Citizen Brief

Supporting Rapid Learning and Improvement for Select Conditions in Canada

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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 view 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 about supporting rapid learning and improvement for select conditions 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?

Bringing about change in health systems is challenging and can be extremely slow. It can take too much time for those working in health systems to act on new research evidence and lessons learned that could improve patient experience and health. Therefore, there is a need to adopt a new approach that allows health systems to learn and improve rapidly. This new approach could help to improve the care experience and health outcomes for individuals with specific conditions. However, four factors make it difficult for health systems to learn and improve rapidly:

- health systems are missing opportunities to learn and improve rapidly based on what is happening with specific conditions;
- some conditions are not prioritized by health systems;
- other initiatives can steer the focus away from specific conditions; and
- not all assets are in place or well connected to allow health systems to learn and improve rapidly.

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

- **Element 1:** Identify strengths and weaknesses in health systems
  - o Patients could be engaged to identify strengths and weaknesses in health systems. This could ensure that health systems are responding to patients' needs, perspectives and aspirations.
- **Element 2:** Build on strengths and address weaknesses to help health systems to learn and improve rapidly
  - o Patients could be engaged in the process of building on strengths and addressing weaknesses to ensure that health systems learn and improve rapidly.
- **Element 3:** Set targets to determine if health systems are making progress
  - o Patients could be engaged to set targets to help determine if health systems are making progress in learning and improving rapidly.

What implementation considerations need to be kept in mind?

- Two of the biggest barriers to implementing these changes are the challenge of introducing a new way of thinking about health-system improvements in Canada, and the challenge of ensuring that all stakeholders are committed to address issues in real time.
- The most promising opportunity is that health systems in Canada are increasingly putting patient engagement, as well as rapid learning and improvement, at their centre.

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 preventing health systems from learning and improving rapidly about your condition?

Questions related to the elements of a potentially comprehensive approach to address the problem
- Element 1 - Identify strengths and weaknesses in health systems (*see worksheet 1*)
  - o What role would you like to play (alongside decision-makers and other stakeholders) to identify strengths and weaknesses in health systems?
  - o What supports would enable you to play that role?
- Element 2 - Build on strengths and address weaknesses to help health systems to learn and improve rapidly (*see worksheet 2*)
  - o What role would you like to play (alongside decision-makers and other stakeholders) to help health systems to learn and improve rapidly?
  - o What supports would enable you to play that role?
- Element 3 - Set targets to determine if health systems are making progress (*see worksheet 3*)
  - o How will we know if health systems are learning and improving rapidly?
  - o What role would you like to play (alongside decision-makers and other stakeholders) to set targets and indicators?
  - o What supports would enable you to play that role?

Question related to implementation considerations
- What do you think are the biggest barriers to supporting rapid learning and improvement for select conditions in Canada? (*see worksheet 4*)
- What do you think are the biggest opportunities for doing better? (*see worksheet 5*)

Box 2: Glossary

Rapid learning and improvement

An approach that helps to identify issues and develop solutions that will improve patient experience and health outcomes through small yet rapid changes. Rapid learning and improvement can happen at various levels: at the level of patients, providers, provider organizations, local and provincial health authorities, and governments.

Chronic pain

A health problem that persists over a long period of time and may require ongoing management. Chronic pain can be disabling, poorly managed, and contribute to a lower quality of life.(1)

Developmental disabilities

A group of conditions (such as physical, learning, language or behavioural) that begin in a child's developmental period that may have an impact on them for their lifetime.(2)

Engagement

A range of efforts used to involve patients in various domains. There is a continuum of engagement: communication, consultation, participation and partnership.(3-4)

Gastrointestinal conditions

This can include inflammatory bowel disease and irritable bowel syndrome. Patients with gastrointestinal conditions often have a lower quality of life and require ongoing medications, and in some cases, surgery.(5)

Patients

We use the word 'patients' here to include:

- patients (those receiving care in the health system);
- potential patients who need care (whether or not they are receiving it now);
- families of and caregivers to these patients (or potential patients);
- citizens (whether as taxpayers or voters or in other roles) who should have a voice in broad system changes; and
- communities (whether defined by geography, lived experience with particular conditions, ethnocultural group or other factors) who should also have a voice in broad system changes.(6)

Health systems should be able to test new approaches, rapidly evaluate them in 'real time,' and quickly adjust the solutions chosen when necessary.

The context: Why is it important for health systems to learn and improve rapidly?

Bringing about change in health systems is challenging and can be extremely slow. It can take too much time for those working in health systems to act on new research evidence and lessons learned that could improve patient experience and health. For example, it is frequently stated that it takes an average of 17 years for new research evidence to change medical practices.(7)

Health systems may benefit from adopting an approach that allows them to learn and improve rapidly (or at least more rapidly than the current pace). The "rapid-learning and improvement" approach works through rapid cycles: identifying new problems, designing solutions, testing these solutions, rapidly evaluating them in 'real time,' quickly adjusting the solutions chosen when necessary, and sharing the findings to benefit others across the health system (see Figure 1 below).

Figure 1. Rapid-learning and improvement cycle
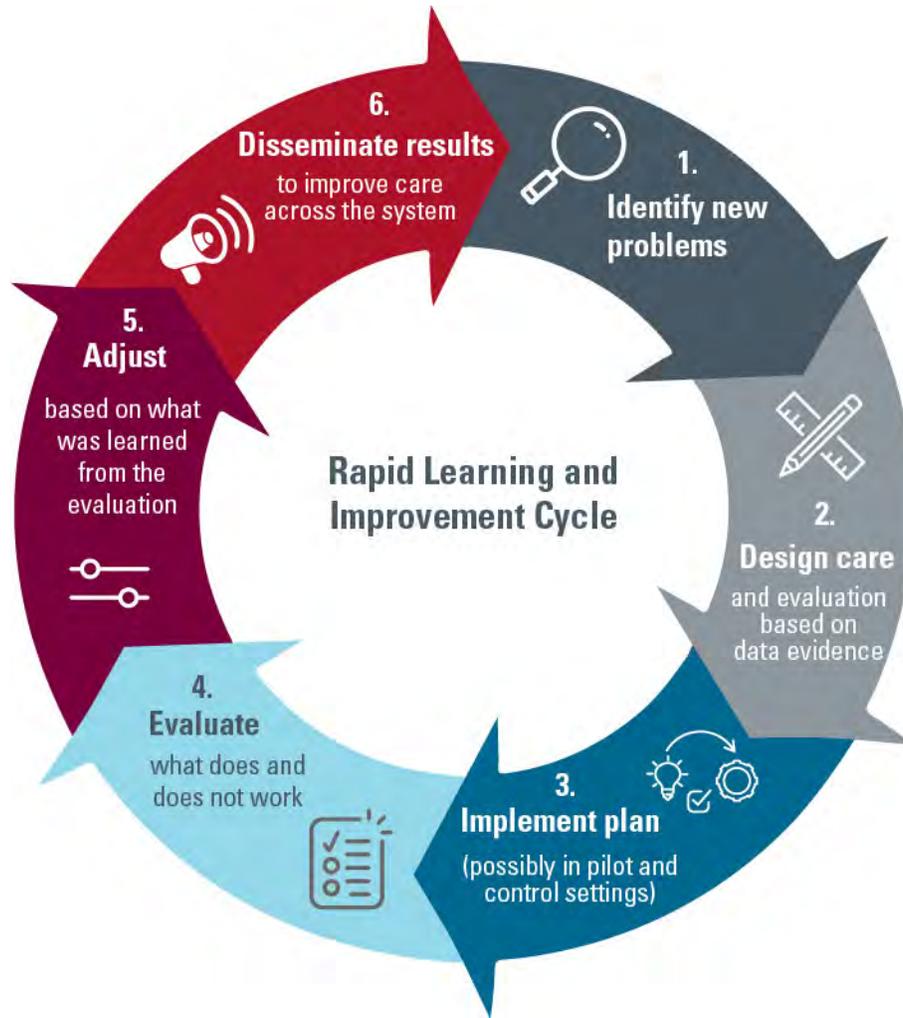
This new approach could be adopted to address problems across an entire health system, but could also help to make targeted improvements to the care experience and health of individuals who have specific conditions. We selected three health conditions that will be used as examples for how this new approach could be adopted. Many other conditions warrant serious considerations as well, and a similar approach could be adopted for any of them. The three health conditions are:

- gastrointestinal conditions (specifically inflammatory bowel disease and irritable bowel syndrome);
- chronic pain; and
- developmental disabilities.

These health conditions have been selected because they affect many Canadians and put a significant burden on health systems (see Table 1 below). Because of their similarities and differences, when taken together, these conditions present opportunities to draw conclusions that may be applicable to a broader range of conditions.

Table 2. Gastrointestinal conditions, chronic pain, and developmental disabilities as examples for a rapid-learning and improvement approach

Conditions	Example
Gastrointestinal conditions	• 270,000 Canadians are living with the condition today, and that number will grow to 403,000 by 2030.(8) • Direct and indirect medical costs related to GI conditions have been estimated to exceed $1.2 billion and $1.5 billion each year, respectively.(9) • Health systems across the country have not established organizational efforts towards better care integration and access to services. • There have been a lot of new discoveries and innovations about gastrointestinal conditions (for example, micro-organisms in the gastrointestinal tract are linked to these conditions) and we need to ensure that individuals suffering from gastrointestinal conditions receive the best possible care.
Chronic pain	• 15-29% of Canadians live with chronic pain. • Chronic pain is associated with the worst quality of life compared to other chronic diseases such as chronic lung or heart disease. • Direct and indirect costs related to chronic pain is estimated to be $37 billion.(10) • There are few efforts to lead Canada-wide initiatives for supporting chronic-pain management. • Chronic pain affects people with many different health conditions and usually requires many different approaches to address.
Developmental disabilities	• There is a wide range of ways to describe and diagnose an individual with a developmental disability. • It is difficult to know who is eligible for services and there is no data to understand the full landscape of individuals with developmental disabilities. • Developmental disabilities are complex conditions that begin early in life, extend into adulthood, and require coordination between the healthcare sector and the social-care sector.

In the next section, we describe in more detail what is known about the "rapid-learning and improvement" approach and how patients can be engaged to bring about change.

What is known about the "rapid-learning and improvement" approach

What does it take for health systems to be able to learn and improve rapidly? Decision-makers and other stakeholders have found a health system must have seven characteristics to achieve this (see Table 2 below).

Table 2. Characteristics of health systems that can learn and improve rapidly (6)

Characteristics	Examples

Engaging patients	• Setting and adjusting targets relevant to patients (for example, improvements to a particular type of patient experience).
	• Engaging patients/clients, families and citizens in:
	  o their own health (for example, self-management);
	  o their own care (for example, shared decision-making);
	  o the organizations that deliver care (for example, through advisory councils);
	  o organizations that provide oversight for the system (for example, through governing bodies involved with improving the quality of healthcare);
	  o policymaking (for example, committees making decisions about which services and drugs are covered); and
	  o research (for example, engaging patients as research partners).
	• Building patient/citizen capacity to engage in all of the above.

Capturing and sharing relevant data	• This could include building:
	  o data infrastructure (for example, electronic health records);
	  o capacity to collect information on patient-related areas;
	  o capacity to capture information across time and settings;
	  o capacity to link information about health, healthcare and social care;
	  o capacity to analyze the data (for example, staff and resources); and
	  o capacity to share 'local' data in ways that are accessible to patients and providers.

Producing research in a timely way	• This could include building:
	  o capacity to produce research evidence in a timely way;
	  o research ethics infrastructure (for example research ethics boards);
	  o capacity to create local evaluations; and
	  o capacity to access, adapt and apply research evidence.

Using appropriate decision supports	• Creating 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).

Adjusting who can make what decisions, how money flows and how the system is organized	• This could include:
	  o centralizing coordination of efforts;
	  o providing guidance for quality-improvement plans and accreditation;
	  o creating funding and payment models that encourage rapid learning (for example, including value-based criteria);
	  o providing funding to support spread of effective practices;
	  o creating standards for provincial/territorial expert groups;
	  o setting rapid-learning and improvement priorities; and
	  o sharing learning.

Fostering a culture of rapid learning and improvement	• Develop a culture of teamwork, collaboration and adaptability, and learn from and move on from 'failure'.

Building the competencies for rapid learning and improvement	• This could include supporting rapid learning and improvement through:
	  o public reporting;
	  o building in-house capacity;
	  o centralizing expertise; and
	  o infrastructure (for example, learning collaboratives).

Developing health systems that can learn and improve rapidly offers great potential, including:
- improving the patient experience and health outcomes in rapid cycles;
- supporting changes that are based on the best available data and research evidence;
- encouraging greater collaboration among all key stakeholders (including patients, caregivers, families, citizens, providers, managers, policymakers and researchers); and
- better using existing resources in the health system and research system.(6)

It is possible to learn and improve rapidly at all levels of a health system:

- at the level of patients (for example, improving how they manage their own health and care);
- at the level of providers (for example, improving how they engage patients in treatment decisions);
- at the level of programs and services (for example, improving patient experiences by re-designing care and evaluating these changes);
- at the level of organizations delivering care (for example, exploring issues in the delivery of care and identifying options on how to address them);
- at the level of local and provincial health authorities (for example, understanding which group or population-targeted programs or services to provide); and
- at the level of governments (for example, deciding who can make what decisions, how money flows, and how the delivery of care should be organized).
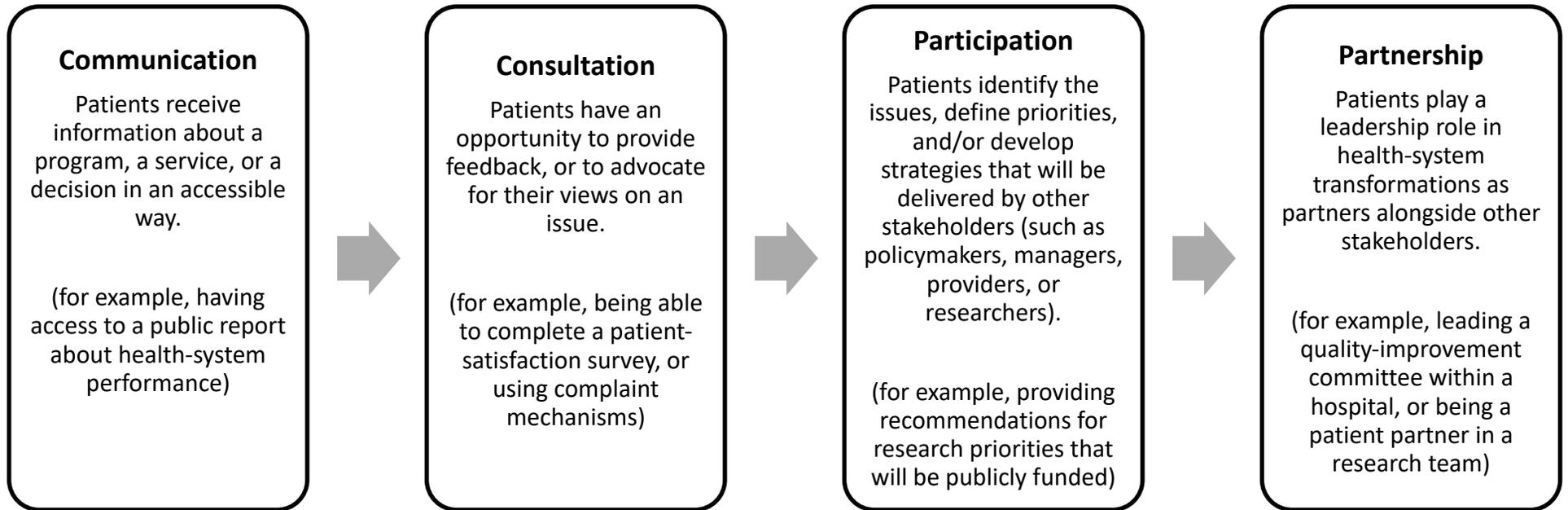
What is known about patient engagement

As described above, engaging patients is fundamental for health systems to learn and improve rapidly. There are many reasons to engage patients, notably:

- it is a fundamental right for patients to be engaged in decisions that may affect their lives (from treatment decisions to broader system changes);
- patients can help us to identify and understand problems in health systems;
- patients can help to find innovative solutions to these problems; and
- patients can offer guidance on how to move forward (for example, identifying what solutions are socially, politically and ethically sound), and advocate for change.

But 'engaging patients' remains a vague idea and can mean different things to different people. In Figure 2 below, we present different ways to engage patients in health systems.

Figure 2. Continuum of patient engagement (3-4)

Communication

Patients receive information about a program, a service, or a decision in an accessible way.

(for example, having access to a public report about health-system performance)

Consultation

Patients have an opportunity to provide feedback, or to advocate for their views on an issue.

(for example, being able to complete a patient-satisfaction survey, or using complaint mechanisms)

Participation

Patients identify the issues, define priorities, and/or develop strategies that will be delivered by other stakeholders (such as policymakers, managers, providers, or researchers).

(for example, providing recommendations for research priorities that will be publicly funded)

Partnership

Patients play a leadership role in health-system transformations as partners alongside other stakeholders.

(for example, leading a quality-improvement committee within a hospital, or being a patient partner in a research team)

At least four key factors make it difficult for health systems to learn and improve rapidly.

The problem: Why is it difficult for health systems to learn and improve rapidly?

We identified at least four factors that make it difficult for health systems to learn and improve rapidly. We illustrate these challenges using gastrointestinal conditions, chronic pain, and developmental disabilities as examples. These factors are:

1) health systems are missing opportunities to learn and improve rapidly based on what is happening with specific conditions;

2) some conditions are not prioritized by health systems;

3) other initiatives can steer the focus away from specific conditions; and

4) not all assets are in place or well connected to support health systems to learn and improve rapidly.

Health systems are missing opportunities to learn and improve rapidly based on what is happening with specific conditions

In every health system across the country, there are many specific conditions for which a rapid-learning and improvement approach would help to ensure patients receive the best care possible. However, despite this potential, opportunities to strengthen existing assets and fill gaps in the seven characteristics of a rapid-learning health system (described in Table 2) are rarely seized. And despite some examples across the country, the rapid-learning and improvement approach continues to be the exception rather than the rule. For example, each of the three conditions that are the focus in this brief face challenges that make them ideal candidates for adopting a rapid-learning and improvement approach, but none of them have been the focus of coordinated or sustained efforts with this goal in mind.

Adopting a rapid-learning and improvement approach could:

- ensure patients and their families are helping to identify the challenges that are most important to address (which is an important consideration for any condition, not just those addressed in this brief);
- strengthen data systems and mechanisms for sharing data, while ensuring research is produced and available when needed to develop the most appropriate solutions (which is a common challenge for many conditions);
- support the development of decision supports such as clinical practice guidelines (helping professionals and patients to make decisions about appropriate care), quality standards (describing what 'quality care' should look like) and care pathways (describing a pre-determined plan of care for patients with a specific condition), which remain either poorly defined or out of date for all three of the conditions discussed in this brief (as well as many other conditions);
- ensure systems are designed in ways that are conducive to addressing these challenges (for example, through the establishment of collaborative governance models with clear lines of accountability for improving patient care and experiences, financial arrangements that facilitate better integration of services); and
- foster a culture of collaboration and teamwork that is essential to learn and improve rapidly (especially when some conditions, like developmental disabilities, span across many sectors and systems), and support the development of capacities to achieve this aim.

Some conditions are not prioritized by health systems

Given the many issues competing for the attention of health-system policymakers, stakeholders and researchers, only a select few end up becoming highly visible priorities. In Canada, two of the most common conditions that have been prioritized are:

- **cancer**, which in many provinces has its own sub-systems to plan and deliver specialty care, as well as a pan-Canadian organization (the Canadian Partnership Against Cancer) focused on improving cancer prevention and treatment across the country; and
- **heart disease**, which is a focal point in most provincial health-system performance monitoring frameworks (e.g., focusing on follow-up visits after hospitalizations due to heart failure and access to cardiac surgery).

However, the reality is that it may not be possible to prioritize every single condition to be the focus of reforms – including the three that serve as illustrations throughout this brief. Looking at research funding in Canada across the three conditions compared to those that tend to be more visible helps to illustrate this point. For example, cancer research funding was estimated at $390 million in 2008 alone, compared to $80.7 million provided over five years for chronic pain research between 2003 and 2008.(11) Additionally, a breakdown of grants and awards funded for each of the conditions over the past years, shows that compared to conditions like cancer (which has been allocated nearly $2 billion by the Canadian Institutes of Health Research, which is the major federal agency responsible for funding health and medical research in Canada) and heart disease (which was allocated close to $1.4 billion when including heart failure or other cardiac research), chronic pain, gastrointestinal conditions and developmental disabilities are prioritized much less for research investments (allocated just under $135 million, $473 million and $23 million, respectively).

The prioritization of specific conditions is the result of a number of different factors including the burden of disease, how important the problem is perceived to be, and the relative power and connections that advocacy groups have, among other things. However, there are also a range of condition-specific challenges that affect whether they are prioritized across the country. For example:

- prioritizing gastrointestinal conditions like inflammatory bowel disease and inflammatory bowel syndrome is difficult given the general lack of awareness and understanding of them across the country;(12) and

- prioritizing chronic pain has been a challenge because there is a lack of clear policy authority and accountability for improving chronic-pain management, which can be linked to difficulties in determining which providers or organizations should take ownership.(13-14) Also, chronic pain is often framed as a symptom associated with many other conditions.(13)

Other initiatives can steer the focus away from specific conditions

In addition to the reality that not all conditions can be highly visible, system-level priorities, there are two types of initiatives in Canada that may also serve to downplay the importance of particular conditions by diverting attention elsewhere. The first type are structural reforms. Examples include:

- major reforms currently unfolding in Ontario (which include the creation of a central agency called 'Ontario Health' and the establishment of Ontario Health Teams that integrate services for an attributed population); and
- the centralization of the health systems in Alberta, Saskatchewan and Nova Scotia.

These types of general – and often fundamental – changes to how health systems are governed, how money flows to the organizations and providers delivering services to patients, and how care is organized and delivered, can detract focus on addressing the problems associated with a particular set of conditions.

On the other hand, the second type of initiative that diverts attention are those that seek to address singular aspects of a condition-specific problem, rather than the range of issues that is required for supporting system-wide rapid learning and improvement. Two examples from the conditions highlighted in this brief are particularly useful illustrations. First, while the challenges (and resulting solutions) associated with chronic-pain management are multifaceted, national and provincial agendas are dominated by the role played by prescription opioids, with little attention paid to establishing comprehensive services for those suffering from chronic pain.(11;14) Second, the issue of publicly-funded support for children with autism and their families has risen to prominence in Ontario, but there has been less focus on what needs to be done to ensure integrated programs and services are available for children across the full range of developmental disabilities over their lifespan.

Not all assets are in place or well connected to support health systems to learn and improve rapidly

For health systems to learn and improve rapidly, the right assets need to be in place, but they also need to be well connected to each other (see the seven characteristics in Table 2). This ensures that those working on improving care for a condition understand where the gaps are and what is being done across the health system(s) to fill those gaps.

For many conditions in Canada, including the three being discussed in this brief, this is not the case. Some assets are in place for each of the conditions such as those being developed through:

- Canada's Strategy for Patient-Oriented Research, which funds the IMAGINE network for gastro-intestinal conditions; and
- the Chronic Pain Network, and the Childbright Network, for individuals and families with developmental conditions.

Each of these networks work to engage patients in research that informs decision-making and can improve patient care. Despite this asset in patient engagement, there remain significant gaps in, for example, establishing supportive culture and competencies for rapid learning and improvement. Furthermore, for each of the three conditions, there are many organizations and initiatives that work at the local, provincial and national levels. However, these organizations rarely speak to each other, nor are their mandates well aligned. Establishing these connections could help them to combine efforts, better define each organization's roles, and reduce the duplication of work. Additionally, when assets are connected, these groups are better able to draw attention to each of the conditions and support a collective call for prioritization within and across provincial and territorial health systems in Canada.

We identified three elements to which we are seeking your 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 supporting rapid learning and improvement for select conditions 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. identify strengths and weaknesses in health systems;
2. build on strengths and address weaknesses to help health systems to learn and improve rapidly; and
3. set targets to determine if health systems are making progress.

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.

Element 1 – Identify strengths and weaknesses in health systems

Overview

If we want health systems to learn and improve rapidly, we first need to understand what are the current strengths and weaknesses in these systems (particularly those related to the seven characteristics defined in Table 2). Given their extensive experiences, patients can play a critical role in identifying strengths and weaknesses.

Use Worksheet 1 below to reflect on how you would like to be engaged to identify strengths and weaknesses in health systems.

Worksheet 1. Potential roles for patients

Communication	Consultation	Participation	Partnership
For example: I want to receive information about strengths and weaknesses in health systems.	*For example: I want the opportunity to provide feedback on strengths and weaknesses in health systems (or advocate for change).*	*For example: I want to help identify strengths and weaknesses, and/or develop a strategy that other stakeholders commit to deliver (such as policymakers, managers, providers or researchers).*	*For example: I want to play a leadership role to identify strengths and weaknesses, and/or develop a strategy that will be delivered in partnership with other stakeholders (such as policymakers, managers, providers or researchers).*
• *Other examples (fill here):*	• *Other examples (fill here):*	• *Other examples (fill here):*	• *Other examples (fill here):*
•	•	•	•
•	•	•	•

Questions to consider

- What role would you like to play (alongside decision-makers and other stakeholders) to identify strengths and weaknesses in health systems?
- What supports would enable you to play that role?

Element 2 – Build on strengths and address weaknesses to help health systems to learn and improve rapidly

Overview

There are opportunities for patients to be engaged in the process of building on strengths and addressing weaknesses within rapid learning and improvement. This could include:

- engaging patients (e.g., self-management, shared decision-making);
- capturing and sharing relevant data (e.g., monitoring own care);
- producing research in a timely way (e.g., joining a research team working on a patient-centred study);
- using appropriate decision supports (e.g., asking and advocating for the use of decision tools to help decide on treatment options);
- adjusting who can make what decisions, how money flows and how the system is organized (e.g., becoming an advisor related to hospital quality improvement projects);
- fostering a culture of rapid learning and improvement (e.g., advocating for patient-focused research); and
- building the competencies for rapid learning and improvement (e.g., being involved in patient-provider partnerships to advocate for rapid changes).

Worksheet 2 provides examples of each opportunity, and the space to jot down additional examples of roles and supports that you may need.

Questions to consider

- What role would you like to play (alongside decision-makers and other stakeholders) to help health systems to learn and improve rapidly?
- What supports would enable you to play that role?

Worksheet 2. Potential roles and supports for patients

Characteristics	Examples	Role(s)	Support(s)

Engaging patients	• Set and adjust patient-relevant targets (for example, improvements to a particular type of patient experience)
	• Engage patients/clients, families and citizens in:
	  o their own health (for example, self-management)
	  o their own care (for example, shared decision-making)
	  o the organizations that deliver care (for example, through advisory councils)
	  o organizations that provide oversight for the system (for example, through governing bodies)
	  o policymaking (for example, committees making decisions about which services and drugs are covered)
	  o research (for example, engaging patients as research partners)
	• Build patient/citizen capacity to engage in all of the above
		• For example, helping my peers to develop their self-management skills, becoming an active partner in health research conducted about my condition, or joining a group to advocate for system-level change
		• O*ther examples (fill here):*
			• *F*or example, having a website describing what patient engagement opportunities are available in my area
			• Other *examples (fill here):*

Capturing and sharing relevant data	• This could include building:
	  o data infrastructure (for example, electronic health records)
	  o capacity to collect information on patient-related areas
	  o capacity to capture information across time and settings
		• For example, documenting my care experiences after each encounter with the health system, identifying patient-reported outcome measures that are relevant, or being consulted about how data sharing and data protection should be handled.
		• Other e*xamples (fill here):*
			• *F*or example, receiving a pamphlet with information about where my health data goes and how I am contributing to improving the health system
			• Other exa*mples (fill here):*

	- capacity to link information about health, healthcare and social care - capacity to analyze the data (for example, staff and resources) - capacity to share 'local' data in ways that are accessible to patients and providers		
Producing research 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 - capacity to access, adapt and apply research evidence	*F*or example, joining a research team to ensure that research is oriented by the needs and insights of patients (helping to develop protocols, to recruit participants, to disseminate findings), or joining an ethics review board as a patient representative - Other exa*mples (fill here):*	- For example, receiving training and guidance on sharing my patient experience in what would be considered useful by the research team, reimbursement for time - Other e*xamples (fill here):*
Using 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)	- For example, proactively asking my care providers if there are relevant patient decision aids, or joining a committee to develop patient decision aids and clinical practice guidelines to ensure that they are aligned with the values and insights of patients - Other examples (fill here):	*F*or example, having access to evidence-based self-management and shared decision-making tools during a care-planning appointment with my care provider - Other exam*ples (fill here):*

Adjusting who can make what decisions, how money flows and how the system is organized	• 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
	  ○ share learning
		• For example, joining a quality-improvement team at my local hospital, becoming a quality advisor to assess whether provider organizations are meeting quality standards
		• Other examples (fill here):
			• For example, receiving training and guidance on sharing my patient experience in what would be considered useful by the research team, reimbursement for time
			• Other examples (fill here):

Fostering a culture of rapid learning and improvement	• Develop a culture of teamwork, collaboration and adaptability, and learn from and move on from 'failure'	• For example, sharing my experiences with students to raise awareness among future providers about the need for greater interprofessional collaboration and patient engagement • Other examples (fill here): .	• For example, webinars or training on the core characteristics and the ability to share with my peers • Other examples (fill here):

Building the competencies for rapid learning and improvement	• This could include supporting rapid learning and improvement through:
	  ○ public reporting
	  ○ building in-house capacity
	  ○ centralizing expertise
	  ○ infrastructure (for example, learning collaboratives)
		• For example, becoming engaged in designing public reports about the performance of providers	• For example, joining patient-provider partnerships to jointly collaborate on public reporting

Element 3 – Set targets to determine if health systems are making progress

Overview

A target is something that you are trying to do or achieve. Patients could play a key role in identifying possible targets and measurable indicators, which can help determine whether health systems are making progress for select conditions.

Use Worksheet 3 below to reflect on possible targets and measurable indicators to monitor progress.

Worksheet 3: Potential targets and indicators to monitor progress

Targets *What are we trying to improve?*	Indicators *How can we measure if we are making progress?*
Access to care	• *For example: unmet care needs (due to costs, waiting times, distances, etc.)* • •
Efficiency	• *For example: healthcare spending, wait times before seeing a specialist* • •
Quality of care	• *For example: hospital readmission rates, patient satisfaction* • •
Equity	• *For example: unmet care needs (due to costs, waiting times, distances, etc.)* • •
Health status	• *For example: life expectancy, the number of years that a person is expected to continue to live in a healthy condition, perception of health status* • •
Health determinants (*the broad range of personal, social, economic and environmental factors that determine individual and population health*)	• *For example: income, employment, education, other socio-economic indicators* • •
Other targets	• • •

Questions to consider

- How will we know if health systems are learning and improving rapidly?
- What role would you like to play (alongside decision-makers and other stakeholders) to set these targets?
- What supports would enable you to play that role?

Implementation considerations

We may face some barriers if we try to implement the three elements discussed above. These barriers may be related to different groups (for example, patients, providers or policymakers), to specific organizations (for example, hospitals), or to specific aspects of a health system (for example, how care is financed). Some of these barriers could be overcome. However, other barriers could be so important that we would need to reconsider whether we should pursue some elements.

The two major barriers are:
- re-orienting patients, health professionals, organizations and systems to a new way of thinking and approach in improving patient care and experiences (especially with defining what is considered a "success") for specific health conditions; and
- ensuring there is 'buy-in' among patients, health professionals, organizations, and policymakers across the system who, by adopting a rapid-learning and improvement approach, are collectively committing to identifying, acknowledging, and working to address a full range of problems in real time.

Use Worksheet 4 below to think about potential barriers to implementing the elements.

Worksheet 4: Potential barriers to implementing the elements

Element	Description of potential barriers	Other barriers
Element 1 – Identify strengths and weaknesses	• Patients who have not been involved in the process for a condition (for which they have experience or have interest) may push back and disagree that a resource exists • Patients may be reluctant to engage if they don't know whether (or how) their efforts will have an impact	• *Other examples (fill here):*
Element 2 – Build on strengths and address weaknesses to help health systems to learn and	• Patients may be hesitant to engage in condition-specific initiatives beyond those addressing a condition (for which they have experience or have interest) • Patients may be hesitant to engage in condition-specific initiatives, when data and research are not available	• *Other examples (fill here):*

Element	Description of potential barriers	Other barriers
improve rapidly	• Patient engagement takes a lot of time and effort, and could be challenging based on their health status • Patients may be reluctant to engage if they don't know whether (or how) their efforts will have an impact	
Element 3 – Set targets to determine if we are making progress	• Patients may be hesitant to engage in prioritizing targets for condition-specific initiatives beyond those addressing a condition (for which they have experience or have interest) • Patients may be hesitant to engage in prioritizing targets for condition-specific initiatives when data and research are not available • Patient engagement takes a lot of time and effort, and could be challenging based on their health status • Patients may be reluctant to engage if they don't know whether (or how) their efforts will have an impact	• *Other examples (fill here):*

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. Use Worksheet 5 below to think about possible windows of opportunity.

Worksheet 5: Potential opportunities to implementing the elements

Element	Description of potential opportunities	Other opportunities
Element 1 – Identify strengths and weaknesses	• **Increase in patient engagement (and family advisors):** there has been an increasing recognition about the importance of patient and family advisors in their own health and care • For example, Alberta's 16 Strategic Clinical Networks engage about 150 patients and family advisors within their networks	• *Other examples (fill here):*
Element 2 – Build on strengths and address weaknesses to help health systems to learn and improve rapidly	• **Interest in rapid learning and improvement**: The approach and key concepts are gaining traction among research institutions and organizations across Canada. There is movement in a national data platform which could support capturing and sharing data of rapid-learning and improvement initiatives. • **Interest in pan-Canadian leadership**: Following the election of a new federal government, collaboration among federal, provincial and territorial governments appears to have new momentum. Also, the use of evidence is now being prioritized in all of the thinking at the federal level, and a pan-Canadian bargaining process (and re-structuring of pan-Canadian health organizations) is already generating greater value for money in price negotiation. • For example, the McMaster Health Forum's Rapid-Improvement Support and Exchange (RISE) supports the rapid learning and improvement by the newly structured, Ontario Health Teams.	• *Other examples (fill here):*

Element	Description of potential opportunities	Other opportunities
Element 3 – Set targets to determine if we are making progress	• **Rapid learning and improvement can be applied at all levels**: There is growing accountability when trying out different approaches, and there are opportunities to measure progress at all levels (e.g., patient, provider, programs and services, organizations delivering care, local and provincial health authorities, and levels of government).	• *Other examples (fill here):*

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