Evidence Brief

Supporting Rapid Learning and Improvement for Select Conditions in Canada

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McMaster Health Forum

Evidence Brief:
Supporting Rapid Learning and Improvement for Select Conditions in Canada

IMAGINE
Inflammation, Microbiome & Alimentation Gastro-Intestinal & Neuropsychiatric Effects

CHILD-BRIGHT Network

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

CPN
CHRONIC PAIN NETWORK

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.

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Conflict of interest

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

Merit review

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

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Table of Contents

KEY MESSAGES

What's the problem?

Adopting a problem-focused rapid-learning and improvement orientation in health systems presents an opportunity for constant and iterative improvements in patient care and experiences across a number of conditions, with those used as illustrative examples in this brief (chronic pain, gastrointestinal conditions such as inflammatory bowel disease and irritable bowel syndrome, and developmental disabilities) providing a widely applicable set of illustrations for how systems can be strengthened to this end. However, there are several challenges which constrain health systems in Canada from being able to identify and fill gaps, while strengthening and taking steps to join up existing assets that can support rapid learning and improvement as it relates to specific conditions. These challenges can best be understood in the context of four inter-related issues:

1) opportunities for problem-focused rapid learning and improvement in health systems exist but are not always acted on;
2) some problems (or conditions) may not be prioritized or resourced centrally;
3) other system initiatives can detract from a focus on a particular problem; and
4) not all assets are in place nor are they well connected to enable problem-focused rapid learning and improvement.

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

- Element 1 – Identify existing assets and gaps in the characteristics needed for rapid learning and improvement for specific conditions
    - This element could include processes to map assets and existing connections (e.g., frameworks, asset-based approaches, gap analysis) and identifying windows of opportunity for problem-focused initiatives. While there are limited systematic reviews on the effectiveness of mapping assets, there are promising frameworks, approaches and key characteristics described in the literature. Growing roles and engagement of patients and family advisors, and strategic planning processes including the Strategy for Patient-Oriented Research (SPOR) networks are examples of potential windows of opportunity.
- Element 2 – Establish supports and integrate characteristics of a rapid-learning health system into a condition-specific programmatic approach
    - This element could include choosing strategies that can help strengthen existing assets and filling gaps based on the characteristics of a rapid-learning health system. The synthesized research evidence identified strategies that can help engage patients and improve their care experiences, identify opportunities to increase the use of timely data, and support the culture of rapid learning and improvement (e.g., integrating research into clinical practice, supportive leadership).
- Element 3 – Prioritize targets and establish accountabilities for rapid learning and improvement
    - This element could include prioritizing performance targets to evaluate the development and implementation of rapid learning and improvement, and assigning accountability for performance. There is a paucity of evidence on this element, but priority-setting practices and public reporting in combination with other initiatives appears promising.

What implementation considerations need to be kept in mind?

While potential barriers exist at several levels, the two biggest barriers lie in:

- re-orienting patients, providers, organizations and systems to a new way of setting targets, establishing accountabilities and, ultimately, measuring what 'success' looks like in Canada; and
- ensuring there is 'buy-in' among patients, providers, organizations and across the system, but also among elected officials who would collectively be committing to identifying, acknowledging and working to address a full range of problems in real time.

The most promising window of opportunity is the fact that the rapid-learning health system framework and related concepts are gaining traction across Canada at the national and provincial levels.

REPORT

Rapid learning and improvement is a systems-level approach that calls for partnerships between patients, care providers, researchers and policymakers that facilitate the real-time identification of challenges, and the development and implementation of solutions to improve care experiences and outcomes in ways that matter to patients. Creating a rapid-learning health system offers the potential to:

1) 'move the needle' for patients in their experiences and outcomes in rapid-improvement cycles;
2) enable data- and evidence-informed transformations at all levels of a health system;
3) motivate greater collaboration among, and enable greater impacts of (and returns on investments in) all elements of the research system; and
4) better leverage quality-improvement and other learning and improvement infrastructures operating at the interface between the health and research systems.(1)

Rapid learning can take place at all levels of a health system (self-management, clinical encounter, program, organization, local and provincial health authority, and government), however, there are at least two different 'ways in' to establishing and strengthening the characteristics required to support rapid learning and improvement. The first is through a focus on a local area (e.g., a region), which conceptualizes a rapid-learning health system broadly, cutting across all levels, sectors, conditions, treatments and populations within the area. The second is through a prioritized problem, which can be defined according to a specific:

- sector (e.g., a lack of capacity in long-term care);
- condition or category of conditions (e.g., cancer);
- treatment or category of treatments (e.g., prescription drugs); or
- population (e.g., elderly).

While it is likely optimal to approach rapid learning and improvement simultaneously through both 'ways in,' the opening of political windows of opportunity to do so can be unpredictable and more/less enabling of one approach compared to another. For example, recent reforms in Ontario have prioritized the reorganization of the system around local Ontario Health Teams, which are accountable for a defined population. In this example, a local-area focus (the first 'way in') more fully aligns with the current transformation (although within the local-area focus, teams may also need to consider whether and how a problem-focused approach to rapid learning and improvement can be used).

Box 1: Background to the evidence brief

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

The preparation of the evidence brief involved five steps:
1) convening a Steering Committee comprised of representatives from the partner organizations and the McMaster Health Forum;
2) developing and refining the terms of reference for the evidence brief, particularly the framing of the problem and three viable approach elements for addressing it, in consultation with the Steering Committee and a number of key informants, and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
3) identifying, selecting, appraising and synthesizing relevant research evidence about the problem, elements and implementation considerations;
4) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence;
5) eliciting citizens' insights about the issue in a citizen panel and integrating them into the brief; and
6) finalizing the evidence brief based on the input of several merit reviewers.

The three approach elements for addressing the problem were not designed to be mutually exclusive. They could be pursued simultaneously or in a sequenced way, and each approach element could be given greater or lesser attention relative to the others.

The evidence brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants' views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. A second goal of the stakeholder dialogue is to generate action by those who participate in the dialogue and by those who review the dialogue summary and the video interviews with dialogue participants.

In Canada, the second 'way in' to rapid-learning and improvement has tended to be the most common, often focused on a specific problem (e.g., hallway medicine) or condition. Examples include Alberta's Strategic Clinical Networks, which focus on improving healthcare delivery, enhancing patients' experiences, improving access and outcomes and increasing staff satisfaction, and reducing variability in care in 16 priority areas (e.g., maternal, newborn, child and youth; neurosciences, rehabilitation and vision; and digestive health, among others).(2) Other examples with a focus on a specific condition include the explicit adoption of a rapid-learning and improvement approach by the Ontario HIV treatment network as part of the "Endgame Strategic Plan to 2026,"(3) and a consideration of how the emergent findings from a randomized trial on how to improve access to and outcomes associated with care for heart-failure patients can provide an input into ongoing rapid-learning and improvement efforts.(4)

This brief will address the more commonly adopted 'way in' – problem-focused rapid learning and improvement – which will provide insights that have the potential for widespread applicability across the many problem-focused system initiatives currently unfolding in Canada. Furthermore, these insights will complement those that have emerged through recent work that has addressed the local-area focused 'way in' at the provincial level,(5;6) as well as at the pan-Canadian level.(1) We prioritize three separate conditions that will be used as illustrative examples throughout for how a problem-focused rapid-learning and improvement approach could be adopted. The three conditions are:

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

While the conditions differ substantially from one another they share the commonality of needing incremental improvements in an environment where they have not traditionally been prioritized to the same extent as many other conditions in the health system (such as cancer or heart disease). Further, these three conditions offer a unique breadth of perspectives that make them good examples that can be drawn on by policymakers, stakeholders and researchers focused on any other condition for which a rapid-learning and improvement approach could be adopted. In particular the unique perspectives provided by the conditions focused on in this brief include:

- a set of conditions for which a rapidly evolving and innovative research and treatment landscape will require an adaptive approach to ensure patients receive the best possible care (i.e., IBD and IBS where the emerging science around intestinal microbiomes have potentially dramatic implications for patient care and health systems);(7;8)
- a cross-cutting condition that has implications for many conditions across the entire health system and requires a multi-pronged approach to address (i.e., chronic pain); and
- a set of conditions that are complex, begin in early life, extend into adulthood and require coordination across sectors and across health and social systems (i.e., child development).

Box 2: Equity considerations

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

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

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

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

- youth from the ages of 14-26 who may be aging out of care designed for children and youth and into adult services.

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

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

Definition of a rapid-learning health system

The concept of a 'learning healthcare system' was originally developed by the U.S. National Academy of Medicine (previously called Institute of Medicine (IOM)). The concept has an analogue in what has been called 'radical incrementalism,' which couples small incremental policy changes that focus on improving cost-effectiveness with small-scale and tightly focused evaluations that identify which policy changes improved cost-effectiveness and warrant keeping.(9)

It was defined by the IOM as a system in which "science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience."(9) A recent search of the literature found no new definitions of a rapid-learning health system that went substantively beyond the original IOM definition.

There are five challenges to using this definition 'as is' in and across Canadian health systems:
1) it uses the language 'healthcare system' (at least in early formulations) and not 'health system' as is more commonly used in Canada and in most other countries (or health and social systems as may be more appropriate in the future as education, housing, social services and other sectors are increasingly engaged in efforts to improve health outcomes);
2) it speaks to a single system rather than the collection of systems, and their unique governance, financial and delivery arrangements that need to be considered when addressing each of these conditions;
3) it is silent on how improving the patient experience needs to be considered alongside the other parts of the 'triple aim' of a health system, namely improving population health and keeping per capita costs manageable (or of the 'quadruple aim,' which adds improving the provider experience);
4) it focuses primarily on the clinical encounter and not the full range of self-management, clinical encounter, program, organization, local and provincial health authority and government levels that are relevant across Canada; and
5) it uses some labels for the categories of the characteristics of a learning health system that are not commonly used in Canada, such as informatics instead of data, science instead of (research) evidence, and incentives instead of decision supports and governance, financial and delivery arrangements.

For the purpose of this evidence brief, we define a rapid-learning health system as the combination of a health system and a research system that is: 1) anchored on patient needs, perspectives and aspirations (and focused on improving their care experiences and health at manageable per capita costs and with positive provider experiences); 2) driven by timely data and evidence; 3) supported by appropriate decision supports and aligned governance, financial and delivery arrangements; and 4) enabled with a culture of and competencies for rapid learning and improvement.

We use the word 'patients' here to mean:
1) patients in the usual sense of those receiving care in the health system;
2) potential patients who need care, whether or not they are receiving it now;
3) families of and caregivers to these patients or potential patients;
4) citizens, by which we mean all Canadians – whether as taxpayers or voters or in other roles, and regardless of their formal citizenship status and whether they may also currently be considered a patient – who should have a voice in the rapid learning about and improvements in the health system; and
5) communities, by which we mean groups of citizens – whether defined by geography, lived experience with particular conditions or treatments (or health determinants), ethnocultural group or other factors – who should also have a voice in the rapid learning about and improvements in the health system.

We use the term 'improvement' not just in the sense of ensuring that care is increasingly safe and effective, but also in ensuring that care is increasingly patient-centred, timely, efficient and equitable. This broader definition of improvement, which was first developed by the IOM and later adopted by many quality councils in Canada,(10;11) includes addressing both underuse and overuse of healthcare.

Characteristics of a rapid-learning health system

In Table 1 below, we outline in detail the four categories and seven characteristics of a rapid-learning health system (and note that 'all levels' refers to self-management, clinical encounter, program, organization, local and provincial health authority, and government levels), which were developed and refined through a rapid synthesis, evidence brief and stakeholder dialogue focused on the province of Ontario, and a rapid synthesis focused on establishing this approach in health systems across Canada.(5;6;12) While these characteristics are the same for both local-area and problem-focused rapid-learning and improvement initiatives, choosing one 'way in' over another will change how those committed to supporting the approach will conceptualize the assets and gaps associated with each (and thus, the approaches needed to strengthen assets and fill gaps).

Table 1: Characteristics of a rapid-learning health system (RLHS)

Category	Characteristic	Examples
Patient-centred	**Engaged patients:** Systems are anchored on patient needs, perspectives and aspirations (at all levels) and focused on improving their care experiences and health at manageable per capita costs and with positive provider experiences	1) Set and regularly adjust patient-relevant targets for rapid learning and improvement (e.g., improvements to a particular type of patient experience or in a particular health outcome) 2) Engage patients, families and citizens in: a. their own health (e.g., goal setting; self-management and living well with conditions; access to personal health information, including test results) b. their own care (e.g., shared decision-making; use of patient decision aids) c. the organizations that deliver care (e.g., patient-experience surveys; co-design of programs and services; membership of quality-improvement committees and advisory councils) d. the organizations that oversee the professionals and other organizations in the system (e.g., professional regulatory bodies; quality-improvement bodies; ombudsman; and complaint processes) e. policymaking (e.g., committees making decisions about which services and drugs are covered; government advisory councils that set direction for (parts of) the system; patient storytelling to kick off key meetings; citizen panels to elicit citizen values) f. research (e.g., engaging patients as research partners; eliciting patients' input on research priorities) 3) Build patient/citizen capacity to engage in all of the above
Data and evidence driven	**Digital capture, linkage and timely sharing of relevant data**: Systems capture, link and share (with individuals at all levels) data (from real-life, not ideal conditions) about patient experiences (with services, transitions and longitudinally) and provider engagement alongside data about other process indicators (e.g., clinical encounters and costs) and outcome indicators (e.g., health status)	1) Data infrastructure (e.g., interoperable electronic health records; immunization or condition-specific registries; privacy policies that enable data sharing) 2) Capacity to capture patient-reported experiences (for both services and transitions), clinical encounters, outcomes and costs 3) Capacity to capture longitudinal data across time and settings 4) Capacity to link data about health, healthcare, social care and the social determinants of health 5) Capacity to analyze data (e.g., staff and resources) 6) Capacity to share 'local' data (alone and against relevant comparators) – in both patient- and provider-friendly formats and in a timely way – at the point of care, for providers and practices (e.g., audit and feedback), and through a centralized platform (to support patient decision-making and provider, organization and system-wide rapid learning and improvement)
	Timely production of research evidence: Systems produce, synthesize, curate and share (with individuals at all levels) research about problems, improvement options and implementation considerations	1) Distributed capacity to produce and share research (including evaluations) in a timely way 2) Distributed research ethics infrastructure that can support rapid-cycle evaluations 3) Capacity to synthesize research evidence in a timely way 4) One-stop shops for local evaluations and pre-appraised syntheses 5) Capacity to access, adapt and apply research evidence 6) Incentives and requirements for research groups to collaborate with one another, with patients, and with decision-makers *Note that for Indigenous peoples, this row would ideally be re-conceptualized to include traditional knowledge, however, more broadly the entire framework would need to be assessed by Indigenous leaders to determine if it adds value to Indigenous peoples-led approaches*

Category	Characteristic	Examples
System supported	**Appropriate decision supports**: Systems support informed decision-making at all levels with appropriate data, evidence, and decision-making frameworks	1) Decision supports at all levels – self-management, clinical encounter, program, organization, local health authority and government – such as a) patient-targeted evidence-based resources b) patient decision aids c) patient goal-setting supports d) clinical practice guidelines e) clinical decision support systems (including those embedded in electronic health records) f) quality standards g) care pathways h) health technology assessments i) descriptions of how the health system works
	Aligned governance, financial and delivery arrangements: Systems adjust who can make what decisions (e.g., about joint learning priorities), how money flows and how the systems are organized and aligned to support rapid learning and improvement at all levels	1) Centralized coordination of efforts to adapt a RLHS approach, incrementally join up assets and fill gaps, and periodically update the status of assets and gaps 2) Mandates for preparing, sharing and reporting on quality-improvement plans 3) Mandates for accreditation 4) Funding and remuneration models that have the potential to incentivize rapid learning and improvement (e.g., focused on patient-reported outcome measures, some bundled-care funding models) 5) Value-based innovation-procurement model 6) Funding and active support to spread effective practices across sites 7) Standards for provincial expert groups to involve patients, a methodologist, use existing data and evidence to inform and justify their recommendations 8) Mechanisms to jointly set rapid-learning and improvement priorities 9) Mechanisms to identify and share the ‘reproducible building blocks’ of a rapid-learning health system
Culture and competencies enabled	**Culture of rapid learning and improvement**: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability	1) Explicit mechanisms to develop a culture of teamwork, collaboration and adaptability in all operations, to develop and maintain trusted relationships with the full range of partners needed to support rapid learning and improvement, and to acknowledge, learn from and move on from ‘failure’
	Competencies for rapid learning and improvement: Systems are rapidly improved by teams at all levels who have the competencies needed to identify and characterize problems, design data- and evidence-informed approaches (and learn from other comparable programs, organizations, local areas about proven approaches), implement these approaches, monitor their implementation, evaluate their impact, make further adjustments as needed, sustain proven approaches locally, and support their spread widely	1) Public reporting on rapid learning and improvement 2) Distributed competencies for rapid learning and improvement (e.g., data and research literacy, co-design, scaling up, leadership) 3) In-house capacity for supporting rapid learning and improvement 4) Centralized specialized expertise in supporting rapid learning and improvement 5) Rapid-learning infrastructure (e.g., learning collaboratives)

Aim of this evidence brief

This evidence brief aims to inform deliberations about how to support the adoption of problem-focused rapid-learning and improvement initiatives. In doing so, the brief explores the overarching question of how to make the rapid-learning health system framework actionable in health systems across Canada, particularly in the context of a problem-focused approach (using the three conditions outlined above – GI conditions, chronic pain and developmental disabilities – as illustrative examples). It mobilizes the best available data and evidence on this topic, including the insights from the aforementioned rapid syntheses and evidence brief (which informed a stakeholder dialogue) on rapid-learning health systems, published by the McMaster Health Forum in 2018 and 2019, respectively.(5;6;12)

In the sections that follow we describe the range of challenges that exist in relation to problem-focused rapid-learning and improvement initiatives, and make the case that the approach is promising to address a range of challenges associated with particular conditions. Following this, we discuss three elements of a potentially comprehensive approach for addressing the challenges, providing those reading this brief with a 'road map' for operationalizing the approach for a select problem or condition. We conclude the brief with key implementation considerations associated with each element.

THE PROBLEM

Adopting a rapid-learning and improvement approach with a focus on a particular problem presents an opportunity for constant and iterative improvements in patient care and experiences for a range of conditions. However, there are several challenges which constrain health systems in Canada from being able to identify and fill gaps, while strengthening and taking steps to join up existing assets that can support rapid learning and improvement as it relates to many conditions, such as those that are the focus of this brief and those that share commonalities with them. These challenges can best be understood in the context of four inter-related issues:

1) opportunities for problem-focused rapid learning and improvement in health systems exist but are not always acted on;
2) some problems (or conditions) may not be prioritized or resourced centrally;
3) other system initiatives can detract from a focus on a particular problem; and
4) not all assets are in place nor are they well connected to enable problem-focused rapid learning and improvement.

Each of these issues are described in greater detail below.

Box 3: Mobilizing research evidence about the problem

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

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

Opportunities for problem-focused rapid learning and improvement in health systems exist but are not always acted on

In every health system across the country, there are many specific conditions for which a problem-focused rapid-learning and improvement approach would help to address challenges that stand in the way of ensuring patients receive the best care possible. However, despite this potential, opportunities to strengthen assets and fill gaps in the characteristics of a rapid-learning health system are rarely seized, and despite some examples across the country, the approach continues to be the exception rather than the rule. For example, each of the three illustrative conditions that are the focus in this brief face health-system 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.

For instance, for GI conditions such as IBD, Canada has among the highest prevalence in the world, with approximately 270,000 Canadians living with the condition today, and estimates indicating that by 2030 this number will grow to 403,000, or 1% of the population.(13) Direct medical costs associated with this condition have been estimated to exceed $1.2 billion each year, driven mainly by medications ($521 million per year), hospitalizations ($395 million per year) and physicians visits ($132 million).(14) The indirect costs to Canadian society (i.e., those outside of the health system) have been estimated at $1.5 billion and are mostly driven by lost work productivity, disability coverage and premature retirement or death.(15-17) Patients with GI conditions are known to have a reduction in quality of life, and often require ongoing medications, and in some instances, surgery.(18) Unfortunately, in Canada patients often have gaps in knowledge about their condition and how to self-manage, face challenges getting access to appropriate and timely primary and specialty care, and in urgent situations may rely on emergency departments.(19;20) Furthermore, participants at a stakeholder dialogue convened by the McMaster Health Forum in collaboration with the Inflammation, Microbiome & Alimentation Gastro-intestinal & Neuropsychiatric Effects (IMAGINE) network in 2018 concluded that health systems across the country have not established the appropriate financial and delivery arrangements that can contribute to better care integration, and ultimately better access to the services patients need most.

Similarly, when considering chronic pain in Canada – a chronic condition that cross cuts many others – it becomes clear that there are challenges for which a rapid-learning and improvement approach could be useful. In particular, many Canadians suffer from chronic pain, with most estimates of prevalence ranging from 15-29% of the adult population, however the prevalence of chronic pain is likely to increase as the population ages. Furthermore, chronic pain has been associated with the worst quality of life compared to other chronic diseases such as chronic lung or heart disease, with patients having double the risk of suicide compared to the national average. Moreover, much like IBD and IBS, chronic pain has broader implications outside of health, including leaving those with the condition less able to work (lower productivity and higher workplace absenteeism) while inhibiting their ability to manage activities of daily living.(21) It has been estimated that when adding both direct and indirect costs, chronic pain costs more than cancer, heart disease and HIV combined, with productivity costs related to job loss and sick days estimated at a national cost of $37 billion.(21) Health systems across the country have not made enough progress in integrating and ensuring patients have access to a range of non-opioid-focused approaches to managing chronic pain (e.g., biopsychosocial approaches, self-management interventions, and multidisciplinary care that includes psychological therapies), and there is a gap in leadership to drive forward ongoing cycles of learning and improvement to improve patient care and experience.(22) Furthermore, participants at a stakeholder dialogue convened by the McMaster Health Forum in collaboration with the Chronic Pain Network in 2017 collectively agreed that there have been few efforts to lead country- and system-wide initiatives that can support improvements in chronic-pain management based on stronger connections between relevant stakeholders and drawing on lessons learned from existing strategies that show promise.(23)

Finally, with respect to developmental disabilities, there are also many challenges which could be more readily addressed within health systems that adopt a rapid learning and improvement approach. First, there is significant variation in the terms used to diagnose development disability, with some definitions being focused on individual impairments while others take a needs approach or one focused on the child's environment. These definitions are particularly important in defining who is eligible for services, but also for understanding who the population is that needs care and examining how they use services.(24) The lack of consistent definition and up-to-date data about developmental disabilities means it isn't possible to develop an accurate national picture on the full extent of the burden developmental disabilities places on families and health systems in Canada. Furthermore, a lack of data makes it difficult to identify particular challenges as they arise (e.g., when a program or service designed to address a need associated with developmental disabilities isn't achieving its intended effects), to measure progress towards achieving goals that are set (e.g., improving access to an essential program or service), and to learn about and share with other health-system stakeholders insights about 'what works' to address particular challenges. Additionally, given the complexity of developmental conditions and the reality that they affect individuals across their life course, there is significant coordination needed between health and social services. Given these systems currently operate separately, there is a need to align governance, financial and delivery arrangements in health, education and social services to allow children and families to benefit from the services available. Not only will this require adjustments to who can make decisions, how money flows and the way in which services are organized, but it will further require explicit mechanisms that support collaboration across these different systems. Furthermore, appropriate transition planning and support is also essential, as children and youth become adults and then access services from different parts of these systems develop.(25;26)

While the above challenges have been framed as they relate to the illustrative conditions addressed in this brief, they are common across a wide range of conditions in Canada. Adopting a rapid-learning orientation, and in particular taking steps towards establishing new or strengthening existing assets across health systems in Canada, would provide an opportunity within the context of each of the conditions outlined above (and likely many other conditions) to address the challenges presented. For instance it could:

- ensure patients and their families are engaged and helping to identify the challenges that are most important to address (which is an important consideration for any condition, not just those outlined above);
- strengthen data systems and mechanisms for sharing data, while ensuring research is produced and available when needed to develop the most appropriate solutions to address these challenges (which would help address the challenges related to data availability and research production outlined above, a common challenge shared across many conditions);
- spur the development of appropriate decision supports such as clinical practice guidelines, quality standards and care pathways, which remain either poorly defined or out of date for all three of the conditions outlined above (as well as many other conditions);
- ensure systems are designed in ways that are conducive to addressing these challenges (e.g., through the establishment of collaborative governance models with clear lines of accountability for improving patient care and experiences, financial arrangements that facilitate cross-sectoral program and service delivery, and better integration of services); and
- foster a culture of collaboration and teamwork that is essential for the pursuit of condition-focused improvements that span sectors and systems (which is particularly important for developmental disabilities, but increasingly important in designing comprehensive care for a wide range of other conditions as well), and support the development of capacities to achieve this aim.

Some problems may not be prioritized or resourced centrally

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, with some of the most common in Canada being:

- cancer, which has its own sub-systems established in many provinces 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;
- heart disease, which is the second leading cause of death in Canada, 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), and associated with an annual economic burden of $28.3 billion (27); and
- mental health and addictions, which is increasingly front and centre in many health systems across the country, is the only specific condition which is profiled as a 'way in' to health data and indicators by the Canadian Institute for Health Information, and which has gained national-level prominence through the Mental Health Commission of Canada.

However, the reality is that for the vast majority of the conditions patients live with – including the three that serve as illustrations throughout this brief – it isn't possible to prioritize them as the focus of reform initiatives or investments. This makes it challenging to gain momentum for efforts such as strengthening and linking assets to promote problem-focused rapid learning and improvement. 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. (22) Furthermore, searching the Canadian Institutes of Health Research's (CIHR) Canadian Research Information System for a breakdown of grants and awards funded for each of the conditions, shows that compared to conditions like cancer (which has been allocated nearly $2 billion by CIHR) and heart disease (which was allocated close to $1.4 billion when including heart failure or other cardiac research), chronic pain, GI 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 health-system issues and conditions is the result of an interplay of factors such as those driving the agenda-setting processes (i.e., problems, policies and politics), as well as the institutional, interest-group related and ideational factors that affect how policy development and implementation unfolds. However, there are also a range of condition-specific challenges that affect whether they are prioritized as focal points for health-system strengthening efforts across the country. For GI conditions like IBD and IBS, a general lack of awareness and understanding of them across the country have resulted in them rarely being prioritized.(20) For example, there is uncertainty about what causes many GI conditions, confusion among non-specialist providers and patients about the differences between certain conditions falling under the GI umbrella, and stigma associated with some conditions which can detract from constructive conversations about how to move forward with efforts to improve care for patients.(20) Further, given some estimates have shown that close to two-thirds of the general population experience some form of GI symptoms each week (28), it could be that it is simply viewed as a 'regular' part of life, and not a priority for policymakers, stakeholders and researchers.

Prioritizing chronic pain in health systems 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.(23;29) One reason for this is because chronic pain is often framed as a comorbidity or symptom associated with many other conditions.(29) Additionally, comprehensive chronic-pain management is relevant to many policy portfolios spanning many sectors and conditions, and there are a number of concurrent treatments that may be considered,(29) which makes it a challenge to establish a 'centre of gravity' that can help to raise the importance of the issue on provincial and national agendas. For developmental disabilities, it is challenging to establish them as a priority for which decision-makers in health systems need to pay attention to given they include a wide range of diverse conditions (e.g., Down Syndrome, Fragile X Syndrome, fetal alcohol spectrum disorders, cerebral palsy, and other pervasive developmental disorders), all of which are driven by a complex array of determinants and associated with several health and social challenges, that require services and supports that span numerous sectors.(24) Similar to chronic pain, this context can make it difficult to establish clear lines of policy authority and accountability and, ultimately, ownership for prioritizing improvements in care.

Other system initiatives can detract from a focus on a particular problem

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 is structural reforms, including the landmark transformations 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), the centralization of the health systems in Alberta, Saskatchewan and Nova Scotia, as well as efforts to ensure universal access to a family physician in 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 are 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 packages of care for those suffering from chronic pain.(22;23) 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 with a range of developmental disabilities over their lifespan.

Not all assets are in place nor are they well connected to enable rapid learning and improvement

As outlined in the previous section of the brief, enabling rapid learning and improvement requires establishing, strengthening and connecting assets across four categories:

1. ensuring systems are patient-centred (e.g., through assets that ensure patients are engaged in setting priorities, designing services, etc.);
2. enabling data- and evidence-driven decision-making (e.g., through assets that facilitate the digital capture, linkage and timely sharing of relevant data, and the timely production of relevant research evidence);
3. ensuring assets are system supported (e.g., by aligning governance, financial and delivery arrangements in ways that facilitate rapid learning and improvement); and
4. establishing supportive culture and competencies (e.g., by ensuring there is 'buy-in' at all levels for rapid learning and improvement, and that key players have the right knowledge and skills to contribute to rapid learning).

For many conditions across Canada, the status quo is that despite assets in some of these areas, there are still many gaps, and this plays out similarly for each of the three conditions considered in this brief. For instance, assets exist for each condition in the first category of ensuring systems are patient-centred. This is mostly linked to Canada's Strategy for Patient-Oriented Research (SPOR), which has funded national networks related to each condition – the IMAGINE Network, Chronic Pain Network, and the CHILD-BRIGHT Network – that support the engagement of patients to help drive research that can inform decision-making and improve patient care and experiences in ways that matter most to them. Each network has dedicated resources and developed strategies specific to how patients can be engaged to improve research and care. Assets also exist for the second category related to enabling data- and evidence-driven decision-making. Specifically, the fact that the Cochrane Upper GI and Pancreatic Diseases (UGPD) Group is Canadian-based (at McMaster University) and led by those also engaged with the IMAGINE Network suggests that there are also assets in this category as it relates to timely production of research for GI conditions. However, for both chronic pain and developmental disabilities, no such centralized (and linked) research assets exist, and for all three conditions, challenges remain with respect to having the full scope of required data to inform rapid learning and improvement. Significant gaps also exist for all three conditions for the last two categories: ensuring assets are system supported, and establishing supportive culture and competencies.

Furthermore, for each of the three conditions (and more than likely for many others not considered here), there is a broad array of organizations and initiatives at the local, provincial and national level that intersect, but with no explicit mechanisms in place to promote alignment between each of their work (outside of the aforementioned SPOR Networks). While each of these organizations and initiatives can provide contributions towards improving the care provided for each of the conditions, establishing connections among them to support the development of a rapid-learning health system would help to consolidate efforts, improve long-term sustainability, provide opportunities to better define the roles of each individual group, and ensure the strengths of each group are acknowledged and used to complement the strengths of others – all in the interest of improving patient care and experiences. When connected, these assets can be used to draw attention to each of the conditions and support a collective call for prioritization of them within and across provincial and territorial health systems in Canada.

Additional equity-related observations about the problem

As noted in box 2, this brief gives particular attention to a group that can help to illustrate equity-related dimensions of the problem in the context of the three conditions: youth from the ages of 14 to 26 who may be aging out of care designed for children and youth and into adult services. This group was consistently identified by key informants across the three conditions as an area particularly in need of improvement, where there is significant potential to 'move the needle' for the health outcomes of young patients.

As many as 15% of youth in North America have a chronic condition such as the three identified in this brief that has an impact on their health and causes some limitation to their lives.(30) Children who have these types of conditions from birth, or develop them early in their childhood, are often partnered with a team of specialists working in pediatrics, however, as they age, adolescents are often required to transition out of child- and youth-specific services into adult services. These transitions have the potential to create a number of gaps where they may be left behind or receive sub-optimal care. These gaps may be created by changes in how services are governed, financed and delivered, as well as by significant differences in the mandate and functioning of pediatric care compared to adult services.

Transitions involve a number of professionals working within and between disciplines, all of whom are responsible for providing care to one individual. Care transitions are often discontinuous and not well coordinated given the range of professionals involved and their differing levels of experience working together. Notably, for each of these conditions, individuals require the support of professionals across sectors (at a minimum, primary care and specialty care) and for some individuals, different systems (health and social services), increasing the potential for gaps to take shape. In addition, transitions in governance and funding such as from the Ministry of Children, Community and Social Services and Ministry of Education to Ministry of Health, may result in additional complications.(31)

Throughout the transition, young people are increasingly responsible for their own care, which may require exercising skills that are not well refined, such as going to appointments alone, initiating discussions with providers, picking up medication, and at times advocating for services.(30) If not well supported, individuals may experience challenges receiving excellent care and may experience disruptions to their daily lives. Moreover, this transition in care takes place at a time in an individual's life that is often marked by a desire for social conformity which can be interrupted by significant changes in the care the individual is receiving, potentially resulting in additional stress or feelings of depression or isolation.(30)

Many organizations have developed programs to specifically support youths' transition from pediatric to adult health systems. Some examples at the provincial level in Canada include Community Living BC, which helps to transition those over the age of 19 with developmental disabilities from youth to adult services, the Good2Go program at SickKids, which has a similar mandate, and the Provincial Council for Maternal and Child Health in Ontario's development of transition guidelines.(32) However, these programs are often institutionally or regionally specific and may be difficult to scale across multiple jurisdictions.(33) One initiative at the national level – the Transition From Paediatric to Adult Health Care for Youth with Special Health Care Needs national guidelines developed by Children's Healthcare Canada – is a relatively recent attempt to provide guidance that aims to be applicable across jurisdictions.(34)

Significant literature (in addition to that cited above) about transitions and transition planning exists, and should be consulted when considering improvements in services for this age group. While providing a full review of that literature is beyond the scope of this brief, guiding goals from the Canadian Pediatric Society for transitional care include:
- adolescent involvement in management of the condition;
- adolescent and family understanding of the condition;
- understanding of personal potential for activity, education, recreation and vocation;
- completion of adolescent developmental tasks; and
- the attainment of self-esteem and self-confidence.(35)

Citizens' views about key challenges related to supporting rapid learning and improvement for select conditions in Canada.

One citizen panel – which engaged a diverse group of 12 citizens (in terms of age, gender, ethnocultural background and socio-economic status) – was convened in Hamilton (Ontario) on 17 January 2020. The panel consisted of panellists from five provinces (British Columbia, Alberta, Ontario, Quebec and Nova Scotia). Panellists were provided with a plain-language version of the evidence brief prior to the citizen panel, which served as an input into citizens' deliberations.

During the deliberation about the problem, citizens were asked to share what they perceived to be the main challenges preventing health systems in Canada from learning and improving rapidly about their condition. In responding, panellists identified a range of important challenges that were linked to their own care experiences. They were then prompted to reflect on whether and how these aligned with the four challenges related specifically to rapid learning and improvement outlined in the brief: 1) health systems are missing opportunities to learn and improve rapidly; 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. Overall, there was a high-level of consistency in the nature of the challenges raised, and broad agreement among the majority of participants regardless of which province they were from or which condition they had experience with. These similarities yielded more general and cross-cutting insights, rather than specific themes linked to a particular provincial health system or condition. Table 2 provides a summary of these reflections.

Table 2: Citizens' views about challenges

Challenge	Description
Health systems are missing opportunities to learn and improve rapidly	• Panellists identified a range of challenges that resulted in missed opportunities for rapid learning and improvement in health systems across Canada, anchoring their responses in how they understood rapid learning and improvement to play out in the context of their own clinical encounters (mostly with health professionals) and for the conditions they have personal experience with. • With respect to **engaging patients**, many panellists expressed their concern that it was difficult to access primary-care physicians and specialists in general, and that they often received inadequate or incomplete care that wasn't patient-centred when they were successful in accessing them (e.g., they are only able to "bring up one case or issue at a time" and physicians "don't want to hear about older issues" already considered dealt with). When prompted, some panellists indicated that the current situation meant it would be very challenging to ensure systems were consistently engaging patients in the fulsome manner required for rapid learning and improvement. • When considering how health systems were currently set up to facilitate **capturing and sharing relevant data,** a number of panellists voiced concerns with the fact that they were not aware of a central location for comprehensive information about patients that could be easily shared and communicated among providers and organizations (e.g., "I have hospitals that don't talk to each other"). This prompted many other panellists to express concern more generally about the lack of routine systems for collecting data about their care experiences and outcomes, and not enough effort to linking information across the entire health system. • In the discussion surrounding Canadian health systems' capacities with respect to **producing research evidence in a timely way**, some panellists perceived this as challenging to weigh in on due to the lack of clarity on how research was funded. Other panellists expressed concern about the lack of capacity and time available to access and apply research among their providers (and in particular, physicians) which could render timely research useless even if it was produced (e.g., this asks "doctors to go out of their way to keep up without extra compensation"). Some panellists mentioned that the health system requires a greater integration of research and clinical practice, and one emphasized the importance of local knowledge in rapid learning and improvement because "one solution doesn't fit all." • Many panellists identified a lack of **appropriate decision supports** for patients, and some described their challenges with accessing their own health information alongside relevant research

Challenge	Description
	evidence. A number of panellists explicitly noted that there was no single trusted source of information for their condition, or for patients more generally. • When expressing their viewpoint on **aligning governance, financial and delivery arrangements** to support rapid learning and improvement (e.g., who can make what decision, how money flows, and how the system is organized), many panellists perceived that the current health system is generally business-oriented and "only focused on the bottom line," which has contributed to inadequate patient care and a lack of accountability for achieving positive care experiences and outcomes. • With regard to **fostering a culture of rapid learning and improvement**, some panellists acknowledged that while there are existing organizations and other research groups that are developing a conducive and adaptive culture, there are still unknowns about the specific mechanisms on how to create these changes among patients, physicians, and across organizations in the system. Panellists also expressed that there isn't enough knowledge and expertise on rapid learning and improvement, or a widespread willingness among the full range of health-system stakeholders to actively engage in efforts to rapidly learn and improve. • Elaborating on the need for **building competencies** for all of the characteristics, one panellist was unclear about the current efforts around rapid learning and improvement, such as whether there is any existing funding, or any research institutes that are building in-house capacity and application of this approach. Another panellist explained that the two characteristics, fostering a culture of rapid learning and improvement and building the competencies for rapid learning and improvement, may first require strengthening the organization of their health system.
Some conditions are not prioritized by health systems	• Some panellists noted, and others agreed, that there is lack of timely research for conditions that are not considered a priority by health systems, and that there is a need for research on these conditions. However, most panellists acknowledged that not all conditions could be prioritized, and felt general discussions about how rapid learning and improvement could be supported are also helpful, as long as they take into consideration the unique challenges and needs of specific patient populations living with specific conditions.
Other initiatives can steer focus away from specific conditions	• When discussing initiatives that redirect focus away from specific conditions (including how to operationalize a rapid-learning and improvement approach to address challenges related to these conditions), there was consensus among the panellists that it is difficult for the health system to prioritize new issues in the face of existing and unresolved high-profile challenges (e.g., hospital overcrowding and wait times). Physicians and other health-system stakeholders were described by some panellists as having limited capacity to drive systemic change and improvements within this context, with one noting that it was important for systems to "get their house in order" to address the most pressing patient needs before trying to achieve broader learning and improvement goals. • Some panellists emphasized that political events and changing government priorities make funding for healthcare initiatives – including coordinated efforts to support strengthening assets for rapid learning and improvement for select conditions – unpredictable. Some panellists noted that the disparity in how much is invested in research and front-line care for some conditions compared to others illustrated this point.
Not all assets are in place or well connected to support health systems to learn and improve	• Panellists identified two critical areas that lack the assets required to support rapid learning and improvement: ○ gaps in health systems' capacity for digital capture, linkage and timely sharing of relevant data, with many panellists pointing to the lack of a central database to collect and capture information in some provinces; and ○ health-system delivery arrangements that could reduce the feasibility of creating rapid-learning health systems in Canada, with many panellists expressing a particular concern with the lack of human resources available to provide even the most basic care across health systems in Canada (using examples such as understaffing in hospitals, and the shortage of primary-care physicians to provide timely quality of care as key illustrations of this point).

THREE ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH FOR ADDRESSING THE PROBLEM

Many approaches could be selected as a starting point for deliberations about an approach for supporting problem-focused rapid learning and improvement for select conditions. To promote discussion about the pros and cons of potentially viable approaches, we have selected three elements of a larger, more comprehensive approach. The elements are:

1) identify existing assets and key gaps in the characteristics needed for rapid learning and improvement for specific conditions;
2) establish supports and integrate characteristics of a rapid-learning health system into a condition-specific programmatic approach; and
3) prioritize targets and establish accountabilities for rapid learning and improvement.

The three elements were developed and refined through consultation with the Steering Committee and key informants who we interviewed during the development of this evidence brief. These elements could be pursued separately or simultaneously, or components could be drawn from each element to create a new (fourth) element. They are presented separately to foster deliberations about their respective components, the relative importance or priority of each, their interconnectedness and potential of or need for sequencing, and their feasibility.

The principal focus in this section is on what is known about these elements based on findings from systematic reviews. We present the findings from systematic reviews along with an appraisal of whether their methodological quality (using the AMSTAR tool) (9) is high (scores of 8 or higher out of a possible 11), medium (scores of 4-7) or low (scores less than 4) (see the appendix for more details about the quality-appraisal process). We also highlight whether they were conducted recently, which we define as the search being conducted within the last five years. In the next section, the focus turns to the barriers to adopting and implementing these elements, and to possible implementation strategies to address the barriers.

Citizens' values and preferences related to the three approach elements

We included in the citizen brief the same three elements of a potentially comprehensive approach to address the problem as are included in this evidence brief. For the purpose of the citizen brief, the elements were re-worded to be more accessible to a group of citizens. These elements were used as a jumping-off point for the panel deliberations, in which the facilitator prompted

Box 4: Mobilizing research evidence about approach elements for addressing the problem

The available research evidence about elements of a potentially comprehensive approach for addressing the problem was sought primarily from Health Systems Evidence (www.healthsystemsevidence.org), which is a continuously updated database containing more than 8,750 systematic reviews and more than 2,760 economic evaluations of delivery, financial and governance arrangements within health systems. The reviews and economic evaluations were identified by searching the database for reviews addressing features of each of the approach elements.

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

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

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

panellists to consider their role in supporting the adoption and implementation of the elements. During the deliberations several values and preferences were identified from citizens in relation to these elements, which we summarize in Table 3. Similar to deliberations about problems, there was consistency and agreement among participants regardless of which province they were from or which condition they had experience with, which yielded general and cross-cutting insights, rather than specific themes linked to a particular provincial health system or condition.

Table 3: Summary of citizens' values and preferences related to the elements

Element	Values expressed	Preferences for how to implement the element
Identify strengths and weaknesses in health systems	• trusting relationship between patients and providers • collaboration among patients, providers and organizations within the health system • continuously improving • decisions based on citizens' values and preferences • empowerment • access • excellent patient experience	• Establish better supports for engaging patients to identify strengths and weaknesses in health systems: o create and increase access to tailored, visually appealing patient information through a variety of dissemination strategies (e.g., online, in-person, suggestion box in a clinic), that can build knowledge about and engagement in assessments of health systems (and assets and gaps related to rapid-learning health systems) o establish quality-improvement teams specifically tasked with gathering confidential patient feedback in order to assess patient experiences, as well as the extent to which they are engaged in care and efforts for rapid learning and improvement o invite citizens to share feedback about health-system strengths and weaknesses in a roundtable with physicians, managers, policymakers (e.g., through consultation, participation, or a combination of the two)
Build on strengths and address weaknesses to help health systems to learn and improve rapidly	• collaboration among patients, providers and organizations within the health system • decisions based on citizens' values and preferences • access • empowerment • continuously improving • excellent patient experience • fairness • efficiency	• Establish better supports for engaging patients to build on strengths and address weaknesses to help health systems to learn and improve rapidly: o invite citizens to share feedback about health-system improvement efforts in a roundtable with physicians and policymakers o provide patients with more opportunities to express their preferences for health-system improvement efforts during clinical encounters o systematize the collection of data and automate the transfer of patient-health information between clinics o create ways for patients and researchers to engage in the timely production of patient-oriented research o draw on patients' experiences to design appropriate decision supports, such as repositories of evidence-informed medical advice for managing their conditions, as well as sources of information about what those with their condition can expect (e.g., prognosis and available care options) o adjust health-system arrangements in ways that reflect the needs of patients (e.g., providing financial assistance for services that aren't covered to those in need, creating an alternative to emergency rooms for patients who seek medical care for non-life-threatening conditions after business hours, ensuring preventive care is prioritized and delivered to at-risk individuals)
Set targets to determine if health systems are making progress	• transparency • accountability • excellent patient experience • efficiency • access to care	• Establish mechanisms that ensure targets are meaningful to patients: o report targets that relate directly to improving patient care and experience (e.g., emergency-department wait times, access to care) o report patient health outcomes based on geography and health status

Element 1 – Identify existing assets and gaps in the characteristics needed for rapid learning and improvement for specific conditions

This element focuses on potential processes to identify existing assets and key gaps in the characteristics needed for rapid learning and improvement, which could be tailored to specific conditions. Such processes could help to mobilize stakeholders with priority setting, decision-making, and shared understanding of existing assets within the system. This element might include:
- engaging in processes to map assets and any existing connections (e.g., frameworks, asset-based approaches, gap analysis); and
- identifying political windows of opportunity with respect to problem-focused initiatives.

Mapping assets and any existing connections

We identified five systematic reviews relevant to identifying existing assets and key gaps; however, these reviews did not directly focus on rapid learning and improvement for specific conditions.

The authors of a low-quality systematic review developed a framework for asset-informed mapping, which includes the following steps: 1) define parameters of the mapping process; 2) identify services; 3) map services; and 4) consultation and implementation. Assigning a core team with strong leadership skills was identified as a facilitator in the development of monitoring and tracking progress with asset mapping.(36)

Additionally, two systematic reviews provided insight on how to identify assets, with one medium-quality review noting that it is critical to first specify the identified problem or condition,(37) while a low-quality review described three methods that can be used to identify assets: 1) assets identified through mapping, assessments, appreciative inquiry or interviews; 2) determining assets through interests, networks and settings; and 3) evaluating assets using qualitative or mixed-method approaches.(38)

The reviews expressed limited evidence on the effectiveness of asset mapping. A medium-quality systematic review described that while there are existing approaches to asset mapping, there is a need to define and standardize these techniques.(39) Similar sentiments are expressed in a low-quality systematic review which explores the adoption of a Learning Health System paradigm. The authors discovered that there are limited details or examples of implementation, thus a stronger focus on assessment and reporting is needed.(40)

'Windows of opportunity' for rapid-learning health systems

Pulling from our previous rapid synthesis on rapid-learning systems, some 'windows' were identified for the health system and generally across the conditions. These could include:
- growing roles and engagement of patient and family advisors;
- the re-configuring of pan-Canadian health organizations;
- growing use of the framework and concepts in health systems (e.g., B.C., Ontario and New Brunswick), including among supporting bodies (e.g., B.C. Academic Health Sciences Network and Canadian Health Services and Policy Research Alliance);
- growing capacity for responsive and timely health-systems research; and
- reorganization of regional health authorities (e.g., Saskatchewan and Northwest Territories).(12)

A summary of the key findings from the synthesized research evidence and primary studies is provided in Table 4. For those who want to know more about the systematic reviews contained in Table 4 (or obtain citations for the reviews), a fuller description for each is provided in Appendix 1. Appendix 2 provides more detail about the included primary studies. Appendix 7 provides more detail about the other types of documents (e.g., a rapid synthesis prepared on the topic) that were identified and that provide conceptual and theoretical insights about rapid-learning health systems included in Table 4.

Table 4: Summary of key findings from systematic reviews, other types of syntheses, and primary studies relevant to Element 1 – Identify existing assets and gaps in the characteristics needed for rapid learning and improvement for specific conditions

Category of finding	Summary of key findings
Benefits	• **Processes to map assets and any existing connections** o A rapid synthesis from the McMaster Health Forum explored assets and gaps in the development of Canadian rapid-learning health systems. Assets commonly described in the synthesis included: advisory committees and boards with patients and caregivers; data systems and repositories; funding for the development, evaluation and scale-up of new approaches to integrated services; and decision supports and community health assessments. The rapid synthesis described how asset mapping could be applied to different problem-focused initiatives, such as: 1) primary-care sector in Newfoundland and Labrador; 2) elderly population in Alberta; 3) opioid crisis in Quebec; and 4) Mississauga Halton region in Ontario.A fifth example was selected to illustrate where assets could be better connected (prescription drugs at the pan-Canadian level).(12) o A technical report discussed the LADDERS paradigm (leadership, alignment, data, demonstration, evaluation, replication, and sustainability) as an underpinning concept for learning health systems. The paradigm has been applied as a tool to different contexts such as program service delivery, evaluation, quality improvement, and research development, with shared success. The authors indicated that the generation of an "objective statement" with stakeholders for identifying the intended outcome as the key component to using the tool effectively. Some users indicated that the tool provided an iterative process to identifying gaps and fostering strategies to address the identified problem.(67) o A synthesis published by the International Union for Health Promotion and Education described an assets model for public health, which consists of: 1) generating an evidence base that identifies actionable steps to address the specific problem; 2) implementing these steps through asset mapping; and 3) developing measures and using evaluation frameworks to assess the effectiveness of the actional steps. The authors conclude that an asset model provides a beneficial opportunity to engage different stakeholders and empower the community.(73)
Potential harms	• None identified
Costs and/or cost-effectiveness in relation to the status quo	• None identified
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	• Uncertainty because no systematic reviews were identified o **Identifying political windows of opportunity with respect to problem-focused initiatives (although insights from a rapid synthesis were drawn on to inform our understanding of this sub-element)** • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review o Not applicable – no 'empty' reviews were identified • No clear message from studies included in a systematic review o **Engaging in processes to map assets and any existing connections** ▪ A medium-quality review described the heterogeneity of the results that made it difficult to draw conclusions about effective coverage metrics (37) ▪ Two low-quality reviews indicated that there is a lack of consistent, rigorous methodological research on asset-informed mapping, and therefore could not draw conclusions (36;40) ▪ A medium-quality review mentioned there is a large variation in definitions, interventions, and outcomes related to understanding assets (39)
Key elements of the policy option if it was tried elsewhere	• **Engaging in processes to map assets and any existing connections** o Despite the call for additional research, we found other syntheses that described processes to map assets, such as the development of health-system performance assessments, gap analysis, and the utilization of an in-DEPtH framework (evidence-

	informed, co-creation framework for the Design, Evaluation and Procurement of Health services).(41-44) For example, the review on the in-DEPtH framework described a multi-step approach to help inform priority setting and decision-making for complex interventions. This includes: 1) identifying a research question; 2) identifying health outcomes and search inclusion criteria; 3) utilizing quantitative and qualitative studies for meta-analysis and identifying facilitators and barriers respectively; 4) conducting assessments of outcomes and costs for the intervention; and 5) engaging in co-creation and gathering input from stakeholders via Delphi process to rank intervention features (i.e., first round based on level of patient benefit, second round based on implementation difficulties, and third round will be ranked by stakeholders).(44) o A primary study analyzed *I Am My Community*, a community-based asset-mapping initiative from the U.K. The authors indicated that it was important to define the relevance of the asset approach, and collaborate with existing initiatives that are involved with priority setting. Additionally, participants in this study indicated that there is greater awareness of local assets, and mutual sharing of skills and resources. The authors discussed a few limitations such as inadequate financial resources and time-intensiveness to recruit and retain staff related to asset-mapping exercises.(45)
Stakeholders' views and experience	• None identified

Element 2 – Establish supports and integrate characteristics of a rapid-learning health system into a condition-specific programmatic approach

This element focuses on establishing supports and integrating characteristics of a rapid-learning health system at a programmatic level. A programmatic approach may vary based on the resources and capacity available amongst those working within the area (e.g., technology, infrastructure, personnel, data-sharing agreements). Specifically, this element might include choosing strategies that can help strengthen existing assets and filling gaps based on some of the characteristics of a rapid-learning health system (e.g., engaged patients to improve care experiences, digital capture, linkage, and timely sharing of relevant data, supportive culture of rapid learning and improvements).

We did not identify any systematic reviews that directly focused on establishing supports and integrating characteristics of a rapid-learning health system at a programmatic level; however, we identified eight systematic reviews with findings that may relate to strengthening three of the seven specific characteristics of a rapid-learning system.

Engaged patients to improve care experiences

Four reviews described engaging patients and the public to improve care experiences. An older low-quality review found that citizen engagement increased citizens' interest and knowledge in different disciplines, and their likelihood of engaging in future forums for citizen involvement.(46) A recent medium-quality review that focused on patient-engagement strategies to help improve healthcare service design and delivery, reported improved quality of care from clearly defining patient-engagement roles, training patients and staff, prioritizing diversity, and involving organizational leaders.(47) Additionally, a recent medium-quality systematic review examined the effect of patient advisory councils and found some positive effects on patient satisfaction, healthcare staff attitudes and culture, and improved patient materials.(48)

An older medium-quality review identified strategies to integrate public values and health technology information on resource allocation decisions in healthcare. The authors reported different approaches for gathering public values, such as ranking of services or programs, Likert-type scales, Delphi processes, and focus groups. Overall, the review indicated that there is no one approach for establishing systematic priority-setting processes, but that it is important to involve stakeholders (e.g., decision-makers), ensure access to timely data as an input, engage staff including those responsible for information management, and consider existing models in other jurisdictions.(49)

Digital capture, linkage, and timely sharing of relevant data

An older low-quality review described data-driven improvements in long-term and home care, and reported difficulty in quality improvement due to high turnover and understaffed facilities, as well as limited opportunities for training.(50)

Supportive culture of rapid learning and improvement

Three systematic reviews were identified that described supporting cultures of rapid learning and improvement. An older low-quality review highlighted that organizational culture is important to creating positive structural changes, but could not determine the effectiveness of specific strategies.(51) A recent high-quality systematic review analyzed the evidence of integrating research culture into clinical practice, which uncovered key elements for success, including: 1) the need for high-level policies within the governance and organizational structures; 2) strong leadership to champion change; 3) available tools to promote a research culture; and 4) individual motivational and behavioural changes (e.g., research and communication skills, confidence).(52)

Additionally, an older low-quality review examined factors associated with large-scale system transformation in Saskatchewan. The authors of the review reported five overarching themes for success: 1) ensuring interest and collaboration from all levels of leadership (e.g., organizational culture, resource allocation); 2) utilizing short- and long-term goals to indicate progress (e.g., evaluative measures, stakeholder engagement); 3) identifying historical context for learning opportunities; 4) engaging physicians (e.g., professional development, disciplinary measures and incentives); and 5) engaging patients throughout the planning stages.(53)

In addition to the synthesized research evidence relating to the characteristics of rapid learning and improvement, we also found seven primary studies that describe key features and findings of the reported interventions.(54-60) Seven descriptive case studies that were relevant to supporting rapid learning and improvement were identified, drawing insights from experiences in several large U.S. health networks (e.g., Learning Networks Care Centres, Veteran's Health Administration) and describing emerging themes for programmatic implementation.(61-67) Full descriptions of the primary and case studies are provided in Appendix 4 and 6 respectively, however, some key findings from these studies include:

- the importance of 10 themes for operationalizing rapid learning and improvement: 1) alignment of learning with system strategic goals; 2) alignment of learning with incentives; 3) integrating cultural and operational silos; 4) balancing learning and work flow; 5) shifting the focus of learning from process improvement to improving outcomes; 6) addressing challenges in current healthcare environment that have an impact on learning; 7) balancing the need to execute and evaluate operational activities given limitations of evaluation methodologies; 8) supporting "make-or-buy" decisions for learning; 9) oversight of the research-quality improvement continuum; and 10) determining the costs and value of learning;(60)
- the core domains to instill into learning health system researchers, such as systems science, research questions and standards of scientific evidence, research methods, informatics, ethics of research and implementation in health systems, improvement and implementation science, and engagement, leadership and research management;(56) and
- five key facilitators to integrating rapid learning into a programmatic approach 1) visionary leadership or influence of a key individual; 2) adaptation to a changing healthcare landscape; 3) external funding; 4) regulatory or legislative influence; and 5) mergers or expansions.(59)

A summary of the key findings from the synthesized systematic reviews is provided in Table 5. For those who want to know more about the systematic reviews contained in Table 5 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 3.

Table 5: Summary of key findings from systematic reviews relevant to Element 2 – Establish supports and integrate characteristics of a rapid-learning health system into a condition-specific programmatic approach

Category of finding	Summary of key findings
Benefits	• **Engaged patients to improve care experiences** o An older low-quality review and a recent medium-quality review reported public engagement increases in patient interest and knowledge in different disciplines, and likelihood of engaging in future forums of citizen involvement, through defining patient engagement roles, training patients and staff, prioritizing diversity; and involving organizational leaders.(46;47) o A recent medium-quality systematic review examined the effect of patient advisory councils and found some positive changes in patient satisfaction, healthcare staff attitudes and culture, and improved patient materials.(48) • **Supportive culture of rapid learning and improvement** o A recent high-quality systematic review reported key elements for successful implementation of a supportive culture, including: 1) the need for high-level policies within the governance and organizational structures; 2) strong leadership to champion change; 3) available tools to promote a research culture; and 4) individual motivational and behavioural changes (e.g., research and communication skills, confidence).(52) o An older low-quality review reported five overarching themes for success in a large-scale system transformation: 1) ensuring interest and collaboration from all levels of

	leadership (e.g., organizational culture, resource allocation); 2) utilizing short- and long-term goals to indicate progress (e.g., evaluative measures, stakeholder engagement); 3) identifying historical context for learning opportunities; 4) engaging physicians (e.g., professional development, disciplinary measures and incentives); and 5) engaging patients throughout the planning stages.(53)
Potential harms	• None identified
Costs and/or cost-effectiveness in relation to the status quo	• None identified
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	• Uncertainty because no systematic reviews were identified o Not applicable • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review o **Supportive culture of rapid learning and improvements** ▪ An older low-quality review identified zero studies for inclusion, and was not able to draw conclusions on the effectiveness of strategies to change organizational culture.(51) • No clear message from studies included in a systematic review o **Engaged patients to improve care experiences** ▪ An older medium-quality review indicated that there is no systematic process for priority setting.(49) o **Digital capture, linkage, and timely sharing of relevant data** ▪ An older low-quality review described data-driven improvements in long-term and home care to be difficult due to high turnover and understaffed facilities, as well as limited opportunities for training.(50)
Key elements of the policy option if it was tried elsewhere	• None identified
Stakeholders' views and experience	• None identified

Element 3 – Prioritize targets and establish accountabilities for rapid learning and improvement

This element focuses on choosing measures to evaluate progress at the level of a specific condition, as well as in achieving maturity across each of the seven characteristics of a rapid-learning health system. In addition, a key piece of this element is to establish who (i.e., what individual or organization) will ultimately be held accountable for ensuring efforts are made towards rapid learning and improvement across each of the seven characteristics. This element might include:

- prioritizing performance targets to evaluate the development and implementation of rapid learning and improvement (both with respect to each condition overall and in terms of the level of maturity of each of the seven characteristics of a rapid-learning health system);
- assigning accountability for performance targets and rapid-learning efforts.

While we were unable to find any systematic reviews that provided evidence relating directly to either prioritization of performance targets or assigning accountability, we identified three systematic reviews where the findings may be relevant for pursuing this element.

One recent low-quality review proposed a framework for priority setting in healthcare at both the macro (system) and meso (organizational) levels. The review suggested that priority-setting practices should meet four conditions: stakeholder satisfaction with the process; stakeholder understanding of the process; tangible changes in prioritization rather than following historical decisions; and implementation of decisions.(68)

Two systematic reviews, one older medium-quality and one older low-quality review, examined the use of public reporting, which relates both to reporting of performance targets as well as maintaining accountability for meeting these targets. The first review found that public reporting was generally associated with improved measures in healthcare quality, finding evidence that it incentivizes healthcare workers to improve the quality of their services. However, the same review found little evidence that public reporting affects patients' decision-making or perceptions of care.(69) The second review provided more context to the use of public reporting as an accountability mechanism, finding that to be effective those using public reporting must be attentive to: its objectives (e.g., what is the goal of reporting?); the audience of the reports (e.g., citizens, decision-makers); and how information is being presented (with evidence showing that relatively short, visual presentations are preferred). The second review generally found similar results to the first, that there are a number of studies which show small improvements in quality of care, but that this approach is best coupled with other initiatives.(69;70)

A summary of the key findings from the synthesized research evidence is provided in Table 6. For those who want to know more about the systematic reviews contained in Table 6 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 5.

Table 6: Summary of key findings from systematic reviews relevant to Element 3 – Prioritize targets and establish accountabilities for rapid learning and improvement

Category of finding	Summary of key findings
Benefits	• **Prioritizing performance targets to evaluate the development and implementation of rapid learning and improvement** o One recent low-quality review proposed a framework for priority setting in healthcare and suggested that priority-setting practices meet four conditions: stakeholder satisfaction with the process; stakeholder understanding of the process; tangible changes in prioritization rather than following historical decisions; and implementation of decisions.(68) o The same review also identified seven procedural conditions for priority setting: stakeholder engagement; stakeholder empowerment; transparency; use of evidence; open to revisions; enforcement of determined priorities; and being grounded in community values.(68) • **Assigning accountability for performance targets and rapid-learning efforts** o One older medium-quality review found that public reporting was associated with improved measures in healthcare quality, however found little evidence that public reporting affects patients' decision-making process in selecting their healthcare providers.(69)
Potential harms	• None identified
Costs and/or cost-effectiveness in relation to the status quo	• None identified
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	• Uncertainty because no systematic reviews were identified o Not applicable • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review o Not applicable – no 'empty' reviews were identified • No clear message from studies included in a systematic review o **Assigning accountability for performance targets and rapid-learning efforts** ▪ One older low-quality review found no conclusive evidence about the impact of public reporting on increasing or improving accountability. ▪ The same review found that while public reporting may lead to improvements in quality of care, the extent to which this takes shape depends on the objectives, audience, content, product, and distribution of the reporting program.(70)
Key elements of the policy option if it was tried elsewhere	• None identified
Stakeholders' views and experience	• None identified

Additional equity-related observations about the three elements

The research evidence identified for each of the three elements did not provide specific equity-related observations about youth from the ages of 14 to 26 who may be aging out of care designed for children and youth and into adult services. The evidence included in the elements tended to focus on different approaches to advance problem-focused rapid learning and improvement. However, those moving forward with the implementation of a problem-focused rapid-learning and improvement approach should keep equity considerations in mind by, among other things, involving youth who may be transitioning between child and adult services in the identification of gaps, design of any new assets and the process of prioritizing performance targets.

IMPLEMENTATION CONSIDERATIONS

Several barriers might hinder implementation of the three elements of a potentially comprehensive approach to supporting rapid learning and improvement for select conditions (Table 7). While potential barriers exist at the levels of providers, organizations and systems (if not patients/citizens, who are unlikely to be aware of or particularly interested in the specifics of these approach elements), perhaps the two biggest barriers lie in:

- re-orienting patients, providers, organizations and systems to a new way of setting targets, establishing accountabilities and, ultimately, measuring what 'success' looks like in improving patient care and experiences for particular conditions in health (and social) systems in Canada; and
- ensuring there is 'buy-in' among patients, providers, organizations and across the system, but also among elected officials 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 (for which substantial measurable results may not be easily demonstrated within a single electoral cycle).

There are also several potential windows of opportunity that should be considered, despite these barriers (Table 8). However, the two most important are likely the fact that the rapid-learning health system framework and related concepts are gaining traction across Canada, and the opportunities for advocating for the adoption of new approaches at the pan-Canadian level in the wake of the recent federal election.

Table 7: Potential barriers to implementing the elements

Levels	Element 1 – Identify existing assets and gaps in the characteristics needed for rapid learning and improvement for specific conditions	Element 2 – Establish supports and integrate characteristics of a rapid-learning health system into a condition-specific programmatic approach	Element 3 – Prioritize targets and establish accountabilities for rapid learning and improvement
Patient/ individual	• Patients who have not been engaged in initiatives classified as assets (e.g., engaging patients for setting targets) for the particular problem for which they have experience or for which they have developed a particular interest may push back and disagree that an asset exists at all	• Patients may be hesitant to engage in problem-focused initiatives beyond those addressing a problem with which they have experience or for which they have developed a particular interest • Patients may be hesitant to engage in problem-focused initiatives for which understandable data, research and decision supports are not available, or for which they are not supported to develop appropriate competencies • Patient engagement that is meaningful hinges on significant time and inputs from patients, which may be challenging depending on an individual's health state (or the burden faced by caregivers)	• Patients may be hesitant to engage in prioritizing targets for problem-focused initiatives beyond those addressing a problem with which they have experience or for which they have developed a particular interest • Patients may not agree with system-level targets that are difficult to relate back to their individual experience (e.g., efficiency targets) • Patients may be hesitant to engage in prioritizing targets for problem-focused initiatives for which understandable data, research and decision supports are not available, or for which they are not supported to develop appropriate competencies • Patient engagement that is meaningful hinges on significant time and inputs from patients, which may be challenging depending on an individual's health state (or the burden faced by caregivers)

Levels	Element 1 – Identify existing assets and gaps in the characteristics needed for rapid learning and improvement for specific conditions	Element 2 – Establish supports and integrate characteristics of a rapid-learning health system into a condition-specific programmatic approach	Element 3 – Prioritize targets and establish accountabilities for rapid learning and improvement
Care provider	• Providers may disagree with assessments of gaps, particularly if framed in a way that implies they are not performing optimally in their clinical practice, or if they are engaged in initiatives they feel should be classified as an asset • Providers may disagree with assessments of initiatives as being assets, particularly if they have not been involved and don't see their value in the context of rapid learning and improvement	• Providers may be hesitant to engage in problem-focused initiatives where patients play a prominent role in 'moving the needle', and given financial arrangements may have already left them feeling overstretched • Providers may be hesitant to transition from using only the types of data, research and decision supports needed to inform their clinical decisions to the types of data, research and decision supports needed to support problem-focused initiatives • Providers may be hesitant to transition from learning and operationalizing the competencies required of their clinical roles to the types of competencies required to provide leadership to and support problem-focused initiatives • Providers may also be hesitant to embrace a model that could demonstrate that their provision of care can be improved	• Providers may be hesitant to engage in prioritizing targets and establishing accountabilities for problem-focused initiatives where patients play a prominent role in deciding on which needles need to be moved (particularly if they are made accountable for particular targets) • Providers may be hesitant to transition from prioritizing targets and being accountable for clinically relevant indicators to those that are relevant to supporting problem-focused initiatives at many levels of the system • Providers may not be able to reach consensus amongst themselves about the most meaningful targets, or who should be held accountable for meeting them
Organization	• Organizational leaders may disagree with assessments of gaps, particularly if framed in a way that implies they are not performing optimally, or if they are engaged in initiatives they feel should be classified as an asset • Organizational leaders may disagree with assessments of initiatives as being assets, particularly if they have not been involved and don't see their value in the context of rapid learning and improvement	• Organizational leaders may have not fully transitioned from sharing information and consulting with patients to more meaningful deliberation and empowerment in prioritizing what problem-focused 'needles to move' (in terms of the care experiences and outcomes that are priorities for rapid learning and improvement) and how to move them • Organizational leaders may view this approach as one that requires substantial investment (e.g., in infrastructure and analytic capacity)	• Organizational leaders may be hesitant to engage in prioritizing targets and establishing accountabilities for problem-focused initiatives where other stakeholders (including patients, providers and partner organizations) play a prominent role in deciding on which needles need to be moved (particularly if they are made accountable for particular targets) • Organizational leaders may be hesitant to transition from prioritizing targets and being accountable for indicators relevant to their own organization, to those that are shared across individuals, providers, and organizations in the system

Levels	Element 1 – Identify existing assets and gaps in the characteristics needed for rapid learning and improvement for specific conditions	Element 2 – Establish supports and integrate characteristics of a rapid-learning health system into a condition-specific programmatic approach	Element 3 – Prioritize targets and establish accountabilities for rapid learning and improvement
			• Organizational leaders may push back on particular targets they are accountable for, particularly if they require additional investments
System	• System leaders may oppose the assessment of assets and gaps, particularly if it is viewed as an external evaluation of performance	• System leaders may lack the types of data, research and decision supports needed to prioritize among problem-focused initiatives • Systems may not have the resources (e.g., technology, infrastructure and personnel), capacity, or supportive system arrangements (e.g., data-sharing agreements) to enable the linkage of assets in ways that could meaningfully support collaborative and integrated rapid learning and improvement • Systems may not have the time or resources to be able to initiate the establishment of the many required infrastructural supports in narrow windows of opportunity	• Systems may have well-established performance monitoring and improvement frameworks and infrastructure that are costly to transition away from if new targets and accountability structures are proposed

Table 8: Potential windows of opportunity for implementing the elements

Type	Element 1 – Identify existing assets and gaps in the characteristics needed for rapid learning and improvement for specific conditions	Element 2 – Establish supports and integrate characteristics of a rapid-learning health system into a condition-specific programmatic approach	Element 3 – Prioritize targets and establish accountabilities for rapid learning and improvement
General	• The rapid-learning health system framework and related concepts are gaining traction across Canada, including among supporting bodies, such as through CIHR's Institute of Health Services and Policy Research (IHSPR), the Canadian Health Services and Policy Research Alliance, (as well as provincially in Ontario through the SPOR SUPPORT network and in B.C. through the B.C. Academic Health Sciences Network) • The recent federal election has created opportunities for new approaches that could result in pan-Canadian health organizations supporting rapid learning and improvement more purposefully and in ways that are more synergistic with provincial initiatives • There is an increasing recognition across health systems in Canada about the key roles played by patient and family advisors, as well as the importance of data- and evidence-informed decision-making • The planned SPOR national data platform would permit benchmarking, the evaluation of natural experiments, as well as other national SPOR assets that could be aligned with a rapid-learning approach		
Element-specific	• The approach for mapping assets and gaps in the characteristics of rapid-learning health systems has been developed and piloted across Canada for a regional (i.e., provincial/territorial) focus, as well as a specific sector (primary care), and for a specific population (older adults) with provincial-level applications in Ontario for HIV, providing a tangible approach that can be adopted for chronic pain, GI conditions such as IBD and IBS, and developmental disabilities	• Two provinces have moved forward with operationalizing problem-focused approaches for specific conditions (a range of conditions in Alberta's Strategic Clinical Networks, and HIV in Ontario) providing insights about how to operationalize a rapid-learning health system for a specific condition	• Rapid-learning and improvement targets and accountabilities are increasingly aligned with the health-system goals established across provinces and territories in Canada

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APPENDICES

The following tables provide detailed information about the reviews identified (and, when applicable, single studies and reports identified). Each row in a table corresponds to a particular review (or study) and the reviews are organized by option element (first column). The focus of the review is described in the second column. Key findings from the review that relate to the option are listed in the third column, while the fourth column records the last year the literature was searched as part of the review.

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

The last three columns convey information about the utility of the review in terms of local applicability, applicability concerning prioritized groups, and issue applicability. The third-from-last column notes the proportion of studies that were conducted in Canada, while the second-from-last column shows the proportion of studies included in the review that deal explicitly with one of the prioritized groups. The last column indicates the review's issue applicability in terms of the proportion of studies focused on policy options to reduce or eliminate area-level price differences.

Appendix 1: Summary of findings from systematic reviews relevant to Element 1 – Identify existing assets and key gaps in the characteristics needed for rapid learning and improvement for specific conditions

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
Identifying methods of asset-informed mapping and developing a framework for this method (36)	In order to identify methods of asset-informed mapping, a literature search was conducted, and 10 articles were examined. The process of how to conduct asset-informed service mapping began with formulating a core team to drive the process. The subsequent steps in this process include identifying a team leader, the target population, and geographical boundaries, developing a plan for data collection, and degerming how the collected data will be used. However, limited details on the methods of asset-informed mapping was present in the studies. Furthermore, facilitators to the effectiveness of the core team included having a designated leader, ensuring frequent meetings, and establishing partnerships between members who have worked with one another previously. Ensuring that cultural considerations are taken into account when establishing a core team, and consistently tracking resources were also identified as facilitators within this process. No barriers were identified within the literature review. Informed by the review of the literature, a framework was developed for asset-informed mapping. This method was as follows: Stage 1 – Define the parameters of the service mapping process; Stage 2 – Identify services; Stage 3 – Map services; Stage 4 – Consultation and implementation. In conclusion, this review highlights the lack of rigorous methodological research on asset-informed mapping and proposed a framework to assist in developing an evidence base.	Not reported	4/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	Not reported in detail	Not reported in detail	Not reported in detail
Examining the key elements and steps of assessing	This review examined 18 studies, in order to examine the key elements and steps of assessing health-system performance through effective coverage metrics.	2017	5/9 (AMSTAR rating from McMaster	Not reported in detail	Not reported in detail	Not reported in detail	Not reported in detail

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
health-system performance through effective coverage metrics (37)	The intervention areas included child health, prenatal and antenatal care and delivery, and chronic conditions (hypertension, diabetes, hypercholesterolemia, vision disorders and cancer). Only four studies contributed findings at the health-system level, and the remaining 14 studies were related to specific intervention assessments. The quality-assessment strategies in the included studies were heterogeneous, and included bio-markers, self-reported surveys, records of disease-management programs, and statistical methods. Due to the diversity in the findings, the included studies could not be combined, the overall quality of the review was low, and the ability to draw conclusions on the outcome of interest – effective coverage metrics – was hindered. This review identified that the first step in implementing effective coverage as a performance assessment tool is the selection of interventions. Selecting specific interventions is known to be difficult and varies by setting, but it is recommended to consider burden of disease, affordable interventions and social priority when selecting interventions. Properly measuring intervention use and tracking intervention coverage over time to avoid biases was also identified to be a challenge. Avoiding relying primarily on administrative data, and integrating other complementary strategies was suggested as a strategy to improve measurement. Due to the variety and complexity of interventions in the health system, it is recommended that health outcomes are not measured using a single method. In conclusion, this study emphasizes that more studies are needed to contribute to the improvement of effective coverage efforts and strategies, and to improve the consistency of the findings. Further efforts should be directed towards strategies and frameworks that better measure the connection between coverage rates and intervention effectiveness.		Health Forum)				

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
Examining attempts to adopt the Learning Health System paradigm, with an emphasis on implementation and evaluating the impact on current medical practices (40)	The review examined 32 documents, including 13 studies, in order to examine the attempts to adopt the Learning Health System paradigm. A learning healthcare system is driven to generate and apply the best evidence for collaborative healthcare, while focusing on innovation, quality, safety and value. Patients are a major factor in this model of health provision, given the emphasis on collaboration and collective decision-making. This review examines the attempts to implement this model of medicine. The results of this review indicate that there has been very little action in terms of implementing learning health systems, despite a great deal of interest. It is possible that there is great trust placed in the learning health system without proper assessment of impact. This may have contributed to the low number of studies qualifying for inclusion in the review. A major focus should be placed on assessment and reporting, considering that many attempts to adopt this system of health have been attempted and not reported. Existing frameworks for assessing medicine applications can be used to assess the efficacy of learning health systems. Further, reporting of the evaluation of these systems must be comprehensive. Lack of consistency across studies diminishes quality and effectiveness and makes it difficult to assess outcomes. Taken together, the Learning Health System paradigm must be of central focus to researchers moving forward. While the central tenets of this approach are supported by researchers, there is a lack of assessment. The impact of such a system must be evaluated in order to boost adoption.	2015	3/10 (AMSTAR rating from McMaster Health Forum)	0/13	Not reported in detail	Not reported in detail	9/13
Assessing how asset-based approaches are operationalized when	This review examined 30 studies in order to assess how asset-based approaches are operationalized when adopted in interventions aimed at promoting health and reducing inequalities in local communities.	2017	4/9 (AMSTAR rating from McMaster	Not reported in detail	Not reported in detail	Not reported in detail	Not reported in detail

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
adopted in interventions aimed at promoting health and reducing inequalities in local communities (38)	Within the included studies, 18 interventions were targeted at people living in communities as a whole and the remainder were targeted at specific populations within the communities. This review proposed three main approaches to understand how assets are mobilized: 1) connecting existing assets; 2) raising awareness of assets; and 3) enabling assets to thrive. Connecting assets to existing assets refers to programs that recognize other organizations as assets and connect together to work and share resources. Raising awareness of assets refers to existing resources that are often underused, or which other community members are not aware of. Enabling assets to thrive refers to a processes where potential assets need further support to develop their potential. Within this review, eight interventions used the connecting existing assets approach, seven used the raising awareness of assets approach, three used enabling assets to thrive approach, and 10 used more than one approach. Using the obtained data, a framework was developed to highlight the key characteristics of asset-based approaches. In summary, assets should be identified through mapping, community engagement, needs assessments, appreciative inquiry or interviews. Planning which assets to use should be done so by examining interests, networks and settings. Assets should be applied in practice by connecting assets among themselves, raising awareness of available assets, or enabling assets to thrive. Outcomes of assets should be assessed at the individual, community or organizational level. Assets should be evaluated using qualitative approaches, or mixed-method approaches. This review is limited by the lack of inclusion of grey literature. It provided an overview of the key characteristics of interventions adopting an asset-based approach. The proposed framework can be used as a foundation when designing assets. Further research is needed to better		Health Forum)				

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	understand how asset-based approaches can support health promotion and reduce inequalities.						
Examining health assets from a global context both from a theoretical and methodological perspective (39)	This review examined 478 publications to provide an overview of health assets in a global context both from a theoretical and methodological perspective, and its applications to address inequalities and achieve sustainable health. A broad variety of health assets were identified. Within the included publications, 316 were included in a health context, 23 were community assets, 28 were individual assets, 43 were religious health assets, 15 were organizational assets, 11 were resilience assets, 28 papers focussed on asset mapping, three focussed on co-production, and nine assets were not clearly defined. A wide variety of interventions and approaches were implemented within the included publications. The most common interventions were education, training, asset mapping and asset approaches. Moreover, a large number of outcomes were also reported across the individual level, community level and organizational level. This review concluded that, globally, most authors referred to general health assets, assets, or community assets in relation to health. The idea of health assets focuses on health prevention and promotion, as opposed to curative approaches. However, due to the large variation in definitions, interventions and outcomes, future research should be directed towards defining and standardizing these assets, which will benefit policymakers and service commissioners.	2018	6/10 (AMSTAR rating from McMaster Health Forum)	11/478	11/478	Not reported in detail	Not reported in detail
Examining health-system performance assessments in the European Region to	This review examined all publicly available online resources and websites of ministries of health, national boards of health, and international organizations in order to determine which domains and indicators were used for measurement in health-system performance assessments. Fifty-three Member States within the European Region	2015	No quality rating tool available for this type of document	0/30	Not reported in detail	Not reported in detail	Not reported in detail

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
determine which domains and indicators were used for measurement (41)	were examined, however only 30 documents were published in English, and included in the analysis. The domains of service delivery (n=30) and improved healthcare (n=29) were covered by nearly all Member States, but the coverage varied for the other domains of information (n=10), medical products, vaccines and technology (n=14), financing (n=26), leadership and governance (n=12), access, coverage, quality, safety, responsiveness, social and financial risk protection, and improved efficiency. There was substantial heterogeneity in terms of the indicators assessed by each Member state, and in the number of indicators contained within each domain.						
Identifying developments in the field of health-system performance assessment relevant to the European context (42)	This review examined 75 websites in order to identify initiatives in health-system performance in the European Union. The synthesis of the initiatives obtained from the search resulted in a total of 64 activities, and four key institutions (Council of the European Union, World Health Organization European Region, European Commission and Organisation for Economic Cooperation and Development). It was determined, through the website search, that international agencies play an important role in the comparison of health-system performance across European countries. Furthermore, the most important data are the Organisation for Economic Cooperation and Development Health Statistics, and the World Health Organization Health for All database. Analytical work focused on the efficiency of healthcare systems also plays a significant role in international initiatives. Collaboration between organizations is integral to produce health-system performance assessments targeted at areas such as finance, health information and health profiles. In	2016	No quality rating tool available for this type of document	Not applicable	Not reported in detail	Not reported in detail	Not reported in detail

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	the future, efforts from these collaborations will be directed towards developing standardized indicators to assess health-system performance across all of the European Union. This review acknowledges the increasing importance of health systems in policy-making in Europe and beyond. However, coordination and collaboration are needed to improve standardization and ensure overall efficiency of ongoing activities.						
Examining the lessons that were learned when the Scalable Architecture for Federated Translational Inquiries Network and electronic health data network was implemented (43)	The Scalable Architecture for Federated Translational Inquiries Network and electronic health data network involved over 50 primary-care practices in three states in the United States. This case-study review performed three analyses to assess the market need and fit in order to inform the Scalable Architecture for Federated Translational Inquiries Network's sustainability planning. The three analyses that were performed were the Product Gap Analysis to better understand the competitive environment, the Strengths-Weaknesses-Opportunities-Threat analysis to examine the strategic market fit within the environment of competing health data alternatives, and the Customer Discovery for identifying the value proposition for target customers and partners. Approximately 150 stakeholders were involved in these analyses to assist in determining the sustaining value proposition for health services researchers, data partners and policymakers. It was determined that the three conducted analyses informed the sustainability strategy of the Scalable Architecture for Federated Translational Inquiries Network. The high-level product needs were similar between credible data, efficient and easy use, and relevance to daily work – which are three primary customer segments. Notably, how these benefits are demonstrated varies between customers and further evidence is required to accurately determine how to assess the differences.	2016	No quality rating tool available for this type of document	Not applicable	Not reported in detail	Not reported in detail	Not reported in detail

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	A limitation to this case-study review is that only a single electronic health data research network and team was used. These analyses should be repeated with other networks and organizations to improve generalizability and strengthen the findings. Ultimately, this review highlights that product-market fit assessments are essential elements for research teams. It suggests that two practical ways in which research teams can increase their capabilities for sustaining network value and health data tools are as follows: (i) actively develop and support a data science, clinical, and translational workforce that is knowledgeable about customer value; and (ii) fund and require customer discovery and value proposition as part of research.						
Description of the steps in the in-DEPtH framework to help inform priority setting and decision-making for complex interventions (44)	The in-DEPtH (evidence-informed, co-creation framework for the Design, Evaluation and Procurement of Health services) framework systematizes the incorporation of evidence, local context, and stakeholder considerations for priority setting. Specifically, the steps entail: 1) identifying a research question; 2) identifying health outcomes and search inclusion criteria; 3) utilizing quantitative and qualitative studies for meta-analysis and identifying facilitators and barriers respectively; 4) conduct outcomes and costs for the intervention; and 5) co-creation and input from stakeholders via Delphi process to rank intervention features (i.e., first round based on level of patient benefit, second round based on implementation difficulties, and third round will be ranked by stakeholders). The framework is based on a realist review approach, which allows researchers to identify contextual and relational factors for a specific intervention.	None identified	No quality rating tool available for this type of document	Not applicable	Not applicable	Not applicable	Not applicable

Appendix 2: Summary of findings from primary studies relevant to Element 1 – Identify existing assets and key gaps in the characteristics needed for rapid learning and improvement for specific conditions

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Examining the implementation and early results of a learning health system (58)	*Publication date:* 2016 *Jurisdiction studied:* U.S. *Methods used:* "Learn From Every Patient" model of care developed by key stakeholders and experts and implemented at Nationwide Children's Hospital in Columbus, Ohio	131 children with cerebral palsy	"Learn From Every Patient" model of care that integrated clinical care, quality improvement and research. One experimental group and two control groups were included in the study. Patients in the "Learn From Every Patient" group were assigned to a care coordinator who aided in navigation.	The development of a learning health system has been called for by the US Institute of Medicine. This model of system improves care while simultaneously reducing costs, through practices such as electronic health records, prioritization of translational research, and the control of expenditures. This model of care was found to reduce healthcare utilization and associated costs, results that were confirmed by comparison to two control groups. This model of care improved clinical care and efficiency while contributing to a dataset. The coordination of care contributed to the success of the "Learn From Every Patient" model. Research was fully integrated into the model in order to provide evidence for improvements in care and cost. A major focus of this study was cost and return on investment. The implementation of this model of care was cost-effective and may serve as a road map for other systems that wish to reduce costs while improving care. The authors point to several key features should other healthcare systems consider implementing a similar model of care. Clinicians must be engaged with research and evidence in order to address important questions in the field. Keeping clinicians invested requires ongoing monitoring of research questions. The implementation of this program required adaptation to new challenges and "culture change" as new settings and expectations were encountered. Data entry must be monitored by staff with time and expertise.
Describing the findings from a community-based asset-mapping exercise (45)	*Publication date:* 2015 *Jurisdiction studied:* U.K. *Methods used:* Qualitative design, utilizing theory of change to determine activities, mechanisms, and outcomes through semi-structured interviews with 11 stakeholders	Community health champions working with two community organizations to identify assets linked to the health and well-being of their neighbourhoods	"I am My Community" is an asset-mapping exercise, with the intention to generate an inventory of resources and capacities available within a community as a method for strategic planning and priority setting	There were two main findings from the study: 1) doing asset mapping; and 2) learning from the asset mapping. In terms of conducting an asset-mapping exercise, there was a strong focus on community strengths, and these were recorded in a questionnaire and through creative activities (e.g., pictures, quiz, local artists drawing pictures), but there was a steep learning curve with understanding how to conduct an asset-mapping exercise. Staff within community organizations played a role in designing the asset mapping and delivering the exercise to the community. The participants within the asset-mapping exercise highlighted a few limitations, including limited volunteers, inadequate financial resources, time-intensive, recruitment and retaining trained staff. There is a need for defining clear goals to asset mapping. Additionally, the evaluation reported a weak correlation between asset mapping and the use of its outputs. Strengths to asset mapping include greater awareness of local assets, and mutual sharing of skills and resources. Overall, the two main learning points involved clearly defining and understanding the relevance of the asset approach, and collaboration with existing initiatives that involves priority setting and decision-making.

Appendix 3: Summary of findings from systematic reviews relevant to Element 2 – Supporting rapid learning and improvement and integrating this into a programmatic approach

Focus of review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
Identifying different strategies that produce change in organizational culture and their ability to improve healthcare performance (51)	The authors assert that organizational culture, which can explain organizational systems and inform research, is imperative in producing positive change in healthcare performance. The specific way change in organizational culture can be produced is under-researched. Thus, the study aimed to identify the effectiveness of different strategies in facilitating change in organizational culture in healthcare. Ultimately, no studies were deemed suitable after appraisal, and the authors were not able to draw any conclusions regarding the effectiveness of strategies. Thus, the review suggests that more rigorous research is needed in this area.	2009	5/6 (AMSTAR rating from McMaster Health Forum)	1/2	Not reported in detail	Not reported in detail	Not reported in detail
Identifying strategies to integrate factors like public values and health technology information on resource allocation decisions in healthcare (49)	The review identified strategies to integrate public value and health technology information on resource allocation decisions in healthcare. The authors reported different approaches for gathering public values such as ranking of services or programs, Likert-type scales, Delphi process, and focus groups. Key informant interviews with decision-makers within the review showcased that there is no systematic approach to priority setting. Overall, the review indicated that there is no one approach for establishing systematic priority-setting processes, but that it is important to involve stakeholders (e.g., decision-makers), ensure access to timely data as an input, engage staff including those responsible for information management, and consider existing models in other jurisdictions.	Not applicable	6/9 AMSTAR rating from McMaster Health Forum)	2/68	Not reported in detail	Not reported in detail	Not reported in detail
Determining the strategies that are most effective at encouraging public engagement with healthcare programs and policies (46)	This review examined 34 published and grey literature documents that identified the effectiveness of a variety of interactive strategies in facilitating positive healthcare policy and program change. The synthesis classifies a method of citizen engagement in healthcare decision-making as an interactive public engagement strategy if it: 1) provides participants with information about a specific topic or	2009	4/9 (AMSTAR rating from McMaster Health Forum)	18/28	Not reported in detail	Not reported in detail	5/28

Focus of review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	problem; 2) provides participants a chance to engage in dialogue with each other and public engagement sponsors; and 3) delineates a specific process for receiving individual or collective input from participants. Specifically, the synthesis aimed to fulfil three main objectives. The first was to discern the current state of the literature regarding effective interactive public engagement in healthcare (paying special attention to rural populations, Canadian bilingual programming, and the determinants of health). The second was to critically analyze both the research available on interactive public engagement and the specific implementation tools identified for leaders of health services and systems. The third objective was to determine implications for further research. In addressing these questions, the authors found numerous results. Broadly, they found that interactive public engagement can be successfully applied in a number of ways to ultimately allow for informed citizen contribution to health decision-making. The extent to which different initiatives are successful, though, depends on different contextual variables, the most important of which are organizational characteristics and issue characteristics. It is imperative that public-engagement initiatives evolve in order to best address the contextual reality of issues. One study focused on the importance of examining broad social systems (political, economic, etc.) on citizen participation. The review asserts that public-engagement mechanisms should be modified depending on the issue, the type of topic, the groups of citizens engaged, the history, and the perceived relations of power. Citizen participants in well-designed public-engagement programs are generally satisfied with the communication of goals, the sufficiency of informational resources, and the deliberation process. The presence of group debate is vital to						

Focus of review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	participant satisfaction with the process. Most views of participants are malleable and likely to change throughout the engagement process (though this does not hold true for participants' most dominant values). One synthesis suggests that public engagement affects patients by increasing their interest and knowledge in different disciplines, the likelihood of engaging in future forums of citizen involvement, and trust in other citizens. The study also found that while literature has started addressing interactive public engagement more frequently, there are still very few publications that provide evaluation measures and criteria. In consulting grey literature, the authors noted that evaluation occurred in two main ways. Firstly was evaluation through procedural or process evaluation which looked at transparency, community reception and legitimacy. Secondly was evaluation through outcome evaluation, which examined increases in outcomes like quality of policy decisions and levels of social cohesion. In order to improve public engagement initiatives, the authors assert there is a need to discern a clear meaning of effective public engagement, identify a common set of evaluation criteria, and evaluate the effects of these initiatives on more outcomes of interest.						
Discerning the ideal frameworks through which patients can actively participate in the decision-making process of healthcare service design (47)	The review included 48 empirical qualitative, quantitative, and mixed methods studies that identified factors that facilitate positive patient engagement in healthcare service design and delivery, patient engagement outcomes, and trends in the experiences of patients involved in engagement initiatives. The review identified patient engagement strategies that were shown to optimally improve quality of care including: clear structure of patient-engagement roles; training sessions for patients and staff; prioritizing diversity; and involving organizational leaders. The review also examined factors that worked to facilitate a receptive context for patient	2016	7/10 (AMSTAR rating from McMaster Health Forum)	3/48	Not reported in detail	Not reported in detail	4/48

Focus of review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	engagement. Factors like the physical environment, location and dialogue-facilitation method were considered. The review also examined the outcomes of engaging patients to improve quality of care. Discrete outcomes identified included the development of educational materials, tools, policy and planning documents. Care process or structural outcomes identified included improvements to care process, service delivery and governance. Discrete outcomes primarily were associated with lower level of patient engagement (i.e., consultative), whereas care process or structural outcomes resulted from higher levels of patient engagement (i.e., co-design). Twelve of the 48 studies formally examined the experiences of patients within these patient engagement initiatives. Ten studies reported positive patient experiences and two studies reported negative patient experiences. Common positive outcomes for patients were increased self-esteem and empowerment, while negative outcomes cited were feelings of tokenism in patient-engagement initiatives.						
Examining the effect of patient engagement through patient advisory councils on clinical care outcomes and patient satisfaction (48)	The review addressed the primary aim of examining the impact of patient advisory councils on clinical care, patient safety and patient satisfaction, and/or the secondary aim of investigating the effect patient advisory councils have on healthcare changes, patient materials, and patient advisor satisfaction. The authors assert that the patient engagement at the clinic or organizational level is under-researched, and they did not identify any rigorous, prospective randomized controlled trials to include. They suggest it is important for the evidence base to grow so it includes more than just case-based studies. In examining their primary aim of examining clinical care, patient safety, and patient satisfaction outcomes, the authors noted that some studies showed success in knowledge	2015	7/10 (AMSTAR rating from McMaster Health Forum)	4/34	Not reported in detail	Not reported in detail	Not reported in detail

Focus of review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	translation of public-health messages, appointment accessibility, and patient satisfaction. The study's secondary question examined the effect of patient advisory councils on healthcare changes, patient materials, and patient advisor satisfaction. The review cited improvements in physical healthcare spaces, changing healthcare staff attitudes and culture, creating educational materials, and expanding clinical services. Ten of the case-based studies included suggested that patient engagement through an advisory council provided benefits to the patients' own experience.						
Examining how data from standardized resident or client assessments has influenced resident outcomes in long-term and home care settings (50)	This review examined 24 studies to gain insight on the influence of standardized resident or client assessments on residents in home care and long-term care. One of the most commonly used standardized resident or client assessments is the Resident Assessment Instrument (RAI), which has been available for use in the continuing-care sector for numerous years. The study aimed to address how RAI and other standardized assessment data has been used to improve the quality of continuing care, and whether the utilization of RAI and other standardized assessment data improved resident or other outcomes. Upon evaluating the 24 publications, the authors cited issues of high staff turnover, understaffed facilities, and limited staff training as contributing to the failures of improvement intervention. In care settings struggling with these sorts of issues, innovative strategies and research are necessary in determining a successful intervention strategy. The authors suggest that research on the optimal ways to encourage practitioners to use data must be conducted.	2008	4/10 (AMSTAR rating from McMaster Health Forum)	0/24	Not reported in detail	Not reported in detail	Not reported in detail

Focus of review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
Analyzing the evidence surrounding allied-health frameworks to determine which are best suited to facilitate the integration of research culture into clinical practice (52)	This review investigated 16 studies which provided frameworks to promote a culture of evidence-based research in allied-health practice. Allied health includes many health disciplines like physiotherapy, occupational therapy, exercise physiology, and speech therapy. As a definition, allied health inherently excludes doctors, nurses, midwives, dentists and complementary therapists. The authors note that in recent years more allied-health professionals are engaging in evidence-based care. The review aims to evaluate the literature on frameworks designed to enable the integration of a research culture in the allied-health disciplines. The study specifically examined frameworks to construct research capability, capacity and implementation. The study also took particular interest in frameworks that engaged at the systems and policy levels. This was important to ensure that research culture implementation is not solely done at the clinical level. The primary aims of the review were to identify current frameworks that construct research culture, and discern the elements necessary to integrate a culture of research in allied health spaces. Upon examining the 16 studies, the authors identified one overarching theme and four other themes. The main overarching theme asserted that high-level policies were necessary to facilitate the implementation of a research culture by organizations and leaders. The four secondary themes provided numerous other suggestions for enabling research culture in allied-health disciplines as follows: 1) regulatory environment, governance, and organizational structures played a large role in successful frameworks by implementing high-level policy and incentivizing individuals/organizations; 2) leadership and management figures with an organization must 'buy-in' to the program; 3) systems, tools, resources and time that are specifically	2017	8/10 (AMSTAR rating from McMaster Health Forum)	1/16	Not reported in detail	Not reported in detail	Not reported in detail

Focus of review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	designated for research are key in promoting a research culture; and 4) attributes of individual clinicians like research skills, communication skills, confidence, and motivation can increase the success of allied-health research culture change.						
Examining large system transformation to garner understanding of the role of government, factors that contribute to success, and potential barriers to transformation (53)	This review aimed to examine large-scale system transformation in the Saskatchewan health system, and thus examined literature on macro-level system transformation. Ultimately, the review identified five overarching themes in successful system transformation. Importantly, this review both consulted literature and collected personal experience and knowledge from those in the field. The first overarching theme identified asserted that for large system transformation in healthcare systems to work, both top system leaders and distributed leadership/personnel at other levels of the system needed to be committed to the change. This theme identified factors like organizational culture, funding/resource allocation, size of the system, and goals of the transformation as important in determining success. The second overarching theme suggested that reporting on the progress of systems transformation at both a short-term and long-term level is vital to facilitate successful transformation. The review cited factors like transparency, knowledge translation, integration of evaluative measures, and stakeholder engagement as important to consider. The third theme asserted that consulting historical context is valuable in increasing stakeholder engagement and evading oversights and mistakes. One study focused on the importance of examining past attempts at system change to	Not applicable	3/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not reported in detail	Not reported in detail	Not reported in detail

Focus of review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
	avoid past mistakes and help guide the internal and public framing for change. The fourth theme states that physician engagement is critical in successfully transforming a health system. This was important due to the relationship of physicians to other stakeholders, organizations and governmental agencies. To facilitate physician engagement, actions like incentive structures, professional development and disciplinary measures should be considered. It is also important that physicians are consulted and engaged within policy development. The final overarching theme states that patient engagement is vital in any transformation that wants to make the health system more patient-centred. Placing value on equity, prioritizing sustained engagement, and involving patients in the planning stages are imperative in strong patient engagement.						

Appendix 4: Summary of findings from primary studies relevant to Element 2 – Supporting rapid learning and improvement and integrating this into a programmatic approach

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Exploring the perspectives of health-system leaders on operationalizing the learning health system (60)	*Publication date:* 2016 *Jurisdiction studied:* U.S. *Methods used:* Interview conducted with health-system leaders	41 system leaders from clinical and administrative areas from Geisinger health system	In-depth interviews were conducted with 41 key informants of the Geisinger Learning Health System group. Participants represented a mix of functional areas from the health system. Interviews fostered open discussion on learning health systems.	The success of learning health systems, which emphasize the integration of learning across clinical, operational and research functions, relies on leadership from healthcare professionals. This project sought to gather perspective on learning health systems and learning activities from these leaders. Ten major themes were identified from the interviews: 1) alignment of learning with system strategic goals; 2) alignment of learning with incentives; 3) integrating cultural and operational silos; 4) balancing learning and work flow; 5) shifting the focus of learning from process improvement to improving outcomes; 6) addressing challenges in current healthcare environment that have an impact on learning; 7) balancing the need to execute and evaluate operational activities given limitations of evaluation methodologies; 8) supporting "make-or-buy" decisions for learning; 9) oversight of the research-quality improvement continuum; and 10) determining the costs and value of learning. The results of the interview suggested that leaders adopt a pragmatic approach to teaching and learning, and that efficiency can outweigh value. However, there was broad interest in receiving guidance in navigating the research quality-improvement innovation continuum. This study found that leaders continue to face challenges and opportunities in learning health system quality improvement. The results suggested that organizations must take an active role in this learning, and that responsibility must be shared across the system.
Examining residents' attitudes about quality improvement and their implications for an effective learning health system (54)	*Publication date:* 2017 *Jurisdiction studied:* U.S. *Methods used:* Focus groups conducted among residents of the neurology, physical medicine and rehabilitation, and emergency medicine departments at	45 residents at University of Utah School of Medicine	Focus groups were conducted with emphasis on the perceptions of quality improvement in learning healthcare systems among residents. Constructs were formed into themes following an iterative process.	This study aimed to understand resident attitudes about quality improvement in learning healthcare systems. Quality improvement is at the centre of learning health system growth, and thus should be of central importance to healthcare workers. Clinician engagement with quality improvement is key for the success of a learning health system. Overall, the results of this study suggest that there is an uncertainty and unsureness among residents in relation to quality-improvement initiatives. Five main themes emerged from discussions with residents: 1) understanding the vision is challenging; 2) there is confusion about the quality-improvement process; 3) residents did not feel valued; 4)

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
	the University of Utah School of Medicine			prioritizing quality-improvement work leads to overload; and 5) there are many positive aspects involved in quality-improvement work. Quality improvement should be central to the training of residents. The authors suggested a number of tactics to improve this process. Providing a mentored experience would guide resident learning, and incentivizing the process would reduce frustrations and confusion. Concerns about the dichotomy of business and clinical goals should be dissolved. Finally, successful quality-improvement strategies should be integrated into training and care.
Examining factors influencing the implementation of a system delivering clinical studies via a distributed electronic network linked to electronic health records (55)	*Publication date:* 2012 *Jurisdiction studied:* U.S. *Methods used:* The requirements for using electronic health records for clinical research were identified, followed by the development of a functional prototype of the software necessary for conducting this delivery of clinical studies	n/a	A functional prototype software delivering clinical studies via a distributed electronic network linked to electronic health records was designed. The barriers to adoption of this software were examined and considered.	Learning healthcare systems turn data into knowledge, use that knowledge to better inform practice, and create new data through advanced information technology. The Electronic Primary Research Care Network was a project aiming to use electronic health records to facilitate clinical research use. Three main requirements were identified in terms of facilitating clinical research using primary-care electronic health records: 1) identification of subjects from clinical data; 2) appropriate security and privacy controls; and 3) collection of clinical study data. In conducting this study, a number of problems and potential solutions arose. First, extracting coded data from an electronic health record leads to the loss and inaccuracy of data due to inconsistencies across the system. A potential solution to this is the uptake of standard clinical concept representations. Second, data extraction standards can be unwieldy. To remedy this, information-exchange standards should be adopted. Third, clinicians are rarely incentivized to maintain good data quality. A possible solution is the provision of clinical reasons for this data quality. Fourth, there are legal and ethical constraints when it comes to this form of research. There must be international consensus on how data can be linked without consent, and privacy-enhancing technologies should be adopted. Last, the benefits of these electronic systems remain foreign to researchers. Well-publicized deployments should be conducted.

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Competencies for learning health system researchers (56)	*Publication date:* 2017 *Jurisdiction studied:* U.S. *Methods used:* Iterative development process including a literature review, key informant interviews, a modified Delphi survey, and three expert panel meetings	197 articles were extracted for review 14 individuals were consulted for key informant interviews An expert panel of 19 members was consulted to develop definitions of competencies	In addition to a literature review, key informant interviews, a survey and expert panels were conducted to develop core competencies for learning health systems. The first phase of the study included the literature review, interviews and expert panel consultations. The second phase involved the panel drafting competencies. The third phase included drafting the final list of competencies with a final consensus-development meeting. The bulk of the work on core-competency development occurred in three meetings with a 19-member expert panel. This panel included individuals with expertise in fields such as statistics, epidemiology and patient-centred research.	Learning health systems combine research, data science and quality improvement. Through patient-clinician interaction, the quality and knowledge of the system are improved. This project defined competencies as “knowledge- or skill-based assets that trainees should acquire during their training.” The iterative development process resulted in the consolidation of seven key competency domains: 1) systems science; 2) research questions and standards of scientific evidence; 3) research methods; 4) informatics; 5) ethics of research and implementation in health systems; 6) improvement and implementation science; and 7) engagement, leadership and research management. Across these seven domains, 33 key competencies were identified. The authors intended these domains and core competencies to inform a framework for training programs for learning health systems researchers. The competencies stress the assets required to generate and apply evidence within health systems, and are intended to guide existing programs. The expert panel identified several skills that a research trainee should possess in order to succeed as a learning health system researcher. These skills, which should all relate directly to health services, include existing research competencies, and basic skills in epidemiology, biostatistics, clinical research, and behavioural and social sciences. Several characteristics of learning health system research were drawn out as having implications for researchers. First, this research must balance the need for rapid and practical evidence with the rigours of scientific standard – learning health system research may not need to meet the same demands as other medical research. Second, this style of research must be able to adapt to ongoing and rapid change. Third, health systems should be positioned to invest in this research, as it may not fit well with conventional funding opportunities.
Examining the implementation and early results of a learning health system (58)	Publication date: 2016 Jurisdiction studied: U.S. Methods used:	131 children with cerebral palsy	The “Learn From Every Patient” model of care integrated clinical care, quality improvement and research. One experimental group and two control groups were included in the	The development of a learning health system has been called for by the US Institute of Medicine. This model of system improves care while simultaneously reducing costs, through practices such as electronic health records, prioritization of translational research, and the control of expenditures. This model of care was found to reduce healthcare utilization and associated costs, results that were confirmed by comparison to two control groups. This model of

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
	"Learn From Every Patient" model of care developed by key stakeholders and experts and implemented at Nationwide Children's Hospital in Columbus, Ohio		study. Patients in the "Learn From Every Patient" group were assigned to a care coordinator who aided in navigation.	care improved clinical care and efficiency while contributing to a dataset. The coordination of care contributed to the success of the "Learn From Every Patient" model. Research was fully integrated into the model in order to provide evidence for improvements in care and cost. A major focus of this study was cost and return on investment. The implementation of this model of care was cost-effective and may serve as a road map for other systems that wish to reduce costs while improving care. The authors point to several key features should other healthcare systems consider implementing a similar model of care. Clinicians must be engaged with research and evidence in order to address important questions in the field. Keeping clinicians invested requires ongoing monitoring of research questions. The implementation of this program required adaptation to new challenges and "culture change" as new settings and expectations were encountered. Data entry must be monitored by staff with time and expertise.
Examining factors allowing a healthcare system to become a learning healthcare system (59)	*Publication date:* 2016 *Jurisdiction studied:* U.S. *Methods used:* Semi-structured interviews conducted with leaders from 25 leading healthcare systems	25 healthcare institutions Participants were recruited using purposive sampling, targeting institutions that were at the forefront of learning health systems change	Hour-long semi-structured telephone interviews were conducted with institutional leaders at 25 healthcare institutions. Interviews focused on the process of transitioning to a learning healthcare system and the ethical issues encountered.	The move to a learning healthcare system is supported, but limited guidance exists for institutions. This study interviewed leaders from 25 healthcare systems in order to understand the motivations for change, challenges, and strategies for success. The interviews resulted in five key themes that are essential to learning healthcare systems transformation, six challenges, and eight strategies to support transformation. The key themes described were: 1) visionary leadership or influence of a key individual; 2) adaptation to a changing healthcare landscape; 3) external funding; 4) regulatory or legislative influence; and 5) mergers or expansions. The main challenges described were: 1) organizational culture; 2) data systems and data sharing; 3) funding learning activities; 4) limited supply of skilled individuals; 5) managing competing priorities; and 6) regulatory challenges. The strategies that should be used to support transformation were: 1) strong leadership; 2) setting a limited number of organizational priorities; 3) building on existing strengths; 4) training programs; 5) "purposeful" design of data systems; 6) internal transparency of quality metrics; 7) payer/provider integration; and 8) academic/clinical integration within academic medical centres. The transition to a learning healthcare system is difficult. These findings should inform other institutions on the obstacles and keys to success for this transition.
Identifying ethical issues arising in the transition to learning health systems (59)	*Publication date:* 2016 *Jurisdiction studied*: U.S.	29 interviews were conducted with leaders within 25 healthcare institutions	Interviews were conducted with leaders from 25 healthcare institutions. Participants were sampled purposively, having been	The transition to a learning healthcare system brings a number of ethical considerations. Identifying these considerations is key to realizing the goals of a learning healthcare system. Interviews with leaders in the learning healthcare system yielded discussion of seven ethical challenges: 1) ethical oversight of learning activities; 2)

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
	Methods used: Semi-structured telephone interviews with participants recruited using purposive sampling, from institutions that were considered to be learning healthcare system leaders		considered leaders in the learning healthcare system.	transparency of learning activities to patients; 3) potential tensions between improving quality and reducing costs; 4) data sharing and data management; 5) lag time between discovery and implementation; 6) transparency to patients about quality; and 7) randomizations for quality-improvement initiatives. Progress will only be achieved if these key ethical issues are addressed. The results of this research suggested that institutions must ask leaders about ethical issues.

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Examining the development and refinement of a Learning Health Systems Training Program for resident physicians (57)	*Publication date:* 2016 *Jurisdiction studied:* U.S. *Methods used*: A Learning Health Systems Training Program was developed by course leaders, with emphasis on the overview of goals, followed by the concepts that comprise these goals The curriculum aimed to build analytical, informatics, and systems engineering skills	Internal medicine residents and sub-specialty fellows recruited based on interest and commitment to the program Six applicants formed the initial cohort, and eight trainees formed the second cohort representing a greater diversity of specialty backgrounds	The first-ever Learning Health Systems Training Program was initiated for resident physicians at Duke University. The development of this program involved a number of disciplines and was delivered over the course of a year in two-hour sessions every two weeks.	Learning health systems require the application and generation of medical knowledge. To achieve this, physicians must be engaged with information, quality improvement, and systems-based practice – skills that are often not taught. The researchers initiated a Learning Health Systems Training Program to address these shortcomings and build skills among resident physicians. The implementation of learning health systems requires organizational structure and support, and a highly skilled workforce. This training program emphasized skills including quality improvement, informatics, statistical reasoning, and systems engineering and systems-based practice. The majority of participants in the program report satisfaction, but only half of the participants felt that contact with mentors was adequate. Many participants expressed interest in remaining involved in the program. In reviewing the program, the researchers drew on early successes and challenges. Successes resulted from a supportive environment, expertise, enthusiasm and financial support. Challenges included irregular attendance, immature data and challenges with mentorship. These challenges have been identified and addressed, with authors pointing to solutions such as greater IT support, greater mentorship, and project quality improvement. Overall, this program demonstrated a great deal of success that has had significant health-system impact. The authors recognize that the program teaches toward an ideal system that has not fully taken form. Thus, ongoing evaluation and feedback must continue to inform curriculum and development.

Appendix 5: Summary of findings from systematic reviews relevant to Element 3 – Prioritize targets and establish accountabilities for rapid learning and improvement

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
Develop an evaluation protocol for healthcare priority setting in macro- and meso-level health systems (68)	This systematic review focused on two sets of literature: studies on priority setting in health systems, and theoretical studies on related topics. Thirty-one papers from the first set of literature were investigated. The authors advocated for frameworks of evaluation that draw from both consequentialist and proceduralist thought, which focus on the outcome and procedural aspects respectively. Commonly appraised outcomes using the consequential framework include stakeholder satisfaction, stakeholder understanding, allocation of resources, and implementation. Procedural approaches emphasize deliberative democracy, public argument, and incorporation of community values, amongst other elements. The authors suggest seven procedural conditions that are suitable for evaluation: stakeholder involvement, empowerment, transparency, revisions, use of evidence, enforcement, and incorporation of community values. In distributing scarce resources, the authors also emphasize efficiency should be balanced with equity considerations. The disconnect between evaluation theory and the literature on evaluating priority setting in health systems may limit the effectiveness of the authors' proposed framework.	2015	2/9 (AMSTAR rating from McMaster Health Forum)	17/31	Not reported in detail	Not reported in detail	Not reported in detail

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
Assess whether public reporting of surgeon outcomes can improve care quality or cause adverse consequences, and to determine how the evidence on public reporting of surgeon outcomes from other countries can predict outcomes of implementing this system in the United Kingdom (69)	Public reporting has been a widely used tool to measure the quality of healthcare providers and facilities, especially in the United States. The authors limited their search to primary reviews, but also searched articles that were referenced in those studies. The majority of the studies found that public reporting was associated with greater reluctance of surgeons to accept high risk patients. Some evidence suggested patients from non-white backgrounds may also experience reduced access to quality surgery. However, the evidence from literature is mixed regarding the strength of these associations. The largest effects of public reporting were observed amongst the lowest-performing providers, some of whom decided to cease their practice. To assess the transferability of evidence across different settings, such as in cross-country learning, many factors must be considered including those regarding the health system, surgeons, data, patients and organizations. Certain studies included in this review may have suffered from responder bias, evidenced from their low reported response rates. Social acceptability bias may have also masked some surgeons' true attitudes towards high-risk patients. Additionally, many studies did not provide control groups or suffered from missing data.	2016	6/10 (AMSTAR rating from McMaster Health Forum)	0/25	Not reported in detail	Not reported in detail	Not reported in detail
Determine whether public reporting could	The authors identified relevant articles published from 1980 to 2011 through database searches and included 198 studies in this review.	2011	7/10 (AMSTAR rating from	8/198	Not reported in detail	Not reported in detail	Not reported in detail

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the three conditions that are the focus of the brief (chronic pain, IBD and IBS, developmental disabilities)	Proportion of studies that deal explicitly with the prioritized equity group (youth aging out of care designed for children and youth into adult service)	Proportion of studies that focused on rapid-learning health systems
improve healthcare quality, affect behaviours of patients or healthcare providers, and have different impacts depending on the context of the public reports (71)	Generally, public reporting was associated with improved measures in healthcare quality. There was weak evidence that public reporting affects patients' decision-making process in selecting their healthcare providers. However, there was stronger evidence that public reporting incentivizes healthcare workers to improve the quality of their services. Studies rarely discussed how the characteristics and contexts of the public reports may have affected their implications. There was also limited research on the potential harmful effects of public reporting. One limitation of this review was the difficulty in adapting systematic-review methods to the multidisciplinary theme of public reporting that draws theories from many fields. For this reason, despite the large volume of articles studied, the authors acknowledge they may have failed to include other relevant research. Additionally, research on public reporting has traditionally focused narrowly on only a few public-reporting initiatives, which can limit the external validity drawn from conclusions made from the literature.		McMaster Health Forum)				

Appendix 6: Summary of findings from descriptive cases of rapid-learning health systems

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
Learning Networks care centres (72)	*Publication date:* 2018 *Jurisdiction:* U.S. *Level (e.g., national, regional, local)* National *Sector (e.g., cancer, mental health)* Various sectors	The network framework aligns participants around a common goal of improving health outcomes, transparency of outcome measures, and a flexible and adaptive collaborative learning system. Team collaboration is promoted by using standardized processes, protocols and policies, including communication policies, data sharing, privacy protection and regulatory compliance. Learning methods include collaborative quality improvement using a modified Breakthrough Series approach and statistical process control methods. Participants observe their own results and learn from the experience of others. A common repository (a 'commons') is used to share resources that are created by participants. Standardized technology approaches reduce the burden of data entry, facilitate care and result in data useful for research and learning.	There are numerous barriers to implementing the Learning Healthcare System vision, and collaboration can be difficult and expensive. Clinicians and patients must learn to engage with each other to coproduce healthcare services, and participants must learn how to share information and use their collective creativity and expertise to solve problems. Data need to be captured, readily available, and shared. Additionally, leadership and management of a Learning Network require a different style from more centralized organizational models. Unlike traditional healthcare structures, networks invite self-organization and individualized actions. Leadership takes place through influence. There may be little or no positional authority because the participants come from many different organizations.

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
Veterans Health Administration (61)	Publication date: 2017 Jurisdiction: U.S. Level (e.g., national, regional, local) National Sector (e.g., cancer, mental health) Various sectors	Key features of this learning healthcare system include: the provision of real-time access to knowledge; digital monitoring of the care experience; programs to develop engaged, empowered patients; salary plans that remove incentives based on volume of care; full transparency; a leadership-instilled culture of learning; and supportive system competencies.	Several takeaways from this program are presented to help inform the implementation of future systems: 1) big data needs to be augmented with deep data; 2) patient-centred metrics are needed to assess progress at the individual level; 3) real system improvement requires attention to all steps of the translation pathway; 4) translational researchers must be matched with clinical leaders; 5) spreading best practices requires a combination of top-down and bottom-up strategies; 6) better methods are needed to evaluate and learn from the numerous innovations occurring in clinical programs; 7) research and improvement efforts need better tools to reduce practice variation among facilities, clinics, and providers; 8) reducing variation will require better strategies to engage and assist low-performing sites; and 9) system improvement requires a focused set of performance measures

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
Indiana University Center for Healthcare Innovation and Implementation Science (62)	Publication date: 2015 Jurisdiction: U.S. Level (e.g., national, regional, local) Various levels Sector (e.g., cancer, mental health) Chronic care	Key features of this learning health system are: 1) effective sensors of its surrounding environment; 2) rapid bidirectional information transportation system; 3) knowledge storage system; 4) critical decision-making process using advanced analytics; 5) efficient, lean, and safe execution system; and 6) reliable data monitoring	In order to achieve its stated goals, the IUSM and the ICTSI have positioned faculty and other resources to provide strategic and operational assistance to its partner healthcare delivery systems in areas such as implementation science, systems redesign, healthcare effectiveness, health services research, and health information technology through the IU-CHIIS.
Washington State's Comparative Effectiveness Research Translation Network (63)	Publication date: 2014 Jurisdiction: U.S. Level (e.g., national, regional, local): Regional (Washington state) Sector (e.g., cancer, mental health): Surgery and transplantation	CERTAIN was initiated as a physician-led quality-improvement project and has emerged into a system which brings together hospitals and outpatient clinics across Washington state to leverage record-based data collection to link existing information with databases about patient function and quality of life. It has implications in vascular disease, spine surgery, gastrointestinal disease and urology. The CERTAIN network of clinical practice includes urban and rural settings, hospitals and outpatient clinics, as well as independent ownership facilities. Clinical cores focused on disease are involved where surgical or interventional techniques are options, and where there are important areas of clinical uncertainty	Patient stakeholders are involved in each phase of the CERTAIN network and data-collection process, however, their lack of participation in the decision-making process has been a barrier to implementation. Retention has also proven to be a challenge in Washington state, as patients' misconceptions about different types of clinical research and the times required for participation have been more problematic, leading to missing data and attrition bias in study results. Revenue streams from providing access to CERTAIN data was

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
			suggested as an opportunity for program sustainability and may help in its implementation in other jurisdictions
A person-centred, registry-based learning health system for palliative care (64)	Publication date: 2018 Jurisdiction: U.S. and Canada Level (e.g., national, regional, local) Not reported Sector (e.g., cancer, mental health) Palliative care	The learning health system coproduction model is centred around the partnership between the patient family and care team. Relying on an enriched information environment that includes "feed forward" patient-generated data available to clinicians in real time along with clinical/biomedical data, coproduction provides an ongoing record of a person's health status and associated treatments. The conceptual model is comprised of four inter-related subsystems: the person/family and clinician/care team service-delivery system; the patient-/family facilitated network system; the research collaboratory system; and the collaborative improvement network system.	Developing a palliative care registry-based learning health system could proceed in four phases: 1) team assembly and clarification of terms; 2) learn from existing models; 3) tailoring of general model to the palliative-care context; and 4) building of the learning health system using rapid cycle tests of change.

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
Collaborative Chronic Care Networks (C3Ns) (65)	Publication date: 2013 Jurisdiction: U.S. Level (e.g., national, regional, local): National Sector (e.g., cancer, mental health): Chronic disease	C3N is a network-based production system that harnesses the collective experiences of patients, clinicians and researchers to distribute the production of knowledge, information and knowhow for chronic-disease care. Progress measures and robust information-technology infrastructure help operating systems to reduce unwanted variation and rapidly adopt new practices. Pediatric working collaboratives and networks have made gains in care outcomes for children. Challenges of researchers not having enough information to treat specific population groups have been dealt with using the C3N program.	Transactional costs of time, money and effort can hinder the ability of organizations and researchers, physicians and patients from participating in C3N. A federated integrated IRB model was implemented in this program to ensure participating centres only need to rely on protocols approved through a central institutional review board. To mitigate challenges of academic norms (publishing for individual/institutional career advancement) have been dealt with using a "commons framework" which shares systematic, strategic, safe and informed patient information. Data sharing is conducted through federated databases to de-identify information and allow for easy informational access.
ImproveCareNow Network (66)	Publication date: 2015 Jurisdiction: U.S. Level (e.g., national, regional, local) Various levels Sector (e.g., cancer, mental health) Chronic care	A key feature of this learning health system involved the creation of EHR-based data collection forms. The automation of existing analytic reports enhanced their ability to store protected health information and track patient consent. A cohort identification tool was also deployed to support feasibility studies and hypothesis generation.	The process for creating EHR-based data collection forms requires groups to work individually with each vendor. A vendor-agnostic model would allow for more rapid uptake. The authors believe that interfacing network-based registries with the EHR would allow them to serve as a source of decision support. Additional standards are needed in order for this vision to be achieved, however.

Appendix 7: Summary of findings from documents exploring conceptual and theoretical underpinnings of rapid-learning health systems

Focus of document	Year of publication	Definition of learning health system	Key findings
Creating rapid-learning systems in Canada (12)	2018	No new definitions identified, but authors refer to the Institute of Medicine definition: a system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience"	The authors identified that there is no checklist for establishing a rapid-learning health system, but found that lists of assets are available for the primary-care sector and elderly population. The rapid synthesis highlights four examples that connect assets to rapid learning and improvement: 1) primary-care sector in Newfoundland and Labrador; 2) elderly population in Alberta; 3) opioid crisis in Quebec; and 4) Mississauga Halton region in Ontario. Windows of opportunity were identified with the current use of the rapid-learning system framework and concepts in health systems in British Columbia, Ontario and New Brunswick. Accreditation, interdependencies, and issue-based commonalities were identified as focal points to facilitate national collaboration on creating rapid-learning health systems.
Examining the LADDERS paradigm for planning, implementing, and evaluating sustainable change in learning health systems (67)	2018	None identified (although the author refers to the work of the Institute of Medicine)	Drawing from the implementation sciences, the author proposes the LADDERS paradigm for planning, implementing and evaluating sustainable change in learning health systems. The acronym stands for: Leadership, Alignment, Data, Demonstration, Evaluation, Replication, and Sustainability. This paradigm is a synthesis of those elements regularly cited by health-system leaders implementing successful transformational changes
Describing health assets and models from a public-health perspective (73)	2007	None identified	The authors utilize WHO European Office for Investment for Health Development definition for assets: "…resources that individuals and communities have at their disposal, which protect against negative health outcomes and/or promote health status…These assets can be social, financial, physical, environmental, or human resources." Health assets could include the following levels: 1) individual (e.g., social competence, social values, self-esteem); 2) community (e.g., family and friendship networks, community cohesion); and 3) organizational (e.g., environmental resources for physical, mental, and social health, employment, equity). The asset model consists of: 1) generating an evidence base that identifies actions to be taken; 2) how to effectively implement these actions through asset mapping; and 3) develop measures and evaluation frameworks to assess the effectiveness. Overall, the benefit of an asset model provides the opportunity for full participation of different stakeholders, shifting the perspective from a deficit model and moving towards empowering the community.

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