McMaster University | HEALTH FORUM

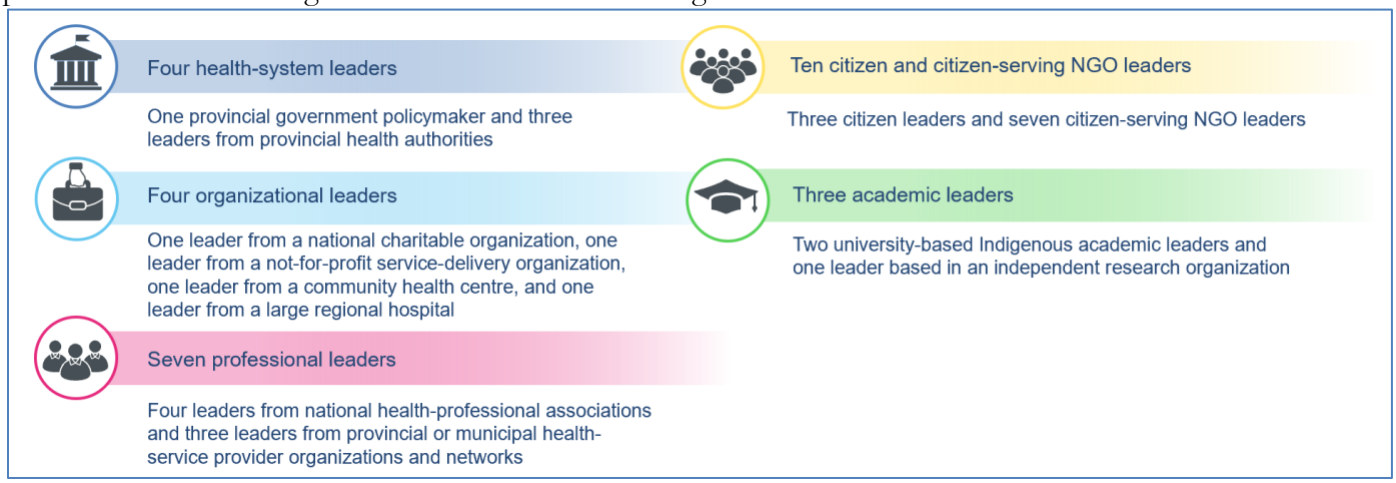
Dialogue Summary

Co-designing Sustainable Approaches to the Citizen Co-led Design, Execution and Oversight of Health-system Transformations in Canada

27 September 2023

Background

In partnership with the McMaster Health Leadership Academy's National Health Fellows Program, the McMaster Health Forum convened a stakeholder dialogue on 27 September 2023 on co-designing sustainable approaches to the citizen co-led design, execution, and oversight of health-system transformation in Canada. Twenty-eight participants – health-system leaders, organizational leaders, professional leaders, citizen leaders and leaders from citizen-serving non-governmental organizations (NGOs), as well as academic leaders (see the figure below) – deliberated about the problem, elements of a potentially comprehensive approach for addressing it, implementation considerations, and possible next steps for different constituencies. Box 1 provides additional background to the stakeholder dialogue.



Box 1: Background to the stakeholder dialogue

The key features of the stakeholder 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, including ten citizen leaders and citizen-serving non-governmental organization (NGO) leaders who brought their own unique perspectives
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"
10) it 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-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.

Summary of the deliberation about the problem

Prior to proceeding with the focused deliberation about the problem as framed in the evidence brief (see figure above), several participants raised two overarching issues that needed to be acknowledged as a group before taking a deeper dive into the more specific issues related to citizen co-led design, execution and oversight of health-system transformation in Canada:

- health systems in Canadian provinces and territories – as well as those overseen by the federal government for Indigenous peoples and for military personnel and Veterans – are failing to deliver the health services that Canadians need (and related to this, the Canada Health Act is no longer 'fit for purpose' given the realities of health systems in 2023, which have moved far beyond hospital-based and physician-delivered services to provide people with the services they need, when and where they need them)
- there has been a lack of progress towards truth and reconciliation and towards self-determination for Indigenous peoples in Canada, and a focus on Indigenous rights holders is a first and fundamental step for collectively staying focused on these goals.

Some participants raised additional issues that they then encouraged others to keep in mind throughout the more specific deliberations about citizen co-led design, execution and oversight of health-system transformation, such as:

- there is a need to carefully think about the language adopted as the work progresses (e.g., the use of 'equity-deserving,' 'marginalized' groups and 'citizens' may not be inclusive of all people for whom the health system is failing or who need to be engaged in efforts to co-lead health-system transformation)
- the dialogue should only be considered the beginning of a longer, iterative process for identifying opportunities to pursue citizen co-led design, execution and oversight of health-system transformation in Canada.

After these points were discussed, participants agreed that they need to be kept front-and-centre in future conversations. They then proceeded to deliberate about the three specific aspects of the problem outlined in the evidence brief, and in doing so raised several important points, which are outlined below.

Participants framed the reasons why we're not seeing the types of health-system transformations that translate into improvements 'on the ground' (the first component of the problem outlined in the evidence brief) around three main themes:

- we don't have a strong track record in Canada of engaging in complex system-change processes, which likely requires deeper dives into understanding problems and their causes (which, as one participant suggested, could involve leveraging approaches and frameworks that help get at 'root causes' of problems and complexity, such as those covered in the MIT professional education course on solving complex problems)

- we continue to 'get stuck' looking for consensus and assuming there is one set of solutions to address pressing health-system challenges in Canada, with the reality being that diverse groups and contexts can lead us to different solutions to the same shared challenges
- we are not routinely sharing provincial and territorial success stories and lessons learned across our borders.

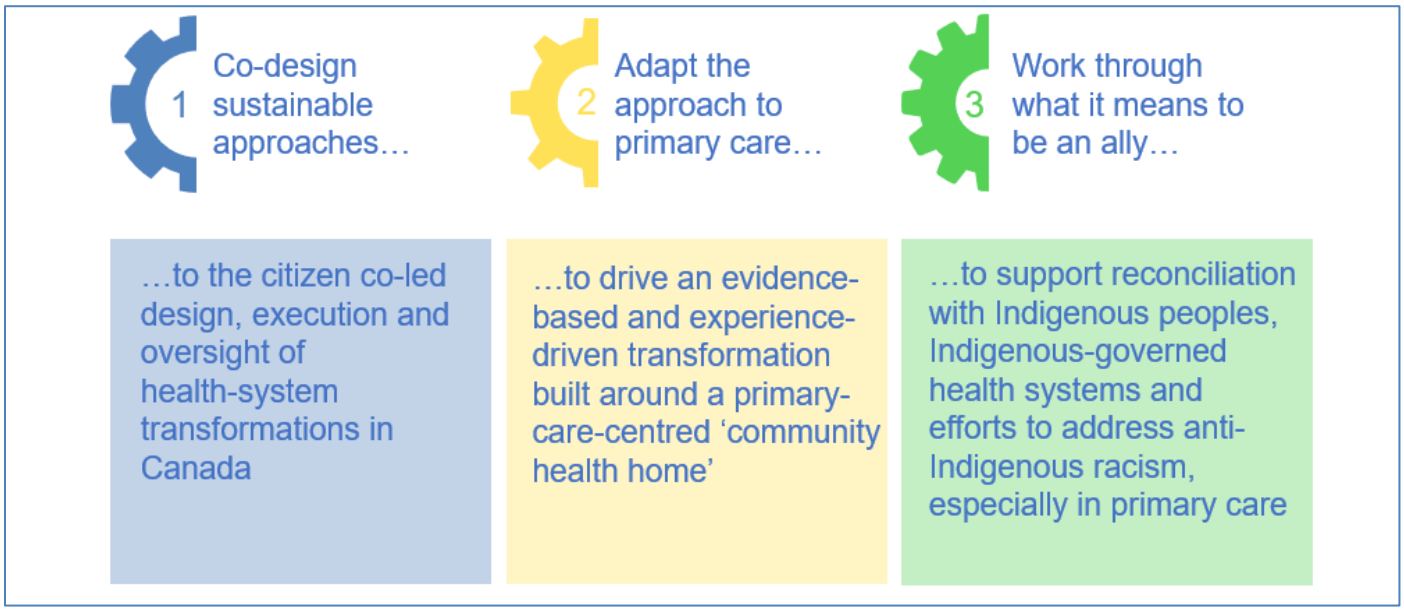
Participants focused on five main challenges associated with getting the approaches in place at scale for diverse people to play important roles in the design, execution and oversight of health-system transformation (the second component of the problem outlined in the evidence brief):

- existing processes for engaging people in health-system decision-making (e.g., patient and family advisory councils, hospital boards) have 'no teeth,' including no levers by which 'everyday people' can hold decision-makers to account
- examples of excellence in public engagement exist across the country (e.g., Centre of Excellence on Partnership with Patients and the Public, Imagine Citizens Network, Engage Nova Scotia) but haven't been meaningfully engaged in helping to drive health-system transformation
- there has been a failure to recognize that 'who sets the table' matters, with the agenda for engaging people often set by those in positions in power, rather than users of the system who need change the most
- there has been a failure to articulate and establish a unifying platform or theme that activates diverse groups with differing perspectives to work together towards a common goal
- there are few examples of people being empowered to hold leaders accountable for health-system goals (other than through their voting rights).

During discussions about the third component of the problem – we don't have the approaches in place at scale to work as allies in support of reconciliation with Indigenous peoples, Indigenous-governed health systems or efforts to address anti-Indigenous racism in health systems – participants offered three key observations:

- it is important to recognize that Indigenous peoples remain among the most marginalized in Canada, and are still 'othered' in many processes, rather than seen as a 'critical ally' with whom trust needs to be nurtured
- Indigenous perspectives and ways of knowing are not drawn upon to the extent that they need to be (e.g., when developing health-system goals and establishing indicators to measure progress towards meeting them)
- there has been a lack of progress towards reconciliation and self-determination.

Summary of the deliberation about elements of a potentially comprehensive approach to address the problem



In deliberating about elements, participants identified three overarching considerations to keep in mind:

1) embracing complexity and different 'horizons of change' (e.g., planned policy and systems change versus social movements like Idle No More that can reform and shape things in ways that are less predictable)
2) keeping people 'at the centre' and orienting any approach to respect the many ways people can define their health (e.g., inclusive of well-being that is best supported by focusing on social determinants of health), while shifting from an 'offer of services' to supporting and meeting a 'need for an offer'
3) recognizing that this is a long-term process, that we aren't likely to get things right the first time and that we need to embrace cycles of rapid learning and improvement (and shouldn't 'let perfect stand in the way of the good' given the importance of the issues at play).

Participants also raised several important points more specifically linked to the elements as they were framed in the brief (see the figure above), which are summarized below.

When discussing the first element – co-designing sustainable approaches to the citizen co-led design, execution and oversight of health-system transformations in Canada – participants focused on the principles for a people-centred governance body, which included suggestions that it should be:

- focused at the provincial and territorial level, and networked to:
  - micro- and meso-level co-design processes within the province or territory, where most of the effort to engage and activate people to support transformational change actually happens
  - social movements focused on health
  - sister initiatives in every other province and nationally to support cross-jurisdictional learning (e.g., Patients for Accountable Healthcare, Imagine Citizens Network, Health Networks in Saskatchewan, Centre of Excellence on Partnership with Patients and the Public, Engage Nova Scotia), some of which have created tools that can be leveraged to bring people into the fold (e.g., the patient-focused health-policy tool from the Canadian Society of Intestinal Research)
  - pan-Canadian initiatives to support the collective shaping of conversations about data collection and sharing (by the Canadian Institute of Health Information and others) and about the principles that need to underpin our health system
- focused on articulating the (human) rights of patients in their health system, including what timely access to quality care means (as well as the responsibilities of patients and the rights and responsibilities of health workers) and concretely how these rights (and responsibilities) are operationalized in the health system
- composed of people (and health workers and system leaders) who are:
  - selected to bring diverse experiences to the table, and take conversations to other groups as 'truth holders' (while acknowledging that the approach to selecting these people is a complex process)
  - supported to build on their existing capacities and to contribute meaningfully to deliberations and decisions as 'co-pilots' of the process (while working to ensure that the burden associated with leading the process does not fall solely on the shoulders of volunteers)
- empowered with:
  - authority to set agendas
  - discretion to pursue the root causes of problems and identify ways to address them
  - discretion to convene the groups whose lives will be affected by the trade-offs being brokered (e.g., professional associations, unions)
  - authority to issue reports and engage in broader communications initiatives that drive and amplify public conversations about what is not working and what needs to change (design), where execution is not achieving desired changes and what needs to change in design or execution, and where equity-centred quadruple-aim metrics are not moving in desired directions and what needs to change in design or execution (oversight)
  - resources (including funding) to do their work
- supported by a secretariat or 'institutional base' that offers legitimacy and enables people to execute these powers.

2 Participants raised two main considerations when discussing how to adapt the approach to primary care to drive an evidence-based and experience-driven transformation built around a primary-care-centred 'community health home:'

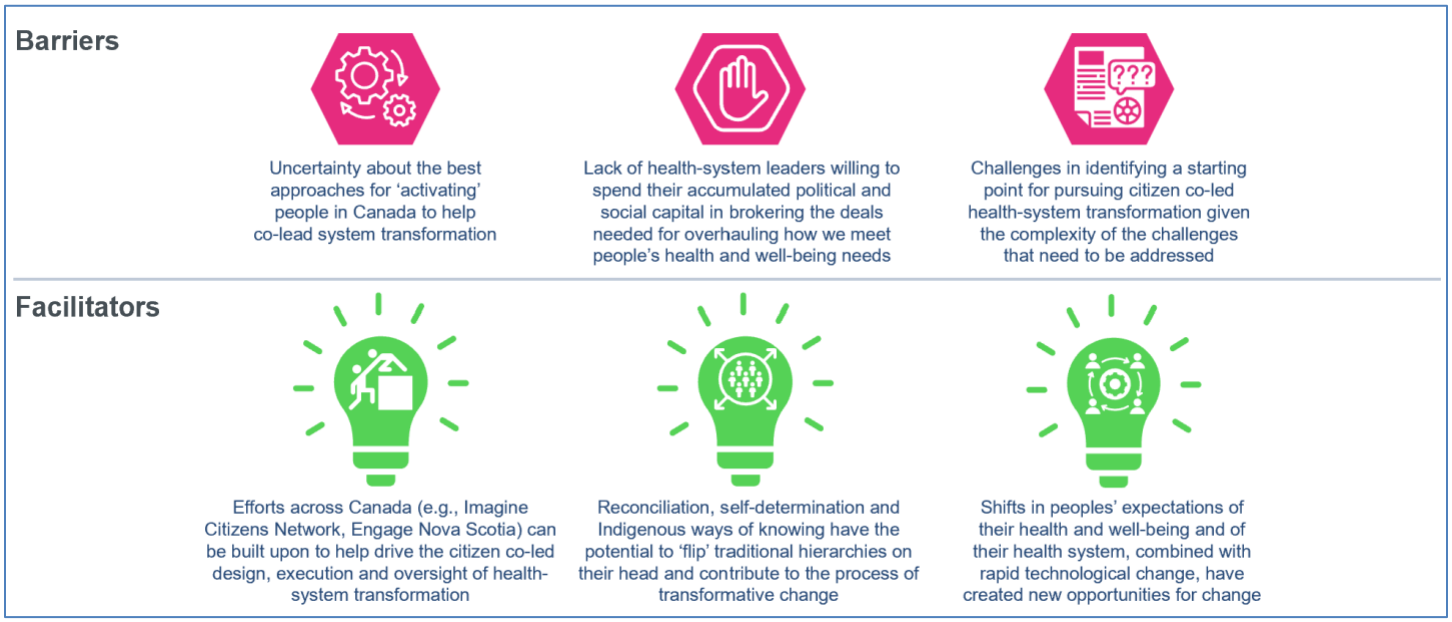
- a social determinants of health framing may provide ways in for broader engagement of the right people, health workers and system leaders from sectors outside of health and from various levels of government (e.g., municipal), all of which are key for improving health and well-being in general and in creating a primary-care-centred 'community health home' in particular (given they have access to many important levers that can influence health)
- it is important to acknowledge and build on insights emerging from key initiatives pushing forward citizen engagement in this area, such as OurCare, with its focus on the first step (design) of three (with the others being execution and oversight).

3 Two considerations were also raised by participants when discussing how to work through what it means to be an ally to support reconciliation with Indigenous peoples, Indigenous-governed health systems and efforts to address anti-Indigenous racism (especially in primary care):

- non-Indigenous groups need to shift from trying to be a 'good ally' to Indigenous communities, and realize that they must be invited to become allies as part of broader relationship and trust building
- we have opportunities to learn from initiatives such as the World Health Organization (WHO) Commission on the Social Determinants of Health in how to (and also how not to) approach Indigenous representation.

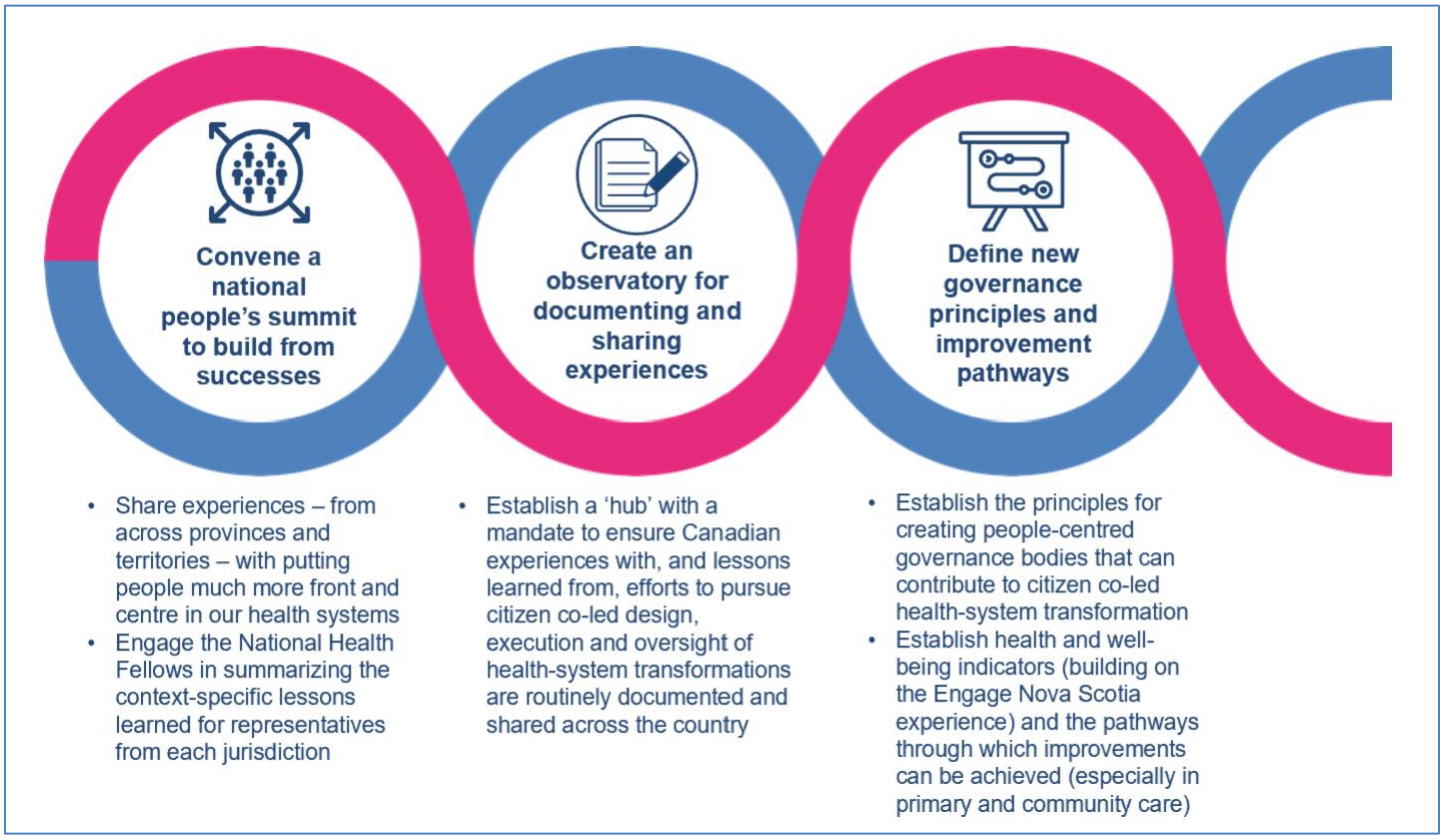
Summary of the deliberation about implementation considerations

During the deliberation about implementation considerations, participants identified three additional barriers to those included in the evidence brief that may present challenges to taking the actions described above, as well as three additional facilitators (see the figure below). The facilitators focused on existing efforts that can be leveraged as well as current processes that have the potential to drive transformational change, such as Indigenous reconciliation and self-determination and broader shifts in people's perspectives of their health and well-being.



Summary of the deliberation about next steps

Participants identified the next three steps that can be pursued in the near term and led by the individuals who participated in the stakeholder dialogue – including the National Health Fellows – or the groups with which they're involved.



Moat KA, Gauvin FP, Lavis JN. Dialogue summary: Co-designing sustainable approaches to the citizen co-led design, execution and oversight of health-system transformations in Canada. Hamilton: McMaster Health Forum, 27 September 2023.

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