

Panel Summary

Supporting Rapid Learning and
Improvement for Select Conditions
in Canada

20 February 2020



HEALTH FORUM

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Supporting Rapid Learning and Improvement for Select Conditions in Canada

McMaster Health Forum

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

About citizen panels

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

About this summary

On the 17th of January 2020, the McMaster Health Forum convened a citizen panel on supporting rapid learning and improvement for select conditions in Canada. This summary highlights the views and experiences of panel participants about:

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

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

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Summary of the panel

During the deliberations about the problem, panellists identified a range of important challenges that were linked to their own care experiences (e.g., access to their providers and health data, inadequate or incomplete care, access to information on their condition). They were then prompted to reflect on whether and how these issues aligned with the four challenges related specifically to rapid learning and improvement outlined in the citizen brief: 1) health systems are missing opportunities to learn and improve rapidly; 2) some conditions are not prioritized by health systems; 3) other initiatives steer away from specific conditions; and 4) not all assets are in place or well-connected to support health systems to learn and improve. Overall, the majority of the panellists, regardless of which province they were from, or which condition they had experience with, raised similar challenges in relation to these issues.

There was broad agreement when discussing the elements of a potentially comprehensive approach to address the problem. Panellists identified the need for better supports for engaging patients in identifying strengths and weaknesses in health systems (**element 1**). This could include creating tailored patient information about assets and gaps in health systems and creating space for them to share feedback with stakeholders. Similarly, panellists indicated that in order for health systems to build on strengths and address weaknesses (**element 2**), there was a need for establishing better supports to engage patients in the process, which would also require efforts to address patient-health information gaps, as well as adjusting health-system arrangements to reflect the current needs of patients. Lastly, panellists briefly discussed that in order to observe improvements and progress from health-system changes (**element 3**), there is a need to establish mechanisms that ensure realistic and meaningful targets are set that relate directly to improving patient care and experience.

Panellists identified limited resources (both human and financial) as one of the biggest barriers to supporting rapid learning and improvement for select conditions. They also expressed their doubts on health system actors' willingness to move away from the status quo to embrace a mindset conducive to continuous learning and improvement. In discussing potential strategies to move forward, panellists identified ways for the health system to engage patients, such as involving them in roundtable discussions with stakeholders, drawing on their lived experiences to design relevant decision supports, and co-creating timely and relevant evidence through patient-oriented research opportunities.



“The system is overwhelmed, and I would like to see changes, but I don’t know where to begin.”

Discussing the problem:

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

During the start of the deliberation about the problem, panellists were asked to share what they perceived to be the main challenges hindering health systems’ capacity for rapid learning and improvement for select conditions. In a general sense, panellists described limited resources (human, digital or data, finance) and an unsupportive culture among important actors in the health system (e.g., health professionals) as key challenges in establishing rapid-learning health systems. When prompted, the panellists further elaborated on these points as they focused their attention on each of the four challenges described in the citizen brief:

- 1) health systems are missing opportunities to learn and improve rapidly (in the context of rapid learning and improvement characteristics);
- 2) some conditions are not prioritized by health systems;

- 3) other initiatives can steer focus away from specific conditions; and
- 4) not all assets are in place or well connected to support health systems to learn and improve.

We review each of these challenges, as well as the insights brought forward by panellists, in turn below.

Health systems are missing opportunities to learn and improve rapidly

Panellists identified a range of challenges that resulted in missed opportunities for rapid learning and improvement in health systems across Canada. They anchored their responses in how they understood the seven characteristics of rapid-learning health systems with illustrations of their own clinical encounters (such as interactions with health professionals) and for the conditions they have personal experience with.

With respect to the first characteristic of a rapid-learning health system – engaging patients – some panellists indicated that their experiences with inadequate access and difficulties receiving timely clinical care meant it would be very challenging to ensure health systems were consistently engaging patients in the fulsome manner required for rapid learning and improvement. Anchoring their specific responses within the context of their own personal clinical-care experiences, many panellists expressed their concern that it was difficult to access primary-care physicians and specialists in general, and even when they

Box 1: Key features of the citizen panel

The citizen panel about supporting rapid learning and improvement for select conditions in Canada had the following 11 features:

1. it addressed a high-priority issue in Canada;
2. it provided an opportunity to discuss different features of the problem;
3. it provided an opportunity to discuss three options for addressing the problem;
4. it provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. it provided an opportunity to talk about who might do what differently;
6. it was informed by a pre-circulated, plain-language brief;
7. it involved a facilitator to assist with the discussions;
8. it brought together citizens affected by the problem or by future decisions related to the problem;
9. it aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. it aimed for open and frank discussions that will preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

were successful in accessing services, they often received inadequate or incomplete care that wasn't centred on their needs. Some panellists expressed that they are only able to "bring up one case or issue at a time" during the time they had with their primary-care physicians and specialists, and that physicians "don't want to hear about older issues" that are already considered dealt with. One panellist also shared her experience waiting for a promised phone call from her doctor for months, without ever receiving one.

When considering the second characteristic of a rapid-learning health system – how health systems are set up to facilitate capturing and sharing relevant data – many panellists expressed concern more generally about: 1) the lack of routine systems for collecting data about their care experiences and outcomes; and 2) the minimal effort from health-system actors to help link information across the entire health system. For example, several panellists voiced concerns with the fact that they were not aware of a central location for comprehensive information about patients that could be easily shared and communicated among providers and organizations. One panellist expressed frustration with the lack of communication and sharing of data: "I have hospitals that don't talk to each other." With the current challenges related to timely collection and sharing of data, many panellists expressed doubts about a health system's capability to operationalize this characteristic in a rapid-learning health system.

In the discussion surrounding the third characteristic of a rapid-learning health system – producing research evidence in a timely way – some

Box 2: Profile of panel participants

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants:

- How many participants?
12
- Where were they from?
Québec (2), British Columbia (3), Ontario (4), Nova Scotia (2), Alberta (1)
- How old were they?
18-24 (1), 25-34 (1), 35-49 (4) 50-64 (4), and 65 and older (2)
- Were they men or women?
men (7) and women (5)
- What was the educational level of participants? *
9% completed elementary school, 9% completed high school, 18% completed community college, 9% completed technical school, 27% completed a bachelor's degree, and 27% completed post-graduate training or professional degree
- What was the work status of participants? * 9% self-employed, 27% working full-time, 9% working part-time, 9% unemployed, 27% retired, and 18% disabled
- What was the income level of participants? * 27% earned less than \$20,000, 18% between \$20,000 and \$40,000, 9% between \$40,000 and \$60,000, 9% between \$60,000 and \$80,000, 18% more than \$80,000, and 18% prefer not to answer
- How were they recruited? Selected based on explicit criteria from the AskingCanadians™ panel

**based on 11 completed evaluations*

panellists perceived this as challenging to weigh in on due to the lack of clarity on how research was funded.

Other panellists expressed concern about the lack of capacity among and time available to their primary-care providers to access and apply relevant research into clinical practice. One panellist explained that this asks “doctors to go out of their way to keep up without extra compensation.” Some panellists mentioned that the health system requires a greater integration of research and clinical practice, and one emphasized the importance of local knowledge in rapid learning and improvement because “one solution doesn’t fit all.” Panellists expressed that there is a need for timely research evidence from a rapid-learning approach in order to understand which strategies can improve health and care experiences.

Additionally, many panellists identified a lack of appropriate decision supports for patients – which relates to the fourth characteristic of a rapid-learning health system. Some panellists described their challenges with accessing their own health information alongside relevant research evidence that could help inform and improve their decision-making when it comes to their own healthcare and experiences. Several panellists explicitly noted that there was no single trusted source of information for their condition, or for patients more generally. The panellists perceived that it would be challenging to be fully engaged in a rapid-learning approach if they do not have access to decision supports.

When expressing their viewpoint on the fifth characteristic that supports rapid learning and improvement – aligning governance, financial and delivery arrangements – many panellists indicated that the current arrangements are not aligned or optimally prioritized to help address their perceived systemic issues, such as the lack of accountability (i.e., governance), limited resources and funding (i.e., financial), and inadequate access to timely patient care (i.e., delivery). Panellists described that aligning governance, financial and delivery arrangements would need to occur before adapting a rapid-learning approach.

With regards to the sixth characteristic of a rapid-learning health system – fostering a culture of rapid learning and improvement – some panellists acknowledged that while there are existing organizations and other research groups that are developing an adaptive culture that is conducive to rapid learning and improvement, there are still unknowns about the specific mechanisms on how to create these changes among patients, physicians, and across organizations in the system. In particular, panellists perceived that there isn’t enough knowledge and expertise on what is meant by rapid learning and improvement generally (or about the specific characteristics needed to establish a rapid-learning health system

specifically). Additionally, panellists weren't sure if there is widespread willingness among the full range of health-system stakeholders to actively engage in efforts to rapidly learn and improve.

Finally, when discussing the seventh characteristic of a rapid-learning health system - building competencies for all of the characteristics – one panellist was unclear about the current efforts around building knowledge and expertise on rapid learning and improvement, such as whether there is any existing funding to support emerging learning-system researchers, or any research institutes that are building in-house capacity and application of this approach.

Another panellist explained that strengthening the sixth and seventh characteristics of a rapid-learning health system (i.e., fostering a culture of rapid learning and improvement and building the competencies for rapid learning and improvement) would be very difficult to pursue in Canada. The panellist explained that focusing on these two vital characteristics would first require health-system stakeholders to feel comfortable moving on from their existing efforts to address current health-system challenges, and given the many high-profile problems across the country (e.g., access to prescription medicines, hospital overcrowding and wait times), this was unlikely.

Some conditions are not prioritized by health systems

Some panellists noted, and others agreed, that there is a lack of timely research for conditions that are not considered a priority by health systems (which was reflected in the pre-circulated citizen brief). These panellists indicated that there is a need for research on these conditions. However, most panellists acknowledged that not all conditions could be prioritized, and felt general discussions about how rapid learning and improvement could be supported are also helpful, as long as they take into consideration the unique challenges and needs of specific patient populations living with specific conditions, and the discrepancies in research funding across various conditions.

Other initiatives can steer focus away from specific conditions

There was consensus among the panellists that it is difficult for the health system to prioritize new issues in the face of existing and unresolved high-profile challenges such as access to prescription medicines, hospital overcrowding and wait times. Physicians and

other health-system stakeholders were described by some panellists as having limited capacity to drive systemic change and improvements within this context, with one panellist noting that it was important for systems to “get their house in order” to address the most pressing patient needs before trying to achieve broader learning and improvement goals.

Some panellists emphasized that political events and changing government priorities make funding for healthcare initiatives – including coordinated efforts to support strengthening assets for rapid learning and improvement for select conditions – unpredictable. Some panellists noted that the disparity in how much is invested in research and front-line care for some conditions compared to others illustrated this point.

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

Many panellists identified and most agreed that there are two critical areas that lack the assets required to support rapid learning and improvement. The first area identified by panellists as being characterized by particularly troublesome gaps was capacity in health systems for digital capture, linkage and timely sharing of relevant data. In illustrating this point, many panellists pointed to the lack of a central database to collect and capture information in some provinces (and to the lack of supports designed to help patients and their families, as well as health professionals in accessing and using this information). The second area identified by panellists as having critical gaps was with existing health-system delivery arrangements that significantly reduce the feasibility of creating rapid-learning health systems in Canada.

In particular, many panellists expressed a concern with the lack of human resources available to provide even the most basic care across health systems in Canada. Some panellists also highlighted that there is understaffing in hospitals and a shortage of primary-care physicians, which reduce the likelihood that patients can access the care they need in a timely way. With such resource shortfalls across existing health systems in Canada, many panellists questioned how moving forward with efforts to strengthen assets and fill gaps across the seven characteristics of a rapid-learning health system would be feasible, as it wasn't clear who could take on the additional work.



Panellists identified the need for informational supports in order to be fully engaged in the efforts to establish rapid-learning health systems.

Discussing the elements:

How can we address the problem?

After discussing the challenges related to the problem, panellists were invited to reflect on three elements of a potentially comprehensive approach to support rapid learning and improvement for select conditions in Canada:

- 1) identify strengths and weaknesses in health systems;
- 2) build on strengths and address weaknesses to help health systems to learn and improve rapidly; and
- 3) set targets to determine if health systems are making progress.

A description of these elements, along with worksheets that focused on potential roles and supports for patients in identifying strengths and addressing weaknesses, in addition to a worksheet to help identify realistic targets to monitor progress, were provided to panellists in the citizen brief that was circulated before the event. During the deliberations several values and preferences were identified by citizens in relation to these elements. Whenever possible, we describe and identify the values underlying the panellists' positions.

Element 1 – Identify strengths and weaknesses in health systems

The first element focused on identifying strengths and weaknesses in health systems. As outlined in the citizen brief, patients can play a critical role in this element as a step towards creating health systems that have the right assets in place for rapid learning and improvement (including efforts to engage citizens and patients in decision-making at all levels). In discussing element one, panellists were encouraged to consider which roles citizens and patients are best positioned to play in identifying strengths and weaknesses in relation to creating rapid-learning health systems.

Box 3: Values-related themes about identifying strengths and weaknesses in health systems (element 1)

Six values-related themes emerged during the discussion about element 1:

- trust (especially in the relationship between patients and providers)
- collaboration (among patients, providers and organizations within the health system)
- values-informed decision-making
- empowerment
- continuous improvement
- excellent patient experience

During the discussion about their roles and the supports needed for engaging patients to identify strengths and weaknesses in health systems, six values-related themes emerged (see Box 3). The first values-related theme was trust (especially between patients and providers). A few panellists expressed their perception that there are a mix of trained providers who genuinely care, and others who appear to not care about improving patient care and experience. Additionally, panellists agreed that there was a shortage of providers, and that this limited a provider's capacity to invest the required time and effort to engage patients, establish trusting relationships, and open up conversations about the patient perspective on health-system performance. Some panellists suggested that in order to establish trust, providers would need to commit to ensuring patients were empowered to discuss their views about the strengths and weaknesses in health systems during clinical visits.

The second and third values-related themes were collaboration (among patients, providers and organizations within the health system) and value-informed decision-making. Many of the panellists suggested increasing opportunities for patient engagement. Panellists raising this point suggested that direct engagement with health-system stakeholders lends an opportunity for patients to proactively collaborate and help identify health-system strengths and weaknesses that impact their health experience and care decisions. Additionally,

engaging citizens at round-table discussions with physicians, managers and policymakers was identified by the panellists as a specific approach.

The fourth values-related theme was empowerment. Specifically, panellists wanted increased access to tailored, visually appealing patient information in a variety of formats (such as online or in-person), that could help them to build their knowledge about and engagement in the process of assessing health systems' readiness for rapid learning and improvement. A number of panellists also suggested that it is important to establish mechanisms that would enable them to provide feedback (such as suggestion boxes and online surveys), as well as clarity about how their feedback would be used to inform decision-making about their health system.

The fifth and sixth values-related themes that underpinned panellists' views were continuous improvement, and excellent patient care. In particular, some panellists suggested that the importance of a rapid-learning and improvement approach from a patient perspective (at least in the way it was described in the citizen brief) was in its prioritization of continuous improvement through the lens of patient care and experiences, with an emphasis on optimizing systems in a way that directly addressed their needs. To ensure that this approach was one that consistently prioritized patient inputs, some of the panellists suggested establishing dedicated quality-improvement teams specifically tasked with continuously gathering confidential patient feedback about their experiences.

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

The discussion about the second element focused on building on strengths and addressing weaknesses in the seven characteristics required for health systems to learn and improve rapidly (i.e., engaging patients, capturing and sharing relevant data, producing research evidence in a timely way, appropriate decision supports, aligning system arrangements, fostering a culture of rapid learning and improvement, and building competencies). Panellists were encouraged to focus on discussing the role that patients could play in this process.

There were six values-related themes that emerged during the discussion about element two (see Box 4), and most were framed by panellists in a way that was similar to how they discussed them in relation to element one. The first values-related theme that emerged was collaboration (among patients, providers and organizations within the health system). Panellists suggested that there is a need for increased opportunities for patient engagement and collaboration with health-system stakeholders (such as sharing real-time feedback about health-system improvement efforts in a round-table discussion with other stakeholders, and during clinical encounters with primary-care providers). Panellists suggested that these improved collaborations would be essential to improving patient health experience and care needs.

The second values-related theme was values-informed decision-making. Many of the panellists described the need for health-system arrangements to be adjusted in ways that reflect the needs of patients (such as providing financial assistance for services that aren't covered to those in need, creating an alternative to emergency rooms for patients who seek medical care for non-life-threatening conditions after business hours, ensuring preventive care is prioritized and delivered to at-risk individuals). By providing these examples on how to adjust the health system (so that it aligns more with patient values and preferences),

Box 4: Values-related themes about building on strengths and addressing weaknesses to help health systems to learn and improve rapidly (element 2)

Six values-related themes emerged among panellists during the discussion about element 2:

- collaboration (among patients, providers and organizations within the health system)
- values-informed decision-making
- access
- efficiency
- continuous improvement
- excellent patient experience

panellists indicated that these were the types of improvements that could help build on strengths and address weaknesses in support of rapid learning and improvement.

The third and fourth values-related themes were access and efficiency of data collection and sharing. These values emerged during the discussion among panellists about access to their own health information. With respect to data access, panellists expressed that it was difficult to retrieve and share their health data with different providers across the health system. Speaking to improving the efficiency of data collection and sharing, many of the panellists suggested that there is a need for a systematized approach to collect health data and automate the transfer of patient-health information between clinics and among providers (such as providing patient data in a portable format or standardizing data software across hospitals and primary-care providers). The panellists expressed that addressing these needs could benefit a health system that is aiming to rapidly learn and improve their health experiences and care.

The fifth and sixth values-related themes were continuous improvement and excellent patient experience. These themes emerged when panellists were discussing how patient experience and care could be incorporated into the health system in specific approaches. For example, panellists generally agreed that there should be increased opportunities for patients to engage in the timely production of patient-oriented research that is anchored in improving their care experiences (as part of a continuous improvement process). Additionally, panellists suggested that patients' experiences could be drawn into the design of appropriate decision supports, such as repositories of evidence-informed medical advice for managing their conditions, as well as sources of information about what those with their condition can expect (e.g., prognosis and available care options).

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

The discussion surrounding element three focused on a broad discussion about targets that can help determine if health systems are making progress. Patients could play a key role in identifying possible targets and measurable indicators. As outlined in the citizen brief, there were potential targets for the panellists to consider, such as:

- access to care;
- efficiency;
- quality of care;
- equity;
- health status;
- health determinants; and
- other targets.

Some panellists indicated that they were unclear about this element and/or what role they could play in supporting the establishment of targets to measure progress of rapid-learning health systems in Canada. Given the uncertainty, panellists had relatively fewer reactions about the element. However, some of the panellists did mention that regardless of the role they were expected to play in setting them, the targets had to be achievable, reachable, or realistic. Overall, panellists raised two values-related themes during the discussion about element 3 (see Box 5).

The two values-related themes were transparency and accountability. Some of the panellists indicated that targets should relate directly to improving patient care and experience by selecting meaningful indicators for patients, such as emergency-department wait times and access to care. Panellists noted that setting these targets would require a transparent process, such as explicitly stating the type of data being collected (e.g., collecting patient health outcomes).

Box 5: Values-related themes about setting targets to determine if health systems are making progress (element 3)

Two values-related themes emerged during discussions about element 3:

- transparency
- accountability

Intertwined with transparency, panellists expressed that there needs to be accountability measures such as clearly stating who is responsible for collecting data related to the proposed targets, explaining how and where the data is being integrated, and establishing mechanisms that help maintain transparency of the funding sources for rapid-learning and improvement approaches. Some panellists expressed concerns about accountability, specifically with the constant changes in government and shifts in the governing bodies.



“There needs to be a willingness to change.”

Discussing implementation considerations:

What are the potential barriers and facilitators to implementing these elements?

After discussing the three elements of a potentially comprehensive approach for addressing the problem and a wrap-up to the day, each panellist was prompted to briefly describe their views about the potential challenges and facilitators for moving forward.

Panellists identified that limited resources (human, digital or data, financial) was one of the biggest barriers for supporting rapid learning and improvement for select conditions. Panellists expressed the following: 1) a shortage of providers (thereby provider time and capacity) could mean fewer opportunities for meaningful engagement and collaboration with patients; 2) the use of outdated technologies may limit the collection and sharing of timely data across health systems; and 3) a shift of financial resources would need to occur in order to prioritize and support rapid learning and improvement.

They also expressed their doubts about whether there was a willingness among health-system policymakers and stakeholders – from all levels – to move from the status quo and embrace a mindset that focuses on solutions and continuous improvement. The panellists described that without a willingness to change or having buy-in from policymakers and

other stakeholders, it would be difficult to foster a culture of rapid learning and improvement.

In discussing potential strategies for moving forward, the panellists listed four opportunities that could help facilitate the creation of a rapid-learning and improvement approach. First, panellists emphasized that patient engagement in care and in research is a feasible approach to strengthen a rapid-learning system. Second, panellists expressed that there is a need for effective communication and information about the strengths and weaknesses of their own health system before identifying rapid-learning approaches. Third, panellists emphasized that a culture shift centred on embracing health-system learning and continuous-improvement opportunities should be built into the approach. Finally, panellists suggested that capturing and sharing patient data first requires stakeholders to embrace new technology and digitization.

Acknowledgments

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Conflict of interest

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