that interventions appeared to benefit disadvantaged groups more than groups with higher literacy, education and socio-economic status.(76) ▪ One medium-quality review found evidence that supports several tools targeted toward shared decision-making in immediate clinical choices, with the two advance care planning tools (a video advance care planning tool to assist in discussions of treatment preference with patients with advanced dementia, and an advanced directive documentation guide designed for patients with low health literacy and available for free on the internet) supported by the strongest evidence.(77) ▪ One medium-quality review indicated that patients reported improved health and physical functioning, improved knowledge about the risks and benefits of different treatment options, and increased satisfaction with the decision-making process.(78) ○ Decision aids - Three high-quality (80;82;83) and four medium-quality (79;81;84;85) reviews found evidence that decision aids: <ul style="list-style-type: none"> ▪ increase patients’ knowledge of screening and treatment options;(79-82) ▪ encourage patient involvement;(82) ▪ support realistic perception of outcomes and risk;(80;83-85) ▪ reduce decision-related conflict;(82) ▪ increase patient-practitioner communication;(82) and ▪ support professionals to provide information and counselling about the available choices.(79) • A recent high-quality review indicated that approaches to self-management: <ul style="list-style-type: none"> ○ can include interventions “designed to develop the abilities of patients to undertake management of health conditions through education, training and support to develop patient knowledge, skills or psychological and social resources”; ○ can be delivered individually or in groups, face-to-face or remotely, and by professionals or peers; and ○ have been found to reduce health service utilization without negatively affecting patient health.(73) • Ensure the full range of care is seamlessly linked across providers, teams and settings <ul style="list-style-type: none"> ○ A recent high-quality review found that approaches used to improve coordination of care significantly reduce the number of people with chronic conditions (except for those with mental illness) being admitted to hospital, as well as emergency department visits for older adults.(89) ○ A recent medium-quality review found that system navigators are a relatively new approach to link people with complex conditions to the care they need, so there is a lack of evidence to determine if they are helpful for supporting transitions between different settings.(90) ○ A recent high-quality review found that creating tailored discharge plans for patients reduces how long they stay in hospital and the likelihood that they will

	<p>be readmitted.(91)</p> <ul style="list-style-type: none"> ○ Two recent medium-quality reviews found that 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, improve the functioning of healthcare practices, as well as health outcomes of patients.(92;93)
<p>Potential harms</p>	<ul style="list-style-type: none"> • Ensure all Ontarians receive the care they need, when they need it <ul style="list-style-type: none"> ○ Telemedicine technology was associated with technical difficulties in the form of failed data transmission and/or video-conferencing, including monitoring systems which did not alert care providers or transmit their responses.(65) • Support the engagement of patients in their care <ul style="list-style-type: none"> ○ A review about interventions on personalized risk communication for informed decision-making about screening tests (e.g., mammography, colorectal cancer screening, etc.) raised concerns that such interventions could be harmful for high-risk patients if they are not introduced and explained carefully.(80) • Ensure the full range of care is seamlessly linked across providers, teams and settings <ul style="list-style-type: none"> ○ Advance access scheduling has not been associated with any specific harms, but patients with chronic conditions may be more likely to be lost to follow-up (e.g., not calling back to book subsequent appointments) in an advanced access system, with rates as high as 50% in one speciality setting and one-fifth of geriatric patients in another.(63)
<p>Costs and/or cost-effectiveness in relation to the status quo</p>	<ul style="list-style-type: none"> • Ensure all Ontarians receive the care they need, when they need it <ul style="list-style-type: none"> ○ An older medium-quality review of patient-centred medical home models found that only one of four high-quality studies found any evidence of savings, and it was limited to the “high-risk” individuals included in the intervention. However, the savings in the “high-risk” group were enough to offset the spending for other groups and achieve a cost-neutral year.(128) ○ The same review found that five of the rigorous interventions reduced hospitalizations by 40% in year two and 44% in year three, with one of the three evaluations finding emergency room department visits were reduced by 24% among target Medicare patients and 35% among “high-risk” Medicare patients.(128) ○ An evaluation of a patient-centred medical home (PCMH) serving seniors found they had significantly greater quality outcomes without significant cost differences between the PCMH and the usual care (total cost difference at 12 months of +\$2.79 for the PCMH and -\$5.92 for the PCMH at 21 months).(66) ○ eTools (electronic tools for health information exchange and health technologies) for people with diabetes showed cost per patient in the usual care group of \$30,226, and \$29,889 in the intervention group, with an incremental cost per patient of -\$337 in the intervention group and 0.006 improvement in quality-adjusted life years (QALYs).(67) ○ An economic evaluation found that: <ul style="list-style-type: none"> ▪ specialized nursing practice (patients treated by a nurse practitioner) for people with diabetes showed costs per patient of \$30,142 as compared to \$30,226 in the usual care group of patients treated by a GP (an incremental decrease of -\$84 and increase in QALYs per patient of 0.003); ▪ enhanced specialized nursing practice (patients treated by a nurse practitioner plus a GP) for people with diabetes showed costs per patient of \$30,210 as compared to \$30,226 in the usual care group of patients treated by a GP (an incremental decrease of -\$15 and increase in QALYs per patient of 0.040); and ▪ enhanced specialized nursing practice (patients treated by a nurse practitioner plus a GP) for people with coronary artery disease showed costs per patient of \$101,855 as compared to \$111,611 in the usual care group of patients treated by a GP (an incremental decrease of -\$9,757 and increase in QALYs per patient of 0.018).(67) ○ A comparison of a non-pharmacological face-to-face treatment program to a telephone-based treatment program for patients with generalized osteoarthritis found the mean total societal costs per patient was estimated at €10,324 in the face-to-face treatment program, and €11,023 for the telephone-based treatment program, producing a difference in total societal costs of €708 (95% confidence interval: -€5058, €3642) between both programs in favour of the face-to-face treatment program.(68) ○ A program serving adults living in a rural community receiving primary healthcare and emergency services from a team that included an on-site nurse practitioner (NP) and paramedics, as well as an off-site family physician, decreased total health and social utilization costs from year 1 (median \$3,085.75) to year 3 (median \$1,918.54), prescription medication from year 1 (median \$67.05) to year 3 (\$24.17) and travel costs in year 1 (mean \$263.88) to year 3 (mean \$30.73).(69) ○ A comparison of general practitioner and nurse-led telephone triage compared to usual care found that the absolute differences in costs between the

	<p>approaches were modest, with -£5.75 for GPs and -£2.58 for nurses per patient compared to usual care.(70)</p> <ul style="list-style-type: none"> ○ A comparison of on-site versus off-site collaborative care for depression found that the telephone group was both more effective and more cost-effective compared with in-person care, with an incremental cost-effectiveness for the telephone group of \$10.78 per depression-free day.(71) <p>• Support the engagement of patients in their care</p> <ul style="list-style-type: none"> ○ A recent high-quality review found unclear evidence about whether limited cost savings resulting from personalized care planning justifies the expense of the model.(72) ○ An older medium-quality review found that both paper and computer-based decision aid tools to support women’s decision-making in pregnancy and birth are cost-effective.(79) ○ A web-based decision aid for parents deciding about MMR vaccination found those using the aid had the highest vaccine uptake with NHS, costs for the aid were £35.06 per patient compared to a leaflet, £42.23, and usual care at £42.23, and societal costs for the aid were £42.23, £50.99 for the leaflet, and £48.85 per patient for usual care.(87) ○ Mobile phone supported self-monitoring of asthma resulted in similar health outcomes and health costs between the intervention and paper-based monitoring group, but the group receiving support through a mobile phone cost more overall because of the need to use an electronic monitoring service (£69 per person), resulting in total higher costs (£315 versus £245).(88) <p>• Ensure the full range of care is seamlessly linked across providers, teams and settings</p> <ul style="list-style-type: none"> ○ A recent medium-quality review of navigation programs to support chronically ill older adults through healthcare transitions, found that five of nine included studies reported positive economic outcomes, including: one study reporting an average savings of \$1,000 USD per participant in the intervention group based on the cost difference between emergency room and outpatient visits; and another study reporting the total cost (hospital, intervention, community services over six months) as being lower in the intervention group (mean difference \$2,545 USD; 95% confidence interval, \$11–\$3,078).(90) ○ A recent medium-quality review of 33 comprehensive care programs for patients with multiple chronic conditions found moderate evidence for a beneficial effect on reducing incremental direct healthcare costs, such as costs of primary-care visits, emergency-room visits, and hospitalization. Incremental savings for the intervention groups ranged from -\$204 per patient per year in one study to -\$12,260 per patient per year in another.(93) ○ Discharge planning (pre-discharge and post-discharge) for people with congestive heart failure was found to cost \$100,353 as compared to \$101,080 (an incremental decrease of -\$728 and a 0.072 increase in QALYs per patient).(67) ○ In-home care for people with congestive heart failure was found to cost \$90,415 per patient as compared to \$101,080 per patient in the usual care group (an incremental decrease of \$10,665 and increase in QALYs per patient of 0.111).(67) ○ An evaluation of 15 care coordination programs serving fee-for-service Medicare patients (primarily with congestive heart failure, coronary artery disease, and/or diabetes) found that none of the groups generated net savings, and the authors identify the need for strong transitional care components and suggest that programs with substantial in-person contact targeted at patients with moderate to severe conditions can be cost-neutral.(94) ○ A nursing health promotion and preventive care intervention as compared to usual homecare within the community resulted in no statistically significant differences in total annual per person direct expenditures.(129)
<p>Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the element were pursued)</p>	<ul style="list-style-type: none"> • Uncertainty because no systematic reviews were identified <ul style="list-style-type: none"> ○ Not applicable – reviews were identified about each sub-element • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review <ul style="list-style-type: none"> ○ Not applicable – no ‘empty’ reviews were identified • No clear message from studies included in a systematic review <ul style="list-style-type: none"> ○ Not applicable
<p>Key components of the element if it was tried elsewhere</p>	<ul style="list-style-type: none"> • Support the engagement of patients in their care <ul style="list-style-type: none"> ○ Shared decision-making <ul style="list-style-type: none"> ▪ One high- and one medium-quality review found that interventions targeting both patients and providers had a positive effect compared to usual care and compared to interventions targeting patients alone.(75;130) ▪ Based on the limited evidence available as well as expert opinion, a low-quality review recommends five components for efforts to frame and communicate clinical evidence: understanding the patient’s (and family members’) experience and expectations; building partnerships; providing evidence, including a balanced discussion of uncertainties; presenting recommendations informed by clinical judgment and patient preferences; and checking for understanding and agreement.(131)

<p>Stakeholders' views and experience</p>	<ul style="list-style-type: none"> • Ensure all Ontarians receive the care they need, when they need it <ul style="list-style-type: none"> ○ A medium-quality review found that patients and clinicians report improved healthcare access, greater satisfaction, and enhanced quality of healthcare in the family health team model.(36) • Put the patient at the centre of care <ul style="list-style-type: none"> ○ Shared decision-making <ul style="list-style-type: none"> ▪ One medium-quality review found that providers reported barriers to implementing shared decision-making in clinical practice such as time constraints, lack of applicability due to patient characteristics, and lack of applicability based on the clinical situation.(132) ▪ The same review found that facilitators reported by providers for implementing shared decision-making in clinical practice were healthcare provider motivation, their perception that putting shared decision-making into practice would lead to improved clinical processes, and their perception that putting shared decision-making into practice would lead to improved patient outcomes.(132)
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Appendix 1b: Systematic reviews relevant to Element 1 - Support patients and clinicians to prevent and manage chronic diseases by putting the patient at the centre of care

Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
Patient-centred care model	Approaches for implementation of the patient's medical home model and its effects on patient and staff experiences, process of care, and clinical and economic outcomes (133)	Across 19 studies of patient-centred medical home interventions there was a small positive effect on patient experiences, small to moderate positive effects on the delivery of preventive care services (moderate strength of evidence), and a small to moderate degree (low strength of evidence) for improvement to staff experience. Among older adults there was a reduction in emergency department visits, but not in hospital admissions (low strength of evidence). There was no evidence for overall cost savings.	2012	7/11 (AMSTAR rating from McMaster Health Forum)	1/19	10/19	4/19
	Current evidence about the patient-centred medical home model (134)	The review found moderately strong evidence that the patient-centred medical home model improves patient experiences and preventive care service, and some evidence of improvements in staff experience, but it did not have an effect on total cost.	2011	9/10 (AMSTAR rating from McMaster Health Forum)	1/27	13/27	1/27
	Review of recent research about the patient-centred medical home (135)	The review identified inconsistencies in how the patient-centred medical home model is defined and how related variables are operationalized. This created challenges for comparing across the included studies and produced mixed results. The most common outcome measured across studies was emergency department visits which proved significant in seven of 11 studies.	2010	7/10 (AMSTAR rating from McMaster Health Forum)	1/21	12/21	13/21
	Review of early evaluations of medical home models (136)	In a review of 12 interventions, six provided rigorous evidence indicating some favourable effects on all three triple aim outcomes and healthcare professional experience, but cost effects were unfavourable, and many of the results were inconclusive.	2010	5/10 (AMSTAR rating from McMaster Health Forum)	0/12	12/12	6/12

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
Ensure all Ontarians receive the care they need, when they need it	Patient and physician and/or practice outcomes resulting from implementation of advanced access scheduling in the primary-care setting (63)	Advance access scheduling which shifts away from pre-arranged schedules to an open schedule where patients are offered an appointment on the day they call or at the time of their choosing (usually within 24 hours), has been found to reduce wait times and no-show rates, but effects on patient satisfaction were mixed.	2010	6/9 (AMSTAR rating from McMaster Health Forum)	0/28	0/28	28/28
	Interprofessional collaboration in Ontario's Family Health Teams (36)	Patients and clinicians report improved healthcare access, greater satisfaction, and enhanced quality of healthcare in the family health team model.	2012	4/9 (AMSTAR rating from McMaster Health Forum)	11/11	11/11	11/11
	Effectiveness of collaborative chronic-care models for mental health conditions across primary, specialty, and behavioural healthcare settings (64)	Models of care that use a collaborative team-based approach for people with mental health conditions improve mental and physical quality of life and social role functions when delivered for different disorders and in different settings.	2011	6/11 (AMSTAR rating from McMaster Health Forum)	0/74	74/74	74/74
	Effects of interactive telemedicine on professional practice and healthcare outcomes (65)	Telemedicine, as compared to usual face-to-face care or just consultation over the phone, achieves similar health outcomes, and can improve the management of some chronic conditions such as diabetes, but evidence about its costs and acceptability to patients and providers is uncertain.	2013	7/11 (AMSTAR rating from McMaster Health Forum)	Not available	Not available	Not available
Support the engagement of patients in their care	Personalized care planning for adults with chronic or long-term health conditions (72)	Personalized care planning has been found to improve some indicators of physical and psychological health status, as well as patients' ability to manage their conditions.	2013	10/11 (AMSTAR rating from McMaster Health Forum)	0/19	19/19	13/19
	Self-management support interventions to reduce healthcare utilization without compromising outcomes (73)	Approaches to self-management: <ul style="list-style-type: none"> can include interventions "designed to develop the abilities of patients to undertake management of health conditions through education, training and support to develop patient 	2012	8/11 (AMSTAR rating from McMaster Health Forum)	7/166	166/166	0/166

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>knowledge, skills or psychological and social resources”;</p> <ul style="list-style-type: none"> • can be delivered individually or in groups, face-to-face or remotely, and by professionals or peers; and • have been found to reduce health service utilization without negatively affecting patient health. 					
	Effects of improved patient participation in primary care on health-related outcomes (74)	This systematic review evaluated the effects of interventions aiming to improve patient participation in primary-care consultations on patient outcomes. Eligible interventions included educational meetings, audit and feedback, reminders, patient-mediated interventions, and distribution of educational material. Seven trials were included, but all studies suffered from substantial bias. The results are non-conclusive.	2011	6/10 (AMSTAR rating from McMaster Health Forum)	1/7	6/7	7/7
	Patients’ perceptions of sharing in decisions: A systematic review of interventions to enhance shared decision-making in routine clinical practice (75)	<p>This systematic review evaluated the effectiveness of interventions to improve health professionals’ adoption of shared decision-making in routine clinical practice, as seen by patients.</p> <p>Only three of the 21 included studies found clinically significant effects for shared decision-making interventions that favoured the intervention examined. These three studies were the only ones that involved multifaceted interventions including both health professional education and a patient-mediated intervention (i.e. patient decision aid). This finding suggests that, from the perspective of patients, interventions that target both the health professional responsible for sharing a decision with the patient, and the patient him or herself, are promising options to enhance shared decision-making in routine clinical practice.</p>	2009	7/11 (AMSTAR rating from McMaster Health Forum)	4/21	18/21	21/21

McMaster Health Forum

Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
	Tools to promote shared decision-making in serious illness (77)	<p>Tools identified in this review address advance care planning, palliative care and goals of care communication, feeding options in dementia, lung transplant in cystic fibrosis, and truth telling in terminal cancer. Tools to promote shared decision-making can be used to inform future decisions through advance care planning, or to support immediate treatment decisions.</p> <p>The two advance care planning tools supported by the strongest evidence are a video advance care planning tool to assist in discussions of treatment preference with patients with advanced dementia, and an advanced directive documentation guide designed for patients with low health literacy and available for free on the internet. Both tools had effects on clinical decisions. The evidence identified in this review supports several tools geared toward shared decision-making in immediate clinical choices. The majority of these tools were shown to improve knowledge, and select tools changed actual treatment decisions.</p>	2014	6/10 (AMSTAR rating from McMaster Health Forum)	1/38	38/38	38/38
	Effects of interventions designed to support shared decision-making on health inequalities (76)	Shared decision-making interventions evaluated by included studies include communication skills workshops or education sessions, coaching sessions targeted at patients or health professionals, computerized decision aids, video-based interventions to improve informed decision-making and shared decision-making, counselling sessions, booklet or DVD decision aids, and paper-based hand-outs promoting informed decision-making. Ten of 21 interventions studied were specifically targeted at disadvantaged groups. These interventions focused on issues such as cultural differences and literacy levels.	2012	10/11 (AMSTAR rating from McMaster Health Forum)	0/19	19/19	2/19

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>The shared decision-making interventions studied had no significant effect on disadvantaged patients' adherence levels, anxiety, and screening/treatment preferences, intentions or uptake. Pooling of study results found moderate positive effects of shared decision-making interventions on knowledge, participation, decisional conflict and self-efficacy of disadvantaged populations.</p> <p>Seven studies compared the effects of interventions between high and low literacy groups. Results indicated that shared decision-making interventions appeared to benefit disadvantaged groups more than groups with higher literacy, education and socio-economic status. Interventions specifically tailored to the needs of disadvantaged groups appeared to be the most effective.</p>					
	<p>Health professionals' perceptions of the barriers and facilitators to implementing shared decision-making in clinical practice (132)</p>	<p>The majority (89%) of participants in included studies were physicians. The most frequently reported barriers to implementing shared decision-making in clinical practice were time constraints, lack of applicability due to patient characteristics, and lack of applicability based on the clinical situation.</p> <p>The most frequently reported facilitators to implementing shared decision-making in clinical practice were healthcare provider motivation, their perception that putting shared decision-making into practice would lead to improved clinical processes, and their perception that putting shared decision-making into practice would lead to improved patient outcomes.</p>	<p>2006</p>	<p>6/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>6/38</p>	<p>0/38</p>	<p>38/38</p>

McMaster Health Forum

Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
	Experience with shared decision-making programs in VA Shared Decision-making® Programs for prostate care (78)	<p>Shared Decision-making® Programs (SDPs) are videos designed to educate patients and involve them in the decision-making process.</p> <p>The evidence on the impacts of SDPs on treatment preferences for prostate care is limited. Patients enrolled in the two included studies demonstrated improved knowledge about prostate cancer after viewing the SDP. In one study, patients reported improved health and physical functioning, improved knowledge about the risks and benefits of different treatment options, and were more satisfied with their decision-making process.</p>	1997	4/9 (AMSTAR rating from McMaster Health Forum)	0/2	0/2	2/2
	Interventions for improving the adoption of shared decision-making by healthcare professionals (130)	<p>Studies that used outcome measures reported by observers to evaluate shared decision-making interventions showed that interventions targeting both patients and providers had a positive effect compared to usual care and compared to interventions targeting patients alone. Studies comparing interventions targeting healthcare professionals with usual care reported that shared decision-making interventions had a positive effect.</p> <p>The low quality of evidence identified by this review makes it difficult to evaluate whether shared decision-making interventions are effective. However, the findings of this review suggest that any intervention that targets patients, providers, or both, is more effective than no intervention.</p>	2009	9/10 (AMSTAR rating from McMaster Health Forum)	7/39	0/39	23/39
	Identification of ways to communicate evidence to improve patient understanding, involvement in decisions and outcomes (131)	<p>There is limited evidence available to guide how physicians can most effectively share clinical evidence with patients facing decisions.</p> <p>Based on the limited evidence available as</p>	2003	0/10 (AMSTAR rating from McMaster Health Forum)	Not reported	Not reported	8/8

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
	<p>Efficacy of different decision aid tools compared to regular care for women facing several options in the specific field of obstetric care (79)</p>	<p>well as expert opinion, the review recommends five components for efforts to frame and communicate clinical evidence: understanding the patient's (and family members') experience and expectations; building a partnership; providing evidence, including a balanced discussion of uncertainties; presenting recommendations informed by clinical judgment and patient preferences; and checking for understanding and agreement.</p> <p>The review found that all decision aid tools, except for Decision Trees, facilitated significant increases in knowledge.</p> <p>The computer-based information tool, the decision analysis tools, individual counselling and group counselling interventions presented significant results in reducing anxiety levels.</p> <p>The Decision Analysis Tools and the Computer-based Information tool were associated with a reduction in levels of decisional conflict.</p> <p>The Decision Analysis Tool was the only tool that presented evidence of an impact on the final choice and final outcome.</p> <p>Decision aid tools can assist health professionals in providing information and counselling about choices during pregnancy, and support women in shared decision-making.</p> <p>The review suggested that the choice of a specific tool should depend on resources available to support their use, as well as the specific decisions being faced by women, their healthcare setting and providers.</p>	2010	7/11 (AMSTAR rating from McMaster Health Forum)	2/10	Not Reported	0/10

McMaster Health Forum

Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
	Effectiveness of decision aids for patients' treatment or screening decisions (82)	<p>Decision aids increase patient involvement, and improve knowledge and realistic perception of outcomes.</p> <p>Patients exposed to decision aids with explicit values clarification versus those without explicit values clarification were better informed and achieved decisions more consistent with their values.</p> <p>Decision aids, compared to typical care interventions, resulted in lower decisional conflict related to feeling uncertain about personal values and feeling uninformed, and reduced the number of passive patients in decision-making and those left feeling undecided post-intervention.</p> <p>In the four studies that measured this outcome, decision aids positively affected patient-practitioner communication.</p>	2009	9/11 (AMSTAR rating from www.rxforchange.ca)	Not Reported in detail - description states: Australia; Canada; China; Finland; Netherlands; U.K.; U.S.	Not Reported	7/86 (focus of studies not reported)
	Overview of the impact on risk perception accuracy of genetic counselling (85)	<p>Overall, studies found that an increased proportion of individuals correctly perceived their risk after counselling rather than before, and those who did not had smaller deviations from their objective risk than before counselling.</p> <p>The positive effects were sustained at follow-up one year later.</p> <p>Some studies observed no impact at all, or only observed an impact for low-risk participants.</p>	2007	5/9 (AMSTAR rating from McMaster Health Forum)	Not Reported	Not Reported	0/19
	To evaluate the effects of attribute framing (positive versus negative) and goal framing (gain versus loss) of the same health information, on understanding, perception of	Attribute framing in a positive manner caused more positive perceptions of effectiveness than negatively-framed messages, but did not cause a change in persuasiveness of the message.	2007	10/11 (AMSTAR rating from McMaster Health	Not Reported	Not Reported	0/35

Strengthening Care for People with Chronic Diseases in Ontario

Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
	effectiveness, persuasiveness, and behaviour of health professionals, policymakers and consumers (83)	For screening messages, loss messages led to a more positive perception of effectiveness than gain messages.		Forum)			
	Effects of different types of personalized risk communication for consumers making decisions about taking screening tests (80)	<p>There was little evidence to suggest that personalized risk communication (written, spoken or visually presented) increases uptake of screening tests, or promotes informed decision-making by consumers.</p> <p>In three studies, personalized risk communication interventions led to a more accurate risk perception, and three other trials reported that interventions led to increased knowledge.</p> <p>More detailed personalized risk communication (i.e., those which present numerical calculations of risk) may be associated with a smaller increase in uptake of tests.</p>	2006	10/11 (AMSTAR rating from McMaster Health Forum)	2/22	Not Reported	5/22
	Effectiveness of interventions that provide patients with cancer risk and cancer screening information tailored to their personal attributes (84)	<p>Tailored information regarding cancer risk and screening led to increased cancer risk perception and knowledge of breast cancer compared to generic information.</p> <p>There is limited evidence to suggest that a website tailored for risk factors would be effective.</p>	Not Reported	7/11 (AMSTAR rating from McMaster Health Forum)	0/40	Not Reported	0/40
	Effectiveness of cancer-related decision aids (81)	<p>Thirty-four randomized controlled trials (RCTs) of decision aids were identified for use in screening or prevention and treatment of cancer.</p> <p>Decision aids were found to significantly improve knowledge about screening as well as preventive/treatment options as compared to usual practice.</p>	2007	4/11 (AMSTAR rating from McMaster Health Forum)	5/34	0/34	0/34

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>General anxiety was not increased in most trials and was significantly reduced in a screening context.</p> <p>Decision-related conflict was reduced, but not when screening and preventive/treatment studies were analyzed separately.</p>					
	Impact of electronic health records on healthcare quality (86)	Electronic health records have been found to improve the quality of healthcare by allowing providers to make more efficient use of time and adhere to guidelines, as well as to reduce medication errors and adverse drug events for patients.	2013	4/11 (AMSTAR rating from McMaster Health Forum)	Not available		
Ensure the full range of care is seamlessly linked across providers, teams and settings	Effectiveness of quality improvement strategies for coordination of care to reduce use of healthcare services (89)	Approaches used to improve coordination of care significantly reduce the number of people with chronic conditions (except for those with mental illness) being admitted to hospital, as well as emergency department visits for older adults.	2014	10/11 (AMSTAR rating from McMaster Health Forum)	2/50	50/50	50/50
	Navigation roles support chronically ill older adults through healthcare transitions (90)	System navigators are a relatively new approach to link people with complex conditions to the care they need, so there is a lack of evidence to determine if they are helpful for supporting transitions between different settings.	2011	5/10 (AMSTAR rating from McMaster Health Forum)	2/9	9/9	9/9
	Discharge planning from hospital to home (91)	Creating a tailored discharge plan for patients has been found to reduce how long they stay in hospital and the likelihood that they will be readmitted.	2012	9/11 (AMSTAR rating from McMaster Health Forum)	2/11	11/11	11/11
	Effectiveness of chronic-care models (92)	This systematic review aimed to synthesize international evidence on the effectiveness of elements of chronic-care models for improving healthcare practices and health outcomes within primary-healthcare settings. With 77 studies included, only two reported improvements to healthcare practices or health outcomes for people living with	2013	6/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	Not reported in detail	77/77

Strengthening Care for People with Chronic Diseases in Ontario

Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		chronic disease. There were significant variations between studies regarding what combination of elements were included in the chronic-care model. Therefore, the study could not identify any optimal combination of chronic-care model elements that led to health improvements.					
	Effectiveness of comprehensive care programs for patients with multimorbidity, and their impact on patients, informal caregivers and professional caregivers (93)	<p>The review included programs that varied greatly in terms of target patient groups, implementation settings, number of interventions, and the number of chronic-care model components.</p> <p>The review found moderate evidence of a beneficial effect of comprehensive care on inpatient healthcare utilization and healthcare costs, health behaviour of patients, perceived quality of care, and satisfaction of patients and caregivers.</p> <p>The review found insufficient evidence of a beneficial effect of comprehensive care on health-related quality of life in terms of mental functioning, medication use, and outpatient healthcare utilization and healthcare costs.</p> <p>The review found no evidence of a beneficial effect of comprehensive care on cognitive functioning, depressive symptoms, functional status, mortality, quality of life in terms of physical functioning, or caregiver burden.</p>	2011	5/9 (AMSTAR rating from McMaster Health Forum)	4/42	33/42	42/42

Appendix 2a: Summary of key findings from systematic reviews relevant to Element 2 – Convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> • Provide clinical leadership for chronic-disease prevention and management for the province <ul style="list-style-type: none"> ○ One recent high-quality review found that collaboration had little to no effect on the social determinants of health and health equity.(95) ○ One older medium-quality review found little evidence to suggest that partnerships in public health could improve health outcomes and equity, but did find that they may help raise the profile of issues on local policy agendas.(97) ○ An older medium-quality review found that collaborative communities of practice resulted in a number of positive health outcomes (e.g. decreased mortality rates, reduced duration of post-operative intubations and fewer surgical-site infections), as well as quality improvements.(96) This review also concluded that strong clinical leadership helped to ensure successful communities of practice and collaboration. • Engage in creating evidence-based tools and other supports <ul style="list-style-type: none"> ○ A recent medium-quality review found that the main benefits of stakeholder engagement in developing and conducting systematic reviews include: identifying and prioritizing topics for research; providing pragmatic feedback on the research protocol; aiding in recruitment of research participants; helping the researchers understand the research subject’s perspective; ensuring that findings are interpreted with the end user in mind and that final products are readable and accessible; and facilitating wider dissemination and uptake of research findings.(100) ○ The same review noted that stakeholder engagement in the topic refinement and research development phase of conducting a systematic review was identified as the point where stakeholder engagement yielded the greatest benefit.(100) • Citizen- and patient-engagement processes <ul style="list-style-type: none"> ○ 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 and access for people with disabilities).(107) ○ Citizen engagement can be helpful for improving dissemination of information and processes for developing interventions, as well as for enhancing awareness and understanding among citizens.(106;111) ○ An older high-quality review found some evidence that community engagement improves the dissemination of information and processes for developing interventions.(111)
Potential harms	<ul style="list-style-type: none"> • Engage in creating evidence-based tools and other supports <ul style="list-style-type: none"> ○ A recent medium-quality review indicated that the biggest challenges of engaging stakeholders in the development and conduct of systematic reviews include time and resources, researcher skills for stakeholder engagement, finding the right people, balancing multiple inputs, and understanding the best/most appropriate time in the review process to engage different types of stakeholders.(100)
Costs and/or cost-effectiveness in relation to the status quo	<ul style="list-style-type: none"> • Citizen- patient-engagement processes <ul style="list-style-type: none"> ○ An older low-quality review found that costs related to public-engagement activities are rarely reported, but noted that well-structured processes range from tens of thousands of dollars to \$1 million or more.(112) ○ While not explicitly providing information about costs, an older medium-quality review noted that, in general, effective patient involvement requires both personnel and financial commitments.(108)
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the element were pursued)	<ul style="list-style-type: none"> • Uncertainty because no systematic reviews were identified <ul style="list-style-type: none"> ○ Not applicable (reviews were identified for both sub-elements) • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review <ul style="list-style-type: none"> ○ Not applicable (no ‘empty’ reviews were identified) • No clear message from studies included in a systematic review <ul style="list-style-type: none"> ○ Citizen- and patient engagement processes <ul style="list-style-type: none"> ▪ Most of the studies included in an older low-quality review about priority setting for health interventions in developing countries were small pilot studies, which did not include evaluations of the priority-setting processes that were described.(137) ▪ One older medium-quality review identified and compared priority-setting approaches for health technology assessment,(138) and another older but

	<p>low-quality review described priority-setting processes for healthcare,(139) but neither evaluated the benefits, harms and costs of these processes given that both were focused on key characteristics of models that have been used (see the section below about key elements of the policy option for more information).</p> <ul style="list-style-type: none"> ▪ An older low-quality review noted that public-engagement exercises are typically not formally evaluated, but that, despite the lack of evaluation, results of engagement processes are typically viewed as a success and claimed to have led to a direct impact on decisions.(112) ▪ A recent, medium-quality review indicated that while there is some evidence to support the developmental role of public involvement (e.g., for enhancing awareness and understanding among citizens), no clear conclusions can be drawn due to lack of clarity about what success looks like.(140) ○ Another medium-quality but older review similarly found few studies that described the effects of involving patients in the planning and development of healthcare.(107)
<p>Key components of the element if it was tried elsewhere</p>	<ul style="list-style-type: none"> • Provide clinical leadership for chronic-disease prevention and management for the province <ul style="list-style-type: none"> ○ An older medium-quality review found a number of critical factors associated with the success of regional collaboration through communities of practice, including: 1) trust among health professionals and institutions; 2) the availability of good quality data; 3) commitment among participating institutions; and 4) adequate infrastructure and methodological support for quality management. This author also found that clinical leadership was an important factor.(96) • Engage in creating evidence-based tools and other supports <ul style="list-style-type: none"> ○ A recent low-quality review focused on engaging stakeholders in research prioritization more generally (i.e. not only as it relates to systematic reviews), and identified several important components of the process that ought to be considered, including: <ul style="list-style-type: none"> ▪ engaging stakeholders early in the research process; ▪ being attentive to relationship building between researchers and stakeholders; ▪ establishing credibility with stakeholders by delivering high-quality project products; ▪ using multiple methods for engagement; ▪ allowing the appropriate amount of time for the engagement of all relevant stakeholder groups; ▪ documenting all input; ▪ employing a skilled facilitator for all group discussions; ▪ planning strategies for managing disruptive or dominating stakeholders; ▪ beginning prioritization processes with a streamlined list of topics; ▪ conducting icebreaking sessions during in-person activities; ▪ providing easy-to-understand informational materials at the beginning of engagement and before meetings; and ▪ offering opportunities for clarification.(101) • Citizen- and patient-engagement processes <ul style="list-style-type: none"> ○ A recent review outlined a model for deliberative dialogues (as one possible component for identifying a clear picture of challenges related to addressing childhood cancer), which included three key features: <ul style="list-style-type: none"> ▪ ensuring an appropriate meeting environment (e.g., by ensuring adequate resources, commitment from participants, transparency, timeliness of the issue, appropriate group size, clear meeting rules, pre- and post-meeting tasks and effective facilitation); ▪ ensuring an appropriate mix of participants (e.g., by ensuring fair and balanced representation of those with an interest in the issue, and that participants are motivated and provided with the resources they need to meaningfully engage in the issue); and ▪ ensuring appropriate use of research evidence (e.g., fostering a clear understanding of the policy issue among all participants by presenting what is currently known about it based on the best available research evidence).(141) ○ An older low-quality review about priority setting for health interventions in developing countries indicated that: <ul style="list-style-type: none"> ▪ most involved policymakers, health workers and the general population in their priority-setting process; ▪ quantitative techniques (e.g., discrete-choice experiments) are most appropriate where general guidance on priority-setting is needed; and ▪ qualitative techniques (e.g., deliberative processes) may be best used in situations where decisions are required. ○ An older medium-quality review found that: the majority of priority-setting frameworks (seven of the 12 that were identified) used a panel or committee to provide advice with all committees engaging representatives from funders, health professionals and researchers; some drew on advice from a board of directors (often in conjunction with a separate committee); one-third used a rating system to inform priorities (all of these were used along with a committee); and only

	<p>two models explicitly considered the balance of costs and benefits in the assessments made.(142)</p> <ul style="list-style-type: none"> ○ An older, medium-quality review of priority setting for healthcare identified formal and informal priority-setting processes.(139) <ul style="list-style-type: none"> ▪ Formal processes – assemble a government-appointed committee, identify principles and factors to be considered during the priority-setting process (e.g., equity, solidarity, equality, and effectiveness and efficacy of healthcare services under review). ▪ Informal processes – informal debates, discussions among policymakers and one-off consensus development meetings. ○ The same review indicated that tools for generating lists of priorities based on data were often found to be impractical or conceptually difficult to understand.(139) ○ Eight reviews focused on public and consumer engagement. <ul style="list-style-type: none"> ▪ A recent medium-quality review about public involvement in healthcare policy found that key features of public involvement are poorly defined and rarely detailed.(140) ▪ A recent low-quality review outlined that having the potential to find common ground is a requirement for using public engagement to address issues, and that common goals include activities related to developing policy direction, recommendations and tools, priority setting, resource allocation and risk assessments.(105) ▪ The same review indicated that public-engagement processes include three broad characteristics: 1) a sponsor seeking input from the public; 2) participants considering an ethical- or values-based dilemma; and 3) provision of accurate and balanced information about the dilemma to participants.(105) ▪ A recent medium-quality review indicated that when adapting public-deliberation processes (e.g., citizen juries) for specific aims, special attention should be paid to recruitment, independent oversight by a steering committee, duration of the jury, moderation, and respect for volunteer participants.(110) ▪ Two medium-quality reviews (one recent and one older) outlined that the mechanisms used for public engagement need to be adapted according to the context of policy development around the issue (e.g., by forming the group in ways that are sensitive to the type of topic, history of the issue and possible power dynamics).(104;105) ▪ An older medium-quality review found that training of patients and healthcare professionals is an important component for successfully involving cancer patients in research, policy, planning and practice.(108) ▪ An older medium-quality review defined patient involvement as “the active participation in the planning, monitoring, and development of health services of patients, patient representatives, and wider public as potential patients.”(107) ▪ An older high-quality review indicated that community-engagement activities used a variety of approaches, including convening community groups, committees and workshops, and engaging educators, champions and volunteers.(111) ▪ A recent medium-quality review indicated that there was considerable overlap in the key features of stakeholder-engagement processes in the literature, and found that the methodological centrepiece of stakeholder involvement is entering into collaboration with a collective willingness to participate, and that draws on the strengths of each member while respecting their unique positions and expertise.(99)
<p>Stakeholders’ views and experience</p>	<ul style="list-style-type: none"> • Stakeholder- and citizen-engagement processes <ul style="list-style-type: none"> ○ A recent medium-quality review found that those who participate in well-designed interactive public-engagement processes report high levels of satisfaction across different components of the process (e.g., communication of objectives, adequacy of the information materials provided to inform discussions, and the logistics and management of the deliberation), as well as increased levels of topic-specific learning.(143) ○ Case studies including project administrators’ views about public engagement in the planning and development of healthcare in an older medium-quality review provided support to the view that patient engagement has contributed to changes in services.(107)

Appendix 2b: Systematic reviews relevant to Element 2 – Convene chronic-disease councils to develop and support the implementation of comprehensive and coordinated approaches to chronic-disease prevention and management

Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
Provide clinical leadership for chronic-disease prevention and management for the province	To assess the impact and effectiveness of inter-sectoral action on the social determinants of health and health equity (95)	Evidence that considers intersectoral action as a promising practice is mixed, and it revealed moderate to no effect on the social determinants of health. Given the challenges in documenting evidence for intersectoral action, it is not surprising that only one primary study is considered methodologically strong, which further limits the evidence on the impact of intersectoral action on health equity. More downstream interventions for population health showed the strongest effects, such as intersectoral collaborations to improve immunization rates among vulnerable populations. The association between upstream interventions and health outcomes was least conclusive, and this is likely due to the increased difficulty in measuring and evaluating the impact of upstream interventions on health equity. For future practice and policy, collaborations between public health and other sectors show promise to create supportive environments, but there is a need to address structural determinants of health across the whole population with more multi-level interventions.	2012	8/11 (AMSTAR rating from McMaster Health Forum)	1/17	TBD	TBD
	To assess the effectiveness of regional surgical collaborations for improved care quality and outcomes (96)	A community of practice framework incorporating the success elements can be used as a model for collaboration amongst surgeons and healthcare organizations to improve quality of care and foster continuing professional development. Significant improvements in clinical outcomes, such as decreases in mortality rates, lower duration of post-operative intubations, and fewer surgical-site infections were reported.	2006	4/11 (AMSTAR rating from McMaster Health Forum)	0/7	TBD	TBD
	To review the impact of organizational partnerships in public health on health	Findings suggest that there is not yet any clear evidence of the effects of public-health	2008	6/9 (AMSTAR	0/15	TBD	TBD

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
	outcomes and inequalities in health (97)	partnerships on health outcomes. However, qualitative studies suggested that some partnerships increased the profile of health inequalities on local policy agendas. Both the design of partnership interventions and of the studies evaluating them meant it was difficult to assess the extent to which identifiable successes and failures were attributable to partnership working.		rating from McMaster Health Forum)			
Engage in creating evidence-based tools and other supports	Defining the benefits of stakeholder engagement in systematic reviews (100)	This review sought to examine the benefits and challenges of engaging stakeholders in the process of developing and performing systematic reviews. Benefits cited include: identifying and prioritizing topics for research; providing pragmatic feedback on the research protocol; aiding in recruitment of research participants; helping the researchers understand the research subject's perspective; ensuring that findings are interpreted with the end user in mind and that final products are readable and accessible; and facilitating wider dissemination and uptake of research findings. In particular, the topic refinement and research development phase of conducting a systematic review was identified as the point where stakeholder engagement yielded the greatest benefit. Challenges include time and resources, researcher skills for stakeholder engagement, finding the right people, balancing multiple inputs, and understanding the best/most appropriate time in the review process to engage different types of stakeholders. Additionally, it was found that very few studies directly measured the impact of or had quality standards for stakeholder engagement, with most relying heavily on observations and inferences.	2013	5/9 (AMSTAR rating from McMaster Health Forum)	4/24	0/24	0/24
	To assess best practices for engaging stakeholders in research prioritization (101)	There are several important components of the process of engaging stakeholders for research prioritization that ought to be considered, including: <ul style="list-style-type: none"> engaging stakeholders early in the research 	2010	2/9 (AMSTAR rating from McMaster Health	TBD	TBD	TBD

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>process;</p> <ul style="list-style-type: none"> • being attentive to relationship building between researchers and stakeholders; • establishing credibility with stakeholders by delivering high-quality project products; • using multiple methods for engagement; • allowing the appropriate amount of time for the engagement of all relevant stakeholder groups; • documenting all input; • employing a skilled facilitator for all group discussions; • planning strategies for managing disruptive or dominating stakeholders; • beginning prioritization processes with a streamlined list of topics; • conducting icebreaking sessions during in-person activities; • providing easy-to-understand informational materials at the beginning of engagement and before meetings; and • offering opportunities for clarification. 		Forum)			
Citizen- and patient-engagement processes	Effectiveness of community-engagement approaches and methods for health-promotion interventions (111)	<p>There is little evidence on the effects of specific interventions on health promotion. Varying qualities of evidence suggest that interventions that engage the community improve the dissemination of information and the development of interventions. The review includes no evidence regarding the effectiveness of community-engagement approaches and methods for health-promotion interventions with regards to optimizing clinical practice.</p> <p>The evidence from one study suggests that community champions used in planning/design or delivery of health-promotion interventions can increase their level of knowledge, skills and confidence following training, and feel that they make the greatest impact in areas in which they</p>	Not reported (published in 2008)	9/10 (AMSTAR rating from McMaster Health Forum)	4/21	Not reported in detail	0/21

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>have ownership and a stronger voice within their communities.</p> <p>The community-engagement approaches reviewed included the use of community groups, committees, educators, volunteers, workshops and champions. In addition, the community-engagement methods and approaches focused on the planning, design and delivery of interventions in areas of cardiovascular health, childhood immunization, injury prevention, sexual health, smoking, alcohol use, nutrition and physical activity.</p>					
	<p>Effective strategies for interactive public engagement in developing healthcare policy and program delivery at a provincial/regional level (104)</p>	<p>Interactive public engagement designed to contribute to decision-making can be successfully implemented in various situations. The relative success of implementation is influenced by a range of contextual variables, of which organizational commitment and issue characteristics play more important roles than other contextual variables. In well-designed interactive public-engagement processes, participants generally report high levels of satisfaction with the communication of objectives, adequacy of the information materials, and the logistics of the deliberations. These public-engagement methods can influence participant views, but are less likely to alter dominant views, such as the highest priorities. Researchers note that continued ambiguity in the terminology, goals, theoretical properties and benefits of public engagement amongst Canadian health-system managers and policymakers will threaten potential meaningful progress towards informing practice and involving the public in the development of healthcare programs.</p>	<p>2009</p>	<p>4/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>11/29</p>	<p>1/29</p>	<p>1/29</p>
	<p>Examining the peer-reviewed empirical evidence on outcomes of public involvement in healthcare policy (106)</p>	<p>The outcome of public involvement in healthcare policies remains largely underdeveloped and poorly documented. There is little to no evidence</p>	<p>2010</p>	<p>4/9 (AMSTAR rating from</p>	<p>5/19</p>	<p>0/19</p>	<p>5/19</p>

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>for the longer-term impact demonstrated by public involvement. There is no clear conclusion on the effectiveness of policy development from involvement activities. The review includes no evidence regarding the effectiveness of public involvement with regards to optimizing clinical practice.</p> <p>There is some evidence for the developmental role of public involvement (e.g. enhancing awareness, understanding and competencies among lay participants), but the unclear definition of success impedes on forming a conclusion about public involvement.</p> <p>There is limited data available to address the primary research questions.</p> <p>The key features of public involvement remain poorly defined, and its objectives are rarely specified in the literature. Indicators used to determine outcomes of this form of intervention remain inconsistent and poorly specified.</p>		McMaster Health Forum)			
	Examining the effects of involving patients in the planning and development of healthcare (107)	<p>A review of 337 studies involving patients in the planning and development of healthcare found that few studies described the effects of involving patients in the planning and development of healthcare. The review defined patient involvement as “the active participation in the planning, monitoring, and development of health services of patients, patient representatives, and wider public as potential patients”.</p> <p>Case studies reporting on project administrators’ views about the impacts of patient engagement support the view that involving patients has contributed to changes to services. An evidence base does not exist for the effects on use of services, quality of care, satisfaction, or health of</p>	2000	5/9 (AMSTAR rating from McMaster Health Forum)	2/42	Not reported in detail	6/40

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>patients.</p> <p>The effects of patient involvement on accessibility and acceptability of services or impact on the satisfaction, health or quality of life of patients, has not been examined. The effect of patient contributions to the planning and development of services on the quality and effectiveness of these services across various settings is unknown.</p>					
	<p>Public deliberation as a method for increasing public input for health research (105)</p>	<p>Public deliberation is presented in the literature as a specific area of political science, and it encourages members of the public to engage in and be informed about issues that shape their public life. Evidence remains consistent in suggesting that public deliberation is a method of obtaining public input on decisions that are important to society. The goals of public deliberation are to obtain informed public opinion, to obtain input that includes under-represented individuals and groups, to bring insights into social values and ethical principles, and to promote the acceptance of public decisions. In addition, the effects of deliberation on participants improve understanding of the complexity of decisions and enhance civic-mindedness. Identified issues that are best suited for public deliberation involve ethical and social dilemmas. It is also important to note that the potential to find common ground is a requirement for issues addressed through public deliberation. Common deliberative tasks in healthcare include the development of policy direction, recommendations and tools, priority setting and resource allocation, and risk assessments.</p> <p>The process of public engagement is facilitated through discussion, and prompts the public to develop solutions to societal problems posed to them. It includes three broad characteristics: a</p>	<p>2010</p>	<p>1/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>Not reported in detail</p>	<p>Not reported in detail</p>	<p>Not reported in detail</p>

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		sponsor seeking input from participants (i.e., the public); participants considering the ethical- or values-based dilemma; and an information phase in which participants are given accurate and balanced information about the relative positions involved by way of educational materials, experts, etc.					
	Effectiveness of the agenda of involvement of people affected by cancer in research, policy and planning, and practice (108)	<p>Training of patients and healthcare professionals is necessary for successful involvement of cancer patients in research, policy and planning, and practice.</p> <p>Patient involvement requires personnel and financial support. The opposing ideologies of individualism and collectivism are the most common rationales as to why people affected by cancer should be involved in research, policy and planning, and practice.</p> <p>Some policy and planning and research organizations have involved people affected by cancer at a strategic level, most notably in the U.K. and the U.S., but it is not clear how much power and influence they hold at a strategic level.</p> <p>‘One-off’ involvement exercises to influence local policy and planning have taken place in the U.K.. in the acute sector, and at a national level to develop guidelines and services, but no examples were found in social care or primary care. The biggest gap in literature about the involvement agenda is rigorous evidence of its impact on research, healthcare services, on those involved, and on the agenda itself.</p>	2004	4/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	Not reported in detail	Not reported in detail
	Strategies in consumer and community engagement in healthcare (109)	This review used the term CCE to encompass the involvement of consumers (patients and their carers) and community members (i.e., non-patient community members and the community more broadly). The authors note that there remains a	Not reported	4/9 (AMSTAR rating from McMaster Health	Not reported in detail	Not reported in detail	2/90

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>paucity of evidence related to the effectiveness of CCE strategies, and participation of different groups of consumers in the CCE process.</p> <p>CCE encompasses strategies that have been used to facilitate the improvement of the level of general service delivery and specific services within preventive care, technology, and related healthcare fields. Various tools and activities are utilized by CCE initiatives, including shared decision-making, decision aids, consumer representation, electronic and internet-based facility application, and peer support and community-based interventions.</p> <p>The review indicated that literature focusing on CCE strategies targeting children found that children and adolescents want to participate in their decision-making, but that healthcare professionals require guidance to assist in their involvement.</p> <p>When reviewing literature focusing on populations from lower socio-economic backgrounds, the authors noted that lowered costs, increased primary-care physician involvement, and modification of communication to better meet individuals' needs were all strategies that facilitated enhanced cancer screening for women in one included study.</p> <p>The authors indicated that a key finding from the review is that CCE initiatives should be rigorously evaluated before their implementation, as they often require immediate resource mobilization and may have hidden costs associated with them (e.g., training healthcare professionals and consumers). Additionally, there are a number of context-related factors that play a role in the success of CCE strategies. The review outlines a</p>		Forum)			

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		model to facilitate assessment of these strategies (i.e., an eight-step process identifying aim, type of activity, participants, preparedness for CCE, engagement methods, measurement, barriers and facilitators).					
	The use of citizens' juries in health policy decision-making (110)	<p>The review describes citizen juries as a method allowing citizens to engage with evidence and deliberate and deliver recommendations surrounding a variety of complex topics. Steering committees and advisory groups involved in the citizens' jury method described in the reviewed studies included key stakeholders (e.g., policymakers), discipline experts, advocacy group representatives, clinical practitioners, deliberative methodologists, patients and caregivers. Studies described the role of the groups in a variety of ways, such as to: prevent bias in expert presentation; guide question development and evidence presentation; disseminate or implement findings; and engage stakeholder representatives.</p> <p>The authors found that among the study population, a large number of juries were shorter in duration than recommended, and few rulings were considered by decision-making bodies (which limited transfer into policy and practice).</p> <p>The authors indicate that when adapting a citizen jury for a particular aim, development of the jury should involve special attention toward recruitment, independent oversight by a steering committee, duration of the jury, moderation, and respect for volunteer participants.</p>	2010	5/9 (AMSTAR rating from McMaster Health Forum)	10/37	0/37	0/37

Appendix 3a: Summary of key findings from systematic reviews relevant to Element 3 - Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> ○ Two recent medium-quality systematic reviews that evaluated 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.(92;113) • Decision-support systems at the provider and patient level <ul style="list-style-type: none"> ○ In addition to the clinical information systems outlined above that are delivered as part of chronic-care models, an older high-quality review found that decision-support systems 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).(123) • Audit and feedback at the practice/organizational level <ul style="list-style-type: none"> ○ A recent high-quality systematic review found that audit and feedback is effective for changing health professional behaviour with a median absolute improvement of 4.3%, and more than 16% absolute improvement is observed when baseline performance is low and/or when key intervention features are incorporated.(117)
Potential harms	<ul style="list-style-type: none"> • None identified
Costs and/or cost-effectiveness in relation to the status quo	<ul style="list-style-type: none"> • Audit and feedback at the practice/organizational level <ul style="list-style-type: none"> ○ The resources required to deliver audit and feedback include data abstraction, analysis and dissemination costs.(117)
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the element were pursued)	<ul style="list-style-type: none"> • Uncertainty because no systematic reviews were identified <ul style="list-style-type: none"> ○ Not applicable • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review <ul style="list-style-type: none"> ○ Not applicable • No clear message from studies included in a systematic review <ul style="list-style-type: none"> ○ One recent medium-quality review,(119) one older medium-quality review (120) and one recent low-quality review (121) reported mixed or limited evidence
Key components of the element if it was tried elsewhere	<ul style="list-style-type: none"> • Decision-support systems at the provider and patient level <ul style="list-style-type: none"> ○ The majority of early studies on computerized reminders were undertaken in highly computerized academic health science centres in the United States, and their generalizability to other settings is less certain.(144) ○ Reminders can be provided on paper or on a computer screen (e.g., computer-aided decision support and drugs dosage), and may be encountered through general education, medical records and/or interactions with peers.(123) • Audit and feedback at the practice/organizational level <ul style="list-style-type: none"> ○ The feasibility of audit and feedback may depend on the availability of meaningful routine administrative data for feedback, which requires information extracted from medical records, computerized databases, or observations from patients, combined with a summary of performance that may include recommendations for clinical action and action planning.(117) ○ The effects of audit and feedback are maximized when feedback is provided more than once, when it includes both explicit targets and an action plan, when the source of feedback is a supervisor or colleague, and when it is delivered both verbally and in a written form.(117) • Performance reporting at the practice/organizational, sub-regional, LHIN and provincial level <ul style="list-style-type: none"> ○ One recent low-quality review found that public reports should target providers and managers who have the power to change things.(121)

	<ul style="list-style-type: none"> ○ One older low-quality review suggested that the following elements are essential to a public reporting strategy: 1) clear objectives; 2) targets; 3) transparent and comprehensive content; 4) easy-to-use formats; and 5) wide distribution using a variety of approaches.(122)
<p>Stakeholders' views and experience</p>	<ul style="list-style-type: none"> • Decision-support systems at the provider and patient level <ul style="list-style-type: none"> ○ A recent low-quality systematic review focused on perceptions related to patient portals found mixed attitudes from patients and their providers regarding the use of patient portals to manage their chronic disease, with the most positive attributes of portals being enhanced communication between patients and providers, and the most negative perceptions being security concerns and lack of user-friendliness.(114)

Appendix 3b: Systematic reviews relevant to Element 3 – Collect and use data across all levels of the system to support and enhance chronic-disease prevention and management

Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
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	Effectiveness of chronic-care models (92)	This systematic review aimed to synthesize international evidence on the effectiveness of elements of chronic-care models for improving healthcare practices and health outcomes within primary healthcare settings. With 77 studies included, only two reported improvements to healthcare practices or health outcomes for people living with chronic disease. There were significant variations between studies regarding what combination of elements were included in the chronic-care model. Therefore, the study could not identify any optimal combination of chronic-care model elements that led to health improvements.	2013	6/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	Not reported in detail	77/77
	Effectiveness of comprehensive care programs for patients with multimorbidity, and their impact on patients, informal caregivers and professional caregivers (93)	<p>The review included programs that varied greatly in terms of target patient groups, implementation settings, number of interventions, and the number of chronic-care model components.</p> <p>The review found moderate evidence of a beneficial effect of comprehensive care on inpatient healthcare utilization and healthcare costs, health behaviour of patients, perceived quality of care, and satisfaction of patients and caregivers.</p> <p>The review found insufficient evidence of a beneficial effect of comprehensive care on health-related quality of life in terms of mental functioning, medication use, and outpatient healthcare utilization and healthcare costs.</p> <p>The review found no evidence of a beneficial effect of comprehensive care on cognitive functioning, depressive symptoms, functional status, mortality, quality of life in terms of physical</p>	2011	5/9 (AMSTAR rating from Program in Policy Decision-making)	4/42	33/42	42/42

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		functioning, or caregiver burden.					
Decision-support systems at the provider and patient level	Effects of on-screen, point-of-care computer reminders on processes and outcomes of care (123)	Computer reminders lead to a 4.2% median improvement in process adherence for all outcomes, 3.3% for medication ordering, 3.8% for vaccinations and 3.8% for test ordering. Generally, point-of-care computer reminders achieve small improvements in physician behaviour.	2008	9/11 (AMSTAR rating from McMaster Health Forum)	1/28	0/28	28/28
Audit and feedback at the practice/ organizational level	Effects of audit and feedback on professional practice and healthcare outcomes (117)	<p>The audit and feedback process consists of an individual's professional practice or performance being measured and compared to professional standards or targets (i.e., auditing of professional performance). The results of this comparison are subsequently delivered to the individual in hopes of encouraging the individual to follow professional standards (i.e., providing feedback). The process is often used in combination with other interventions such as reminders or educational meetings, and is often used in healthcare settings. Most of the studies included in the review measured the effects of audit and feedback on physicians, and some measured the effects on nurses or pharmacists.</p> <p>In all comparisons (audit and feedback alone compared to no other interventions, audit and feedback with educational meetings compared to no intervention, audit and feedback as part of a multifaceted intervention compared to no intervention, audit and feedback combined with complementary interventions compared to audit and feedback alone, and audit and feedback compared to other interventions) audit and feedback was found to be generally effective. However, the authors note that it is uncertain according to the evidence whether audit and feedback is more effective when used in combination with other interventions.</p>	2010	8/11 (AMSTAR rating from www.rxforchange.ca)	11/140	Not reported	140/140

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		Using multivariable meta-regression, the authors indicated that the effectiveness of feedback may increase when baseline performance is low, when feedback is provided more than once, when it includes both explicit targets and an action plan, when the source of feedback is a supervisor or colleague, and when it is delivered both verbally and in a written format.					
Performance reporting at the practice/ organizational, community, regional and provincial levels	Examining the effects of public reporting on patient care to promote quality of care (120)	<p>Overall, there is mixed evidence on the impact of public reporting in improving patient outcomes, while the impact on improving patient safety and patient-centredness remains relatively unknown.</p> <p>Eight studies found mixed results on the effects of public reporting on selection of health plans. Some studies found that individuals were willing to switch their current health plans to a higher consumer-rated health plan.</p> <p>Nine studies found that publicly reporting performance data did not affect selection of hospitals by individuals. However, 11 studies found an increase in quality-improvement activity due to releasing performance data to the public. There is mixed evidence for using publicly released performance results to improve outcomes (i.e. effectiveness, patient safety, patient-centredness, decrease in mortality rates).</p> <p>Five studies found that publicly released performance data affected consumers' choice of providers. Individuals were less likely to select a provider with higher published mortality rates. Some studies indicated that public reporting may cause unintended consequences such as reluctance among surgeons to operate on high-risk patients in fear of receiving low ratings.</p>	2006	5/11 (AMSTAR rating from McMaster Health Forum)	0/45	0/45	0/45
	Evaluating the effectiveness of	The report found that public reporting is	2011	7/10	2/198	0/198	0/198

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
	public reporting of healthcare quality as a quality-improvement approach (118)	<p>associated with improvement in healthcare performance. Nineteen medium-quality studies that focused on public reporting in hospitals found a decrease in mortality. Among 19 high-quality studies that involved health plans and long-term care, there was generally a positive impact on patient outcomes (i.e. satisfaction with care, reduced pain).</p> <p>Studies that examined harms (i.e. reduced access to services and patient engagement) resulting from public reporting found more evidence of no harm than evidence of harm. In one study, there was an increase in mortality that was attributed to public reporting. Thirteen low-quality studies found that public reporting does not contribute to reduced access for patients.</p> <p>Ten studies showed that healthcare providers made positive changes after public reports, including offering new services, policy changes, and participating in quality-improvement activities.</p> <p>Forty-seven medium-quality studies found little to no impact of public reporting on the selection of healthcare providers by patients or their caregivers. The qualitative studies indicate public reports may not have been readily accessible to patients when they were selecting healthcare providers.</p> <p>The characteristics of public reports and the context were rarely described among the quantitative studies. One study found that the communication method affected the use of public reports.</p> <p>The report's findings indicated that public reports have more of an impact in competitive markets, and that improvements are more likely among</p>		(AMSTAR rating from McMaster Health Forum)			

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		providers with lower ratings in initial public reports.					
	Examining the impact of public reporting on patient outcomes and disparities (119)	<p>Three studies in nursing homes assessed quality measures and found improvements in measures of pain, delirium and activities of daily living. There is limited evidence that public reporting has a favourable effect on outcomes in nursing homes.</p> <p>Two of the 14 studies conducted in hospitals showed positive effect on patient outcomes (i.e. reduced mortality rates, general quality of care). The remaining studies showed no effect or a mixed effect.</p> <p>The review found no studies that focused on the effect of public reporting in the outpatient setting.</p>	2013	7/10 (AMSTAR rating from McMaster Health Forum)	0/25	0/25	0/25
	Identifying successful key factors of an effective reporting program (122)	<p>The report identified six key components of effective public reporting programs: objective(s), audience, content, products, distribution and impacts (intended and unintended).</p> <p>The authors suggested that the objectives of public-reporting programs should include accountability, quality improvement and consumer choice. The view of accountability sees citizens as active participants in health systems transformation. For quality improvement, there is mixed evidence on whether making reports public has a greater impact. Consumer choice is more applicable to market-based healthcare systems rather than publicly funded healthcare.</p> <p>The audience of public reporting is key to developing the remaining components. Five studies indicated that reports that are intended to promote quality improvement should be targeted to healthcare organizations that can bring about changes.</p>	Not reported	2/9 (AMSTAR rating from McMaster Health Forum)	1/13	Not reported in detail	Not reported in detail

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>The content of public reporting may need to address the level of aggregation in reports, limitation of existing data, usefulness, and context for providers and healthcare organizations that can be acted on directly.</p> <p>The product must reduce cognitive effort for citizens (i.e. visual cues, readable text size) and address the needs of multiple audiences.</p> <p>Distribution encompasses paper reports, websites and news media; however, there is little evidence in the literature that describes which method of distribution is more effective. Direct engagement may get information and key messages distributed, without the use of traditional reporting material.</p> <p>The authors found no studies to evaluate effective accountability. Three studies found improvement among quality measures (i.e. number of health regions that are using a report in their planning, number of referenced journal citations, number of media stories) after the implementation of public reporting.</p>					
	<p>Examining the factors associated with dissemination of performance information and continuous improvement (121)</p>	<p>The review focused on potential factors that are associated with the dissemination of performance information in health organizations. Dissemination is not enough to produce improvement initiatives, but depends on the cohesion of interrelated factors, which include: context of governance; organizational context of potential users; nature of knowledge; and processes and incentives.</p> <p>Coherence is an important factor on the dissemination of performance information, as organizations that value cumulative knowledge-based changes are more likely to succeed.</p>	<p>2010</p>	<p>3/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>Not reported in detail</p>	<p>Not reported in detail</p>	<p>Not reported in detail</p>

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Sub-element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on chronic disease
		<p>Producers of knowledge and potential users play a key role in dissemination of performance information. Knowledge producers play a key role through their leadership and credibility during knowledge dissemination and providing user support. Potential users are important to develop user capacity to interpret the information and apply changes.</p> <p>The review suggests that managers and clinicians are the preferred beneficiary of performance information due to their key roles in a health system.</p> <p>The review suggests that it is preferable to use more than one incentive, but also to ensure balance between the incentives used, and ensure that they are in line with the context of system governance.</p>					



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