Evidence Brief

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

27 September 2023

Box 1: Approach and supporting materials

This document was prepared to inform a stakeholder dialogue, which provides individuals – specifically those who will be involved in or affected by decisions about co-designing sustainable approaches to the citizen co-led design, execution and oversight of health-system transformations – with an opportunity to deliberate about a problem, elements of an approach for addressing it, key implementation considerations, and next steps for different constituencies. The process was informed by ongoing consultations with Steering Committee members and by interviews with key informants who play diverse roles (policymakers, organizational leaders, professional leaders, citizen leaders, researchers and other stakeholders from across the country) and bring diverse types of lived experience (including as members of equity-deserving groups and Indigenous peoples). A separate document contains nine appendices:

1) background to and methods used in preparing the evidence brief
2) evidence syntheses relevant to co-designing sustainable approaches to citizen co-led transformations (element 1)
3) jurisdictional scan of promising examples of citizens being 'in the driver's seat' for health-system transformations
4) evidence syntheses relevant to adapting the approach to primary-care transformations (element 2)
5) jurisdictional scan of promising examples of citizens being 'in the driver's seat' for primary-care transformations
6) evidence syntheses relevant to working through what it means to be an ally (element 3)
7) jurisdictional scan of promising examples of working as an ally
8) citizen-engagement assets that could be leveraged to enable citizen co-led transformations
9) references.

Context for the brief

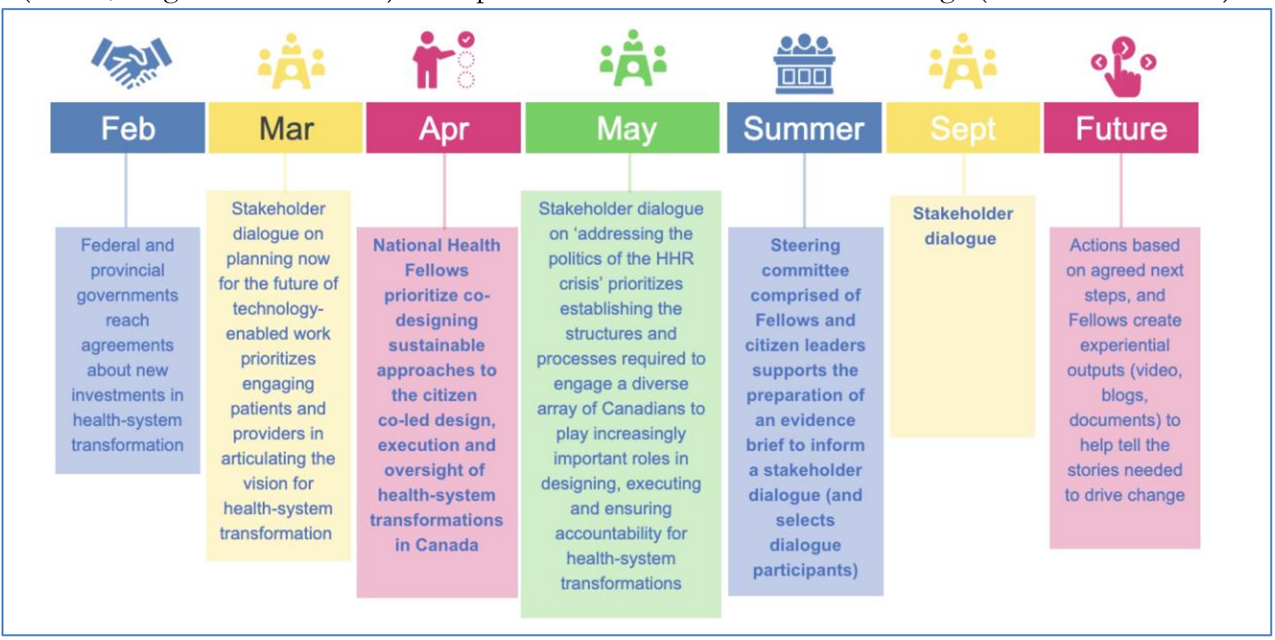
There have been growing calls for fundamental changes across health systems in Canada from health-system and organizational leaders.(1) These calls are driven in part by patients' ongoing frustration with not getting timely access to the care they need, delivered to them through models of care that are responsive to their needs, values and preferences. These calls are also driven by growing citizens' and stakeholders' concerns about budgets that are increasingly viewed as unsustainable, and frustration with health-system leaders' inability to resolve long-standing crises (e.g., the health human resources crisis) and to scale up promising health innovations.(2-4)

Recently, a new set of bilateral federal/provincial/territorial (FPT) agreements were announced, with the expectation that they would address some of the most pressing health-system challenges in the country.(5) The federal government will increase health funding to provinces and territories by $196.1 billion over 10 years, including $46.2 billion in new funding. While these new federal investments were long-awaited and raised expectations about forthcoming health-system transformations, it is unclear whether general increases in how much is being spent will change how the money is spent. In fact, these bilateral FPT agreements may help to stabilize and make incremental changes to existing systems, without leading to system transformations that are experienced by everyday Canadians as significant improvements.

During this same period, the CMA Health Summit, as well as a events convened by the McMaster Health Forum (including a stakeholder dialogue on technology-enabled healthcare and a living stakeholder dialogue and citizen panel series on addressing the politics of the health human resources crisis, yielded insights that emphasized our failure to achieve transformative change

that could lead to concrete improvements for diverse Canadians and Indigenous peoples. These events also surfaced a growing interest in putting citizens in the 'driver's seat' for health-system transformations. (6-10)

The National Health Fellows Program, developed and hosted by the Health Leadership Academy at McMaster University, is bringing together health leaders from across Canada who are looking for ways to strengthen the networks, behaviours, and tools needed to advance health and well-being within and across provincial and territorial (PT) health systems. A key component of the curriculum for this year's cohort of National Health Fellows is convening a stakeholder dialogue to drive action that can help bring about transformative change, particularly given the many challenges that exist in PT health systems across Canada (including Canadians' growing frustrations with these systems, as well as persistent health inequities facing many groups and Indigenous peoples). During a week-long module in April 2023, the Fellows collectively agreed to prioritize the topic of co-designing sustainable approaches to the citizen co-led design, execution and oversight of health-system transformations in Canada, building on the growing interest in the topic noted above, as well as their unique position to help drive this process. This evidence brief aims to inform this stakeholder dialogue (see Box 1). The dialogue aims to position participants to take action based on what they learn at the dialogue, as well as to position the Fellows to create experiential outputs (videos, blogs and documents) to help tell the stories needed to drive change (see Timeline below).



The problem: We are failing to achieve transformative change

We have identified three facets of the problem, which are described in the sections that follow.

We're not seeing the types of health-system transformations that translate into concrete improvements 'on the ground' for diverse Canadians or Indigenous peoples

Despite the growing call for health-system transformations, there is no common definition of what it should entail. In this brief, we use the following definition:

1) improving the care experienced 'on the ground' by patients, families and caregivers and as measured by changes for the better in equity-centred quadruple-aim metrics (i.e., enhancing the patient experience, improving health outcomes, improving provider satisfaction, and keeping per capita costs manageable)
2) doing so in coordinated ways that involve multiple types of organizations and professionals, which can include altering one or more delivery arrangements (i.e., how care is organized to reach those who need it), financial arrangements (i.e., how money flows through the system), and governance arrangements (i.e., who can make what types of decisions).

This type of change is rare in Canadian health systems, although two examples specific to Ontario – the Hospital Sector Restructuring Commission from 1996 to 2000 and the integration of cancer services from 2002 to 2004 – align with our proposed definition.(11-12) More recently, the creation of Ontario Health Teams (OHTs) show the promise of transformative change, with OHTs moving toward adopting a population-health management approach to proactively get the right programs, services and products to all population segments in their attributed population, receiving a single integrated funding envelope for the full range of covered services, and being held accountable for achieving equity-centred quadruple-aim metrics.(13) Other examples include the creation of Indigenous-governed health systems like the First Nations Health Authority, which took over responsibility from the federal government for the planning, management, and delivery of health programs to better meet the needs of First Nations in British Columbia.

Rather than system transformation, we often see pilot projects that aren't sustained and expanded, with the Primary Health Care Transformation Fund – an $800-million investment with no requirement that provincial and territorial governments would sustain and expand successful pilots to transform systems – serving as one illustration among many of why Canada has long been dubbed 'a country of perpetual pilot projects.'(3;14) Furthermore, what is often framed as transformative change across the country rarely aligns with the above definition, and are usually more accurately described as:

- incremental system changes that do not fundamentally alter existing delivery, financial and governance arrangements, with examples that include:
  - more federal government investments and performance indicators with a 'black box' between the two
  - exploring national pharmacare and considering an expansion of the Canada Health Act beyond hospital and physician services without corresponding efforts to improve prescribing or the delivery of home care, mental health and other services (and expansion efforts being often piecemeal and varying by provinces/territories)
  - calls for more interdisciplinary primary-care teams for the few new graduates willing to consider this model and without a pathway to full coverage of the population (i.e., a 100% attachment rate), the incorporation of these teams in local health systems (like those envisioned as part of the Ontario Health Teams transformation noted earlier) and provincial health authorities (like Alberta Health Services), and the interoperability of primary care and hospital electronic medical records
  - care model re-design for one population segment
- system-stabilization efforts, with example that include:
  - increasing the intake of internationally educated health workers without concurrent efforts to make workplaces excellent (to increase retention and recruitment of domestically trained health workers) and to plan now for the future of technology-enabled healthcare work
  - tackling surgical backlogs with time-limited contracts to stand-alone surgical centres.

While health-system transformation is rare and challenging, it is possible, particularly when the right constellation of factors – many within the control of elected officials rather than appointed health-system leaders – align. That said, health-system leaders with a strong mandate, long-standing relationships with key health-system stakeholders, the willingness to broker the necessary tradeoffs among these stakeholders by using their accumulated political and

social capital, as well as appropriate investments in change-management capacity, can help to facilitate transformative change when opportunities arise.(11-12;14)

We haven't got the approaches in place at scale for diverse Canadians to play important roles in designing, executing and ensuring accountability for health-system transformations

The idea of seeking input from diverse Canadians about health-system transformations is not a new one. Indeed, some have argued that health systems in Canada have a mandate for democratic participation, meaning that citizens should be engaged in shaping their own health and health system.(15) In this evidence brief, we use the umbrella term of 'citizen' to refer to:

- citizens – whether as taxpayers or voters or in other roles, and regardless of their formal citizenship status[1] and whether they may also currently be considered a patient
- 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 may be affected by health systems
- patients in the usual sense of those receiving care in health systems
- potential patients who need care, whether or not they are receiving it now
- families of and caregivers to these patients or potential patients.

We have several decades of rich experience with citizen engagement in Canada, most notably:

- large-scale public consultations to identify citizens' values and preferences that should shape health-system transformations, many being hosted by federal and provincial or territorial governments (e.g., the National Health Forum, the Royal Commission on the Future of Health Care in Canada, or the Health Services Review Committee in New Brunswick) or by various stakeholders (e.g., Rendez-vous national sur l'avenir du système public de santé et de services sociaux in Quebec, or pan-Canadian conversations like OurCare to craft a vision for primary-care transformation or the town halls hosted by the Canadian Medical Association on public and private healthcare)
- citizen-led governing bodies in regional health authorities to establish priorities and guide resource allocation (16-17)
- the 'deliberative turn' of citizen engagement, a period that saw many organizations experimenting with a growing array of deliberative mechanisms to inform coverage policies or coverage decisions, or address complex social and ethical dilemmas (e.g., citizen panels, citizen juries, consensus conferences, and more) (18)
- the 'patient revolution' during the last decade that saw the emergence of many patient-partnership initiatives in research, in education, in designing programs and services, in quality-improvement committees, and in advisory councils.(19)

Despite the rich experience with citizen engagement, we can highlight some limitations:

- these initiatives vary widely in terms of who leads them; what level of decision-making they aim to inform; which sectors, conditions and populations they aim to benefit; and which roles citizens play in the decision-making process (20)
- citizens have rarely been 'in the driver's seat' of health-system transformations (with most initiatives aiming to elicit citizens' values and preferences for health reforms, which can help to inform the 'designing' part of a vision, while fewer are engaging citizens in executing the vision or providing oversight as the vision is being implemented and adapted over time)
- there is a limited data and evidence infrastructure to support citizen engagement (e.g., dashboards presenting data and indicators to citizens about health-system performance, and organizations dedicated to packaging the best available evidence to support citizen deliberations)

[1] We include undocumented individuals and we recognize that Indigenous peoples were sometimes forced to decline their Indigenous status to achieve citizenship of a country that now includes their traditional lands.

- while many citizen-engagement initiatives are complementary, they have not been connected and collectively leveraged to support health-system transformations
- citizen-engagement initiatives often struggle to achieve the principles of equity, diversity, and inclusion (and alternatively, some may be questioning the diversity, representativeness or authenticity of the 'citizens' who are engaged).

Regarding the last point, these initiatives often struggle to engage a diverse array of citizens, including equity-deserving groups.(16-17;21-23) Canada is known to be an increasingly diverse country, and many groups are facing important health and social inequities.(24-25) This diversity can take many forms, such as – using the PROGESS-Plus framework – place of residence (e.g., urban, rural and remote areas), race/ethnicity/culture/language, occupation, gender/sex, religion, education, socioeconomic status, social capital, and other personal characteristics (e.g., age and disability).(26) If we are unable to elevate the voices of equity-deserving groups to shape health-system transformations, not only are we failing from a democratic standpoint, but we are also facing the risk of perpetuating or exacerbating health and social inequities.

We haven't got 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

For the past two decades, many commissions and inquiries have called for meaningful reconciliation with Indigenous peoples, most notably the United Nations Declaration on the Rights of Indigenous Peoples (2007) and the Truth and Reconciliation Commission of Canada (2008-2015), the National Inquiry into Missing and Murdered Indigenous Women and Girls Calls to Justice (2016-2019), and the Public Inquiry Commission on Relations Between Indigenous Peoples and Certain Public Services in Quebec (2016-2019).

The Truth and Reconciliation Commission of Canada defined reconciliation as a process "establishing and maintaining a mutually respectful relationship between Aboriginal and non-Aboriginal peoples in this country."(27) To achieve reconciliation, "there has to be awareness of the past, an acknowledgement of the harm that has been inflicted, atonement for the causes, and action to change behaviour."(25) The commission highlighted 94 calls to actions involving civil society organizations and government sectors to take concrete actions towards reconciliation. If those, many concrete actions can be taken by health-system leaders (see calls to action 18 to 24).

While there is a growing number of promising initiatives, there is still a long way to go on our journey towards reconciliation:

- Indigenous peoples are still facing important health and social inequities (25)
- anti-Indigenous racism is still widespread (28-29)
- there are concerns about 'performative reconciliation' (meaning health-system leaders taking strictly symbolic actions that have little or no substance).(30)

The last point is a reminder that health-system leaders across the country must demonstrate a clear understanding of their obligations to Indigenous peoples. Then, they must 'get their house in order,' meaning that they need to examine all parts of health systems to coordinate and re-orient them in the direction of equity, as well as taking concrete actions to dismantle the systemic racism facing Indigenous peoples. In addition, the path to reconciliation also requires establishing Nation-to-Nation relationships that can accelerate the self-determination of Indigenous peoples, including Indigenous-governed health systems.

Elements of a potentially comprehensive approach for addressing the problem

Three elements of a potentially comprehensive approach to address the problem were developed and refined through consultation with the Steering Committee and key informants who we interviewed during the development of this evidence brief.

Co-design sustainable approaches to the citizen co-led design, execution and oversight of health-system transformations in Canada

This first element builds on the renewed interest in citizens playing a co-leadership role in health-system transformations. It recognizes that they can help fundamental roles at the design stage (e.g., setting the agenda for reforms and identifying the core values that should shape these reforms),(31) at the execution stage (e.g., being agents of change and 'disruptors' who can speak truth to power, and being 'brokers' who can facilitate collaboration among stakeholders and help them work through trade-offs),(32-33), as well as the oversight stage (e.g., establishing stronger accountability relationships with health-system leaders that are built upon trust, openness and responsiveness).(34)

This element could include:

- identifying strategies to put citizens in the driver's seat for health-system transformations (including to co-lead the design, execution and oversight of such transformations)
- identifying strategies to embed equity, diversity, inclusion, and Indigenous reconciliation in such approaches.

We identified 17 evidence syntheses that addressed this element (see Appendix 2), which revealed that:

- engaging both health workers and citizens has been identified as a key success factor for large health-system transformations, but there is limited description about how to achieve this (35)
- there is mixed evidence about the effectiveness of various citizen-engagement approaches to co-lead the design, execution and oversight of system changes (mostly due to the lack of robust evaluations allowing us to determine what approaches are most effective in what context), (36-41) but one evidence synthesis found that higher levels of engagement (i.e., co-design strategies) appear to lead to more structural changes (42)
- citizen engagement can be influenced by contextual factors (e.g., information asymmetries and public officials' attitudes), organizational arrangements (e.g., community representation criteria and process design) and process-management patterns (e.g., group dynamics and collaboration quality) (43)
- little is known about the most optimal way to package information to support citizen deliberations (44)
- sources of concerns include tokenism, power imbalances, and engagement procedures/methods that can exclude equity-deserving groups (36;42;45)
- there is a growing body of evaluation frameworks and tools, which highlight theoretical and normative criteria for meaningful citizen engagement (including criteria related to diversity or representativeness of participants, as well as the capacity of all to express themselves).(46-47)

We also conducted a jurisdictional scan (see Appendix 3), which revealed promising examples, notably:

- examples of citizen engagement in health-system transformations
  - patient, family and caregiver advisors have been – at least in some communities – co-leading the design, execution and oversight of Ontario Health Teams since 2019

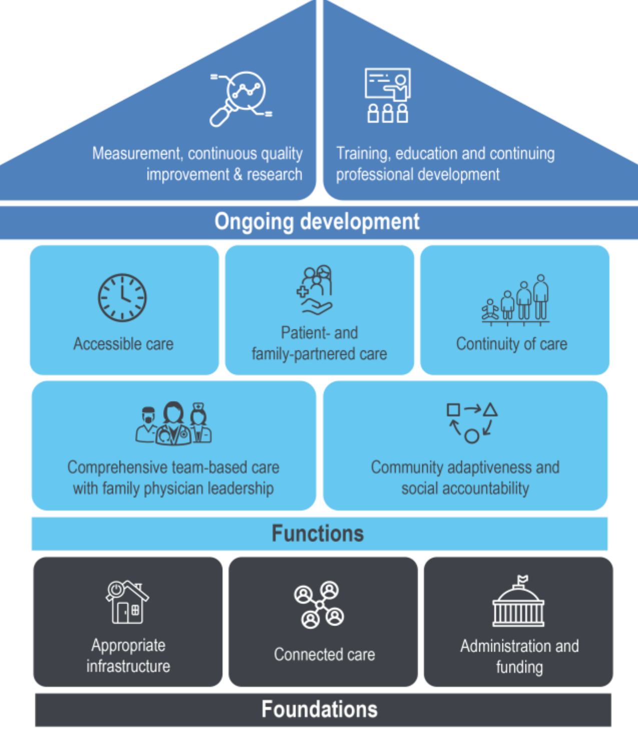
- most Canadian commissions on health reforms have engaged citizens at the design stage (from the National Health Forum in 1997 to the Royal Commission on the Future of Health Care in Canada in 2002)
  - many organizations are hosting co-design initiatives that engage patients, families and caregivers in designing new care models, programs and services (as well as the initiatives that build capacity for and support such work, such as the Centre of Excellence on Partnership with Patients and the Public)
  - a few citizen-engagement initiatives provide oversight of health-system transformations (e.g., Quebec's Consultation Forum providing oversight of health-system performance) and organizational improvement (e.g., Accreditation Canada's patient surveyors program)
- examples of embedding equity, diversity, inclusion, and Indigenous reconciliation
  - a few organizations are engaging equity-deserving groups to address pressing health-system challenges (e.g., Imagine Citizens Network and Health Commons Solutions Lab)
  - the Public Engagement in Health Policy project, in collaboration with the Public and Patient Engagement Collaborative, published an interactive tool to support equity-centred engagement

Adapt the approach to primary care to drive an evidence-based and experience-driven transformation built around a primary-care-centred 'community health home'

This second element aims to adapt the approach (identified as part of element 1) and apply it with a focus on citizen co-led design, execution and oversight of primary-care transformation built around a primary-care-centred 'community health home,' which will be informed by the best available evidence and the lived experiences of citizens. This element could include:

- identifying key elements of a primary-care-centred 'community health home' that could address barriers to accessing care and the social determinants of health
- putting citizens 'in the driver's seat' for design, execution and oversight of the approach as well as in efforts to ensure the principles of equity, diversity, inclusion and Indigenous reconciliation (EDIIR) are embedded in the approach, particularly as part of efforts to humanize primary care for those who were first here, people who settled here, and newcomers.

With respect to the first sub-element, the following model developed by the College of Family Physicians of Canada, which rests on 10 key pillars, is a useful starting point for consideration (see figure below).



Adapted from: https://patientsmedicalhome.ca/

While the model is gaining traction across the country, there have been discussion among the National Health Fellows and key informants about how to expand it so that it can address barriers to accessing care, address the social determinants of health, and humanize primary care. For instance, a primary-care-centred ‘community health home’ could include:

- approaches to address anti-Black racism as well as other challenges affecting ‘visible’ and ‘invisible’ communities
- approaches (e.g., in-reach and out-reach services) to provide more support when people do have an encounter with the health system and to ‘bring the system to patients’ when they are not accessing it
- approaches (e.g., social prescribing) to better connect people to non-clinical supports in their communities (e.g., housing and income support)(48)
- other approaches to address the social determinants of health.

We identified 31 evidence syntheses that addressed this element (see Appendix 4):

- with respect to the key elements of a primary-care-centred ‘community health home’, we found that: 1) co-designed social prescribing can lead to positive well-being outcomes for patients and communities (49-50); 2) the social determinants of health can be integrated in health screening,(42) in comprehensive shared-care plans,(51) in referrals and follow-up,(42) as well as in training curricula (42); and 3) financing and budgeting mechanisms are necessary to support intersectoral actions for health (52)
- with respect to putting citizens ‘in the driver’s seat’ for primary-care transformations, we found that patient advisors have played key roles in the design, execution and oversight of ‘medical homes’ (e.g., ad-hoc patient committees, community advisory councils, and experience-based co-design) (53-54); and that community engagement can lead to improved health and health behaviours among disadvantaged populations (55-56)
- with respect to humanizing primary care, we found that: 1) the concept of ‘humanization’ includes three areas (relation, organizational and structural) (57); 2) provider training programs that engage people with lived experience appear promising (e.g., training on social justice, racial justice, health equity, cultural competency and safety, and anti-stigma) (58); and 3) a robust and invigorated primary-care system can drive population health and health equity, as well as democratic participation and civic engagement.(59)

We also conducted a jurisdictional scan (see Appendix 5) to identify promising examples, notably:

- examples of citizen engagement in primary-care transformations
  - a pan-Canadian conversation (OurCare) organized by researchers to design a vision for the future of primary care using national surveys, priority panels and community roundtables
  - two mechanisms to inform primary-care transformations in Alberta (the Primary Health Care Virtual Patient Engagement Network that connects patients, families and caregivers to primary healthcare teams by to co-design healthcare integration solutions, and Alberta’s Strategic Advisory Panel that was comprised of members with expertise in primary care, health-system transformation and citizen leaders to identify opportunities to modernize primary care)
  - a dashboard that could provide relevant data, indicators and analyses to help citizens oversee primary-care transformations (e.g., the Massachusetts Primary Care Dashboard)
- examples of initiatives to humanize primary care
  - the Primary Care Networks in British Columbia providing culturally safe and appropriate care for Indigenous peoples (which includes drawing on Indigenous resources and having traditional healers as part of each team)
  - the Equity, Inclusion, Diversity and Anti-Racism Framework developed by Ontario Health to build an organizational culture of equity, inclusion, diversity and anti-racism.

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

This third element focuses on working through what it means to be an ally to Indigenous peoples. More specifically, this element could include:

- identifying strategies to support reconciliation with Indigenous peoples
- identifying strategies to support Indigenous-governed health systems
- identifying strategies to address anti-Indigenous racism in health systems.

We identified a total of nine evidence syntheses and one synthesis being planned that addressed this element (see Appendix 6). With respect with the first sub-element, four evidence syntheses revealed the importance of:

- recognizing Indigenous knowledge, their rights to self-determination, and their resilience and agency (60)
- ensuring free, prior informed consent, along with meaningful engagement whenever a policy may affect Indigenous peoples (61)
- monitoring reconciliation efforts (e.g., using the United Nations' Indigenous Navigator tool) (61)
- decolonizing and Indigenizing health professions education (e.g., tackling misunderstandings and cultural bias toward Indigenous people; increasing community-driven Indigenous partnerships; integrating Indigenous health curricula; and adapting enrollment, evaluation, and instructional design for Indigenous students).(62-63)

With respect to the second sub-element, we found one evidence synthesis examining strategies to support Indigenous-governed health systems.(64) Findings revealed that:

- creating new health governance structures and funding models are important to support the devolution of health services and self-determination
- no single model of governance or funding arrangements will work across all Indigenous contexts (i.e., Indigenous peoples have diverse histories, cultures, languages, beliefs, and practices, as well as interests, needs, and capacities).

With respect with the third sub-element, we found four evidence syntheses and one protocol about identifying strategies to support efforts to address anti-Indigenous racism in health systems. Findings revealed the importance of:

- improving the five dimension of access to care (i.e., approachability, acceptability, availability and accommodation, affordability, and appropriateness)(65-66), as well as addressing the cultural and social determinants of health and meaningfully engaging Indigenous communities in identifying and addressing their care needs (66)
- investing in cultural competency and safety training for providers (65;67), although it is unclear what training format is most effective (e.g., group discussion, case studies, and online modules)(68)

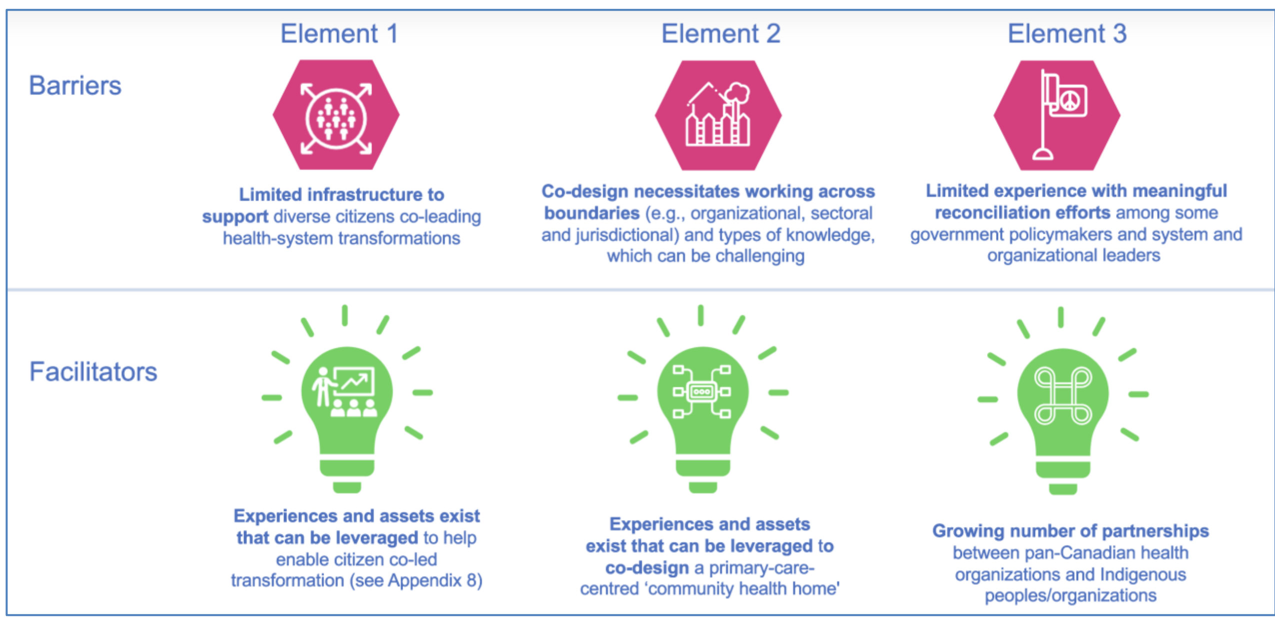
We also conducted a jurisdictional scan (see Appendix 7) allowing us to identifying promising examples:

- many initiatives are currently underway by governments, pan-Canadian health organizations, professional associations and universities to advance reconciliation and allyship with Indigenous peoples
- there is a growing number of Indigenous-governed health systems, as well as frameworks highlighting the core values and principles that should guide Indigenous health-system transformations
- many initiatives aim to address anti-Indigenous racism, including: a national campaign about anti-Indigenous racism; anti-Indigenous racism, cultural safety and humility training programs; accreditation requirements developed for health organizations; initiatives to integrate traditional healing approaches and culturally safe care in many settings; and processes to report racism and discrimination.

Implementation considerations

A number of barriers might hinder our capacity to implement the three elements, which need to be factored into any decision about whether and how to pursue any given element. Perhaps four of the biggest barriers are: 1) jurisdictional complexity may impede pan-Canadian efforts; 2) citizen engagement may be necessary, but not sufficient, to spark action and bring about change (e.g., some levers of change are solely held by policymakers and other stakeholders); 3) citizen engagement is about sharing power and influence, which is extraordinarily challenging to achieve (e.g., small 'p' politics and big 'P' politics of transformative change); and 4) inclusive decision-making processes do not always lead to 'progressive' decisions (e.g., NIMBYism towards various projects such as affordable housing, supervised injection sites, or community-care facilities). Other potential barriers that are specific to each element are presented in the figure below.

On the other hand, a number of facilitators could create a window of opportunity for advancing these elements. Perhaps the greatest facilitator is that health-system leaders and citizens agree about the need to start building now the future health systems we want.(9) Other potential facilitators that are specific to each element are presented in the figure below.



References – see Appendices

Gauvin FP, Moat KA, Lavis JN. Evidence brief: 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.

The evidence brief and the stakeholder dialogue it was prepared to inform were funded by the National Health Fellows Program (NHFP) led by the Health Leadership Academy (HLA): a partnership between the Faculty of Health Sciences and the DeGroote School of Business at McMaster University, through a donation from Michael G. DeGroote. The McMaster Health Forum receives both financial and in-kind support from McMaster University. The views expressed in the evidence brief are the views of the authors and should not be taken to represent the views of the DeGroote Family or McMaster University.

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ISSN 1925-2250 (online)

>> Contact us
1280 Main St. West, MML-417
Hamilton, ON, Canada L8S 4L6
+1.905.525.9140 x 22121
forum@mcmaster.ca

>> Find and follow us
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