Citizen Brief

Enhancing the Delivery of Comprehensive Care for People Living with HIV in Canada

12 April 2019

McMaster University | HEALTH FORUM

EVIDENCE >> INSIGHT >> ACTION

The McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 14-16 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. A citizen panel can be used to elicit the values that citizens feel should inform future decisions about an issue, as well as to reveal new understandings about an issue and spark insights about how it should be addressed.

About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panel on how to enhance the delivery of comprehensive care for people living with HIV in Canada.

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

- the underlying problem;
- three possible elements of an approach to addressing the problem; and
- potential barriers and facilitators to implement these elements.

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

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Key Messages

What's the problem?

Enhancing care for people living with HIV in Canada is challenging because:

- the burden of HIV remains an important public-health issue and continues to affect those who are often stigmatized and marginalized in society;
- people are living longer with HIV and with more chronic conditions;
- progress still needs to be made on meeting targets, which will require addressing complex challenges; and
- many system-level factors make it complicated to ensure that people living with HIV get the care and supports they need.

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

- **Element 1:** Strengthening comprehensive HIV care within the health system
  - This element focuses on improving the availability and accessibility of existing health services to address the complex needs of people living with HIV from diagnosis to death.
  - This could mean improving point-of-care testing (for example, access to testing and who can provide the tests) and adopting patient-centred approaches to care.
- **Element 2:** Providing supports across social systems to address all of the challenges faced by people living with HIV
  - The focus of this element is on ensuring that efforts to diagnose people living with HIV and involving them in their own care are comprehensive. This will require combining care from health systems with care from social systems to address the unique challenges associated with living with HIV, such as stigma and discrimination.
- **Element 3:** Making small yet rapid changes to improve HIV care and supports over time
  - This element focuses on an approach called rapid-learning systems that makes small yet rapid changes to health and social systems at all levels to improve care experiences and health at manageable per capita costs with positive provider experiences.

What implementation considerations need to be kept in mind?

- An important barrier to implementation to consider is that funds in health and social systems are typically kept separate. This makes the flexible flow of funds required for the elements (particularly for elements 2 and 3) difficult to achieve.
- An important opportunity for implementing the elements is the Pan-Canadian Sexually Transmitted and Blood-Infections Framework for Action. This framework provides guidance for achieving global targets and is an opportunity for collaboration across provincial/territorial and federal governments, organizations and stakeholders.

Questions for the citizen panel

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

Box 1: Questions for citizens

Questions related to the problem

- What do you think are the biggest challenges for providing comprehensive care for people living with HIV?
  - Accessing care?
  - Managing multiple chronic conditions?
  - Addressing needs as people living with HIV age and/or in older adults with HIV?
  - Engaging hard-to-reach and/or stigmatized or marginalized groups?
  - Providing social supports (for example, housing, employment, food security, etc.)?

Questions related to the elements of a potentially comprehensive approach to address the problem (see the elements section for additional, more specific questions)

  - What's needed to strengthen comprehensive care within the health system?
  - What's needed to better provide the full range of supports available from social systems (for example, to address challenges related to stigma, housing, poverty, employment, food security and criminalization)?
  - What is essential for adopting an approach to making small yet rapid changes to improving health and social systems to achieve the goal of enhancing comprehensive care for people living with HIV over time?

Questions related to implementation considerations

- What are the biggest barriers to pursuing these elements?
- What are the biggest opportunities that could help to implement these elements?

Box 2: Glossary

Healthy aging

Staying healthy, active and engaged as long as possible, so that older adults can actively participate in society and lead an independent and high-quality life.(1)

Chronic disease

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

Multimorbidity

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

Patient-centred care

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

Self-management

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

Primary care

The first point of contact or entry into the health system. Individuals involved in providing primary care are: family physicians, nurse practitioners, registered nurses, social workers, dietitians and other health professionals.

Specialty care

Specialized medical services, such as physicians specialized in infectious diseases.

Point-of-care testing

Provides rapid access to screening results within one clinical encounter through a finger-prick to obtain a small amount of blood.(32; 36)

Care for people with HIV poses unique challenges, including stigma and discrimination, poverty, food security, homelessness, cognitive impairments and mental health and addictions) that require tailored responses

The context: Why is enhancing care for people living with HIV a high priority?

Canada and some provinces have supported the 90-90-90 targets set by The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO). These targets indicate that by 2020 that:

- 90% of all people living with HIV will be diagnosed;
- 90% of all people diagnosed with HIV will be on antiretroviral therapy (ART); and
- 90% of all people receiving ART will not have detectable HIV.(4-7)

The Pan-Canadian Sextually Transmitted and Blood-borne Infections (STBBI) Framework for Action now provides a strategy for Canada to meet these targets. The framework has extended the target date to 2030 and focuses on four pillars:

1) prevention;
2) testing;
3) initiation of care and treatment; and
4) ongoing care and support.(8)

However, provincial and territorial health systems need to be strengthened to continue progress towards achieving this target. These efforts also need to focus on improving health outcomes (for example, quality of life). In addition, it will be important to focus on those

who are undiagnosed and hard-to-reach, which represents one of every five people living with HIV in Canada.(9)

To do this, integrated approaches to care for people living with HIV focus on the care cascade.(10) This refers to the steps needed to help people receive ART and not have detectable HIV, which include:

- diagnosing HIV;
- linking and retaining them in care; and
- supporting early and sustained access to ART.

These steps improve health and prevent the spread of HIV.

Many provinces and territories in Canada have and continue to prioritize health-system reforms to support integrated care for people living with complex conditions. This includes providing access to coordinated, comprehensive and continuous care across:

- home and community care;
- primary care;
- specialty care;
- rehabilitation;
- long-term care; and
- public health.

However, care for people with HIV poses unique challenges. This can include stigma and discrimination, poverty, food security, homelessness, cognitive impairments and mental health and addictions that require tailored responses.(11-14)

Given this, the time seems right for action given the need to achieve the 90-90-90 targets and the potential to build upon efforts to address the needs of people with complex conditions.

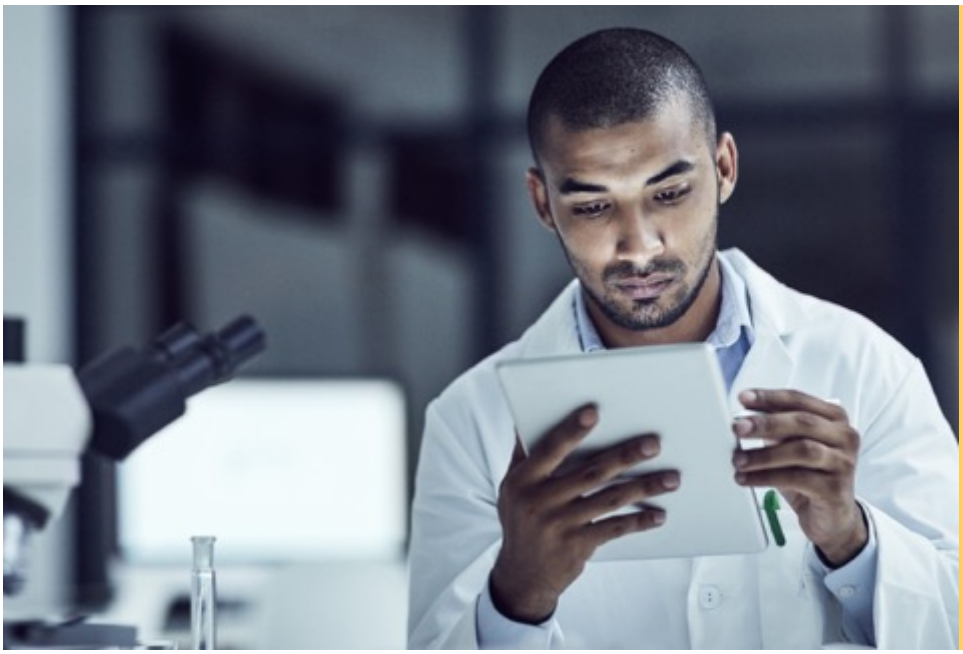
Box 3: Key features of provincial and territorial health systems in Canada

Key features of health systems

- The responsibility for health systems falls primarily to the provinces and territories, with broad rules set by the federal government.(2)
- Medically necessary care provided in hospitals or by a physician is fully paid for as part of each publicly funded provincial/territorial health system.(2)
- Other healthcare providers (for example, nurses, physiotherapists, occupational therapists) are typically not paid for by provincial/territorial health systems, unless their care is provided in a hospital or long-term care setting. Public coverage outside of these settings varies by province and territory.
- Other aspects of healthcare (for example, assistive technology and prescription drug coverage) and community services (for example, mental health supports, home care and long-term care homes) may be partly government funded, with the remaining portion of the costs paid through private insurance plans and/or out-of-pocket.(3)
- Healthcare is increasingly organized by region within provinces and territories. Planning and funding of healthcare is the responsibility of the regions.(2)

Features most relevant to HIV care

- Given the diversity and complexity of symptoms associated with HIV, many other professionals working across a number of settings could be involved in providing comprehensive care for people living with HIV, including:
  - Primary-care provider (family physician or nurse practitioner);
  - Infectious-disease specialist to diagnose and manage HIV and other infections (for example, hepatitis C and tuberculosis);
  - nurses with experience in HIV;
  - pharmacists to help manage medications;
  - mental health providers, such as psychologists or psychiatrists to provide emotional supports;
  - social workers who can help with system navigation and connect patients with appropriate supports (for example, peer support groups, or guidance on employment and financial-related issues); and
  - case manager to coordinate care.



There are approximately 63,100 people living with HIV in Canada, six Canadians are infected with HIV every day, and approximately one in seven of those infected with HIV in Canada are not aware of their infection.

The problem: Why is enhancing care for people living with HIV challenging?

We have identified four key challenges associated with enhancing care for people living with HIV in Canada:

- the burden of HIV remains an important public-health issue and continues to affect those who are often stigmatized and marginalized in society;
- people are living longer with HIV and with more chronic conditions;
- progress still needs to be made on meeting targets, which will require addressing complex challenges; and
- many system-level factors make it complicated to ensure that people living with HIV get the care and supports they need.

We describe each of these challenges below.

HIV is an important public-health issue and affects those who are often stigmatized and marginalized in society

According to data from 2016 and as outlined in Figure 1:

- there were an estimated 63,100 people living with HIV in Canada;
- six Canadians are infected with HIV every day; and
- approximately one in seven of those infected with HIV in Canada are not aware of their infection.(15; 16)

In 2017, there were 2,402 new HIV cases reported, with the national diagnosis rate being 6.5 per 100,000 people.(17) Ontario had the highest number and proportion of reported HIV cases (935, 39%), followed by Quebec (670, 28%), Alberta (282, 12%) and British Columbia (187, 8%).(17) The most recent statistics from the Public Health Agency of Canada from 2016 show that the transmission of HIV occurs through:

- male-to-male sexual contact (53%);
- heterosexual contact (33%);
- injection drug use (11%); and
- both male-to-male sexual contact and injection drug use (3%).(16)

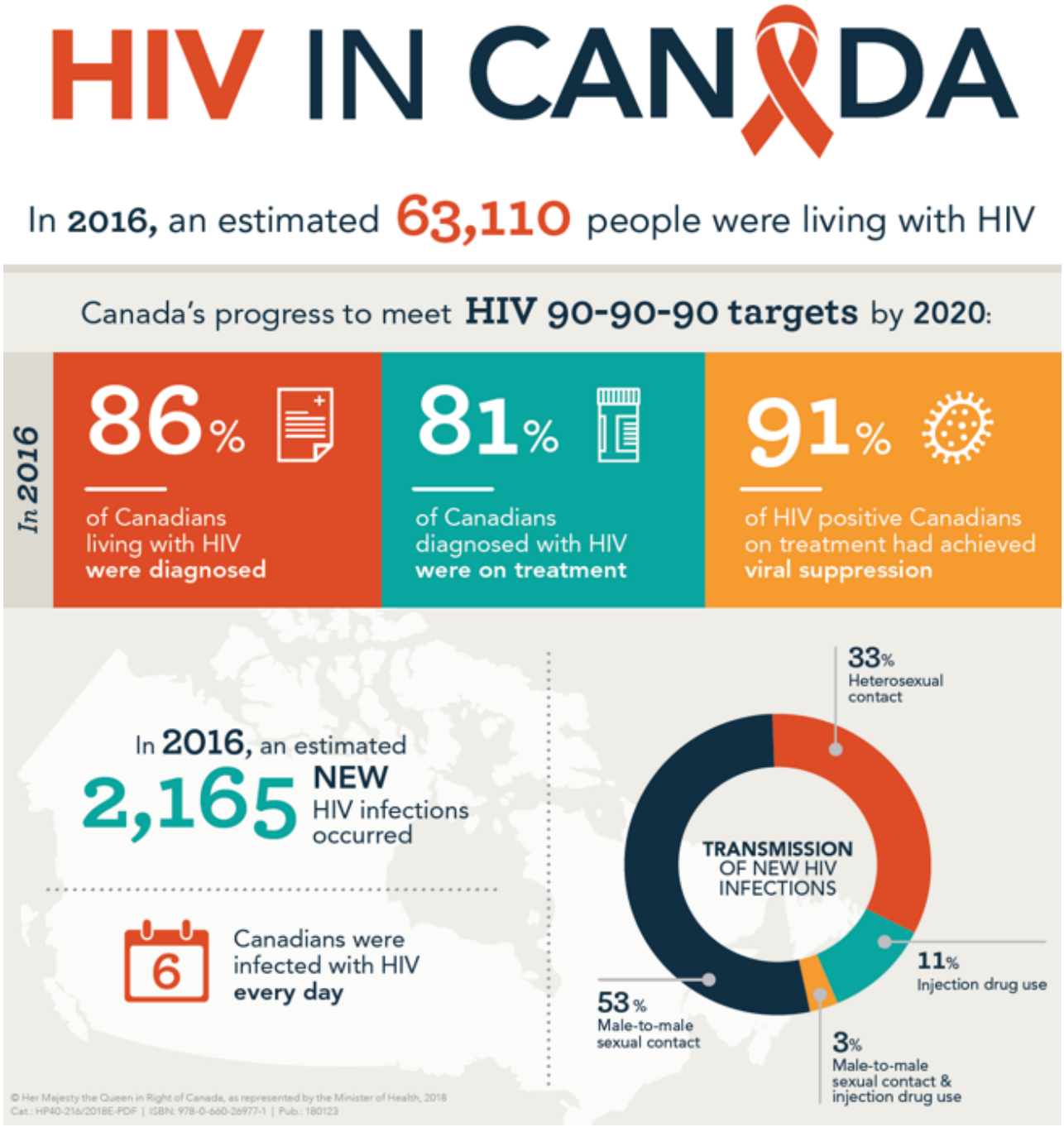
As a result, HIV mainly affects groups that are often stigmatized and marginalized in society. For example, 49% of people living with HIV are gay, bisexual or other men who have sex with men, and 15% are people who inject drugs. Also, while African, Caribbean and Black people make up less than 3% of the population in Canada, it has been found that they account for 14% of HIV infections (and 25% of new infections in Ontario).(18; 19)

In addition, Indigenous peoples are significantly affected by HIV. For example:

- just under 10% of people living with HIV were Indigenous (even though Indigenous peoples comprise only 4.9% of the population);(20)
- Indigenous peoples accounted for 20% of newly reported HIV cases in 2017, of which 17% were First Nations, 2% Métis and 0.2% Inuit;(17)
- Indigenous women, youth and people who inject drugs are over-represented in the HIV epidemic as compared to the general Canadian population;
- there is over-representation of Indigenous peoples in the Canadian prison system, which is linked to a higher risk of contracting HIV;

- Indigenous peoples face increased vulnerability to HIV due to factors such as historical legacies of colonization, cultural dispossession and racism, and the social determinants of health (for example, income and social status, childhood experiences and physical environments);(21; 22) and
- stigma and discrimination have been identified as key barriers to Indigenous peoples accessing needed health and social services.(23)

Figure 1. HIV in Canada (figure reproduced with permission) (24)



People are living longer with HIV and with more chronic conditions

A greater number of older adults are now living with HIV. Key reasons for this are the improved treatment options that are available and that more people are receiving an HIV diagnosis later in life.(17) However, life expectancy for people living with HIV still lags behind that of people without HIV.(25-28)

Since there are now more older adults living with HIV, there are also more HIV-positive individuals with multiple chronic diseases such as cardiovascular disease, diabetes and cancer.(25; 29-32) The association between aging and chronic disease is well-known. However, this association is stronger among people living with HIV.(33) This is due to the effects of long-term antiretroviral therapy (ART). It is also driven by the negative impact of factors related to the social determinants of health (for example, income, housing and social status) that also have an impact on health.(34)

This means that the number of people who need complex care and who are living with different disabilities is increasing. As a result, HIV is increasingly seen as a complex condition, which requires better coordinated services that are able to address this complexity.

Progress still needs to be made on meeting agreed upon goals, which will require addressing complex challenges

As noted earlier, Canada and some provinces have supported achieving the 90-90-90 targets. These targets refer to the aim of having 90% of all people living with HIV be diagnosed, having 90% of all people diagnosed with HIV infection be on ART, and that 90% of all people receiving ART will not have detectable HIV (this is called viral suppression).(4-7)

The most recent indicators for the 90-90-90 targets in Canada (as noted in Figure 1) are from 2016 and indicate that:

- 86% of Canadians living with HIV were diagnosed;
- 81% of Canadians diagnosed with HIV were on treatment; and
- 91% of HIV-positive Canadians on treatment had achieved viral suppression.

The good news is that the majority of people living with HIV have been diagnosed and engaged in care. Also, the overall incidence rates remain stable.

However, these facts do not tell the full story. In particular, it is important to note that progress towards the 90-90-90 targets is calculated with only those included in the previous category. Including all people living with HIV in the calculation shows that:

- 86% of Canadians living with HIV were diagnosed;
- 69% of those with HIV (not just diagnosed) were on treatment; and
- 63% of those with HIV (not just on treatment) had achieved viral suppression.

It is also important to consider the following:

- the targets do not provide a focus on the undiagnosed and hard-to-reach populations (for example, individuals experiencing homelessness) who are often not engaged in care;
- the targets focus on people already living with HIV and not on prevention and/or addressing the broader issues that put people at risk for HIV and make it difficult for them to become involved in care;
- there are priority populations with increasing rates of HIV infection (for example, injection drug users), as well as groups that are affected more by HIV than others (for example, Indigenous peoples and African, Caribbean and Black communities) and therefore need more attention;

- there are differences across provinces in what is considered virally supressed; and
- the time it takes to publish data is long, making it difficult to address new challenges quickly.

Given this, efforts towards achieving these targets, providing care for the most hard-to-reach populations and improving prevention efforts will need to focus on addressing several challenges. These include:

- HIV-related stigma and discrimination;
- implications related to criminalization of HIV;
- poverty, food security and homelessness;
- cognitive impairments; and
- mental health and addictions.(35-38)

Each of these challenges can present difficulties for achieving viral suppression. For example, the stigma of living with HIV is unique given that levels of stigma are higher as compared to other chronic conditions. Also, criminalizing non-disclosure of HIV may have a number of negative consequences related to HIV diagnosis and care. This can include increasing the levels of stigma and discrimination and discouraging people from getting tested. As a result, HIV-related stigma and discrimination has been noted as one of the biggest challenges facing people living with HIV.(39) However, approaches to criminalization of HIV have recently been revised to help address some of these issues.(40)

Many system-level factors make it complicated to ensure that people living with HIV get the care and supports they need

Several system-level factors make it more difficult to enhance the delivery of comprehensive care for people living with HIV in Canada. In Table 1, we describe several important health-system challenges related to:

- governance arrangements (who can make what types of decisions);
- financial arrangements (how money flows from taxpayers to government to organizations and professionals); and
- delivery arrangements (how care is organized).

Table 1. Summary of system-level challenges

Challenge	Example/description of the challenge

Governance arrangements (who can make what types of decisions)	**Jurisdictional complexity**
	• Decision-making authority for addressing the many social determinants of health spans a wide variety of government departments and bridges health and social systems.
	• For example:
	  ○ there is a 'patchwork' of care in the federal and provincial/territorial governmental roles in the delivery of healthcare for Indigenous peoples;(41; 42) and
	  ○ there are legislative and regulatory barriers to implementing point-of-care testing (for example, who can administer the test) which has created variability in its availability across the country.(43)
	HIV-related data
	• There are several national and provincial surveillance systems for HIV, but coordination and integration of them has proven difficult.
	• The result is that the time lag in providing access to data is often years. This makes it hard to support rapid policy action based on data and evidence.

Financial arrangements (how money flows from taxpayers to government to organizations and professionals)	**The cost of ART and the public coverage for it and other treatments vary across the country** • Many can face financial barriers to treatment (especially those without employer-based insurance who need to pay out-of-pocket). • This can affect the ability of some to access and sustain treatment even though international guidelines recommend starting ART shortly after diagnosis to improve outcomes and prevent transmission.(44; 45) • The list price for single-tablet regimens is roughly $15,000 per year, but only some of the publicly funded provincial/territorial drug plans provide universal

Challenge	Example/description of the challenge

	coverage.(45) Only the federal programs and British Columbia, Alberta, New Brunswick, Prince Edward Island, Northwest Territories and Nunavut provide universal coverage.
	• This means that depending on where people live, they may pay different amounts for prescribed medications.(45)
	• A recent study on public prescription-drug-plan coverage for ART in Canada found:
	  ○ considerable variability across public drug plans;
	  ○ British Columbia, Alberta, Northwest Territories, Nunavut, New Brunswick and Prince Edward Island offered universal coverage for ARTs, and all other jurisdictions have either a co-payment or a deductible (or both) for ARTs;
	  ○ all jurisdictions listed most ARTs under public drug programs, with the exception of Newfoundland and Labrador; and
	  ○ there is variability in the criteria for the amount of individual subsidies (for example, some have HIV diagnosis as the only requirement for eligibility for a subsidy, while others include income and age to determine eligibility).(45)
	• Coverage for other needed medications (for example, opportunistic infections) are often not included.
	Many require care from allied health professionals (for example, mental health professionals, occupational therapists, etc.), but coverage also varies across the country
	• Such services are often only paid for by provincial/territorial health systems when provided in a hospital or long-term care setting.
	Those living in rural and remote areas experience cost barriers to seeking specialty care in urban centres
	• Some have to travel longer distances to healthcare providers and face increased transportation costs.(46)
	• A study conducted in British Columbia found that people living with HIV in rural settings were more likely to be older, female, identified as having Indigenous ancestry, and have a medical history of hepatitis C co-infection.(46)

Delivery arrangements (how care is organized)	**Lack of timely access to diagnostic services (primarily point-of-care testing)** • Point-of-care testing for HIV was approved in Canada in 2005 and provides rapid access to screening results within one clinical encounter through a finger-prick to obtain a small amount of blood.(43; 47) • Existing programs have high acceptance and satisfaction rates.(43) • Those who are aware of their HIV status are more likely to adopt behaviours that lower the risk of transmission compared to those who do not know their status.(43; 48; 49) • However, it has been found that:

Challenge	Example/description of the challenge
	○ no point-of-care testing is available in the territories or Atlantic provinces; and ○ it is unavailable in many rural and remote communities, including many First Nations, Inuit and Métis communities. • There is an action plan to improve point-of-care testing in Canada,(47) but the variability in access within and between provinces will need to be addressed. **Primary-care providers often lack supports to provide truly comprehensive HIV care (that is, that address both health and social challenges)** • Approaches to care for people living with HIV has shifted from specialist-provided care to primary care with a focus on the prevention and management for comorbidities.(25) • This can have benefits, such as having one 'most responsible' primary-care provider for HIV care and other needs (for example, for chronic diseases and/or disabilities that often emerge as people age). • It can also create other challenges as primary-care providers may require support (for example, sensitivity training for working with marginalized populations in a culturally sensitive/appropriate way) to: ○ provide care in an area that they may have had little exposure to or training in; and ○ ensure access to comprehensive, continuous and coordinated care across a range of specialists when needed. **Those in rural and remote areas may have limited access to care** • Approximately one in five (19%) Canadians live in rural areas,(50) there are 292 remote communities in Canada with a total population of approximately 194,281, and there are few HIV specialists in rural settings.(25; 51; 52) • People living with HIV in rural and remote areas face barriers to accessing healthcare services because health professionals, programs and services are not distributed equitably across Canada.(53) • Barriers can include isolation from medical and psychosocial supports, and significant travel required to access community supports, primary care and specialist care.(46)

We have identified three elements of an approach to address the problem for which we are seeking public input

Elements of an approach to address the problem

>> To promote discussion about the pros and cons of potential solutions, we have selected three elements of an approach to enhancing care for people living with HIV in Canada

Many approaches could be selected as a starting point for discussion. We have selected the following three elements of an approach for which we are seeking public input:

1. strengthening comprehensive HIV care within the health system;
2. providing supports across social systems to address all of the challenges faced by people living with HIV; and
3. making small yet rapid changes to improve HIV care and supports over time.

These elements should not be considered separately. Instead, each should be considered as contributing to a potentially comprehensive approach to addressing the problem. New elements could also emerge during the discussions. Box 4 below summarizes research evidence that has been identified, selected and synthesized for each element.

Box 4: Identification, selection and synthesis of research evidence presented in this brief

- Whenever possible, we describe what is known about each element based on systematic reviews.
- A systematic review is a summary of all the studies looking at a specific topic.
- A systematic review uses very rigorous methods to identify, select and appraise the quality of all the studies, and to summarize the key findings from these studies.
- A systematic review gives a much more complete and reliable picture of the key research findings, as opposed to looking at just a few individual studies.
- We identified systematic reviews in Health Systems Evidence (www.healthsystemsevidence.org). Health Systems Evidence is the world's most comprehensive database of research evidence on health systems.
- A systematic review was included if it was relevant to one of the elements covered in the brief.
- We then summarized the key findings from all the relevant systematic reviews.

Element 1 – Strengthening comprehensive HIV care within the health system

Overview

There are many unique challenges associated with providing comprehensive care for people living with HIV, including stigma and discrimination, poverty, housing insecurity and mental health and addictions problems.(54-56) Element 1 focuses on improving the availability and accessibility of existing health services to address the complex needs of people living with HIV across from diagnosis to death.

This could mean:

- improving point-of-care testing (for example, access to testing and who can provide the tests); and
- adopting patient-centred approaches to care that empow people living with HIV to become participants in their healthcare, such as:
  - the Chronic Care Model, which engages patients in their own care while preparing proactive healthcare teams;(57)
  - patient-centred primary-care teams providing supports that are tailored to the unique needs of specific populations (for example, chiefs, elders, knowledge keepers and translators who can offer cultural and linguistic supports); and
  - geriatric models of care that are sensitive to the needs of the growing number of older adults living with HIV (including integration with long-term care settings).

For more insight into patient-centred approaches to care, we have provided a summary of the pillars of the Patient's Medical Home model in Figure 2.

Evidence to consider

We found several systematic reviews that were related to strengthening comprehensive HIV care within the health system. We present a summary in Table 2.

Questions to consider

Overarching questions to consider

- What's needed to strengthen comprehensive HIV care within the health system?

Additional questions to consider

- What do you think needs to be done to enhance HIV testing?
  - How can it be made more accessible for hard-to-reach populations?
  - Who should be able to administer the test (including the availability of self-administered tests)?
- What approaches do you think are most important for a model of care that would enhance the delivery of comprehensive care for people living with HIV?
  - What are the best ways to engage people in their own care?
  - What would help make care teams more proactive in providing care?
  - What from the Patient-Centred Medical Home Model in Figure 2 would you prioritize?
- Who do you think should be the person who is most responsible for care for people living with HIV (for example, a family physician, a family physician who is focused on HIV care, or a specialist)?

Figure 2. The Patient's Medical Home (figure reproduced with permission from the College of Family Physicians of Canada) (58)

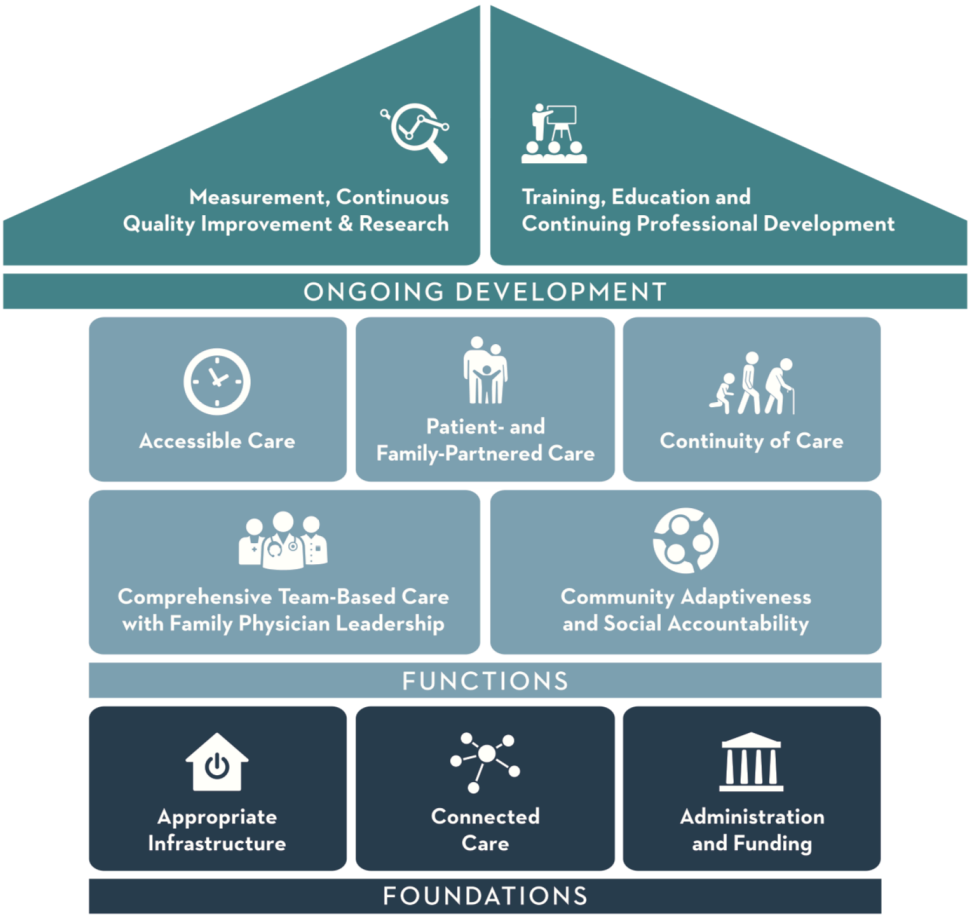


Table 2. Summary of evidence about element 1

Sub-element	Evidence
Improving point-of-care testing (for example, access to testing and who can provide the tests)	• Point-of-care testing can help patients stay engaged in their care before starting antiretroviral therapy.(59) • Young people accept and prefer rapid point-of-care HIV tests when offered.(60) • Patients who selected a rapid point-of-care method were more likely to receive their test results within the follow-up period compared to patients who chose a traditional test.(60)

Adopting patient-centred and 'whole body' approaches to care	• Medication adherence rates among Indigenous peoples improved with dose administration aids, Indigenous community engagement, medication cost reductions, and involvement in medication dispensing.(61) However, providing physicians with feedback about their patients' medication adherence did not improve adherence rates, health outcomes, or service use.(62)
	• Improvements in HIV care engagement were associated with:
	  ○ patient education and counselling;
	  ○ collaborative patient-provider relationships;
	  ○ supportive social networks;
	  ○ strengths-based case management counselling sessions;
	  ○ co-locating services;
	  ○ sending appointment reminders to patients and providers;
	  ○ help with navigating health services;
	  ○ transportation support, outreach, and culturally competent care; and
	  ○ involving peers as workers on the care team.(63-65)
	• People living with HIV commonly reported the following in relation to their access to care:
	  ○ impersonal, rushed, discriminatory and/or judgmental treatment of patients;
	  ○ long wait times;
	  ○ difficulty paying service fees; and
	  ○ fear of disclosure.(66)
	• To deal with these challenges, there are seven aspects of care that were valued by people living with HIV:
	  1) strong relationships with care providers;
	  2) health professional knowledge of HIV;
	  3) considering practical issues related to providing care;
	  4) availability of support and education to promote self-care;
	  5) coordinating services;
	  6) respecting confidentiality; and
	  7) involving patients in treatment decisions.(67)

	• Co-locating HIV care with other services (for example with source for social support, non-HIV primary care, maternal care and mental health supports) helped improve links to needed care and use of ART. • Also, combining HIV services and mental health supports improved healthcare team collaboration, decreased access barriers for patients, and supported continuity of care.(68) • Group psychosocial interventions improved depression scores among adults living with HIV.(69) • Implementing key parts of the chronic care model (for example, decision supports and clinical information systems) for people with HIV contributed to better health (including mental health) and economic outcomes.(70) • Specialty-based care was associated with improved health outcomes. However, there was limited evidence to describe the effectiveness of other care models such as advanced practitioner-based care, team-based care and shared care.(71)

Element 2 – Providing supports across social systems to address all of the challenges faced by people living with HIV

Overview

The focus of this element is on ensuring that efforts to diagnose people living with HIV and involving them in their own care are comprehensive. This will require combining care from health systems (for example, through the types of activities described in element 1) with care from social systems to address the unique challenges associated with living with HIV (for example, mental health and addictions, stigma, poverty, housing and homelessness, employment, food security and criminalization).

This element could include activities focused on integrating delivery arrangements (how care is organized), financial arrangements (how money flows from taxpayers to government to organizations and professionals) and governance arrangements (who can make what types of decisions) in health and social systems. We provide possible activities in each of these areas below.

- Delivery arrangements (how care is organized)
    - Improved navigation supports for people living with HIV to ensure a seamless care experience between health and social systems (for example, supporting access to needed social supports through primary-care settings)
    - Care teams that include individuals who can provide access to needed social supports, such as housing
    - Peer-support networks to offer help with navigating the system, as well as mental health supports from others with lived experience
- Financial arrangements (how money flows from taxpayers to government to organizations and professionals)
    - Flexible budgeting that makes it easier for money to flow between systems and reshuffling funds within systems to address emerging needs and/or include promising new approaches
- Governance arrangements (who can make what types of decisions)
    - A shared leadership model that allows collaborative decision-making across health and social systems (for example, inter-ministerial policy-development teams) and levels within them (for example, through improved collaboration and coordination

among provincial, regional and local decision-makers) to better support a 'whole person' approach to providing care.

Evidence to consider

We found a lot of literature that was related to providing supports across social systems to address the unique challenges faced by people living with HIV. In Table 3, we describe our findings as they relate to health-system governance, financial and delivery arrangements.

Table 3: Summary of evidence about element 2

Health-system arrangements	Evidence
Governance arrangements (who can make what types of decisions)	• There is limited evidence on approaches to governance, however, cooperation and collaboration between different government sectors have been identified as essential.(72)

Financial arrangements (how money flows from taxpayers to government to organizations and professionals)	• One review found that three types of financial mechanisms can support more collaborative health promotion activities:
	  ○ earmarked funding by a ministry or agency;
	  ○ delegated financing (for example, funds allocated to an independent body such as a health promotion foundation); and
	  ○ joint budgeting between different sectors.(73)
	• Another review found that integrated funding for health and social care and supports led to some unplanned consequences, such as leaving hospital too early and increased risk of hospital readmission.(74)
	  ○ Views of staff, patients and carers on their experiences with integrated funding included both positive perceptions (for example, improved service access and knowledge) and negative perceptions (for example, feeling less involved in care).(74)

Delivery arrangements (how care is organized)	• Providing housing support for people living with HIV was associated with regular use of primary care services and also increased the use of antiretroviral medications.(75)
	• Improved system-navigation supports (for example, through case managers, patient navigators and nurse navigators) led to a number of benefits, including:
	  ○ identification of barriers such as health insurance, employment, emotional and social support, transportation, and more continuous care;(76-79)
	  ○ improved attendance at appointments;(76; 80)
	  ○ improved engagement in care;(77)

	○ improved medication adherence and viral load suppression;(77) and ○ decreased emergency-department visits.(80) • Greater collaboration and communication among patients, providers and communities improved linkage to needed care, however, stigma, misinformation about HIV, anxiety and fear may have a negative impact on care engagement among patients.(79; 81) • Several factors were identified that support the inclusion of social determinants of health (for example, housing) into shared care plans: ○ merging health and social sectors; ○ improving the ability of technological systems or software to exchange and make use of information; ○ standardizing vocabulary and interventions; ○ supporting process implementation; ○ addressing professional tension; and ○ ensuring patient-centred care.(82)

Questions to consider

Overarching question to consider

- What's needed to better provide the full range of supports available from social systems (for example, to address challenges related to stigma, housing, poverty, employment, food security and criminalization)?

Additional questions to consider

- Drawing on the examples from the description of the element and from the evidence, what specific types of changes do you think are needed across social systems in relation to delivery, financial and governance arrangements?

Element 3 – Making small yet rapid changes to improve HIV care and supports over time

Overview

This element focuses on an approach called rapid-learning systems that makes small yet rapid changes to health and social systems at all levels. For example, changes could be to self-management, interacting with care providers, programs, organizations, regions within a health system and government policy. The rapid-learning approach is:

- anchored on the needs, perspectives and aspirations of people living with HIV through the 'Greater Involvement of People Living with HIV/AIDS/ Meaningful Involvement of People Living with HIV/AIDS' principles (GIPA/MEPA);
- driven by up-to-date evidence and data;
- supported by coordinated governance, financial and delivery arrangements (for example, adjust who can make what decisions, how money flows and how the systems are organized); and
- enabled with a culture of and competencies for rapid learning and improvement.

Evidence to consider

The most relevant evidence for element 3 comes from two recent rapid syntheses produced by the McMaster Health Forum. One focused on creating a rapid-learning health system in Ontario,(83) and the other on creating a rapid-learning health system in Canada.(84) The description of the element provided above is based on the definition from these syntheses. However, we changed the first sub-element focus on meaningful involvement of people living with HIV.

We provide an overview of the four features and seven characteristics of rapid-learning health and social systems in Figure 3. Appendix 1 provides a more detailed outline of the seven characteristics associated with the features and provides examples of activities for each characteristic.

Questions to consider

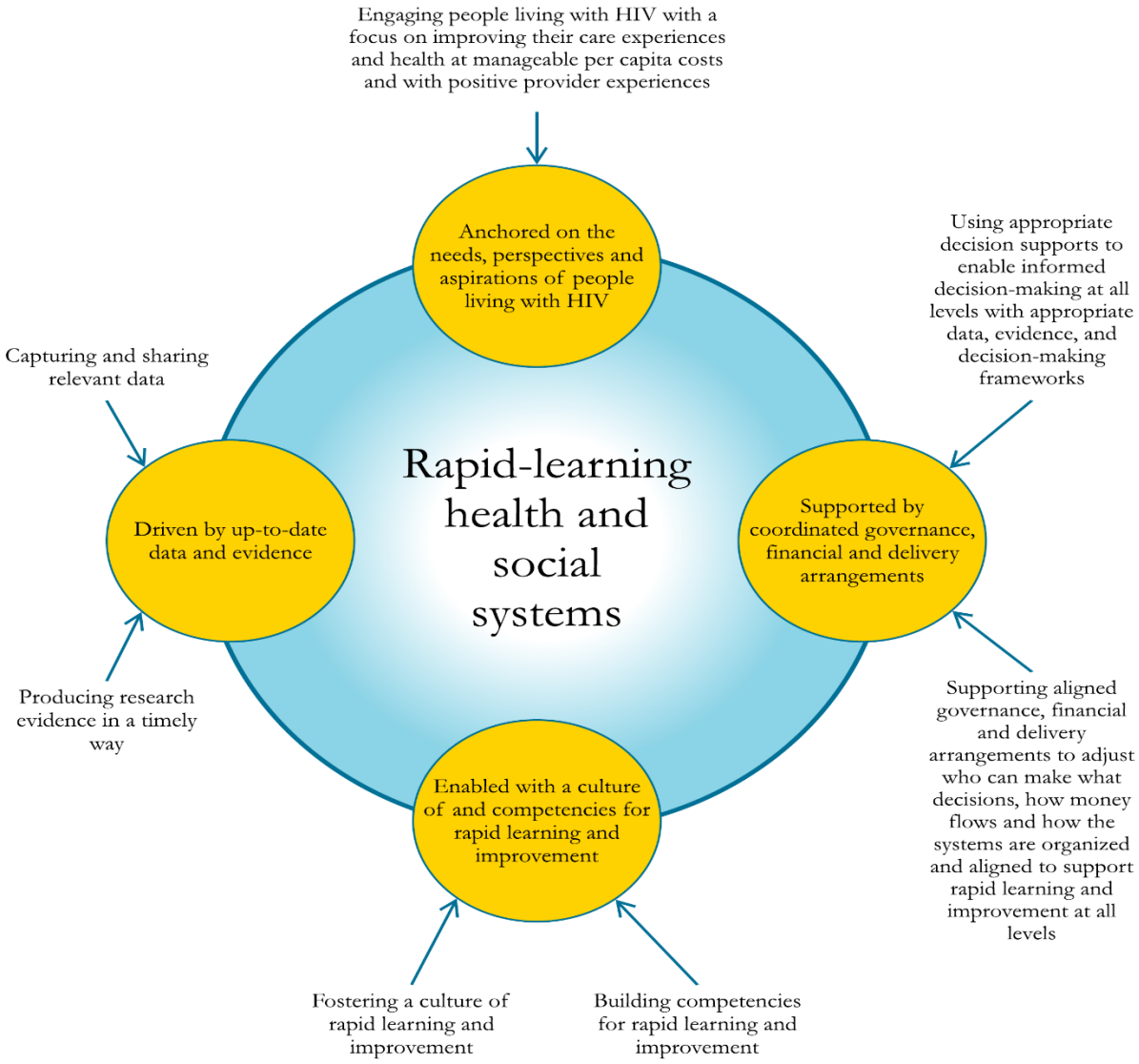
Overarching question to consider

- What is essential for adopting an approach to making small yet rapid changes to improve health and social systems to achieve the goal of enhancing comprehensive care for people living with HIV over time?

Additional questions to consider

- Drawing on the characteristics of rapid-learning systems listed above and in Figure 3 and Appendix 1, what specific types of changes do you think are needed to create rapid-learning systems in order to enhance comprehensive care for people living with HIV?

Figure 3: Overview of features of rapid-learning health and social systems



Implementation considerations

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

The main barrier to implementation is likely that funds in health and social systems are typically kept separate. This makes the flexible flow of funds required for the elements (particularly for elements 2 and 3) difficult to achieve.

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

Examples of potential windows of opportunity

- The Pan-Canadian Sexually Transmitted and Blood-Infections Framework for Action. This framework provides guidance for achieving global targets and is an opportunity for collaboration across provincial/territorial and federal governments, organizations and stakeholders.
- Canadian health systems have both a health system and a research system that are increasingly putting patients and rapid learning and improvement at their centre.

Box 6: A reminder of the questions to consider for your deliberations

Questions related to the problem

- What do you think are the biggest challenges for providing comprehensive care for people living with HIV?
  - Accessing care?
  - Managing multiple chronic conditions?
  - Addressing needs as people living with HIV age and/or in older adults with HIV?
  - Engaging hard-to-reach and/or stigmatized or marginalized groups?
  - Providing social supports (for example, housing, employment, food security, etc.)?

Questions related to the elements of a potentially comprehensive approach to address the problem (see the elements section for additional, more specific questions)

- What's needed to strengthen comprehensive care within the health system?
- What's needed to better provide the full range of supports available from social systems (for example, to address challenges related to stigma, housing, poverty, employment, food security and criminalization)?
- What is essential for adopting an approach to making small yet rapid changes to improve health and social systems to achieve the goal of enhancing comprehensive care for people living with HIV over time?

Questions related to implementation considerations

- What are the biggest barriers to pursuing these elements?
- What are the biggest opportunities that could help to implement these elements?

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Conflict of interest

John Lavis is currently Chair of the Board of Directors of the Ontario HIV Treatment Network, which is one of the funders of this evidence brief. The rest of 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 citizen brief was reviewed by a small number of citizens, other stakeholders, policymakers and researchers in order to ensure its relevance and rigour.

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Appendix 1: Overview of rapid-learning systems (84)

Category	Characteristic	Key examples
Patient/ client centred	Engaging patients/ clients	• Set and adjust patient-relevant targets (for example, improvements to a particular type of patient experience) • Engage patients/clients, families and citizens in: ○ their own health (for example, self-management); ○ their own care (for example, shared decision-making); ○ the organizations that deliver care (for example, through advisory councils); ○ organizations that provide oversight for the system (for example, through regulatory bodies) ○ policymaking (for example, committees making decisions about which services and drugs are covered); ○ research (for example, engaging patients as research partners) • Build patient/citizen capacity to engage in all of the above
Data and evidence driven	Capturing and sharing relevant data	• This could include building: ○ data infrastructure (for example, electronic health records); ○ capacity to collect information on patient-related areas; ○ capacity to capture information across time and settings; ○ capacity to link information about health, healthcare and social care; ○ capacity to analyze the data (for example, staff and resources); and ○ capacity to share 'local' data in ways that are accessible to patients and providers
	Producing research evidence in a timely way	• This could include building: ○ capacity to produce research evidence in a timely way; ○ research ethics infrastructure; ○ capacity to create local evaluations; and ○ capacity to access, adapt and apply research evidence
System supported	Appropriate decision supports	• Create decision supports at all levels – self-management, clinical encounter, program, organization, regional health authority and government (for example, patient decision aids, clinical practice guidelines and health technology assessments)
	Coordinated governance, financial and delivery arrangements	• This could include: ○ centralize coordination of efforts; ○ guidance for quality-improvement plans and accreditation; ○ funding and payment models that encourage rapid learning (for example, including value-based criteria); ○ funding to support spread of effective practices;

		○ create standards for provincial/territorial expert groups; ○ set rapid-learning and improvement priorities; and ○ share learning
Culture and competencies	Culture of rapid learning and improvement	• Develop a culture of teamwork, collaboration and adaptability, and learn from and move on from 'failure'
	Competencies for rapid learning and improvement	• This could include supporting rapid learning and improvement through: ○ public reporting; ○ building in-house capacity; ○ centralizing expertise; and ○ infrastructure (for example, learning collaboratives)

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