Rapid Synthesis

Creating a Rapid-learning Health System in Ontario

31 March 2018

Rapid Synthesis:
Creating a Rapid-learning Health System in Ontario
60-day response

31 March 2018

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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Timeline

Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business day timeframe. This synthesis was prepared over a 60-business-day timeframe. An overview of what can be provided and what cannot be provided in each of the different timelines is provided on McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response).

Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the rapid synthesis, however, the work of their organizations is frequently cited. The funder played no role in the identification, selection, assessment or synthesis of the research evidence profiled in the rapid synthesis, however, a staff member of the funder contributed as a co-author to its presentation.

Merit review

The rapid synthesis 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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KEY MESSAGES

Questions
- Three questions are addressed in this rapid synthesis:
  1) what is an Ontario-appropriate definition of, and set of characteristics for, a rapid-learning health system?;
  2) what assets and gaps exist in Ontario's health system that can be leveraged or addressed, respectively, in creating a rapid-learning health system?; and
  3) what 'windows of opportunity' can be capitalized on or created to stimulate the development and consolidation of a rapid-learning health system in Ontario?

Why the issue is important
- Creating a rapid-learning health system in Ontario offers the potential to:
  o enable data- and evidence-informed transformations at all levels of the health system, including the nascent Local Health Integration Network (LHIN) sub-regions, in ways that are more rapid, better sustained locally and more widely spread across teams, programs, organizations, LHIN sub-regions and LHINs (and thereby join up the different parts of the system so they work well together);
  o motivate greater collaboration among, and enable greater impacts of (and returns on investments in), all elements of the research system; and
  o better leverage the quality-improvement infrastructure operating at the interface between the health and research systems.

What we found
- We propose the following Ontario-appropriate definition of a rapid-learning health system: the combination of a health system and a research system that at all levels – self-management, clinical encounter, program, organization, LHIN sub-region, LHIN and government – 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. By patients we mean actual and potential patients, families and caregivers, among others. We also propose an Ontario-appropriate ordering and wording of the seven characteristics (in four categories) of a rapid-learning health system.
- Many assets can be leveraged and many gaps need to be addressed to create a rapid-learning health system in each of four levels or domains: 1) province; 2) LHINs (using Mississauga Halton as the example); 3) sector (using primary care as the example); and 4) category of conditions (using mental health and addictions as the example). Assets and gaps now need to be documented for other LHINs, sectors and prioritized categories of conditions – as well as for prioritized categories of treatments (e.g., prescription drugs) and health determinants (e.g., housing), and prioritized populations (e.g., francophones and Indigenous peoples) – while keeping in mind what's needed at self-management, clinical encounter, program and organization levels. Such assessments need to be updated periodically, and steps need to be taken to join up these assets and to address gaps. A rapid-learning health system in Ontario will almost certainly take the form of a great many, inter-connected rapid-learning health and social systems.
- Windows of opportunity to pursue such an agenda can be found in the health system (e.g., with the emergence of LHIN sub-regions, which create a natural focal point for rapid learning and improvement at the local population level), in the research system (e.g., with the possible renewal of the Ontario SPOR SUPPORT Unit and with the revitalization of the Health System Research Fund awards), and in the province's quality-improvement infrastructure (e.g., with Health Quality Ontario well positioned to create and host the mechanisms that support connections at multiple levels between the health and research systems).

QUESTIONS

Three questions are addressed in this rapid synthesis:
1) what is an Ontario-appropriate definition of, and set of characteristics for, a rapid-learning health system?;
2) what assets and gaps exist in Ontario's health system that can be leveraged or addressed, respectively, in creating a rapid-learning health system – in four levels or domains:
    a) province,
    b) Local Health Integration Network (LHIN), using the Mississauga Halton LHIN as an example,
    c) sector, using primary care as the example,
    d) category of conditions, using mental health and addictions as the example?; and
3) what 'windows of opportunity' can be capitalized on or created to stimulate the development and consolidation of a rapid-learning health system in Ontario?

For details about our approach to answering these questions, see **Box 1** and **Box 2**.

WHY THE ISSUE IS IMPORTANT

Ontario has both a health system and a research system that are increasingly putting patients and rapid learning and improvement at their centre. For the health system, a recent notable example of such efforts was the *Patients First Act 2016* which, among other things, mandated the creation of Patient and Family Advisory Councils at multiple levels in the health system,(4) the formalization of LHIN sub-regions as the focal point for local improvements to the patient experience, and the preparation of annual Quality Improvement Plans by many health organizations. For the research system, a notable example is the efforts by the Ministry of Health and Long-Term Care (MoHLTC) and the Ontario SPOR SUPPORT Unit (OSSU) to support the conduct and use of patient-oriented research.

Creating a rapid-learning health system in Ontario offers the potential to:
1) enable data- and evidence-informed transformations at all levels of the health system, including the nascent LHIN sub-regions, in ways that are more rapid, better sustained locally and more widely spread across teams, programs, organizations, LHIN sub-regions and LHINs (and thereby join up the different parts of the system so they work well together);
2) motivate greater collaboration among, and enable greater impacts of (and returns on investments in), all elements of the research system; and

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Box 1: Background to the rapid synthesis

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum's Rapid Response program. Whenever possible, the rapid synthesis 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 rapid synthesis does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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This rapid synthesis was prepared over a 60-business-day timeframe and involved four steps:
1) submission of a question from a policymaker or stakeholder (in this case, the Ontario Ministry of Health and Long-Term Care to inform the work of the Ontario SPOR SUPPORT Unit (OSSU) Renewal Executive Group);
2) identifying, selecting, appraising and synthesizing relevant research evidence about the question (and taking additional steps to complement this evidence, as outlined in box 2);
3) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence; and
4) finalizing the rapid synthesis based on the input of merit reviewers.

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3) better leverage the quality-improvement infrastructure operating at the interface between the health and research systems.

With the first five years of matched funding from the MoHLTC (through the Health System Research Fund) and the Canadian Institutes of Health Research coming to an end for the OSSU, an advisory body – the OSSU Renewal Executive Group – has been charged with assessing whether a case should be made to renew this funding for another five years. In doing so, the group has considered using the concept of a rapid-learning health system to identify how OSSU could leverage existing assets and address current gaps, particularly in the research system. Doing so requires an Ontario-appropriate definition of, and set of characteristics for, a rapid-learning health system, a documentation of existing assets and identification of current gaps, and the identification of 'windows of opportunity' that can be capitalized on or created to stimulate the development and consolidation of a rapid-learning health system. This rapid synthesis addresses this need.

WHAT WE FOUND

Definitions

We found no definitions of a rapid-learning health system that went substantively beyond the definition of a 'learning healthcare system' originally developed by the Institute of Medicine: 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."(5)

We noted four challenges to using this definition 'as is' in the Ontario health system:
1) it uses the language 'health care system' (at least in early formulations) and not 'health system' as is more commonly used in Ontario (or health and social systems as may be more appropriate in the future);
2) 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 like Ontario's, namely improving population health and keeping per capita costs manageable (or of the 'quadruple aim,' which adds improving the provider experience);
3) it focuses primarily on the clinical encounter and not the full range of self-management, clinical encounter,

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Box 2: Identification, selection and synthesis of research evidence and use of additional sources to complement this evidence

We identified research evidence (systematic reviews and primary studies) by searching Health Systems Evidence (www.healthsystemsevidence.org) and PubMed in February 2018. In both databases we searched for "learning health" and "system."

The results from the searches were assessed by one reviewer for inclusion. A document was included if it fit within the scope of the questions posed for the rapid synthesis, and specifically whether it:
1) provided a definition that goes beyond the standard Institute of Medicine (IOM) one;
2) operationalized the characteristics of a rapid-learning health system beyond the standard IOM characteristics;
3) examined what has been learned from empirical studies about the impacts of the characteristics taken as a whole or individually, and about factors that stimulated the development and/or consolidation of a rapid-learning health system; and
4) used these characteristics to document assets and identify gaps or to identify 'windows of opportunity' in a given health and research system (or level or domain within a health system, such as a LHIN, sector, category of conditions or treatments (or health determinants), or population).

For each systematic review we included in the synthesis, we documented the focus of the review, key findings, last year the literature was searched (as an indicator of how recently it was conducted), methodological quality using the AMSTAR quality appraisal tool (see the Appendix for more detail), and the proportion of the included studies that were conducted in Canada. For primary research (if included), we documented the focus of the study, methods used, a description of the sample, the jurisdiction(s) studied, key features of the intervention, and key findings. We then used this extracted information to develop a synthesis of the key findings from the included reviews and primary studies.

We complemented this search for research evidence with: 1) a review of a book about how the Ontario health system works (to identify assets and gaps);(1) 2) a review of an evidence brief and dialogue summary that we prepared about optimizing clinical practice in Ontario based on data, evidence and guidelines (to identify assets and gaps);(2; 3) 3) 28 key-informant interviews (to solicit feedback about, and to identify additional assets and gaps); and 4) five key-informant reviews of penultimate drafts of 'assets and gaps' tables.

program, organization, LHIN sub-region, LHIN and government levels that are relevant in Ontario;
4) it uses some labels for the categories of the characteristics of a learning health system that are not commonly used in Ontario, such as informatics instead of data, science instead of (research) evidence, and incentives instead of decision supports and governance, financial and delivery arrangements.

Accordingly we propose the following Ontario-appropriate definition of a rapid-learning health system: the combination of a health system and a research system that at all levels – self-management, clinical encounter, program, organization, LHIN sub-region, LHIN and government – 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. The concept of a rapid-learning health system at the government level 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 identifies which policy changes improved cost-effectiveness and warrant keeping.(6)

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;
4) citizens, by which we mean all Ontarians – 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 improvement of 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 improvement of 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 quality, which was first developed by the U.S. Institute of Medicine and later adopted by Health Quality Ontario,(7; 8) includes addressing both underuse and overuse.

Characteristics

We also found no set of characteristics of a rapid-learning health system, or labels for the categories of these characteristics, that went substantively beyond those characteristics originally described by the Institute of Medicine. We list these original categories and characteristics in the first two columns of **Table 1**.

We again noted many challenges to using these categories and characteristics, and even their ordering, 'as is' in the Ontario health and research systems. Accordingly we propose the following Ontario-appropriate ordering and wording of the four categories and seven characteristics (and note that 'all levels' refers to self-management, clinical encounter, program, organization, LHIN sub-region, LHIN and government levels).
1) Patient-centred
   a) 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
2) Data and evidence driven
   a) 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) alongside data about other process indicators (e.g., clinical encounters) and outcome indicators (e.g., health status)

b) Timely production of research evidence: Systems produce, synthesize, curate and share (with individuals at all levels) research about problems, improvement options and implementation considerations

3) System supported
   a) Appropriate decision supports: Systems support informed decision-making at all levels with appropriate data, evidence, and decision-making frameworks
   b) 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 (which includes performance management and accountability)

4) Culture and competencies enabled
   a) Culture of rapid learning and improvement: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability (and who allow and support learning from failure)
   b) 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, LHIN sub-regions and LHINs 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 (as well as to engage key constituencies, prioritize areas for improvement, and join up existing efforts)

We list these proposed new categories and characteristics in their original (IOM) order in the last two columns of **Table 1**.

Table 1: Characteristics of a rapid-learning health system

Original Institute of Medicine (IOM) categories	Original IOM characteristics	Proposed new labels (and ordering) for characteristics	Proposed new labels (and ordering) for categories
Science and informatics	**Digital capture of the care experience:** System captures the care experience on digital platforms for real-time generation and application of knowledge for care improvement	**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) (2a)	Data and evidence driven (2)
	Real-time access to knowledge: System continuously and reliably captures, curates, and delivers the best available evidence to guide, support, tailor, and improve clinical decision-making and care safety and quality	**Timely production of research evidence**: Systems produce, synthesize, curate and share (with individuals at all levels) research about problems, improvement options and implementation considerations (2b)	
Patient-clinician partnerships	**Engaged, empowered patients:** System is anchored on patient needs and perspectives and promotes the inclusion of patients, families, and other caregivers as vital members of the continuously learning care team	**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)	Patient centred (1)
Incentives	**Incentives aligned for value:** System has incentives actively aligned to encourage continuous improvement, identify and reduce waste, and reward high-value care	**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 (3b)	System supported (3)

	Full transparency: System systematically monitors the safety, quality, processes, prices, costs, and outcomes of care, and makes information available for care improvement and informed choices and decision making by clinicians, patients, and their families	**Appropriate decision supports**: Systems support informed decision-making at all levels with appropriate data, evidence and decision-making frameworks (3a)	
Continuous learning culture	**Leadership-instilled culture of learning:** System is stewarded by leadership committed to a culture of teamwork, collaboration, and adaptability in support of continuous learning as a core aim	**Culture of rapid learning and improvement**: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability (4a)	Culture and competencies enabled (4)
	Supportive system competencies: System constantly refines complex care operations and processes through ongoing team training and skill building, systems analysis and information development, and creation of the feedback loops for continuous learning and system improvement	**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, LHIN sub-regions and LHINs 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 (4b)	

While we did not find research literature that provided a definition of a rapid-learning health system that goes beyond, or that operationalized the characteristics of a rapid-learning health system in ways that went beyond the Institute of Medicine standard, we did find two systematic reviews and two qualitative studies that complement the above (see **Appendix Table B1** for more details):

- one low-quality systematic review examined attempts to adopt the rapid-learning health system paradigm, with an emphasis on implementation and evaluating the impact on current medical practices, and it identified three main themes:(9)
  - clinical data reuse (i.e., building learning health systems by extracting knowledge from geographically distributed data collected in daily clinical practice),
  - patient-reported outcome measures (i.e., using patient reporting mechanisms for collecting health-related quality indicators),
  - collaborative learning (i.e., using peer specialists for both capturing the indicators of healthcare delivery and encouraging changes through support/pressure);
- another low-quality systematic review examined the spectrum of ethical issues that arise in a rapid-learning health system and it grouped the 67 distinct ethical issues within four phases of the rapid-learning health system: (10)
  - designing activities: the risk of negative outcomes (e.g., reducing the quality and usability of results) from designing learning activities less rigorously so they are not classified as research, and the risk of inadequate engagement of stakeholders (which can affect the success of the learning activity due to a lack of established trust and support),
  - ethical oversight of activities: the conflict between current oversight regulations and a learning health system, which can delay or even prevent learning activities from being conducted due to confusion regarding which learning activities require ethical oversight, and an inconsistent and burdensome oversight process,
  - conducting activities: risks of misguided judgments regarding when and how participants should be notified and asked for consent, and the conflict between current data-management practices and regulations, and the goals of a learning health system,

- o implementing learning: difficulties with changing practice in a timely manner (e.g., due to conflicts with the current research infrastructure or current financial incentives), issues of transparency (e.g., due to underperforming providers or commercial interests), and unintended negative consequences from implementation (e.g., widening health disparities or increasing the risk of liability);
- the same review identified three types of strategies to address these ethical issues:(10)
  - o clear and systematic internal policies and procedures to determine which learning health system activities require ethical review, how data sharing and data protection should be handled, and how to inform patients in routine and systematic ways about learning health system activities being conducted,
  - o training and guidance for ethics committee members to learn how to apply ethical principles in the context of learning health system activities, and for researchers to learn about ethics guidelines,
  - o simplified ethical review and consent process to make it easier for learning health system activities to be conducted, including implementing dedicated ethical review process, standardizing and harmonizing the ethical review process across multiple research sites, and streamlining the consent process;
- one qualitative study identified seven ethical issues arising in the transition to learning health systems:(11)
  - o ethical oversight of learning activities (i.e., distinguishing which learning activities should go to an ethics review board),
  - o transparency to patients about learning activities (i.e., determining whether and how to disclose information to patients about ongoing learning activities),
  - o potential tensions in improving quality and reducing costs (i.e., concern that moving toward continuous learning is not always in the financial interest of organizations),
  - o ethics of data sharing and data management (i.e., potential implications of sharing electronic data for patient privacy),
  - o lag time between discovery and implementation (i.e., recognition of shortcomings of the current system in both identifying and implementing evidence-based practices),
  - o transparency to patients about quality (i.e., determining whether and how to inform patients about underperforming providers or groups),
  - o ethics of randomization for care and quality-improvement initiatives (i.e., concern that randomizing individuals to the placebo arm might fail to provide them with potential benefits); and
- another qualitative study identified six sources of learning, including intelligent automation, clinical decision support, predictive models, positive deviance, surveillance, and comparative effectiveness research.(12)

We also did not find particularly germane evidence about the impacts of the characteristics taken as a whole or individually, or about factors that stimulated the development and/or consolidation of a rapid-learning health system, however, we did find two systematic reviews (see **Appendix Table B2** for more details) and a number of primary studies (see **Appendix Table B3** for more details) that spoke to aspects of these issues:

- one high-quality systematic review found a lack of evaluative research about the capacity of human-resource information systems (i.e., systems dealing with the management of human resources, such as recruitment, teaching, planning and resource allocation) to enable learning health systems;(13)
- one low-quality systematic review examined attempts to adopt the learning health system paradigm, with an emphasis on implementation and evaluating the impact on current medical practices, and found minimal focus on evaluating impacts on healthcare delivery and patient outcomes;(9)
- one study examined factors allowing a health system to become a learning health system:(14)
  - o five themes emerged about the process of transitioning towards a learning health system: 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,
  - o six challenges emerged: 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,
  - o eight strategies were identified to support transformation: 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) within academic medical centres, academic/clinical integration;

- one study identified four key factors supporting the successful implementation of a rapid-learning health system: 1) clinician engagement with primary research and existing research evidence; 2) ongoing collection of robust data; 3) flexibility of the model in order to adapt to new challenges; and 4) culture change;(15)
- one study identified six principles to advance an organization's learning capabilities, as a core element of a rapid-learning health system: 1) draw on the wisdom of groups and value connections; 2) embrace sense-making over decision-making in dealing with the unexpected; 3) bring diverse perspectives to complex challenges; 4) animate people, provide direction, update regularly, and interact respectfully; 5) appreciate the power and ubiquity of emergent change and the limitations of planned change; and 6) concentrate on small wins and characterize challenges as mere problems;(16)
- one study revealed that implementing a mechanism to share data and research evidence (via electronic health records) may not be sufficient for creating a rapid-learning health system, and the study identified:(17)
  - four key barriers for the timely sharing of data and research evidence via electronic health records: 1) different electronic health record systems do not record clinical data items consistently; 2) providers are rarely incentivized to maintain good data quality on the basis of research use alone; 3) legal and ethical constraints in many countries limit linkage of data and its use for research without consent; and 4) researchers are largely unaware of potential benefits offered by electronic systems to support research, and do not therefore create demand for wider deployment,
  - four solutions to address these barriers: 1) promoting the mandatory adoption of information-exchange standards for the exchange of data across electronic health record systems; 2) provide good clinical reasons for data quality and detailed record keeping (e.g., audit or decision support); 3) promote international consensus as to how and when data can be linked without consent, and develop systems for managing consent to extraction or study participation across systems; and 4) conduct well-publicized pilot deployments and evaluations;
- one study explored the perspectives of health-system leaders regarding the operationalization of a rapid-learning health system and identified 10 themes related to operationalization: 1) align the learning infrastructure and learning health system activities in support of the system's strategic goals; 2) align learning with employee incentives; 3) integrate cultural and operational silos; 4) balance learning and work flow; 5) shift the focus of learning from process improvement to improving outcomes; 6) address challenges in the current healthcare environment that have an impact on learning; 7) balance the need to execute and evaluate operational activities given limitations of evaluation methodologies; 8) support 'make-or-buy' decisions for learning (e.g., build an application or learning tool in house versus purchase the product from a vendor); 9) integrate the oversight of the research-quality improvement continuum; and 10) determine the costs and value of learning (i.e., not adding additional costs to the health system through operationalizing the learning health system);(18)
- one study examined residents' attitudes about quality improvement, which may have implications for the implementation of rapid-learning health systems, and it identified four barriers to residents' participation in quality-improvement initiatives: 1) challenges with understanding the vision of quality improvement; 2) confusion about basic aspects of quality improvement; 3) the perception that residents' contributions to quality improvement are not valued/valuable to the quality-improvement process; and 4) challenges with prioritizing responsibilities relating to quality improvement compared with other responsibilities;(19)
- two studies examined the development of core competencies to support the implementation of rapid-learning health systems:
  - the first study examined the development and refinement of a Learning Health Systems Training Program for resident physicians and found that:(20)
    - challenges encountered during the implementation of the program included scheduling, mentoring, data standardization, and iterative optimization of the curriculum for real-time instruction,

- successful methods for teaching the curriculum included diverse multidisciplinary educators, just-in-time instruction, tailored content, and mentored projects with local health system impact; and
  o the second study identified 33 core competencies for learning health system researchers to guide the development of training programs, which were grouped into seven 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.(21)

Documenting assets and identifying gaps

The original IOM conception of the learning health system was focused primarily at the clinical encounter, program and/or organization levels (hereafter called clinical levels) and it identified six phases of the learning health system:
1) identifying problems (and potentially innovative solutions) through an internal and external scan;
2) designing care and evaluation based on data and evidence generated locally and elsewhere;
3) implementing the plan in pilot and control settings;
4) evaluating to identify what does and does not work;
5) adjusting, with continuous improvement based on what was learned from the evaluation; and
6) disseminating the results to improve care across the system.(22; 23)

The first four of these steps have their analogues at the LHIN sub-region, LHIN and government levels (hereafter called policy levels):
1) clarifying problems (and their causes);
2) selecting options;
3) identifying implementation considerations; and
4) monitoring implementation and evaluating impact.
However, at these levels, the problems and options may be clinical in nature (e.g., which individually targeted programs, services or drugs to fund?) or public health in nature (e.g., which group- or population-targeted programs or services to provide?), or involve governance, financial and delivery arrangements (e.g., who can make what decisions, how money flows, and how the delivery system is organized to get the right programs, services and products to those who need them?).

There is also an analogue at the self-management level or with the patient components of the clinical encounter level (hereafter called patient levels):
1) understanding their risk factors and/or conditions;
2) making treatment choices (as part of a shared decision-making with their clinician or care team) and making decisions about how to self-manage their diseases and/or live well with their conditions;
3) adhering to chosen courses of action; and
4) monitoring their condition, either alone or in partnership with their clinician or care team.
Of course patients can and should also be a partner at clinical and policy levels (e.g., as part of a team that is co-designing a program or program evaluation, a participant in a citizen panel convened to address a particular LHIN-level challenge, and a member of the MoHLTC's Patient and Family Advisory Council).

To illustrate the types of complementarities that exist among groups in Ontario's research system that can support three of the seven characteristics of a learning health system – data analysis, research production and the development and maintenance of decision supports – we provide in **Table 2** a listing of eight types of groups and note how they focus on one or more phases of the patient, clinical or policy levels of a rapid-learning health system (and in the case of the latter, how they focus on one or more of clinical topics, public-health topics or health-system arrangements).

Table 2: Types of groups that can be involved in data, evidence and decision supports

Groups (with those using existing, synthesized research evidence marked with an asterisk)	Focus		
	Phases at the patient levels of rapid-learning health system (not counting patient roles at clinical and policy levels)	**Phases at the clinical levels of a rapid-learning health system** (not counting clinician roles in patient and policy levels)	**Phases at the policy levels of a rapid-learning health system** (and, in brackets, the nature of topics typically addressed)
Data analytics	Not applicable (n/a), although possibly a role in monitoring	Identifying problems	Clarifying problems and monitoring implementation (typically for clinical and public-health topics)
Clinical practice guidelines*	Making treatment choices (if guideline-derived patient materials produced as well)	Designing care	Selecting options (typically for clinical practice)
Health technology assessments (HTA)*	n/a	Designing care	Selecting options (typically for clinical and public health 'technologies,' such as prescription drugs and immunizations)
Modelling	n/a	Designing care and evaluation	Selecting options (typically for reach and needs but for any topic)
Implementation research (behavioural insights)	n/a	Implementing the plan	Identifying implementation considerations (typically for clinical and public-health interventions)
Self-management and shared decision-making supports*	Understanding conditions, making treatment choices, adhering, and monitoring	n/a	n/a
Evidence-informed policymaking supports*	n/a	n/a	Clarifying problems, selecting options, and identifying implementation considerations (typically for health-system arrangements)
Evaluation	n/a	Designing evaluation and evaluating	Monitoring implementation and evaluating impact (typically for clinical and public-health interventions)

We now use the structure of **Table 3** to document the assets and identify the gaps that exist in Ontario's health system that can be leveraged or addressed, respectively, in creating a rapid-learning health system. We do so in four levels or domains:

1) province (see **Appendix Table A1**);
2) LHIN, using the Mississauga Halton LHIN as an example (see **Appendix Table A2**);
3) sector, using the primary-care sector as the example (see **Appendix Table A3**); and
4) 'category of conditions,' using the mental health and addictions sub-system as the example (see **Appendix Table A4**).

Table 3: Template to assess assets and gaps

Characteristic	Health system		Research system	
	Receptors and supports	Gaps	Supports	Gaps
Engaged patients				
Digital capture, linkage and timely sharing of relevant data				
Timely production of research evidence				
Appropriate decision supports				
Aligned governance, financial and delivery arrangements				
Culture of rapid learning and improvement				
Competencies for rapid learning and improvement				

Many assets can be leveraged and many gaps need to be addressed to create a rapid-learning health system in each of these four levels or domains (see **Table 4 for** our high-level observations about them). Assets and gaps now need to be documented for other LHINs, sectors and prioritized conditions – as well as for prioritized categories of treatments (e.g., prescription drugs), health determinants (e.g., housing), and populations (e.g., francophones and Indigenous peoples) – while keeping in mind what's needed at self-management, clinical encounter, program and organization levels. Such assessments need to be updated periodically, and steps need to be taken to join up these assets and to address gaps. A rapid-learning health system in Ontario will almost certainly take the form of a great many, inter-connected rapid-learning health and social domains (or systems).

Table 4: High-level observations about the domains we did and didn't assess

Levels/domains	Options for focus	Observations about levels or domains assessed	Observations about levels or domains not assessed
Province	Provinces and territories	Ontario • Robust health and research systems, with OSSU acting as a centripetal force within the research system and considering a rapid-learning health system as a framework • Several groups independently using rapid-learning health systems as a framework, and many groups that could do so easily	Other provinces and territories • B.C. is also starting to use a rapid-learning health systems framework
Regions	LHIN and LHIN sub-regions • 14 LHINs • Many LHIN sub-regions	Mississauga Halton LHIN • Trillium Health Partner's Institute for Better Health is led by Rob Reid, who has experience with rapid-learning health systems • LHIN is at an important inflection point in its developmental trajectory as a rapid-learning health system	Other LHINs • None singled out as also moving in this direction LHIN sub-regions are too new to assess
Sectors	Six sectors • Home and community care • Primary care • Specialty care • Rehabilitation care • Long-term care	Primary care • Association of Ontario Health Centres is working with Merrick Zwarenstein on using rapid-learning health systems as a framework (24) • Sector shares with home and community care being at a nascent stage in becoming a rapid-	Specialty care • Academic hospitals have ARTIC, which uses elements of this thinking

13

		learning health sector (but is not in the midst of absorbing a new set of functions)	No other sectors singled out as also moving in this direction
	• Public health		
Categories of conditions	Many potential categories – e.g., • Cancer (and renal disease) • End of life • HIV/AIDS • Mental health and addictions • Work-related injuries and diseases • Multimorbidity	Mental health and addictions • Many assets could be re-oriented easily within a rapid-learning health systems framework • Sub-system shares with cancer a significant 'separateness' from the rest of the health system (but does not have the additional funding and other managerial levers available to Cancer Care Ontario)	Cancer • Cancer Care Ontario used the framework in its research strategy (25) • Ontario HIV Treatment Network is considering using the framework for its work on HIV/AIDS No other sub-systems singled out as also moving in this direction
Categories of treatments or health determinants	Many potential categories – e.g., • Prescription and over-the-counter drugs • Complementary and alternative therapies • Dental services • Social systems (e.g., housing)	n/a	No other domains singled out as also moving in this direction
Populations	Many potential populations – e.g., • Francophones • Indigenous peoples	n/a	No other domains singled out as also moving in this direction

While we did not find research literature that used the characteristics of learning health systems to document assets and identify gaps, we did find a number of descriptive case studies of rapid-learning health systems (see **Appendix Table B4** for more details):

- the descriptive case studies showcased various rapid-learning health systems, including for a health system as a whole, as well as some implemented in specific organizations (e.g., academic health centres) and sectors (e.g., specialty care) and for specific categories of conditions (e.g., chronic diseases and cancer), categories of treatments (e.g., surgery and palliative care), and populations (e.g., children and youth);
- the descriptive case studies generally focused on the key factors influencing the successful implementation of rapid-learning health systems, with the following common themes emerging:
  - o meaningful stakeholder engagement, partnership and co-production being key pillars in the development and implementation of rapid-learning health systems,(26-30)
  - o a robust data infrastructure being a central component of rapid-learning health systems (e.g., data need to be systematically and consistently captured, readily available, and shared; the system must allow multi-institutional data sharing; standardized technological approaches should be used to reduce the burden of data entry such as electronic health record-based data collection forms; and patient-centred metrics are critical),(28; 31-34)
  - o leadership-instilled culture of learning required,(26; 28; 31)
  - o strategic and operational assistance required to support the development of core competencies in various areas (including implementation science, systems redesign, health services research, and health information technology),(31; 35)
  - o clear set of performance and quality measures required to evaluate the development and implementation of rapid-learning health systems (including public reporting on performance and quality);(29; 31) and
- one descriptive case study highlighted the need to proceed in sequence: 1) assembling the core team and clarifying terms; 2) learning from existing models; 3) tailoring the model to the specific setting or sector; and 4) building the learning health system using rapid-cycle testing.(27)

Identifying 'windows of opportunity'

We found no studies about the factors that stimulated the development and/or consolidation of a rapid-learning health system. Accordingly we focused instead on identifying 'windows of opportunity' that can be capitalized on or created to stimulate the development and consolidation of a learning health system in Ontario. We have grouped these windows of opportunity according to where they are primarily located.

1) Health system
   a) emergence of LHIN sub-regions, which create a natural focal point for rapid learning and improvement at the local population level
   b) LHIN transformation initiatives, which introduce the potential for hospital research institutes to begin to see value in investing some of their research dollars in rapid learning and improvement in their LHINs and LHIN sub-regions (as Trillium Health Partners, as well as academic hospitals through ARTIC, have done)
2) Research system
   a) possible renewal of OSSU, which provides the government the opportunity to leverage the Health System Research Fund awards and to use both sources of funding to sustain the well-functioning supports that exist already, to establish a mechanism to ensure that access to these supports is appropriately prioritized within and across levels, and to address the gaps in these supports that were noted above
3) Quality-improvement infrastructure
   a) existence of a government agency (Health Quality Ontario) charged with supporting quality improvement, which positions it well to create and host the mechanisms that support connections at multiple levels between the health and research systems (e.g., process for establishing joint learning opportunities)

While not a question posed to us directly, we list below some of the factors that might 'close' these windows of opportunity:

1) health-system leaders make one-time-only decisions that do not push the health system down a path of increasingly become a rapid-learning health system (much as accreditation failures often focus the attention of organizations for only the brief period required to address deficiencies, rather than stimulate the routinization of rapid learning and improvement processes);
2) advocates for investments in data only, rapid primary research only or investigator-driven research only encourage decisions that do not ensure an appropriate balance among timely data sharing, timely primary research, and timely syntheses of existing research evidence (or an appropriate balance between supporting the conduct <u>and</u> use of data, research and evidence syntheses); and
3) quality-improvement leaders seek to 'own' the whole process in a way that does not develop and sustain decentralized capacity for rapid learning and improvement across both health and research systems.

More generally, the one area where there were marked differences of opinion among key informants was in the use of the word 'rapid.' Some expressed skepticism that learning and improvement would ever happen rapidly (to which one member of the writing team responded: "it's relative – it should happen faster than the glacial pace of learning and improvement we have now"). Others expressed concern that rapid, particularly on the research side, would mean consistently lower quality.

Conclusion

We offer three potential implications of this work, the first of which could be taken forward by the MoHLTC, the second by the OSSU, and the third by both:

1) consider centralizing the coordination (e.g., in the office of the MoHLTC assistant deputy minister for strategic policy) of efforts to:
   a) use the framework,
   b) document assets and gaps in levels or domains where they're missing (i.e., for other LHINs, sectors, and prioritized categories of conditions, as well as for prioritized categories of treatments and health determinants, and prioritized populations) and update them periodically,
   c) incrementally join up assets and fill gaps in these levels or domains:
      • MoHLTC (e.g., as new funding models are piloted and as new HSRF calls are designed),
      • LHINs (e.g., as new reporting templates are developed for LHIN sub-regions),
      • sectors (e.g., as funding agreements are updated for community-governed primary-care teams),
      • prioritized categories of conditions (e.g., as governance arrangements are worked out for the mental health and addictions sub-system),
      • prioritized categories of treatments and health determinants,
      • prioritized populations;
2) consider clarifying:
   a) where and how OSSU elements align with the seven characteristics of a rapid-learning health system beyond the obvious alignment with the 'timely production of research evidence' (e.g., does OSSU limit its support for capacity-building to patient engagement in the conduct and use of research, or broaden it to include patient engagement at all levels – from the clinical encounter to the MoHLTC – and across all domains?),
   b) whether OSSU is well positioned to help bridge the differences of opinion among key informants in what rapid means (beyond "faster than the glacial pace of learning and improvement we have now"), which could take the form of a simple framework to help organize examples of differently paced rapid learning and improvement efforts and the rationales for the differential pacing,
   c) how OSSU's future funding can be patient-driven and supportive of multiple levels (e.g., LHIN sub-regions), and
   d) how OSSU can best reconcile its role in supporting a rapid-learning health system at the provincial level and its role in supporting national networks and contributing to nationally identified priorities (and how it can achieve synergies in these roles through efforts like sharing lessons learned about rapid-learning health systems across provinces and enabling access to national datasets); and
3) consider convening key focal points from each of the above levels or domains, as well as from the hospitals and other organizations that are investing in creating rapid-learning health organizations and contributing to cultural change in their LHINs, to discuss ways of supporting a joining up of efforts (which could include the creation of a community of practice).

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APPENDIX A

Appendix Table A1: Assets and gaps at the level of the Ontario health system

Characteristic	Health system		Research system	
	Receptors and supports	**Gaps**	**Supports**	**Gaps**
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	• Some patients have access to their health information through a patient portal (e.g., MyChart if they are a patient at Sunnybrook Health Sciences Centre or 'my results' if they receive laboratory services through LifeLabs) • Some patients have opportunities to be engaged in self-management and focused on living well with their conditions • Some clinicians use patient decision aids and more use informal approaches to support shared decision-making • Some organizations use co-design approaches in designing programs • Patient and Family Advisory Councils (PFACs) or their equivalent (e.g., Ontario Citizens' Council; Patient and Caregiver Advisory Table for Home and Community Care) help to set direction for the system (or for organizations) at the Ministry of Health and Long-Term Care (MoHLTC), in Local Health Integration Networks, and for select sectors (specialty hospital care; long-term care), conditions (e.g., cancer; mental health and addictions) and treatments (e.g., prescription drugs) • Health Quality Ontario is leading several initiatives on patient engagement in quality improvement (e.g., patient-engagement tools and resources, patient advisors program, and Choosing Wisely campaigns) • MoHTLC has a team of five staff to support patient engagement and a growing database of individuals who have signed up to act as patient advisors in the health system	• Limited supports for self-management and living well in primary care • Limited supports and incentives for shared decision-making in primary and specialty care • No requirements, incentives or guidance for co-design of publicly funded programs and services • No mandated PFACs or their equivalent in select sectors (e.g., primary care outside select models) or for most conditions, treatments (or health determinants) and populations (and concerns about the limited support to, and influence of, the PFACs that do exist) • No consensus about the value of the systematically elicited insights of patients or of engaging patients in helping to contextualize and complement data and evidence with patient stories • No recognition of the need to explain to patients how the health system works, to engage them about its performance (e.g., with reports from HQO or ICES) or to develop their capacity to participate in driving system improvements • No recognition of the need for tailoring approaches, no training about tailoring approaches, and no menu of different approaches to engaging distinct patient groups (e.g., vulnerable populations, ethnocultural groups)	• OSSU has supported three masterclasses on the conduct and use of patient-oriented research (for patients as well as providers, policymakers and researchers), as well as smaller patient-engagement projects and patient-partnership training workshops, and national SPOR networks (some of which are based in Ontario) and CIHR have provided additional training and support • See patient-targeted decision supports below • Several research groups are actively studying co-design • Many research groups and 'intermediary groups' (e.g., Change Foundation) work with a standing citizen panel and the McMaster Health Forum convenes citizen panels on a range of topics • Patient and Public Engagement Evaluation Tool (PPEET), and a broader Patient and Public Engagement Evaluation Toolkit, can be used to evaluate patient engagement (both in health research and in health-system transformation)	• Focus is primarily on producing patient-oriented research and not a balance between producing and supporting the use of patient-oriented research • No requirements or incentives for research groups to act on lessons learned about robust patient-engagement processes • No community of practice focused on the science (and practice) of patient engagement

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)	• Many organizations collect patient experience data and these are often then aggregated and reported on by Health Quality Ontario
	   o e.g., hospitals collect standardized data using NRC Health templates, submit the data on a daily basis, and can easily access comparative data
	   o e.g., home and community care organizations collect standardized data through the Client and Caregiver Experience Evaluation Survey and through the Inter RAI assessment tools and make them available through the Client Health and Related Information System
	• Some organizations and one professional association (Registered Nurses' Association of Ontario through its NQuIRE program) have the staff and infrastructure to manage, link, analyze and present data to support learning and improvement
	• Some organizations have access to linked patient-experience data (e.g., organizations participating in practice-based research networks such as UTOPIAN; the 65 organizations across six LHINs that are participating in the Integrated Decision Support (IDS) initiative)
	• Other organizations have access to complementary structure, process and/or outcomes data (e.g., through registries)
	• A new MoHLTC initiative (SPARK) is helping digital health innovators to provide provincial health information to patients and providers
	• A Canadian Institute for Health Information project is linking patient-satisfaction and utilization data
		• Much of the data being collected are about providers and not about patient-reported experiences and outcomes (or about outcomes in general), about caregivers or about the broader social determinants of their health (and some of the data continue to be collected manually)
		• No consistent standards for what types of patient experience data to collect and how (e.g., about services, transitions and longitudinally, not just services) across sectors, conditions, treatments and populations (and the management, linkage, analysis and presentation of data are particularly under-developed in some of these areas, such as in the primary-care sector)
		• Many organizations don't have the staff and infrastructure to analyze and present locally contextualized data to support learning and improvement
		• Ongoing uncertainty about what privacy policies mean for sharing data beyond the 'circle of care'
		• Patients typically cannot access patient-experience data
		• Patients are typically not actively offered performance data at the point of care
			• MoHLTC funds ICES to provide a data management and analytics platform, and ICES and other groups are laying the groundwork for more comprehensive datasets
			• Ontario SPOR SUPPORT unit has funded the ICES Data and Analytic Services to respond to data requests, including for data linkage, by decision-makers
			• MoHLTC commissions periodic, large-scale patient surveys (e.g., Primary Care Access Survey, which is undertaken by York University's Institute for Social Research)
			• Some research groups have experience in designing and conducting surveys or other types of studies to capture patient experiences
			• Commonwealth Fund conducts periodic patient surveys to enable cross-country comparisons
			• Canadian Institute for Health Information presents cross-provincial comparisons using available data
			• A research group is collecting data about the use of unnecessary services that will enable cross-provincial comparisons
				• No centralized platform for capturing, analyzing and sharing (especially in a timely way) patient experience data or for linking these data to utilization, cost, health and well-being data
				• No robust understanding of the drivers of patient satisfaction across sectors, conditions, treatments and populations

| **Timely production of research evidence**: Systems produce, synthesize, curate and share (with individuals at all levels) research about problems, improvement options and implementation considerations | • Some patients have developed capacity to act as champions and mentors for the conduct and use of patient-oriented research, through the Ontario SPOR SUPPORT Unit masterclasses (and a smaller number to conduct it themselves, through the Patient and Community Engagement Research program)
• Some organizations have developed in-house capacity to conduct rapid-cycle evaluations | • Few organizations have developed in-house capacity to find and use pre-appraised, synthesized research evidence (or, in its absence, single studies) or developed a culture of rapid learning and improvement that draws on either the work of others or evaluations done in-house
• Limited incentives and no consistent standards for both introducing innovations and then evaluating them and scaling up proven approaches (so when there is activity the focus is typically only on introducing the innovations unless evaluation and scale-up is part of the organization's 'brand')
• No distributed research ethics infrastructure to support rapid-cycle evaluations
• Most organizations do not fully document or make publicly available the findings from their own evaluations | • MoHLTC funds research groups to work on priority system challenges and requires them to use 25% of their funds to respond to emerging research requests by decision-makers (called Applied Health Research Questions)
• OSSU funds a joined-up approach across 12 research groups to provide: 1) data platforms and services; 2) methods support and development; 3) real-world (pragmatic) clinical trials; 4) health-systems research, implementation research, and knowledge translation; 5) career development in methods and health-services research; and 6) consultation and research services (with cross-cutting support for sex and gender issues and francophone and Indigenous populations), as well as one-off funding to patient- and impact-oriented research projects that involve decision-makers
• Ontario researchers (Monica Taljaard and Charles Weijer) are using CIHR funding to work through the ethical issues involved in rapid-learning health systems
• Ontario researchers can benefit from the Ministry of Research, Innovation and Science funding for clinical health research and CIHR's Institute of Health Services and Policy Research allocating strategic research funds to the creation of rapid-learning health systems, which is its first strategic priority | • MoHLTC research funding program does not explicitly seek to ensure support is available to all LHINs (or to LHIN sub-regions), sectors, categories of conditions or populations
• OSSU research funding doesn't, with few exceptions, provide dedicated funds to respond to emerging research requests by decision-makers
• Limited requirements or incentives for research groups to work collaboratively with one another and with decision-makers at all levels in support of rapid learning and improvements (beyond OSSU for the former and MoHLTC's Applied Health Research Questions for the latter)
• No effort among MoHLTC and OSSU as 'backbone organizations' to use a 'collective impact' lens to guide a common agenda, performance measures, mutually reinforcing activities or continuous communications
• High-profile journals often don't publish 'negative' or very 'local' findings |

Evidence >> Insight >> Action

| **Appropriate decision supports**: Systems support informed decision-making at all levels with appropriate data, evidence, and decision-making frameworks | • Many groups make recommendations to providers about optimal care
  o Registered Nurses' Association of Ontario produces guidelines for optimal interprofessional practice and healthy work environments (and support their inclusion in order sets)
  o CORhealth makes recommendations about cardiac, stroke and vascular care
  o Cancer Care Ontario (through the Program in Evidence-Based Care) produces guidelines for cancer care
  o Health Quality Ontario produces 'quality standards' on a broad range of topics
  o MoHLTC produces care pathways for select clinical areas (funded using the Quality-Based Procedures approach) and organizational and program standards for public health
• eHealth Ontario (and Canada Health Infoway) provide supports to providers for electronic health records that incorporate decision supports
• MoHLTC provides a rapid evidence service for government staff
• Health Quality Ontario and Public Health Ontario have a formal role, and many other government-supported groups play an informal role, in providing data and research to inform managerial and policy decision-making (e.g., to inform decisions about which prescription drugs and which non-drug technologies to pay for publicly)
• As noted in the 'data' row, some organizations have the staff and infrastructure to analyze and present data to support learning and improvement | • No patient-targeted 'way in' to the 21 sites that publicly report data about the performance of (select parts of) the health system
• Many care teams are not aware of existing decision supports or don't support their use by their patients
• Decision supports are typically 'siloed' (rather than part of an integrated decision-support system operating across the health system or across health and social systems) and do not follow best practices about data visualization, audit and feedback, etc. | • McMaster Optimal Aging Portal provides patient-targeted, evidence-based resources to support self-management and shared decision-making
• Health TAPESTRY supports goal setting and achievement in select communities
• Ottawa Hospital Research Institute (OHRI) Patient Decision Aids provides pre-appraised patient decision aids (which are also included in the Portal)
• A book (available on the McMaster Health Forum website) describes how the Ontario health system works, including by sector and for select conditions, treatments and populations (and will soon be supplemented by an online course)
• ACCESSSS provides access to pre-appraised studies and reviews about clinical interventions
• Health Evidence provides access to pre-appraised systematic reviews about public-health interventions
• Health Systems Evidence and Social Systems Evidence provide access to pre-appraised synthesized research evidence about how to strengthen health and social systems and get the right programs, services and products to those who need them
• Ontario SPOR SUPPORT Unit (OSSU) funds several research groups to provide support in the areas of health systems, knowledge translation, and implementation
• McMaster Health Forum harnesses the best available evidence about problems, options and implementation considerations (through a rapid synthesis or evidence brief), citizen values (through citizen panels) and stakeholder insights (through stakeholder dialogues) for use in decision-making | • Systematic review and clinical guidelines expertise is not being effectively harnessed
• Advisory group co-chaired by Doris Grinspun and Jeremy Grimshaw have not yet reported on a proposed common language and framework to support evidence-based implementation of effective practices |

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	• Hospitals, long-term care homes and interprofessional team-based primary-care organizations are now required to prepare (following guidance from HQO), share and report on Quality Improvement Plans (and to incorporate equity considerations in these plans) • Many types of organizations seek accreditation from Accreditation Canada, which could include rapid learning as a focus for its accreditation efforts • New financial arrangements are beginning to or have the potential to incentivize rapid learning and improvement (e.g., Quality-Based Procedures, bundled care models) and to focus attention on patient-reported outcome measures (e.g., EQ-5D-5L and Oxford Hip and Knee surveys to elicit patient-reported outcomes measures for hip- and knee-replacements) • A new value-based innovation procurement model has the potential to enable the more rapid assessment, sourcing, and integration into clinical practice and spread across the province of health technology solutions and processes • ARTIC (Adopting Research to Improve Care) provides funding and active support to spread across sites the use of proven clinical interventions or practice changes that have already been successfully implemented in at least one site	• Policy legacies make alignment difficult, and election cycles, interest-group pressure and competing 'shiny penny' ideas complicate sustained movement towards alignment • No centralized coordination of efforts to use this framework, incrementally join up assets and fill gaps, and periodically update the status of assets and gaps at the level of the MoHLTC (e.g., as new funding models are piloted), LHINs (e.g., as new reporting templates are developed for LHIN sub-regions), sectors, conditions, treatments (or health determinants) and populations • Some types of organizations (e.g., most in primary care) are not required to prepare, share and report on Quality Improvement Plans or to seek accreditation • Organizations are funded and providers are remunerated in ways that are difficult to understand and change, and that typically do not reward patient engagement or improvements to patient-reported experiences and outcomes • No consistent standards for provincial expert groups to involve patients, involve a methodologist, use existing data and evidence to inform their recommendations or justify their recommendations based on the best available research evidence • No mechanism for health and research systems to jointly set learning and improvement priorities • No mechanism for identifying and sharing the 'reproducible building blocks' of a rapid-learning health system (e.g., data-sharing agreements; agreements with Research Ethics Boards about rapid-cycle evaluations)	• See data and evidence rows for funding arrangements • As noted in the evidence row, OSSU funds a joined-up approach across 12 research groups • Appointment of Ontario's first Chief Scientist (in November 2017) offers promise for greater alignment	• As noted in the evidence row, no effort among MoHLTC and OSSU as 'backbone organizations' to use a 'collective impact' lens to guide a common agenda, performance measures, mutually reinforcing activities or continuous communications (i.e., to create a true 'research system') • As noted two cells to the left, no mechanism for health and research systems to jointly set learning and improvement priorities

Evidence >> Insight >> Action

Culture of rapid learning and improvement: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability	• Some organizations are explicitly developing a culture of a rapid-learning health organization • Emerging leaders are often technologically savvy and more aligned with a culture of rapid learning and improvement	• Most health organizations do not have a culture of embedding rapid learning and improvement in their operations, of developing and maintaining trusted relationships with the full range of partners needed to support rapid learning and improvement, or of acknowledging, learning from and moving on from 'failure'	• OSSU is proposing to use a rapid-learning health system as the organizing frame for their renewal application	• Most research groups do not have a culture of working with decision-makers at all levels to support rapid learning and improvement
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, LHIN sub-regions and LHINs 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	• Health Quality Ontario monitors and publicly reports on quality and supports rapid learning and improvement • Many organizations in the specialty care sector have quality-improvement units and staff • Some sub-systems, such as the cancer sub-system, have structures and processes to prioritize scale-up opportunities and ensure alignment between the health system and the research system	• Lack of agreement about the competencies needed (e.g., data literacy, co-design, scaling up, and leadership) and which are needed in all organizations versus in more centralized support units • Largely lack learning collaboratives and other elements of the infrastructure needed to support rapid learning and improvement across LHINs, sectors, conditions, treatments (and health determinants) and populations (e.g., to inform what and how to sustain, and what and how to scale up) • Uneven understanding among decision-makers about how research can help them, how to find and use existing research evidence, and how to engage researchers when evidence is lacking	• IDEAS provides training in quality improvement to large cohorts of providers and managers (although the total pool of trainees remains small compared to the numbers needed) • OSSU funds a provincial implementation science laboratory that works in partnership with Health Quality Ontario to design and test approaches to rapid learning and improvement at the clinical encounter level,(36) and other centres of expertise (e.g., Centre for Implementation Research at the Ottawa Hospital Research Institute) either contribute to or complement this laboratory	• Limited to no mechanisms to support a distributed model of data and research supports across the full spectrum of LHINs (and LHIN sub-regions), sectors, conditions, treatments (and health determinants) and populations

Appendix Table A2: Assets and gaps at the level of the Mississauga Halton LHIN

Characteristic	Health system		Research system	
	Receptors and supports	Gaps	Supports	Gaps

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	• As noted at the provincial level
	   o Some patients have opportunities to be engaged in self-management and focused on living well with their conditions
	   o Some clinicians use patient decision aids or more informal approaches to support shared decision-making
	
	 • Trillium Health Partners (THP), a large hospital in the LHIN, is using a co-design approach to develop bundled care pathways and is developing a standard co-design approach for use in all such work in future
	 • Patient and Family Advisory Councils (PFACs) help to set direction for the LHIN and for local health organizations
	 • Patient representatives sit on a range of governance, executive and clinical program committees
	 • Patient stories are used by clinical program committees and at the front-line to support learning and improvement
		• Most front-line providers lack the competencies to support self-management and (especially among physicians) to support shared decision-making, particularly when a reasonable option is to not have a procedure
		 • No patient representatives on all LHIN committees
		 • Difficult to identify patients who can be engaged in ways that are more time-intensive than filling out a questionnaire
		 • No standardized way to 'on-board' patient partners, including helping them to understand their role (e.g., not advocating for personal needs) and ensuring they have the competencies to execute it
			• THP's Institute for Better Health has experience in patient engagement in co-design	• No ethical framework for engaging patients in patient-oriented research
				 • No research advisory board or other robust process to engage patients in research governance
				 • Limited 'bridges' between the health and research systems at the regional level

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)	• Many health organizations in the LHIN collect patient experience data at multiple levels (e.g., at service, unit and organizational levels within the hospitals) • LHIN and THP have staff who understand the available data and the context in which the data were collected and who can manage, link, analyze and present that data to support learning and improvement • LHIN, THP and other organizations provide standardized quarterly reports to the MoHLTC about volume, wait times for priority procedures, etc. • LHIN and the hospitals have an emergency-communication tool to communicate with the Ministry about emergencies	• Limited infrastructure for: 1) identifying common data elements (for patient experience data) to enable cross-organization comparisons; 2) digitally (not manually) collecting patient experience data (particularly across sectors); and 3) digitally (not manually) linking patient experience data with discharge, finance, human resources and other types of data • In-house staff do not have consistent approaches to data analysis and data interpretation • No privacy agreement for sharing data	• THP's Institute for Better Health has experience in designing and conducting surveys and other types of studies to capture patient experiences	• No centralized platform for capturing, analyzing and sharing (especially in a timely way) patient experience data or for linking these data to utilization, cost, health and well-being data • No robust understanding of the drivers of patient satisfaction across sectors, conditions, treatments and populations

Timely production of research evidence: Systems produce, synthesize, curate and share (with individuals at all levels) research about problems, improvement options and implementation considerations	• Some organizations have developed in-house capacity to conduct rapid-cycle evaluations	• No infrastructure to collect and curate existing research evidence
		• No research ethics infrastructure to support rapid-cycle evaluations
			• THP's Institute for Better Health is growing in-house capacity to conduct rapid-cycle evaluations
			• MoHLTC funds the Health System Performance Network (the principal investigator of which is based at THP) to conduct research on performance measurement and improvement and requires them to use 25% of their funds to respond to emerging research requests by decision-makers (called Applied Health Research Questions)
				• As noted at the provincial level
				  o Limited requirements or incentives for research groups to work with one another and with decision-makers at all levels in support of rapid learning and improvements
				  o No effort to use a 'collective impact' lens

Appropriate decision supports: Systems support informed decision-making at all levels with appropriate data, evidence, and decision-making frameworks	• As noted at the provincial level ○ Many groups make recommendations to providers about optimal care ○ eHealth Ontario (and Canada Health Infoway) provide supports to providers for electronic health records that incorporate decisions supports • As noted in the 'data' row, LHIN and THP have staff who understand the available data and the context in which the data were collected and who can manage, link, analyze and present that data to support learning and improvement	• Inconsistent approaches to making recommendations to providers about optimal care across the LHIN • Some decision-making frameworks exist, but they are not always well known or consistently applied • As noted in the data row, in-house decision support personnel do not always have consistent approaches to data analysis and data interpretation	• THP's Institute for Better Health is developing a community-based data strategy that will address both data analytics and decision supports, and is well positioned to help with this work	
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	• Hospitals, long-term care homes and interprofessional team-based primary-care organizations are now required to prepare, share and report on Quality Improvement Plans • All THP leaders at the manager level or above have a performance indicator (in the Leader Evaluation Management tool) that is based on patient satisfaction and that contributes to performance pay • The implementation of bundled care pathways demonstrated early successes with co-design and rapid-cycle evaluations • A primary-care network has been developed in the LHIN and now a hub model is being developed as a key piece of infrastructure to share best practices (initially in primary care and in mental health)	• No centralized coordination (e.g., in the office of the LHIN vice president for strategy) of efforts to use this frame, incrementally join up assets and fill gaps, and periodically update the status of assets and gaps at the level of the LHIN and of sectors, categories of conditions, and populations within the LHIN • Some types of organizations (e.g., most in primary care) are not required to prepare, share and report on Quality Improvement Plans • Funding comes from different ministries and from different funding models within MoHLTC, each of which may have its own expectations and accountabilities • No mechanism for regional health and research systems to jointly set learning and improvement priorities	• THP's Institute for Better Health is well positioned to provide recommendations about needed alignments	• As noted two cells to the left, no mechanism for regional health and research systems to jointly set learning and improvement priorities

Evidence >> Insight >> Action

Culture of rapid learning and improvement: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability	• The LHIN and some local health organizations are now developing a culture of a rapid-learning health organization and it has for several years modeled a commitment at all levels of the organization to collaboration with partners	• More work needs to be done to build: 1) an appreciation within clinical operations about the value of rapid learning and improvement; and 2) a commitment to taking the extra time and making the extra effort in a context characterized by the 'tyranny of the urgent'	• THP's Institute for Better Health used a rapid-learning health system as the organizing frame for its renewal application and it has a culture of collaboration with partners at all levels of the organization • THP's Institute for Better Health has a culture of working with decision-makers at all levels of the organization to support rapid learning and improvement	• Research (e.g., modeling of trends or patterns in utilization and quality) hasn't been embedded in clinical operations and when it is done it is as a reaction to the work of others
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, LHIN sub-regions and LHINs 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	• THP and other health organizations in the LHIN have a strong quality-improvement department that understands rapid-cycle evaluations	• As noted at the provincial level o Lack of agreement about the competencies needed (and physicians and other staff typically don't have the competencies) o Lack of learning collaboratives o Uneven understanding among decision-makers about how research can help them, etc. • No competency-based, regional (cross-organization) approach to education and no measurement of competencies in the region	• THP's Institute for Better Health has some expertise in characterizing problems and supporting the design and implementation of data- and evidence-informed approaches	• No regional governance framework or strategy for research

Appendix Table A3: Assets and gaps in the primary-care sector

Characteristic	Health system		Research system	
	Receptors and supports	**Gaps**	**Supports**	**Gaps**
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	• Some patients have opportunities to be engaged in self-management and focused on living well with their conditions • Some primary-care providers use patient decision aids or more informal approaches to support shared decision-making • Patient and Family Advisory Councils (PFACs) help to set direction for community-governed primary-care teams • Resources are available from HQO, the Association of Family Health Teams of Ontario and the Association of Ontario Health Centres to support primary-care organizations in patient engagement	• Limited supports for self-management and living well in primary care • Limited supports and incentives for shared decision-making in primary care • No requirements or incentives for co-design of primary-care programs and services • No mandated PFACs, or reporting about patient-experience data in Quality Improvement Plans, in primary care outside interprofessional team models • No explicit requirements or incentives for primary-care organizations outside interprofessional team models to progressively strengthen their approaches to patient engagement	•	• No resource centre to support patient engagement in primary care (although as noted below, there is one for research)
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)	• Some primary-care organizations collect patient experience data (e.g., using a survey developed by the Association of Family Health Teams of Ontario) • MoHLTC commissions the Health Care Experiences Survey (formerly the Primary Care Access Survey) annually and the Commonwealth Fund's annual survey sometimes addresses primary care • HQO's MyPractice reports provide practice-level performance data for primary-care providers	• No consistent standards for what types of patient experience data to collect and how (e.g., about services, transitions and longitudinally, not just services) in primary care • Few primary-care organizations outside interprofessional team models have the staff and infrastructure to collect, analyze and present locally contextualized data to support learning and improvement • HQO's MyPractice reports are only sent to those who subscribe to them and the reports don't yet provide comparators that reflect comparable patient populations or focus on indicators that have been prioritized by patients and primary-care providers	•	•

Timely production of research evidence: Systems produce, synthesize, curate and share (with individuals at all levels) research about problems, improvement options and implementation considerations	•	• Few primary-care organizations have explicit arrangements to ensure access to supports for rapid-cycle evaluations or to find and use existing research evidence • Limited incentives and no consistent standards for both introducing innovations and then evaluating them and scaling up proven approaches • No research ethics infrastructure to support rapid-cycle evaluations in primary-care organizations	• MoHLTC funds INSPIRE (Innovations Strengthening Primary Healthcare through Research) and BeACCoN (Better Access and Care for Complex Needs) to conduct research in primary care and requires them to use 25% of their funds to respond to emerging research requests by decision-makers (called Applied Health Research Questions) • Primary Health Care Patient Engagement Resource Centre provides tools and resources to support patient engagement in primary-care research	•
Appropriate decision supports: Systems support informed decision-making at all levels with appropriate data, evidence, and decision-making frameworks	• Health Quality Ontario and other groups make recommendations to providers about optimal primary care • eHealth Ontario (and Canada Health Infoway) provide supports to providers for electronic health records that incorporate decision supports • As noted in the 'data' row, few primary-care organizations outside interprofessional team models have the staff and infrastructure to analyze and present locally contextualized data to support learning and improvement	• Many care teams are not aware of existing decision supports or don't support their use by their patients	• McMaster Optimal Aging Portal provides patient-targeted, evidence-based resources to support self-management and shared decision-making in primary care • Health TAPESTRY supports goal setting and achievement in primary care in select communities • Ottawa Hospital Research Institute Patient Decision Aids provides pre-appraised patient decision aids (which are also included in the Portal) • Centre for Effective Practice provides support for electronic medical record integration and evidence use	•
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	• Interprofessional team-based primary-care organizations are now required to prepare, share and report on Quality Improvement Plans • LHIN sub-regions, and primary-care networks within them, will provide the basis for community-driven decisions about rapid learning and improvement priorities, approaches, etc. • MoHLTC and LHINs have decision-making authority over the governance, financial and delivery arrangements that can help or hinder rapid learning and improvement in primary care	• Other types of primary-care organizations are not required to prepare, share and report on Quality Improvement Plans • Primary-care providers have no incentives or supports to enter data appropriately	•	•

Culture of rapid learning and improvement: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability	• Primary-care funding models have supported the emergence of more team-based primary care • Many community-care governed primary-care organizations are explicitly developing a culture of rapid learning and improvement	• Other types of primary-care organizations are typically not focused on developing a culture of rapid learning and improvement	• UWO's Centre for Studies in Family Medicine is working with the Association of Ontario Health Centres to support its use of a rapid-learning health system as the organizing frame for much of its work with community-governed primary-care organizations	•
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, LHIN sub-regions and LHINs 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	•	• Lack of agreement about the competencies needed (e.g., data literacy, co-design, scaling up, and leadership) and which are needed in all primary-care organizations versus in more centralized support units • Largely lack learning collaboratives in primary care, however, the Ontario College of Family Physicians has supported communities of practice and mentorship networks focused on opioid management and medical assistance in dying	•	• Limited to no mechanisms to support a distributed model of data and research supports across primary care

Appendix Table A4: Assets and gaps in the mental health and addictions sub-system

Characteristic	Health system		Research system	
	Receptors and supports	Gaps	Supports	Gaps
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	• MoHLTC involves people with lived experience in setting direction for the sub-system: e.g., 1) Persons with Lived Experience Reference Panel; 2) Family Reference Panel; and 3) Mental Health and Addictions Leadership Advisory Council • LHINs (e.g., Mississauga Halton) are investing in Peer Support System Leads to help build capacity for peer-support workers in health organizations • Mental health and addictions hospitals are required to have Patient and Family Advisory Councils (PFACs) to help set direction for their organizations and to involve patients in developing their Quality Improvement Plans • Provincial organizations involve people with lived experience in their work: e.g., 1) Ontario Peer Development Initiative; 2) New Mentality (for youth); 3) Family Association for Mental Health; 4) Parents for Children's Mental Health; 5) Mood Disorders Association of Ontario; and 6) Schizophrenia Society of Ontario • Resources, such as 'Strengthening Your Voice,' are available to support people with lived experience to become engaged in the sub-system	• No requirements or incentives for co-design of publicly funded programs and services • No mandated PFACs in community-based organizations or explicit requirements or incentives for them to progressively strengthen their approaches to patient engagement • People with lived experience are not always well prepared to participate confidently in system- and policy-level conversations • No supports for organizations about how to approach or document patient engagement when their client base is comprised of many individuals who are involuntary patients, patients with a substitute decision-maker and patients whose care is under treatment orders from the courts or Ontario Review Board • No explicit process for reconciliation when the input of people with lived experience conflicts with research evidence, provider perspectives or policy direction	• Evidence Exchange Network (EENet) maintains a panel of people with lived experience to steer its efforts to create and shared evidence to build a better sub-system • The 'Ontario Perception of Care Tool for Mental Health and Addictions' provides a standardized way of gathering client feedback on the quality of care received in community and hospital settings across all LHINs • A partnership among Addictions and Mental Health Ontario, Canadian Mental Health Association and HQO (through the Excellence through Quality Improvement Project, EQIP), as well as a DeGroote School of Business research group, have been actively using co-design principles in their work • Many researchers engage people with lived experience as members of their research team or as key partners in their research	• Engaging people with lived experience in research is still not consistent (it is often dependent on the values of individual researchers) or systematic (it is often dependent on existing relationships)

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)	• Ontario Mental Health and Addictions Leadership Advisory Council proposed in its final report performance indicators that include patient experience • Mental Health and Addiction Quality Initiative has developed quality indicators for mental health and addictions hospitals (and these hospitals have access to utilization data through the IntelliHEALTH system) • Drug and Alcohol Treatment Information System (DATIS) collects, studies and reports substance abuse and problem gambling demographic and clinical utilization data for more than 170 organizations • Project underway to document wait times for mental health and addictions services, beginning with the four mental health and addictions hospitals and supported by the Centre for Addiction and Mental Health's Provincial System Support Program and Cancer Care Ontario • The Resident Assessment Instrument – Mental Health is increasingly being used across the sub-system (and the Mental Health Clinical Assessment Protocols are increasingly being used for care planning) • HQO's MyPractice reports provide practice-level performance data about opioid prescribing for primary-care providers	• Mental Health and Addiction Quality Initiative is still paper-based and not 'real time' (and other data may only be submitted quarterly) • Wait-times project (described in the cell to the left) is led by an organization outside the sub-system (Cancer Care Ontario) and data are not 'real time' or yet publicly available • No consistent definition of wait times, restraint and other key indicators • No consistent standards for what types of 'people with lived experiences' data to collect and how • Data for those obtaining care in community-based organizations (although some are being collected through an ICES pilot), for children (although those for 13 key performance indicators about children and youth services are being aggregated centrally through a pilot) and to support equity analyses are particularly under-developed • Many organizations don't have the staff and infrastructure to analyze and present locally contextualized data to support learning and improvement, although this is improving through initiatives like EQIP (see previous row) • HQO's MyPractice reports are only sent to those who subscribe to them	• .	• .

Timely production of research evidence: Systems produce, synthesize, curate and share (with individuals at all levels) research about problems, improvement options and implementation considerations	• Centre for Addiction and Mental Health's Provincial System Support Program, Evidence Exchange Network (EENet), Centre of Excellence for Child and Youth Mental Health, and School Mental Health Assist each synthesize, curate and share research evidence in their respective areas with individuals at all levels through a variety of mechanisms	• Few organizations have explicit arrangements to ensure access to supports for conducting rapid-cycle evaluations or to find and use research evidence • No distributed research ethics infrastructure to support rapid-cycle evaluations	• ICES recently launched a mental health and addictions sub-system performance scorecard, which provides baseline data on provincial quality indicators (client-centered, timely, safe, effective, efficient and equitable) • Yona Lunsky linked ICES data with data from the Ministry of Community and Social Services to create a more fulsome understanding of the health needs and healthcare use of adults with developmental disabilities • Some mental health and addictions hospitals (e.g., Waypoint) collaborate with local agencies to jointly set research priorities	• Lack of timely access to data, lack of centralized patient-experience data and community-based organization data, and limited capacity for linkage of these data limits the ability of researchers to use existing data to answer relevant questions • Limited research in community-based organizations and for children and youth, and lack of a centralized platform for researchers seeking partners for such research
Appropriate decision supports: Systems support informed decision-making at all levels with appropriate data, evidence and decision-making frameworks	• Many groups (e.g., HQO) make recommendations to providers about optimal care • All four mental health and addictions hospitals are taking steps to standardize order sets and care pathways	• No individualized feedback is sent to frontline providers about their performance – on its own, in comparison to relevant peers or in comparison to recommendations for optimal care (beyond the opioid prescribing example provided above)	•	•

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	• Mental health and addictions hospitals are now required to prepare, share and report on Quality Improvement Plans • MoHLTC has appointed a special advisor to recommend a governance model for the sub-system • Mental health and addictions hospitals have some joint planning groups that can be harnessed to support rapid learning and improvement (e.g., CEO forum, forensic directors group)	• Governance of the sub-system is effectively distributed across the government ministries that fund parts of it (health, child and youth services, education and justice), although lead agencies in 33 geographical service areas are attempting to provide more integration for children and youth services • Regulatory colleges do not emphasize competencies for rapid learning and improvement among mental health and addictions professionals • Financial arrangements often reinforce silos, which pose challenges for rapid learning and improvement • Community-based organizations are not required to prepare, share and report on Quality Improvement Plans • No mechanism for health and research systems to jointly set learning and improvement priorities or to fund initiatives to address them		
Culture of rapid learning and improvement: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability	• Mental health and addictions hospitals have created the Mental Health and Addictions Quality Initiative, which supports regular meetings of the CEOs to undertake joint initiatives aimed at improving quality	• Most mental health and addictions organizations do not have a culture of embedding rapid learning and improvement in their operations (or of supporting collaboration across professions or 'silos' and across data analytics, decision support, quality improvement and research groups) • Many mental health and addictions organizations have faced a great deal of change in a short amount of time		

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, LHIN sub-regions and LHINs 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	• Addictions and Mental Health Ontario, Canadian Mental Health Association, and Health Quality Ontario have been collaborating on the Excellence through Quality Improvement Project to enhance the ability of community-based organizations to understand and apply quality-improvement methods • Centre for Addiction and Mental Health's Provincial System Support Program and the Centre of Excellence for Child and Youth Mental Health have developed tools, resources and training on effective implementation approaches	• Lack of agreement about the competencies needed (e.g., data literacy, co-design, scaling up and leadership) and which are needed in all organizations versus in more centralized support units • Lack of learning collaboratives and other elements of the infrastructure needed to support rapid learning and improvement	• Training workshop are offered by many organizations (e.g., Mental Health Council of Canada and SickKids) to support researchers and knowledge-translation practitioners, often for those in the mental health sub-system or other domains where 'evidence-based programs' are rolled out, to gain competencies in knowledge translation	• Many mental health and addictions researchers don't have a sufficient understanding of program, organization, sub-system and government contexts to support rapid learning and improvement at these levels

APPENDIX B

The following tables provide detailed information about the relevant research evidence identified for this rapid synthesis. The ensuing information was extracted from the following sources:

- documents exploring the conceptual and theoretical underpinnings of rapid-learning health systems – the focus of the document, year of publication, definition of learning health system, and key findings;
- systematic reviews - the focus of the review, key findings, last year the literature was searched, and the proportion of studies conducted in Canada;
- primary studies - the focus of the study, methods used, study sample, jurisdiction studied, key features of the intervention and the study findings (based on the outcomes reported in the study); and
- descriptive cases of rapid-learning health systems – the case characteristics, the key features of the rapid-learning health systems, and the implementation considerations.

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

All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Appendix Table B1: Summary of findings from documents exploring the conceptual and theoretical underpinnings of rapid-learning health systems

Focus of document	Year of publication	Definition of learning health system	Key findings
Describing the framework and progression of a national learning health system, as well as the advantages of and challenges to public-health involvement in a learning health system (37)	2015	A learning health system is defined as "a platform that seeks to leverage health data to allow evidence-based real-time analysis of data for a broad range of uses, including primary care decision making, public health activities, consumer education, and academic research."	The article highlights 10 core values of learning health systems: 1) person-focused; 2) privacy; 3) inclusiveness; 4) transparency; 5) accessibility; 6) adaptability; 7) governance; 8) cooperative and participatory leadership; 9) scientific integrity; and 10) value.
Examining how learning health systems can learn and 'forget', (or programmatically decommission, obsolete practices) (38)	2017	The author suggests the need for the definition of learning health system to evolve (from definition 1 to definition 2). • Definition 1: "A system with explicit systemic learning mechanisms characterized by the use of information to generalize lessons within the system." • Definition 2: "A system with explicit systemic learning and decommissioning mechanisms characterized by the use of information to both generalize lessons from within the system and maintain efficient system function through controlled decommissioning or forgetting."	The author argues that learning health systems need to find ways to remember processes that shape quality and safety (using data that often resides beyond electronic health records), but also need to 'forget' (or programmatically decommission) obsolete practices.

Examining the path to continuously learning health care in America (39)	2013	A learning health system is defined as "one in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience."	A continuously learning health system has the following characteristics:
			• Science and Informatics
			  o real-time access to knowledge
			  o digital capture
			• Patient-Clinician Partnerships
			  o engaged, empowered patients
			• Incentives
			  o incentives aligned for value
			  o full transparency
			• Continuous Learning Culture
			  o leadership-instilled culture of learning
			  o supportive system competencies
			
			The report highlights 10 recommendations to implement a continuously learning health system
			Foundational Elements
			• The digital infrastructure: Need to improve the capacity to capture clinical, care-delivery process, and financial data for better care, system improvement, and the generation of new knowledge.

Focus of document	Year of publication	Definition of learning health system	Key findings
			• The data utility: Need to streamline and revise research regulations to improve care, promote the capture of clinical data, and generate knowledge. *Care Improvement Targets* • Clinical decision support: Need to accelerate integration of the best clinical knowledge into care decisions. • Patient-centered care: Need to involve patients and families in decisions regarding health and health care, tailored to fit their preferences. • Community links: Need to promote community-clinical partnerships and services aimed at managing and improving health at the community level. • Care continuity: Need to improve coordination and communication within and across organizations. • Optimized operations: Need to continuously improve healthcare operations to reduce waste, streamline care delivery, and focus on activities that improve patient health. *Supportive Policy Environment* • Financial incentives: Need to structure payment to reward continuous learning and improvement in the provision of best care at lower cost. • Performance transparency: Need to increase transparency on healthcare system performance. • Broad leadership: Need to expand commitment to the goals of a continuously learning healthcare system.
Examining the progress toward building a rapid-learning health system in the United States (40)	2014	A rapid-learning health system "learns as quickly as possible about the best treatment for each patient − and delivers it. It makes optimal use of information technology and electronic health record (EHR) capabilities and new databases with tens of millions of patients' records. A rapid-learning system enables and speeds up all elements in the knowledge production and adoption process: discovery science, new drugs development, testing and approval, comparative effectiveness research, physician and patient decision support, and incentives for best practices. A rapid-learning system builds learning networks, delivery systems, and professional societies that use EHRs and computerized databases to assess performance, adopt best practices, assess results, and feedback these lessons."	There are key barriers to the implementation of a rapid-learning health system, including: the concept being too ambitious for America's pluralistic health system; advancing biomedical science is going to prove more difficult than expected (even with massive new databases, learning networks, and analytic tools); and capacity constraints (e.g., in software capabilities or the number of data scientists able to analyze massive datasets).
Describing an ethics framework for a learning healthcare system (41)	2013	A learning health system is a system "in which knowledge generation is so embedded into the core of the practice of medicine that it is a natural outgrowth and product of the healthcare delivery process and leads to continual improvement in care."	The proposed ethics framework consists of seven obligations: 1) to respect the rights and dignity of patients; 2) to respect the clinical judgment of clinicians; 3) to provide optimal care to each patient; 4) to avoid imposing nonclinical risks and burdens on patients; 5) to reduce health inequalities among populations; 6) to conduct responsible activities that foster learning from clinical care and clinical information; and 7) to contribute to the common purpose of improving the quality and value of clinical care and healthcare systems.

Focus of document	Year of publication	Definition of learning health system	Key findings
Examining how to conceptualize and create a global learning health system (42)	2013	Uses the Institute of Medicine's definition of a learning health system: "one in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health and health care."	To achieve this vision of a modern learning health system giving best care for citizens, a number of actions are needed: • embrace the learning health system concept as a core philosophy; • alter the rhetoric from 'secondary use' to 'co-use'; • establish explicit governance, privacy and consent protocols, and a robust oversight mechanism with effective potential sanctions that makes possible a functioning system; • establish a norm of reciprocity; • learn from and about the learning process; • invest in systematic analysis of learning organization national or population-level data; • recognize the value of the minimal additional costs in making learning system data available; and • recognize the importance of enterprise-wide activity.

Identifying the fundamental scientific and engineering research challenges to achieving a national-scale learning health system (43)	2015	Uses the Institute of Medicine's definition of a learning health system: "one in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health and health care."	The article highlights the following system-level requirements that a high-functioning learning health system must satisfy:
			1. A learning health system trusted and valued by all stakeholders
			  • defining, measuring, and tracking confidence and trust
			  • building confidence and trust in the data inputs
			  • building confidence and trust in the process
			  • generating value while building confidence and trust in the outputs
			  • building confidence and trust in the system as a whole
			2. An economically sustainable and governable learning health system
			  • private sector incentives and markets
			  • the role of the public sector in the learning health system
			  • conceptualizing value in the context of the learning health system
			  • the learning health system and the healthcare/health system as a whole
			3. An adaptable, self-improving, stable, certifiable, and responsive LHS
			  • an adaptable learning health system
			  • a self-improving learning health system (that builds trust in the system)
			  • a certifiable learning health system
			  • a stable learning health system (through trust and confidence)
			  • a responsive learning health system
			4. A learning health system capable of engendering a virtuous cycle of health improvement
			  • rapidly creating knowledge that engenders learning
			  • communication within the learning health system: What mechanisms will enable communication of methods used and results obtained, in actionable forms, to all stakeholders with interest in the results?

Focus of document	Year of publication	Definition of learning health system	Key findings
			• building a smart system: How can the learning health system become smart enough? • learning about learning, research about research • key questions specific to health improvement
Examining the fundamental properties of a highly participatory rapid learning system (44)	2010	A federated national learning system in which "data remain in place until they are needed elsewhere for a particular purpose. Predicated on a policy framework that ensures public trust in the process, organizations that are members of a learning system are eligible to place queries to all other members who would then provide relevant information to address the query."	Achieving this vision "will require mutually reinforcing technologies, standards, and policies created in specific anticipation of nationwide implementation. The national program to achieve EHR meaningful use will contribute many but not all of these."
Describing an evolving learning health system at Group Health Cooperative, the six phases characterizing its approach, and examples of organization-wide applications (22)	2012	A rapid-learning health system "leverages recent developments in health information technology and a growing health data infrastructure to access and apply evidence in real time, while simultaneously drawing knowledge from real-world care-delivery processes to promote innovation and health system change on the basis of rigorous research."	The conceptual foundation of the rapid-learning health system has both human and technological aspects. The six phases of the rapid-learning health system are: • internal and external scan (i.e., identify problems and potentially innovative solutions); • design (i.e., design care and evaluation based on evidence generated here and elsewhere); • implement (i.e., apply the plan in pilot and control settings); • evaluate (i.e., collect data and analyze results to show what does and does not work); • adjust (i.e., use evidence to influence continual improvement); and • disseminate (i.e., share results to improve care). The rapid-learning health system model "promotes bidirectional discovery and an open mind at the system level, resulting in willingness to make changes on the basis of evidence that is both scientifically sound and practice-based. Rapid learning must be valued as a health system property to realize its full potential for knowledge generation and application."
Identifying and reflecting on current strategies and programs advancing public understanding of a transformative, patient-centred learning health system (45)	2011	A transformative, patient-centred learning health system is "a system designed to generate and apply the best evidence for care; provide evidence discovery as a natural outgrowth of patient care; and strive for innovation, quality, safety, and value in health care."	Ten common themes emerged about the importance of a patient-focused culture in the content, structure and functioning of a patient-centred, learning health system: • Listening: Each patient-clinician interaction starts with uninterrupted attention to the patient's voice on issues, perspectives, goals and preferences. • Participatory: Health outcomes improve when patients are engaged in their own care. • Reliable: All patients should expect proven best practice as the starting point in their care. • Personalized: With proven best practice as the starting point, science-based tailoring is informed by personal biological traits, circumstances and preferences. • Seamless: Care delivered by multiple providers in multiple settings should be fully integrated and seamless.

Focus of document	Year of publication	Definition of learning health system	Key findings
			• Efficient: Patients, their families and clinicians should expect care to be appropriate to the need, available resource and time required. • Accountable: All relevant aspects of the clinical experience, including patient perspectives, should be captured and routinely assessed against expectations. • Transparent: Information on the outcomes of care − both effectiveness and efficiency − should be readily accessible and understandable to patients and their families. • Trustworthy: Patients should expect a strong and secure foundation of trust on all dimensions − safety, quality, security, efficiency, accountability and equity. • Learning: The patient is an active contributor to and supporter of the learning process.
Exploring strategies for accelerating the development of the digital infrastructure for the learning health system (46)	2011	A learning health system is "a system designed to generate and apply the best evidence for care; provide evidence discovery as a natural outgrowth of patient care; and strive for innovation, quality, safety, and value in health care."	Ten common themes and principles emerged: • build a shared learning environment • engage health and healthcare, population and patient • leverage existing programs and policies • embed services and research in a continuous learning loop • anchor in an ultra-large-scale systems approach • emphasize decentralization and specifications parsimony • keep use barriers low and complexity incremental • foster a socio-technical perspective, focused on the population • weave a strong and secure trust fabric among stakeholders • provide continuous evaluation and improvement
Identifying promising areas for application of engineering principles to the design of a learning healthcare system (47)	2011	A learning health system is "a system designed to generate and apply the best evidence for care; provide evidence discovery as a natural outgrowth of patient care; and strive for innovation, quality, safety, and value in health care."	Eleven common themes emerged: • the system's processes must be centered on the right target − the patient • system excellence is created by the reliable delivery of established best practice • complexity compels reasoned allowance for tailored adjustments • learning is a non-linear process • emphasize interdependence and tend to the process interfaces • teamwork and cross-checks trump command and control • performance, transparency and feedback serve as the engine for improvement • expect errors in the performance of individuals, but perfection in the performance of systems • align rewards on key elements of continuous improvement • education and research can facilitate understanding and partnerships between engineering and the health professions • foster a leadership culture, language and style that reinforce teamwork and results
Examining issues important for improving the	2007	A learning healthcare system "is designed to generate and apply the best evidence for the collaborative healthcare choices of each patient and provider; to drive the process of	Among the most pressing needs to achieve the learning healthcare system are: • adaptation to the pace of change • stronger synchrony of efforts

Focus of document	Year of publication	Definition of learning health system	Key findings
development and application of evidence in healthcare decision-making (23)		discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care."	- culture of shared responsibility - new clinical research paradigm - clinical-decision support systems - universal electronic health records - tools for database linkage, mining and use - notion of clinical data as a public good - incentives aligned for practice-based evidence - public engagement - trusted scientific broker - leadership
Describing an architectural framework to guide the development and implementation of learning health systems (48)	2017	Uses a 2006 definition of the Institute of Medicine: a learning health system is 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 propose the use of architectural frameworks to develop learning health systems which would adhere to a recognized vision while being adapted to their specific organizational context. An architectural framework is a high-level description of an organization as a system (including structures and components, inter-relationships among these, and guiding principles). Learning health systems are generally described and compared based on: - their focus (domain-specific vs multi-domains); and - their scale (single health organizations versus multi-organizations/regional versus national) The proposed architectural framework for learning health systems includes five dimensions: - goal dimension; - scientific dimension; - social dimension; - technical dimension; and - ethical dimension. The proposed framework also highlights six decision layers that model these dimensions: - the performance layer (identifying the goals pursued by a learning health system, as well as measures to track the achievement of these goals); - the scientific layer (identifying the learning activities that will be undertaken in a given learning health system, such as quality improvement or comparative-effectiveness research); - the organizational layer (capturing the chosen governance model and associated responsibilities); - the data layer (providing a common way to describe and share data across organizational boundaries);

Focus of document	Year of publication	Definition of learning health system	Key findings
			- the information technology layer (enabling a standardized manner of categorizing information and communication-technology assets, whether software, hardware or network related); and - the ethics and security layer (capturing the ethical and privacy dimensions of health data collection and use as they relate to security controls and measures).
Examining activities that are necessary for developing a rapid-learning health system (49)	2007	Not reported in detail	Four considerations are important for establishing learning health systems: - recognize that the patient is paramount; - trust is essential; - agreeing to agree on some things is elemental; and - learn what we can about the risks of findings that come from studies other than the randomized clinical trial.

Appendix Table B2: Summary of findings from systematic reviews about rapid-learning health systems

Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
Systematic review addressing other questions	Examining the processes and impacts of developing, implementing and adopting human resource information systems (HRIS) in health organizations (13)	The review examined 68 publications in order to examine human resource information systems in health care. Human resource information systems (HRIS) are a subcategory of administrative systems within health organizations. These systems deal with the management of human resources, including recruitment, teaching, planning and resource allocation. HRIS has potential benefit in healthcare, but further research is needed to identify its usefulness, effectiveness and implementation barriers. The review aimed to assess evidence on HRIS across healthcare organizations, focusing on the methods employed and the focus of interest across studies. In collecting and interpreting the existing evidence on HRIS in healthcare organizations, this review found that few studies considered the socio-contextual and technological factors that influence the operation of HRIS in this context. These factors are crucial in considering the impact of this system. Many studies applied theoretical frameworks, but these frameworks varied across research. Most research in this area focuses on applied projects – in order to advance theoretical understanding, there must be an emphasis on the theory of HRIS development, implementation and use. The focus of studies varies, with high-income countries largely focusing on smaller-scale projects. Lower-income countries mainly focus on broader systems of decision- and policy-making. Finally, there are a limited number of studies focusing on the development and outcomes of HRIS projects as most current research emphasizes usage of HRIS. The review explored HRIS in healthcare, and found that there are important gaps in knowledge when it comes to the impact and effectiveness of these systems. As the cost and size of the healthcare system grows, the need for linkage between administrative data and clinical outcomes grows in importance. In order to enhance "learning" health systems, future research should broadly examine the value of information within health systems.	2014	8/9 (AMSTAR rating from McMaster Health Forum)	5/42
Systematic review addressing other questions	Examining attempts to adopt the Learning Health System paradigm, with an emphasis on implementations and	The review examined 32 documents, including 13 studies, in order to examine the attempts to adopt the Learning Health System paradigm.	2015	2/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail

Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	evaluating the impact on current medical practices (9)	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.			
Systematic review addressing other questions	Examining the spectrum of ethical issues that is raised for stakeholders in a Learning Health System (10)	The review examined 65 studies in order to determine the spectrum of ethical issues raised for stakeholders in a "Learning Health Care System". A Learning Health Care System embodies an approach for integrating clinical research and clinical practice, in order to address problems of effectiveness and efficiency in the healthcare system. In such a system, knowledge generation should be embedded so that health systems can learn and grow. However, this blend of research and practice raises ethical dilemmas such as confidentiality and consent. This review aimed to summarize pertinent ethical issues in order to guide decision-making among healthcare professionals and policymakers. The ethical issues arising in Learning Health Care Systems can be broken down into different phases. In the phase of designing activities, ethical issues include the risk of negative outcomes that may result	2015	1/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail

Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		from activities that are not academically rigorous. As well, it is possible that stakeholders will not engage with this stage, which can affect trust and support in a learning activity. In the ethical oversight of activities, confusion surrounding ethical obligations and regulations can hinder progress. In conducting activities, the involvement of participants can lead to ethical difficulties with consent and data management. In implementing learning, main difficulties arise in changing practice efficiently, maintaining transparency, and reducing unintended negative consequences. The distinction between "research" and "practice" often creates ethical confusion, as many learning healthcare activities do not fit this dichotomy. Strategies to cope with these ethical problems include implementing policies and procedures, providing training and guidance for ethical committee members, and streamlining ethical review processes. The rights of individuals must be protected as healthcare quality improves. Future research should focus on clarifying these ethical dilemmas and contribute to improving the quality of healthcare.			

Appendix Table B3: Summary of findings from primary studies about rapid-learning health systems

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 (15)	*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.
Identifying core competencies for learning health system researchers to guide the development of training programs (21)	*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	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.

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
			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.	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 residents' attitudes about quality improvement and their implications for an effective learning health system (19)	*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 the University of Utah School of Medicine	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) 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.

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 (20)	*Publication date:* 2016 *Jurisdiction studied:* U.S. *Methods used:* A Learning Health Systems Training Program was developed by course leaders. Emphasis was placed 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 were 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.	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.
Exploring the perspectives of health-system leaders on operationalizing the learning health system (18)	*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

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
				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.
Identifying ethical issues arising in the transition to learning health systems (11)	*Publication date:* 2016 *Jurisdiction studied:* U.S. *Methods used:* Semi-structured telephone interviews Participants were recruited using purposive sampling. Institutions that were considered to be learning health-care system leaders were targeted.	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 considered leaders in the learning healthcare system.	The transition to a learning healthcare system brings a number of ethical considerations. Identifying these considerations is key to realizing the goals of learning healthcare. Interviews with leaders in the learning healthcare system yielded discussion of seven ethical challenges: (1) ethical oversight of learning activities; (2) 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.
Examining factors influencing the implementation of a system delivering clinical studies via a distributed electronic network linked to electronic health records (17)	*Publication date:* 2012 *Jurisdiction studied:* U.S. *Methods used:* The requirements for using electronic health records for clinical research were identified. Following this, a functional prototype of the software necessary for conducting this delivery of clinical studies was developed.	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

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
				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.
Examining how to advance an organization's learning capabilities, as a core element of learning health systems (16)	*Publication date:* 2017 *Jurisdiction studied:* U.S. *Methods used:* An environmental scan of the literature on learning health systems was conducted, followed by semi-structured interviews with clinic staff	In addition to a literature search, interviews were conducted with 127 staff members from Billings Clinic, an integrated healthcare delivery system in Montana	n/a	Literature on learning health systems focuses on the information technology that is needed to translate the knowledge derived from data. This process demands an understanding of the process of learning, a topic which is given insufficient attention. This study examined the literature and drew on evidence from semi-structured interviews in order to determine the principles that guide effective learning. Six key learning principles were derived: (1) draw on wisdom of groups and value connections; (2) embrace sense-making over decision-making in dealing with the unexpected; (3) bring diverse perspectives to complex challenges; (4) animate people, provide direction, update regularly and interact respectfully; (5) appreciate the power and ubiquity of emergent change and the limitations of planned change; and (6) concentrate on small wins and characterize challenges as mere problems. This study presented evidence of the success of these guiding principles through emerging initiatives at Billings Clinic. Relational coordination, a theory that explores the attributes contributing to team success with complex tasks, became a learning method in the ICU. Staff members cited the success of this initiative in interviews. A project with Safe and Reliable Healthcare led to a project between the inpatient medical unit and the emergency department, in which initial failure translated into ultimate success. Finally, Project ECHO (Extension for Community Healthcare Outcomes) saw mental health and addictions services brought to marginalized populations in Montana.
Examining factors allowing a healthcare system to become a learning healthcare system (14)	*Publication date:* 2016 *Jurisdiction studied:* U.S. *Methods used:*	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	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.

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
	Semi-structured interviews conducted with leaders from 25 leading healthcare systems		learning healthcare system and the ethical issues encountered.	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.
Examining the role for learning health systems in quality improvement within healthcare providers (12)	*Publication date:* 2017 *Jurisdiction studied:* U.S. and U.K. *Methods used:* A literature review, semi-structured interviews, focus groups, and site visits were undertaken	Experts in the field of learning health services were identified from the literature. Participants were based in the United Kingdom and United States. A snowball approach to sampling was undertaken until a group of key experts emerged.	The first phase of this study included a literature review on learning healthcare systems. The second phase included in-depth semi-structured interviews or focus groups with experts identified from the literature review, as well as site visits. The third phase was a final deductive thematic analysis of the literature, interviews, focus groups and site visits.	Learning healthcare systems can improve quality of care by closing gaps in research evidence. However, this study focused on how learning healthcare systems might address the six dimensions of healthcare quality: safe, effective, patient-centred, timely, efficient, and equitable. Six types of learning health systems were identified in this study: 1) intelligent automation; 2) clinical decision support; 3) predictive models; 4) positive deviance; 5) surveillance; and 6) comparative effectiveness research. These types of learning health systems are broad and overlapping, and each has a unique impact on the dimensions of quality of care. Further research should explore issues of evaluation and monitoring for all forms of learning heath systems, in order to build an evidence base. Equity should be of primary focus within the learning healthcare-services community. This study found that learning health systems can have positive and negative impacts on quality, a finding that provides a framework and direction for future research.

Appendix Table B4: Summary of findings from descriptive cases of rapid-learning health systems

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
A person-centred, registry-based learning health system for palliative care (27)	*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.
Learning Networks care centres (28)	*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.
Veterans Health Administration (31)	*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)

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
			system improvement requires a focused set of performance measures.
Ontario's cancer services (29)	*Publication date:* 2015 *Jurisdiction:* Canada *Level (e.g., national, regional, local)* Regional *Sector (e.g., cancer, mental health)* Cancer	Key features of this learning health system include: a Quality Council, which assembles and reports publicly on a provincial and regional picture of performance and quality; a Clinical Council, which ensures engagement of specialty discipline and disease site leaders; and a regional Provincial Leadership Council, which brings the regional vice-presidents together to align overall planning, performance measurement, and reporting activities.	Not reported
Geisinger Health System (26)	*Publication date:* 2015 *Jurisdiction:* U.S. *Level (e.g., national, regional, local)* Various levels *Sector (e.g., cancer, mental health)* Various sectors	The framework of this Learning Health Care System (LHCS) focuses attention on nine key operational components: data and analytics; people and partnerships; patient and family engagement; ethics and oversight; evaluation and methodology; funding; organization; prioritization; and deliverables	Important lessons are presented around four main themes. First, a realistic assessment of the capacity and capabilities of the organization and its data and analytic infrastructure is critical to defining the scope of operationalization and setting expectations among leaders and staff. Second, it was found that patient and family engagement is core to the LHCS. Patient engagement requires trust, redefined relationships with the system, and consideration of health literacy so that patients can successfully navigate new LHCS practices. Third, integrating patients and their families, clinical care, and various modes of discovery requires a defensible ethical framework that undergirds a system of strong but flexible oversight. Fourth, supportive leadership is imperative for advancement of the LHCS model.
ImproveCareNow Network (34)	*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.

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
Indiana University Center for Healthcare Innovation and Implementation Science (35)	*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.
PEDSnet (32)	*Publication date:* 2014 *Jurisdiction:* U.S. *Level (e.g., national, regional, local)*: National *Sector (e.g., cancer, mental health)*: Pediatrics	PEDSnet is a clinical data research network which provides the infrastructure to support a national pediatrics learning health system. It includes eight academic medical centres and national data partners from the National Pediatric Learning Health System. PEDSnet implements flexible architecture which incorporates data models and national standards to support data integration, discovery and advanced analytics.	Data and information infrastructure are not consistent across state lines in the United States and pose significant barriers to multi-institutional data sharing. This requires PEDSnet to synchronize variables and values using a standardized approach set forth by the U.S. government. The National Library of Medicine is seen as an important facilitator in this process and can help serve as a national resource for defining all terms that support quality reporting from electronic health records.
Washington State's Comparative Effectiveness Research Translation Network (CERTAIN) (30)	*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 suggested as an opportunity for program sustainability and may help in its implementation in other jurisdictions.

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
American Society of Clinical Oncology's CancerLinQ (33)	*Publication date:* 2013 *Jurisdiction:* U.S. *Level (e.g., national, regional, local):* National *Sector (e.g., cancer, mental health):* Cancer	ASCO runs a program called CancerLinq, a learning information network for quality that collects clinical data in real time to analyze and compare with existing guidelines, and feeds this information to physicians on the ground to increase the quality and outcomes of care for patients in real time. CancerLinq operates on an iterative process of providing services at the point of care, in-taking data, transforming data, aggregating data and analyzing data based on peer review and feedback.	The preliminary success of CancerLinq was achieved in part with an open source electronic health record system to engage with regional and national compliance standards for specific procedures and guidelines. Clinicians were willing to sign data-use agreements and share data; this helped the CancerLinq prototype in California de-identify and enter data in accordance with the Health Insurance Portability and Accountability Act, ultimately leading to case enrollment of 130,000 cases.
Collaborative Chronic Care Networks (C3Ns) (50)	*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 know-how 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.
Pediatric collaborative improvement networks (51)	*Publication date:* 2013 *Jurisdiction:* U.S. *Level (e.g., national, regional, local):* National *Sector (e.g., cancer, mental health):* Pediatrics	Pediatric collaborative improvement networks have been designed to close quality gaps, engage patients and caregivers in shared learning, and act as sources for accelerated translational research to improve children's health outcomes. Unlike traditional models, these improvement networks plan to persist until aims are achieved and improvement is sustained. The improvement networks described are amalgamations of the collaborative efforts taken by the Children's Oncology Group, Northern New England Cardiovascular Disease Study Group and Cystic Fibrosis Foundation. The networks focus on: high-impact conditions; health topics and safety issues; support from clinical content and quality improvement experts; use of the Model for Improvement which sets measurable targets for testing changes in small scales and "learns by doing"; infrastructure for monthly data collection and analysis; and learning workshops and physician and nurse engagement for issues such as infection control and diet management.	Start-up funding and ongoing grant-related funding challenges, as well as the "pay to play" concept for participant fees present barriers for low-revenue sub-specialties such as rheumatology and adolescent medicine. Furthermore, the relatively low amount spent on child health, even for those with chronic or rare diseases, present challenges in getting the attention of insurers or specialized pediatric-care facilities. Potential facilitators to the success of this program in other jurisdictions largely involve incentives for funding this multidisciplinary learning health system in other academic institutions and among lower-revenue specialties.
University of Wisconsin (51)	*Publication date:* 2017 *Jurisdiction:* Wisconsin, U.S.	In the University of Wisconsin, change domains were not restricted to any particular domain of health practice, but were instead catered toward integrating strategic planning processes, governance structure to establish enterprise-wide goal setting and	Academic health centres have traditionally struggled with establishing clear learning health systems. These difficulties stem from variable organizational structures, a poor alignment of culture, strategy and resources, especially

58

Case	Case characteristics	Key features of the rapid-learning health systems	Implementation considerations
	Level (e.g., national, regional, local): Regional *Sector (e.g., cancer, mental health):* Academic health centres	improvement, as well as patient-centred design initiatives, health leadership, performance reporting and EHR-embedded tools for clinical decision-making set as primary targets of the learning health system. Performance was measured across the Triple Aim, and population health measurement was focused on publicly reported performance metrics.	between hospital administration and faculty. Autonomy also threatens efforts to standardize care practices, often impeding efforts to implement evidence-based care between various hospital departments.

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