Dialogue Summary

Creating a Pan-Canadian Learning Health System for Neurodevelopmental Disorders

14 & 15 December 2020

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McMaster Health Forum and Forum+

The goal of the McMaster Health Forum, and its Forum+ initiative, is to generate action on the pressing health- and social-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 and social systems – locally, nationally, and internationally – and get the right programs, services and products to the people who need them. In doing so, we are building on McMaster's expertise in advancing human and societal health and well-being.

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funders reviewed a draft dialogue summary, but the authors had final decision-making authority about what appeared in the dialogue summary.

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Dialogue

The virtual stakeholder dialogue about creating a pan-Canadian learning health system for neurodevelopmental disorders was held on 14 & 15 December 2020 via MS Teams and hosted by the McMaster Health Forum.

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SUMMARY OF THE DIALOGUE

During the deliberation about the problem, participants generally agreed with the key issues and how they were framed in the evidence brief. However, they also highlighted five additional aspects of the problem that are critically important to address as part of efforts to create a pan-Canadian rapid-learning health system for neurodevelopmental disorders:

1. challenges in striking the right balance between understanding individual needs through diagnoses compared to functional abilities;
2. lack of consensus around how to define conditions, identify needs and establish approaches to care, which can make it challenging to coordinate efforts and drive the changes needed to establish rapid-learning and improvement assets;
3. rewards systems and politics that have historically reinforced an emphasis on clinical diagnoses for particular conditions, often with the unintended consequences of creating both disincentives for adopting a 'lifespan' approach, and an imbalance in the assets that exist to support rapid learning and improvement;
4. lack of coordinated and integrated programs and services across the lifespan for individuals with neurodevelopmental disorders (e.g., pediatric to adult care); and
5. older adults with neurodevelopmental disorders are underserved in all areas of care.

Deliberations about the elements illustrated that participants generally agreed with the approaches as described in the evidence brief. For Element 1 – prioritize service needs and design a rapid-learning and improvement approach to meet them – participants indicated that this approach should prioritize the utilization of existing assets and strengthen current networks instead of mobilizing new resources to create new assets and networks For Element 2 – strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada – nearly all participants agreed that while this approach is needed, there was a level of uncertainty on what the process would look like. Some participants suggested conducting a targeted community-level mapping and priority-setting exercise as the first step, which could then be scaled up. For Element 3 – establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action – some participants suggested the need to clarify who is responsible for specific high-level decisions across the health and social systems, and to identify existing assets and gaps (e.g., access to data systems), and that this could be done in tandem with the mapping planned in element 2. The mapping framework or road map could be utilized as next steps in conceptualizing and fostering a collaborative network of key individuals and 'rapid-learning champions.' Participants also collectively identified a set of underlying principles to guide these efforts moving forward. When discussing implementation considerations, two important barriers were raised by participants, including a lack of clarity about scope and how best to establish an appropriate organizational structure for supporting the creation of a pan-Canadian learning health system, as well as challenges in shifting the culture in health- and social-care systems to be supportive of the approach. In terms of opportunities, participants collectively agreed that they share a strong desire to continue moving forward with creating a pan-Canadian learning health system for neurodevelopmental disorders, which has created and will continue to propel a 'coalition of the willing.'

Participants suggested five broad next steps required to establish a rapid-learning health system for neurodevelopmental disorders in Canada: 1) establish a core leadership group to develop and iteratively revise a compelling vision and road map; 2) identify and engage with key stakeholders, stewards and funders to clarify roles, operationalize the road map, and normalize a culture that is supportive of rapid learning and improvement; 3) develop and pilot a proof of concept that reflects a lifespan approach and is based on functional needs; 4) mobilize the networks required to scale up the approach to engage a wider array of players; and 5) use existing success stories of learning health-system models as a platform to move forward with additional efforts across Canada.

SUMMARIES OF THE FOUR DELIBERATIONS

The McMaster Health Forum, with support from the Azrieli Foundation in partnership with McMaster University, virtually convened a stakeholder dialogue about creating a pan-Canadian learning health system on the 14th and 15th of December, 2020. There were 18 participants, including a mix of policymakers, stakeholders and researchers from across the country, all of whom read a pre-circulated evidence brief in advance of the dialogue. The agenda for the dialogue was organized around four deliberations: clarifying the problem; identifying elements of a potentially comprehensive approach to address the problem; identifying key implementation considerations; and discussing next steps. Below, we provide a thematic summary of the key insights to emerge within each deliberation over the course of the event.

DELIBERATION ABOUT THE PROBLEM

During the deliberation about the problem, participants generally agreed with the key issues and how they were framed in the evidence brief. However, they also highlighted five additional aspects of the problem that are critically important to address as part of efforts to create a pan-Canadian rapid-learning health system for neurodevelopmental disorders:

1. challenges in striking the right balance between understanding individual needs through diagnoses compared to functional abilities;
2. lack of consensus around how to define conditions, identify needs, and establish approaches to care, which can make it challenging to coordinate efforts and drive the changes needed to establish rapid-learning and improvement assets;
3. rewards systems and politics that have historically reinforced an emphasis on clinical diagnoses for particular conditions, often with the unintended consequences of creating disincentives for adopting a 'lifespan' approach, and an imbalance in the assets that exist to support rapid learning and improvement;
4. lack of coordinated and integrated programs and services across the lifespan for individuals with neurodevelopmental disorders (e.g., pediatric to adult care); and
5. older adults with neurodevelopmental disorders are underserved in all areas of care.

Each of these additional dimensions of the problem are described in greater detail in the sections that follow.

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

1) it addressed an issue currently being faced in Canada;
2) it focused on different features of the problem, including (where possible) how it affects particular groups;
3) it focused on three elements of a potentially comprehensive approach for addressing the policy issue;
4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three approach elements, and key implementation considerations;
5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible elements of an approach to addressing it;
6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
7) it ensured fair representation among policymakers, stakeholders and researchers;
8) it engaged a facilitator to assist with the deliberations;
9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed;" and
10) it did not aim for consensus.

We did not aim for consensus because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health- and social-system leaders typically need to engage elected officials, boards of directors and others about detailed commitments.

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

Regarding the first additional dimension of the problem identified, a number of participants noted that there are significant challenges associated with balancing how individuals' needs are understood, and what the right balance is between understanding these needs through specific diagnoses or through a determination of an individual's functional abilities. Several participants discussed that both aspects are important for individuals with neurodevelopmental disorders and their families. In particular, some participants noted that during initial assessments, a diagnosis can be used to determine the health and social services an individual and their family can expect to receive, which can help to reduce their uncertainty surrounding next steps, while also creating a sense of belonging and community for some individuals. However, a number of participants also raised the issue that diagnostic-based service allocation may result in many individuals not having access to the full spectrum of services and supports they require, leading to solutions that only address a subset of their needs. With respect to determining service needs based on functional abilities, some participants stated that this can be useful in situations where a diagnosis is difficult or particularly complex, and facilitates a 'big tent' approach to understanding and supporting individuals with neurodevelopmental disorders given it does not emphasize (or de-emphasize) particular conditions. Overall, participants agreed that reliance on either approach alone is likely to be problematic, and that striking the right balance will continue to be a challenge. However, a number of participants suggested a 'layered' approach where an initial diagnosis could be used to initiate access to care, services, research funding and general awareness, while functional abilities could be viewed as addressing needs at key transitional phases over the course of an individual's lifetime.

In discussing a second additional dimension of the problem identified during the deliberation, participants focused on discussing the challenges in reaching consensus around how to define conditions, identify needs, and establish approaches for supporting individuals with neurodevelopmental disorders and their families. Several participants agreed that it is often difficult to define neurodevelopmental disorders due to the multitude of ways in which they manifest. Some participants suggested that this is particularly troublesome for complex conditions (or combinations of conditions) that do not have a diagnostic billing code within a health system. A number of participants noted that there is significant complexity in accurately diagnosing neurodevelopmental disorders, and a lack of consensus – even among expert and specialists – about how to identify certain conditions, which exacerbates these challenges. One participant expressed that there could be a 'textbook of labels' to describe and emphasize the wide array of definitions related to neurodevelopmental conditions. Another participant acknowledged the sensitivity around this challenge, as labels can become ingrained in an individual's identity and shape their perspectives on whether and how to access specific types of health and social care. Additionally, one participant suggested that the term 'neurodiversity' could be a helpful way to fully acknowledge the full extent of heterogeneity that is characteristic of the individuals requiring support for neurodevelopmental disorders in Canada, but a number of participants noted that adopting this view and implementing it in practical terms would remain a challenge across health and social systems in Canada.

During the discussion, participants also raised specific concerns about inefficiencies that exist in health and social systems with respect to identifying the needs of individuals with neurodevelopmental disorders, linking these needs to services, and holistically planning their care across the lifespan. Elaborating on this challenge, a number of participants described that the disparities in accessing initial diagnostic assessments and subsequent services and care (especially for adults) lead to missed opportunities to identify new individuals who have neurodevelopmental disorders as well as their functional needs. In terms of establishing approaches to address these challenges, one participant noted that a 'generic all-inclusive approach' to designing care and services for individuals with neurodevelopmental disorders would be incredibly difficult, as this would not account for differences in existing and emerging needs across the lifespan. One participant suggested that this makes it increasingly challenging to configure health and social programs and services for individuals with neurodevelopmental disorders. Overall, participants agreed that the challenges in reaching consensus around how to define conditions, needs and approaches can become a barrier to making progress in improving care for individuals with neurodevelopmental conditions.

During the deliberation about the third additional dimension of the problem identified, a number of participants noted that there are challenges with current organizational funding mechanisms, approaches to provider remuneration, and in how service delivery is planned. Some participants raised the issue – and most participants voiced their agreement – that funding, remuneration and service delivery are often directly linked to particular conditions (e.g., autism) and their explicit diagnosis. Consequently, this has shaped how data systems are structured (e.g., what information is collected and prioritized by organizations), which types of care are paid for publicly (e.g., physician-based services versus those provided by others), and how care pathways are designed (e.g., what choices are made by providers in terms of the programs and services recommended to individuals and their families). One participant further elaborated on this point, and noted that the way systems are structured also creates a myopic view of which information ought to be documented about individuals with neurodevelopmental disorders, resulting in the omission of important information that can support a holistic determination of an individual's health and social needs. To address this challenge, one participant indicated that the involvement of individuals with neurodevelopmental disorders and their families is important, suggesting that the field of oncology can serve as a helpful illustration of approaches to leveraging the voices of individuals in order to understand gaps in their care across an entire lifespan.

While agreeing with the points made in relation to how information is collected and leveraged, another participant expressed their view that the current data infrastructure focuses too heavily on dimensions that are clinical in nature, which can also pose challenges in scaling up other methods of research – such as patient-oriented research – that are vital in the context of neurodevelopmental disorders specifically, and important contributors to rapid-learning health systems more broadly. Some participants pointed out that this focus could lead to the unintended consequence of creating disincentives for adopting a 'lifespan' approach, which requires consideration of a full continuum of individual needs across health and social dimensions throughout their life. Another participant suggested that the approach to information collection has likely contributed to an imbalance in the assets that exist to support rapid learning and improvement. Providing additional context related to the third additional dimension of the problem, some participants also noted that politics have historically reinforced an emphasis on clinical diagnoses for specific conditions. The participant suggested that this could drive further disparities with respect to identifying and addressing the needs of individuals with neurodevelopmental disorders that aren't at the top of the governmental agenda.

When describing the fourth additional dimension of the problem, several participants agreed that there are concerning gaps in care across the lifespan of individuals with neurodevelopmental disorders (e.g., pediatric to adult care). This is especially concerning for adults during their transition from youth services, which although imperfect, in most jurisdictions across Canada consists of a system of programs and services that are designed with their needs (and the needs of their families) in mind. When adult services are available, they are often planned for in isolation from those offered to youth, resulting in a lack of care continuity for individuals as they transition from youth to adult services. As a number of participants noted during the discussion, this lack of planning for and integration of transitional services for youth and adults results in missed opportunities to fully adhere to the principles of a 'lifespan' approach.

Regarding the final additional dimension of the problem identified, one participant highlighted that older adults are a historically overlooked and underserved population of individuals with specific needs related to neurodevelopmental disorders. This led to several participants expressing the same concern, with some noting that this is especially important given that there are little to no data to inform the appropriate care for this specific population group. This challenge can make it difficult to coordinate efforts and drive the changes needed to establish rapid-learning and improvement assets for older adults, which is a very important gap.

When considered together, many participants noted that the five additional challenges raised were relatively well-known system-level challenges associated with neurodevelopmental disorders in Canada. While these challenges are occasionally considered outside of establishing a rapid-learning health system, many participants also agreed that in order to fully embrace a rapid-learning and improvement approach, awareness of these challenges – alongside those mentioned in the evidence brief – need to anchor approaches adopted to create rapid-learning health systems. One participant signalled that this is particularly important if the broad vision is to strike a better balance between the status quo and an approach to care that focuses on an individual's functional needs over an entire lifespan.

DELIBERATION ABOUT ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH

The additional challenges raised during deliberations about the problem led participants to pose several questions that need to be answered when moving forward with the approach elements in support of creating a pan-Canadian learning health system for neurodevelopmental disorders. Deliberations on the elements and additional questions are described in detail below.

Element 1 - Prioritize service needs and design a rapid-learning and improvement approach to meet them

As framed in the evidence brief, element 1 focuses on the steps required to prioritize, design, and incrementally implement programs and services for neurodevelopmental disorders. Examples of this approach could involve an initial pilot project in various settings and then scaling up effective interventions across settings (or scaling up promising approaches to additional priority populations).

Several participants agreed that this approach should prioritize the utilization of existing assets and strengthen current networks instead of mobilizing new resources to create new services. One participant expressed that tapping into existing assets such as staff capacity, training and research opportunities, and current health services would help focus opportunities to improve care. Many participants agreed that the needs of the neurodevelopment community are well known to researchers, but there is a need to conduct and engage priority setting with other stakeholders such as decision-makers, policymakers, and organizational leaders who have the capacity to operationalize and implement programs and services. This would help to create a cohesive vision for what the learning health system could look like in the short, medium, and longer term, as well as establish shared goals that can ensure realistic and collectively agreed-upon priorities. Collectively, the participants discussed other aspects that may be required to design services with a rapid-learning and improvement approach, such as engaging patient advocacy groups, focusing on an individual's lifespan to identify specific services for each transitional phase, and expanding data systems to the population and national levels.

Outstanding question(s) raised by participants as important to answer as part of operationalizing the element

In discussing element 1, participants highlighted at least one outstanding question that would need to be addressed if it was pursued. The question raised was: should priorities for initial rapid-learning and improvement efforts be defined in terms of specific diagnoses or conditions (particularly if there were easier ways in for some compared to others), or are there immediate and tractable ways to anchor efforts in key stages of a 'lifespan' perspective that helps elucidate the commonalities across conditions (and are there better opportunities to gain traction with the approach with one framing compared to another)?

Element 2 - Strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada

Element 2 was framed in the evidence brief as identifying and pooling assets to advance rapid-learning health systems for neurodevelopmental disorders. This could help to: 1) understand which assets are required to operationalize the approach; 2) determine where more support is required for strengthening and linking assets; and 3) identify system gaps that need to be filled to operationalize the approach. To facilitate these aspects, sub-elements could include efforts to use established frameworks to identify rapid-learning assets and gaps at the provincial/territorial and national levels (such as those developed and applied by the McMaster Health Forum in its pan-Canadian assessment of rapid-learning and improvement assets), take steps to ensure assets are 'joined up', and strengthen areas where there are gaps in rapid-learning characteristics, and strengthen technical supports that draw on provincial and national networks of expertise across the country to ensure individuals with neurodevelopmental disorders and their families, providers, organizations and system leaders interested in building their competencies for rapid learning and improvement are enabled to do so.

Nearly all participants agreed that while this approach is needed, there was a level of uncertainty on what the process would look like. Some participants suggested conducting a targeted community-level mapping and priority-setting exercise as the first step, which could then be scaled up. As part of the process, they suggested further analysis of the political and health systems across Canada (such as documenting lessons learned and information on data systems) to set the correct context for linking and strengthening assets required to operationalize a rapid-learning and improvement approach.

Outstanding question(s) raised by participants as important to answer as part of operationalizing the element

In discussing element 2, participants highlighted at least two outstanding questions that would need to be addressed if it was pursued. The questions raised were:

- how can assets be identified and leveraged to facilitate the first steps towards creating a rapid-learning health system (e.g., can existing frameworks be used, or do they need to be adapted to the context of neurodevelopmental disorders, and what is the best way for identifying and engaging the right stakeholders to continually advance the work); and
- should the existence of strong assets be used as a basis for defining priorities (e.g., strong data and research infrastructure among a particular network of providers in one region leading to initial efforts focused there)?

Element 3 - Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action

In the evidence brief, element 3 was framed as fostering a collaborative network of key individuals ('rapid-learning champions') who can foster rapid learning and improvement for neurodevelopmental disorders. These key individuals could help identify strengths and efficiencies to embolden existing networks. This approach is about ensuring the sustained spread and scale across Canada, drawing on lessons learned from elements 1 and 2. The sub-elements include:

- identify and engage individuals with neurodevelopmental disorders and family partners, knowledge brokers, providers, and organizational and system leaders who can advocate for and lead the work related to establishing rapid-learning health systems for neurodevelopmental disorders;
- set up an administrative home for efforts to support the development of rapid-learning health systems for neurodevelopmental disorders (could be an existing organization or research network); and
- define the range of activities required to continuously build and strengthen the network (e.g., through capacity-building workshops, webinars, and supports for a community of practice).

Similar to elements 1 and 2, participants briefly discussed additional considerations for element 3. Some participants suggested as part of the targeted community-level mapping and priority-setting exercise, to clarify who is responsible for specific high-level decisions across the health and social systems and to identify existing assets and gaps (e.g., access to data systems). The mapping framework or road map could be utilized as next steps in conceptualizing and fostering a collaborative network of key individuals and 'rapid-learning champions.' To facilitate this process, two participants expressed that a culture shift fuelled by ongoing collaborations between researchers and management in health organizations, would be beneficial. At the national level, one participant suggested developing a Canada-wide community of practice for neurodevelopmental disorders, while emphasizing a need for consistent use of language and labels of conditions, needs and approaches.

Outstanding question(s) raised by participants as important to answer as part of operationalizing the element

In discussing element 3, participants highlighted at least two outstanding questions that would need to be addressed if it was pursued. The questions raised were:
- how do different priorities established in operationalizing elements 1 and 2, and the existence of assets in priority areas, affect the approach to identifying, engaging and working with a network of champions that span all levels in the system (i.e., how wide should the net initially be cast for engaging individuals with neurodevelopmental disorders and their families, providers, organizations, government); and
- what role should a network of champions play in supporting ongoing efforts to strengthen rapid learning and improvement (e.g., providing intellectual leadership, technical support, operational support, an illustration of 'what it looks like in practice' or all of the above)?

Considering the full array of approach elements

The elements were generally supported by dialogue participants, while many of them also acknowledged that there are outstanding questions to be answered for each approach. However, despite the need to think through some of the practical concerns related to the elements, all participants discussed and collectively agreed to five overarching principles that should guide any approach considered. These principles are:
1. **collaborative priority setting** informed by ongoing assessments of the priorities established by individuals with neurodevelopmental disorders and their families as well as government agendas, and anchored in the need to consider a lifespan approach;
2. **enhancing existing programs and services, rather than system-wide overhaul**;
3. **building upon and learning from existing assets** at local, provincial and national levels (e.g., particular areas of strength in patient engagement or in data collection and analysis);
4. **setting standards** for and **enabling a culture** that is supportive of a rapid-learning and improvement approach; and
5. **emphasizing and expanding upon existing patient-engagement initiatives** to engage individuals with neurodevelopmental disorders and their families in different aspects of improving care and services.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

When discussing implementation considerations, two important barriers were raised by participants. The first barrier raised was a lack of clarity about scope and how best to establish an appropriate organizational structure for supporting the creation of a pan-Canadian learning health system. In particular, one participant suggested that there needed to be more effort placed on establishing stewards early in the process, and it still wasn't clear who could take on this role. The participant characterized this type of support by stating: "while we need boots on the ground, we also need a coach off the field who knows how to play." A contributing aspect to this barrier includes the confusion on where and how different stakeholders (including individuals with neurodevelopmental disorders, their families and caregivers, researchers, decision-makers, organizational and system leaders) "fit in the sandbox" in relation to their roles and responsibilities to develop a learning health system for neurodevelopmental disorders. Some participants expressed that leveraging existing networks and involving think tanks to help identify key actors could help overcome this barrier.

The second barrier raised by participants related to challenges in shifting the established culture in health- and social-care systems to be supportive of the rapid-learning and improvement approach, which emphasizes a proactive problem-oriented, solutions-based mindset (rather than one that is reactive). In discussing this barrier, a number of participants noted that the priorities among important stakeholders that would ideally be engaged in driving change are often misaligned, which creates additional issues that need to be addressed within this barrier to implementation.

In terms of opportunities, participants collectively agreed that they share a strong desire to continue moving forward with creating a pan-Canadian learning health system for neurodevelopmental disorders, which has created and will continue to propel a 'coalition of the willing.' Participants also identified some opportunities to facilitate next steps in laying the groundwork for such an initiative, including:

- leveraging existing data systems such as electronic medical records and national databases to facilitate monitoring and evaluation of implementation;
- tapping into assets and buy-in from relevant, ongoing initiatives and key stakeholders such as the Autism & Intellectual-Developmental Disabilities Knowledge Exchange Network, the Canadian Academy of Health Sciences' Assessment on Autism initiative, Canadian Autism Spectrum Disorder Alliance, the CHILD-BRIGHT Network, Children's Healthcare Canada, the Kids Brain Health Network, the Holland Bloorview Kids Rehabilitation Hospital, provincial and federal governments, foundations, and non-profit organizations; and
- engaging stewards and think tanks with expertise in developing road maps with key aspects of the rapid-learning and improvement approach

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

Participants suggested five broad next steps required to establish a rapid-learning health system for neurodevelopmental disorders in Canada:

1) establish a core leadership group to develop and iteratively revise a compelling vision and road map;
2) identify and engage with key stakeholders, stewards and funders to clarify roles, operationalize the road map, and normalize a culture that is supportive of rapid learning and improvement;
3) develop and pilot a proof of concept that reflects a lifespan approach and is based on functional needs;
4) mobilize the networks required to scale up the approach to engage a wider array of players; and
5) use existing success stories of learning health-system models as a platform to move forward with additional efforts across Canada.

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