McMaster University | HEALTH FORUM

Evidence Brief Appendices

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

27 September 2023

Appendices

Appendix 1: Background to and methods used in preparing the evidence brief

This evidence brief mobilizes global and local research evidence about a problem, three approach elements for addressing the problem, and key implementation considerations. It also draws on the experiences from a purposive sample of jurisdictions, which were gathered through reviews of government documents and websites, as well as through key-informant interviews. Whenever possible, the evidence brief summarizes research evidence drawn from evidence syntheses and occasionally from single research studies. An evidence synthesis is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies and to synthesize data from the included studies. An evidence brief does not contain recommendations, which would have required the authors of the brief to make judgments based on their personal values and preferences, and which could pre-empt important deliberations about whose values and preferences matter in making such judgments.

The preparation of this evidence brief involved five steps:

1) regularly convening the project Steering Committee comprised of representatives from the National Health Fellows Program, citizen leaders and the McMaster Health Forum to help inform the framing of the evidence brief
2) conducting key-informant interviews with policymakers, organizational leaders, professional leaders, citizen leaders, researchers and other stakeholders (many working with or representing equity-deserving groups and Indigenous peoples)
3) identifying, selecting, appraising and synthesizing relevant research evidence for each section of the brief
4) conducting additional jurisdictional scans to identify initiatives related to the three proposed elements
5) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence, and insights from the jurisdictional scan.

The three approach elements for addressing the problem were not designed to be mutually exclusive and could be pursued in a number of ways. The goal of the dialogue is to spark insights and generate action by participants and by those who review the dialogue summary.

Mobilizing research evidence about elements for addressing the problem

To identify the best-available research evidence about the elements, we searched Health Systems Evidence (www.healthsystemsevidence.org), which is a continuously updated database containing more than 9,400 evidence syntheses and more than 2,800 economic evaluations of delivery, financial and governance arrangements within health systems. We also searched Social Systems Evidence (www.socialsystemsevidence.org), which is a continuously updated database containing more than 4,500 evidence syntheses and more than 300 economic evaluations about strengthening 20 government sectors and program areas, and achieving the Sustainable Development Goals. We also complemented this with searches in PubMed, and hand searches of the McMaster Health Forum's recently prepared evidence syntheses, if there was overlap in the issues addressed or the elements considered. The authors' conclusions were extracted from the syntheses whenever possible. Some syntheses may have contained no studies despite an exhaustive search (i.e., they were 'empty' syntheses), while others may have concluded that there was substantial uncertainty about the approach elements based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the syntheses' quality, the local applicability of the syntheses' findings, equity considerations and relevance to the issue.

Being aware of what is not known can be as important as being aware of what is known. When faced with an empty synthesis, substantial uncertainty or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an approach element could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a synthesis that was published many years ago, an updating of the synthesis could be commissioned if time allows. No additional research evidence was sought beyond what was included in the evidence syntheses. Those interested in pursuing a particular element may want to search for a more detailed description of the element or for additional research evidence about the element.

Appendices 2, 4 and 6 provide detailed information about the evidence syntheses identified that relate to the three elements. In the first column we list the sub-elements, and provide hyperlinks to the search strategies used, as well as the breakdown of number of identified syntheses for each sub-element according to their quality. In the second column, we provide a hyperlinked 'declarative title' that captures the key findings from each synthesis. Columns 3–6 list data related to the criteria that can be used to determine which reviews are 'best' for a single category (i.e., living status, quality, last year literature searched and availability of a GRADE profile, which provides insights about the strength of the evidence included in a particular synthesis), and column 7 highlights the type of questions addressed by each synthesis.

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

Appendix 2: Evidence syntheses relevant to element 1 – Co-designing sustainable approaches to citizen co-led transformations

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
Putting citizens 'in the driver's seat' for health-system transformation (including the co-led design, execution and oversight) (Search 1, Search 2, Search 3, Search 4, Search 5, Search 6) *Total syntheses: 17 (of which six are high quality and seven are moderate quality)*	The trial-based evidence is uncertain on the effects of health consumer and provider partnerships in achieving greater person-centredness of health services that will inform best approaches to guide such process, with most evidence only describing the indirect influence of partnerships on service planning and delivery.(37)	No	11/11 (AMSTAR rating from McMaster Health Forum)	2019	Yes	• Selecting an option for addressing the problem
	Evidence on the effects of consumer participation in health policy and research development is scarce. Further work is needed to ascertain the differential effects of various methods of recruitment and levels of involvement in such processes. Nevertheless, some evidence suggests likely positive effects with consumer involvement in developing informational materials and assuming interviewer roles.(40)	No	10/11 (AMSTAR rating from McMaster Health Forum)	2009	Yes	• Selecting an option for addressing the problem
	Bridging power imbalances in formal partnerships between health consumers and providers is critical to the success of this relationship. Such arrangements improves health service design and delivery but may present positive and negative impacts for health consumers and providers alike. A set of best practice principles were developed to inform these formal partnerships.(45)	No	8/9 (AMSTAR rating from McMaster Health Forum)	2018	Yes	• Selecting an option for addressing the problem • Identifying implementation considerations
	Health service re-design outputs may be influenced by the level of patient engagement undertaken to inform such a process. Lower-level engagement (e.g., consultations) tends to give rise to discrete products (e.g., policy) while higher-level engagement (e.g., partnership) gives rise to process and structural changes (e.g. governance and delivery). Consideration for strategies and contextual factors enabling a patient engagement approach to successfully result in improved care or outcomes is needed to ascertain its sustainability in a generalized organizational or systemic context.(42)	No	7/10 (AMSTAR rating from McMaster Health Forum)	2016	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	A growing set of 20+ tools to evaluate patient and public engagement in health research and system decision-making were identified, with most pertaining to the process rather than the outcomes of engagement. As with decision-making itself, the evaluation of decision-making (through the development of tools) needs increased patient and public engagement at the design stage, not just during data collection.(47)	N/A	6/9 (AMSTAR rating from McMaster Health Forum)	2016	No	• Identifying implementation considerations
	Though various methods of patient and public engagement in health service reconfiguration exist, the impact and sustainability of any single method is not well described in the literature. Nevertheless, the success of this process may be facilitated by many factors (e.g., understanding of local context, early engagement, follow-up). Assessment for engagement sustainability would benefit from prospective and longer-term evaluations with data collection from patients and the public in real time.(69)	No	6/9 (AMSTAR rating from McMaster Health Forum)	2014	No	• Selecting an option for addressing the problem • Identifying implementation considerations

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
	The normalization of patient participation in health service development may be facilitated by health professionals' awareness of various approaches to enable participation. Across the levels of patient participation in service development processes, further understanding at the intermediary level is needed.(70)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2019	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	There is limited evidence about approaches for synthesizing and summarizing information to support informed citizen deliberations.(44)	No	5/9 (AMSTAR rating from McMaster Health Forum)	April 2017	No	• Selecting an option for addressing the problem
	A taxonomy of 100+ metrics to evaluate patient engagement at various levels of healthcare decision-making was developed that comprises two overarching outcome and process categories, with each further encompassing domains and subdomains. The use of such metrics is enabled by 20+ tools identified, but none measures sustainability or scalability of engagement.(46)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2015	No	• Identifying implementation considerations
	Contextual factors, organizational arrangements and process management patterns are identified as the sets of obstacles that influence citizen participation effectiveness. Meanwhile, relations and structure are identified as the most crucial factors in improving participation.(43)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2014	No	• Identifying implementation considerations
	The emerging role of the patient partner in health systems reveals that the literature is dominated by context-specific descriptive studies from high-income countries, which has yet to shift its focus to impacts and best practices that are generalizable to entire systems. The nature of patient partnerships differs across health system domains; their role in agenda-setting is prominent and longitudinal in the health research domain, but is limited in others (health policy, governance, technology assessment and professional education programs).(38)	No	4/9 (AMSTAR rating from McMaster Health Forum)	2021	No	• Identifying implementation considerations
	The evidence base is inadequate and inconsistent on the definition, purpose and approach of public involvement in health policy development, as are means to ascertain the impact of such activity on policy, particularly in the long-term. While outcome is important, an argument may be made to consider the intrinsic value of involvement by way of its deliberative nature. Perception of the facilitators or barriers to public involvement are contextual factors mediating its success and impact.(39)	No	4/9 (AMSTAR rating from McMaster Health Forum)	2010	No	• Selecting an option for addressing the problem
	Five theory-based rules that are identified to facilitate the success in large-system transformations in healthcare pertain to leadership, feedback, history and parties for engagement, acting through various mechanisms to elicit change. Greater understanding of these rules is required through practical applications.(35)	No	4/9 (AMSTAR rating from McMaster Health Forum)	Not reported (published in 2012)	No	• Identifying implementation considerations

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
	Public and patient engagement is commonly understood with Arnstein's ladder of citizen participation and Carman's continuum of engagement. At the organizational level, research on engagement has largely focused on strategies. At the systems level, research has built upon such strategies to also consider community structures and factors that influence engagement.(41)	No	4/9 (AMSTAR rating from McMaster Health Forum)	Not reported (published in 2022)	No	• Identifying implementation considerations
	Patient and public involvement approaches in healthcare are often characterized by tokenism and exclusive selection of representation. Democratization of this process to achieve shared decision-making involves bridging power imbalances among stakeholders at organizational and community levels, including addressing social inequities and empowering the role of patients.(36)	No	3/11 (AMSTAR rating from McMaster Health Forum)	2016	No	• Identifying implementation considerations
	Consequentialism (focused on outcomes) and proceduralism (focused on procedures) are two prominent schools of thought to evaluate various levels of priority setting activities in healthcare, where the latter informs most existing evaluation approaches. A framework that integrates both, and informed by community values, was proposed in response to increased awareness of such need.(71)	No	2/9 (AMSTAR rating from McMaster Health Forum)	Not reported	No	• Identifying implementation considerations
	The underrepresentation of communities in health systems strengthening frameworks can be improved by more explicitly defining the role and activities of community involvement in the areas of planning, implementation, evaluation and advocacy.(72)	No	1/9 (AMSTAR rating from McMaster Health Forum)	2014	No	• Identifying implementation considerations
Embedding equity, diversity, inclusion and Indigenous reconciliation in such approaches (Search 1, Search 2, Search 3) *Total syntheses: None identified*	None identified					

*'Note: 'best' is defined as most up-to-date (i.e., literature searched within the last five years), highest quality and transparently presented evidence syntheses (i.e., a medium or high AMSTAR score)

Appendix 3: Jurisdictional scan of promising examples of citizens being 'in the driver's seat' for health-system transformations

Focus	Examples
Health-system transformation (including co-led design, execution and oversight)	• Since 2019, patient, family and caregiver advisors are – at least in some communities – co-leading the design, execution and oversight of Ontario Health Teams (OHTs) ○ OHTs use a population-health management approach to proactively get the right programs, services and products to all population segments in an attributed population, receive a single integrated funding envelope for the full range of covered services, and are held accountable for achieving equity-centred quadruple-aim metrics

Design stage primarily	• Several Canadian commissions have engaged citizens to varying degrees, most via traditional consultation methods and a few using deliberative dialogues:
	  ○ National Health Forum (1997) hosted deliberative dialogues, telephone surveys and regional conferences to find innovative ways to improve health systems in Canada and the health of the population
	  ○ Commission on Medicare in Saskatchewan (2001) hosted a series of public consultations
	  ○ Commission of Study on Health and Social Services in Quebec (2000) hoted a series of public hearings
	  ○ Standing Senate Committee on Social Affairs, Science and Technology on the State of the Health Care System in Canada (2002) hosted public hearings
	  ○ Health Services Review Committee in New Brunswick (2002) hosted 25 public hearings and over 100 private sessions, conducted a public opinion survey and solicited responses by e-mail and a 1-800 number
	  ○ Royal Commission on the Future of Health Care in Canada (2002) hosted public hearings, workshops, deliberative dialogues and other consultations
	• 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)
	• Many organizations are using deliberative mechanisms to address pressing health- or social-system challenges (e.g., town halls and other public consultations hosted by the Canadian Medical Association, face-to-face and online conversations hosted by Imagine Citizens Network, citizen panels by the Canadian Partnership Against Cancer and by MASS LBP, the Ontario Citizens' Council to inform drug policies (although this was dissolved in 2021 and replaced with other initiatiaves, such as the Minister's Patient, Family and Advisory Council), the dialogues "Rendez-vous en santé" hosted by the Institut du Nouveau Monde)
	• Patient, family and caregiver advisory councils exist in many health authorities and organizations (when they are engaged in the design of a transformation), including those specific to Indigenous peoples (e.g., Alberta Health Services' Wisdom Council) and aging adults and caregivers (e.g., SE Health's Wiser Advisors)

Execution stage primarily	• The 'Wigan Deal,' a citizen-led transformation of health and social care in a U.K. community
Oversight stage primarily	• Health and Welfare Commissioner's Consultation Forum, a hybrid deliberative forum composed of citizens and experts providing oversight of health-system performance in Quebec • Accreditation Canada's patient surveyors, who support the accreditation of Canadian health organizations
Engaging citizens to embed equity, diversity, inclusion and Indigenous reconciliation	• Imagine Citizens Network working in partnership with internationally educated health workers to engage diverse communities in Alberta • Health Commons Solutions Lab working in partnership with leaders in high-priority communities to respond to COVID-19 and to improve preventive and primary care • The Public Engagement in Health Policy project, in collaboration with the Public and Patient Engagement Collaborative, published an interactive tool on Supporting Equity-Centred Engagement Guide

Appendix 4: Evidence syntheses relevant to element 2 – Adapting the approach to primary-care transformations

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
Identifying key elements of a primary-care-centred 'community health home' that could address barriers to accessing care and the social determinants of health (Search 1, Search 2, Search 3, Search 4) *Total syntheses: eight (of which two are high quality and two are moderate quality) and one evidence synthesis is being planned*	Positive patient well-being outcomes were associated with the co-productive and co-designed approach to social prescribing, with facilitators include shared norms and values, communications between stakeholders, evaluating the intervention consistently and adequate resources and obstacles including transport, lack of confidence, negative previous experiences and cost.(48)	No	8/9 (AMSTAR rating from McMaster Health Forum)	2020	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	Findings of the impact of social prescribing services on service users was mixed on health and well-being and social interactions; positive on health-related behaviours; and mostly positive on self-concepts and feelings and day-to-day functioning.(49)	No	7/10 (AMSTAR rating from McMaster Health Forum)	2018	No	• Selecting an option for addressing the problem
	Three discourses of social prescribing are identified – social prescribing as overcoming the social determinants of health, supporting self-activation and enhancing personalized care – and an alternative "care-based" discourse is proposed.(73)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2020	No	• Identifying implementation considerations
	Identified themes of integrating social context into comprehensive care plans include interoperability, integrating health and social sectors, standardizing ontologies and interventions, process implementation, professional tribalism and patient centredness.(50)	No	5/10 (AMSTAR rating from McMaster Health Forum)	2016	No	• Identifying implementation considerations
	Patient-centred medical homes show improvement in quantitative health outcomes, follow-up and adherence, and quality of care, in addition to decreases in emergency room use, inpatient care and medical costs.(74)	No	4/11 (AMSTAR rating from McMaster Health Forum)	Not available	No	• Selecting an option for addressing the problem
	Factors to consider when choosing funding options for intersectoral health promotion activities (dedicated earmarked funding, delegated financing and joint budgeting) include: combination of financial and regulatory mechanisms; importance of collaboration and accountability; realistic funding duration; importance of legal and regulatory frameworks; importance of quantifying costs and benefits; and importance of trust between partners.(51)	No	3/9 (AMSTAR rating from McMaster Health Forum)	2016	No	• Identifying implementation considerations
	Integration of social determinants of health in health systems can be categorized from least to most integrated as Bounded, Production, Reciprocal, Joint or Systems; Joint or Systems models are recommended for use.(75)	No	3/9 (AMSTAR rating from McMaster Health Forum)	2012	No	• Identifying implementation considerations

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
	Screening tools were identified for food insecurity, housing, healthcare literacy, trauma, social support and multiple social determinants of health.(25)	No	3/9 (AMSTAR rating from McMaster Health Forum)	Not available	No	• Identifying implementation considerations
	Protocol for a review investigating facilitators, barriers and implementation strategies for screening, referral and follow-up of social determinants of health.(76) [Protocol]	n/a	n/a	n/a	n/a	• Identifying implementation considerations
Putting citizens 'in the driver's seat' for primary-care transformations (Search 1, Search 2, Search 3) *Total syntheses: five (of which two are high quality, two are medium quality, and one is low quality)*	Three guiding principles of patient, family and community advisory boards/councils (PFACs) are: 1) in-person deliberation is more effective; 2) patients with community credibility are more effective PFAC participants; and 3) outcomes require more time and resources, and may be of lower quality.(52)	No	8/10 (AMSTAR rating from McMaster Health Forum)	2016	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	Community engagement is an effective method to improve health behaviours, health consequences, self-efficacy and perceived social support outcomes in disadvantaged groups; facilitators include acceptability of interventions, relationships between partners, intervention implementation and project management.(55)	No	8/11 (AMSTAR rating from McMaster Health Forum)	2011	No	• Selecting an option for addressing the problem
	Patient advisory councils have positive outcomes on clinical care, patient safety, patient satisfaction, identifying priority setting in healthcare and personal benefits to patients and staff.(53)	No	7/10 (AMSTAR rating from McMaster Health Forum)	2015	No	• Selecting an option for addressing the problem
	Factors of community engagement programs that facilitate positive impacts on disadvantaged populations include established community advisory councils, collaboration and accountability of stakeholders, power-sharing between community and research team, community involvement in research design, and involvement of Indigenous and ethnic communities in research proposals.(54)	No	6/9 (AMSTAR rating from McMaster Health Forum)	2015	No	• Selecting an option for addressing the problem
	Barriers to healthcare co-production include different priorities of provider and patient, information asymmetry and perceived lack of patient capabilities, yet patient involvement was shown to improve service quality, patient satisfaction, health outcomes and knowledge creation.(77)	No	2/9 (AMSTAR rating from McMaster Health Forum)	2015	No	• Identifying implementation considerations
Humanizing primary care for those who were first here, people who	Anti-stigma training focuses either on specific groups that experience health-related stigma or on health advocacy, and programs should be interactive, draw on the roles/responsibilities of professionals and include people with lived experiences.(57)	No	7/10 (AMSTAR rating from McMaster Health Forum)	8 May 2022	No	• Selecting an option for addressing the problem

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
settled here, and newcomers (Search 1, Search 2, Search 3) *Total syntheses: 17 (of which one is high quality and 9 are moderate quality)*						• Identifying implementation considerations
	Compassionate, respectful and caring health service delivery has a positive impact on the utilization of health services, and barriers to this type of care include human resources, infrastructure and socio-demographic characteristics. Patients are primarily concerned with patient-centre communication, and respect in healthcare is a neglected factor that has a large impact on patient satisfaction and healthcare utilization.(78)	No	6/9 (AMSTAR rating from McMaster Health Forum)	2020	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	Social justice curricula for medical students have reported positive outcomes such as increased understanding of bias, ability to work in disadvantaged communities, cultural awareness, awareness of health disparities, understanding social determinants of health and connecting patients to appropriate public health resources; positive outcomes may be supported by best practices including using several educational techniques, addressing hidden curriculum and including community perspectives.(79)	No	6/9 (AMSTAR rating from McMaster Health Forum)	2020	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	The concept of humanization of care includes three areas (relational, organizational, structural) and 30 key elements (e.g., relationship bonding, holistic approach, adequate working conditions).(56)	No	6/9 (AMSTAR rating from McMaster Health Forum)	December 2017	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	Self-reflection, skills-based training, field experience and continuous integration of people with lived experiences are identified as prominent themes in conducting effective professional development training to improve healthcare delivery that is based on equity, diversity, inclusion, Indigeneity and accessibility considerations.(80)	No	6/10 (AMSTAR rating from McMaster Health Forum)	Not reported (published in 2013)	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	Eight community-based models of care that address the needs of ethno-racial communities were identified, and these models were characterized by facilitating access through engaging community-health workers; providing services such as patient education for self management, preventive care and services for chronic conditions; and including features such as cultural safety, culturally tailored services, ethnically matched providers, partnerships across sectors and involvement of the community.(81)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2023	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	Positive patient experiences in communicating with primary-care physicians are primarily characterized by being treated with respect, negative experiences are characterized by feelings of vulnerability as the patient, and outcomes of the communication experience are generally related to the patient's positive or negative perception of the experience as a whole.(82)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2015	No	• Understanding a problem and its causes

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
	Cultural competency is organized into three elements: knowledge, awareness and attitudes, and skills and behaviours, all of which must be developed in General Practitioners; yet, formal training on cultural competency is underdeveloped and currently relies on informal learning and experiential exposure.(83)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2013	No	• Identifying implementation considerations
	Barriers to health advocacy include contemporary economic and political approaches, the focus on biomedical health, cross-sectoral cooperation, political short-termism, reluctance of academics to advocate and marketization of higher education. Effective advocacy can be increased through practices including social mobilization, establishing collaborative networks and recognizing windows of opportunity.(84)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2013	No	• Identifying implementation considerations
	Training for public health students in racial justice and health equity is not widely discussed in the literature; however, identified studies reported a range of program designs that covered topics such as health inequities, structural issues, social determinants of health, racism and social justice, in various formats with evaluation styles ranging from feedback on lessons to the more rigorous pre-tests and post-tests of knowledge.(85)	No	4/9 (AMSTAR rating from McMaster Health Forum)	2020	No	• Selecting an option for addressing the problem
	Primary healthcare models may be better equipped to address social determinants of health, and have more potential to reduce immigrant populations' health inequities.(86)	No	4/9 (AMSTAR rating from McMaster Health Forum)	30 November 2013	No	• Selecting an option for addressing the problem
	Important considerations for anti-racism action include clear objectives, anti-racism language, leadership, resources and partnerships. Identified strategies for anti-racism include a multi-level long-term approach, links to broader systems of oppression and built-in reflection mechanisms.(87)	No	4/9 (AMSTAR rating from McMaster Health Forum)	Not avaiilable	No	• Identifying implementation considerations
	Collective efficacy to reduce health disparities can be increased through interventions that target all five building blocks of collective efficacy (social bonding, social bridging, social leveraging, empowerment and civic engagement) and intervene on multiple social ecological levels.(88)	No	3/9 (AMSTAR rating from McMaster Health Forum)	2017	No	• Selecting an option for addressing the problem
	Humanization policies in primary care include three domains: organization and infrastructure of primary healthcare services, work processes, and technology of relations (e.g., the reception, bonding, listening, respect and dialogue with patients).(89)	No	3/9 (AMSTAR rating from McMaster Health Forum)	January 2012	No	• Selecting an option for addressing the problem • Identifying implementation considerations

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
	Characteristics of social work in primary care include building close relationships with patients, working towards specific goals, generalist attention to the patient's various life areas, strengthening individual and group ability to gain control of their life, and focusing on individual change.(90)	No	3/9 (AMSTAR rating from McMaster Health Forum)	Not available	No	• Identifying implementation considerations
	The authors developed a community resilience model that demonstrates that health outcomes are the result of the interactions of many systems and factors outside of healthcare and public health including housing, public schools, law enforcement and criminal justice.(91)	No	2/9 (AMSTAR rating from McMaster Health Forum)	Not available	No	• Identifying implementation considerations
	A robust and invigorated primary-care system can drive population health and health equity, as well as democracy and citizen engagement.(58) [Not a systematic review]	No	n/a	n/a	No	• Selecting an option for addressing the problem

*'Note: 'best' is defined as most up-to-date (i.e., literature searched within the last five years), highest quality and transparently presented evidence syntheses (i.e., a medium or high AMSTAR score)

Appendix 5: Jurisdictional scan of promising examples of citizens being 'in the driver's seat' for primary-care transformations

Focus	Examples

Primary-care transformation	• OurCare is a pan-Canadian conversation about the future of primary care in Canada through the use of national surveys, priority panels and community roundtables
	  ○ A recent report from the initiative's first regional panel made several recommendations for the province of Ontario, including shifting away from solo medical practices and towards team-based care, improving patients' access to their electronic medical records, creating a digital system for specialist referrals that is centralized and significantly increasing family medicine residency spaces (other provincial reports are forthcoming)
	• Alberta Health Services has a Primary Health Care Virtual Patient Engagement Network that connects patients, families and caregivers to primary healthcare teams by matching patients and their family advisors to primary healthcare initiatives that best fit their availability, experiences and interests
	• Alberta's Strategic Advisory Panel, which included one citizen leader and a leader of a citizen-serving non-governmental organization (among others), has made recommendations for modernizing Alberta's primary-care system over the next 10 years, guided by the goals of access, integration, quality, partnership with Albertans and culturally safe and appropriate care
	• In the U.S., the Massachusetts Primary Care Dashboard monitors the health of the primary-care system along the four domains of finance, capacity, performance and equity
	  ○ This dashboard was created to provide baseline data to support policy initiatives (that could include citizen engagement as part of the development process)

Humanizing primary care for those who were first here, people who settled here and newcomers	• Primary Care Networks in British Columbia provide quality team-based care from healthcare providers to address the primary-care priorities of communities, including:
	  ○ culturally safe and appropriate care for Indigenous peoples (which includes drawing on Indigenous resources and having traditional healers as part of each team)
	  ○ providing better access to chronic care
	  ○ improving mental health and substance-use services
	  ○ coordinating comprehensive services for the vulnerable and people living in poverty
	• Indigenous Primary Health Care Council has several resources to humanize primary care for Indigenous peoples, including a framework for Indigenous health-system transformations and cultural safety and anti-Indigenous racism training program
	• Ontario Health has an Equity, Inclusion, Diversity and Anti-Racism Framework to guide their work in building an organizational culture of equity, inclusion, diversity and anti-racism in an effort to improve outcomes for patients, families and providers within the health system
	• The Community Health Centre model in Ontario promotes the delivery of primary-care services as well as health promotion and illness prevention services with a strong community development focus
	  ○ Programs that contribute to family and child health include anti-racist initiatives, domestic violence prevention/treatment and education for parents and resources for children
	• Inner City Health Associates provides specialized services for people experiencing homelessness in Toronto

Appendix 6: Evidence syntheses relevant to element 3 – Working through what it means to be an ally

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
Supporting reconciliation with Indigenous peoples (Search 1, Search 2, Search 3) *Total syntheses: four (of which two are high quality and two are moderate quality)*	Indigenous healing strategies in Canada most commonly consist of artistic expression, games and exercises, ceremonies and cultural teachings, and they often incorporate consultation/participatory research and Indigenous protocols that engaged Indigenous peoples.(59)	No	7/9 (AMSTAR rating from McMaster Health Forum)	February 2019	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	In support of the United Nations Declaration on the Rights of Indigenous Peoples, free, prior and informed consent should be obtained by engaging with Indigenous communities early and on an ongoing basis when policies and initiatives affect Indigenous peoples.(60)	No	6/9 (AMSTAR rating from McMaster Health Forum)	April 2019	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	Indigenous curricula in graduate medical education can be impacted by cultural bias of resident physicians towards Indigenous peoples, course implementation challenges (e.g., lack of knowledge expertise, ample funding) and the development of community-driven Indigenous partnerships to create a safe learning environment.(62)	No	5/9 (AMSTAR rating from McMaster Health Forum)	April 2021	No	• Selecting an option for addressing the problem • Identifying implementation considerations
	To improve their work with Indigenous peoples, occupational therapists should critically examine any Western cultural assumptions about Indigenous cultures and peoples.(63)	No	4/9 (AMSTAR rating from McMaster Health Forum)	2018	No	• Identifying implementation considerations
Working as ally with Indigenous-governed health systems (Seach 1, Search 2. Search 3) *Total syntheses: one of low quality*	Strategies to support equity-oriented care can include developing partnerships with Indigenous communities, taking action at all levels of health systems, being sensitive to biases and responding to challenges that may arise with each strategy.(64)	No	3/9 (AMSTAR rating from McMaster Health Forum)	Published December 2020	No	• Identifying the problem • Selecting an option for addressing the problem • Identifying implementation considerations
Addressing anti-Indigenous racism in health systems (Search 1, Search 2, Search 3) *Total syntheses: four (of which two*	Facilitators of cultural competency and safety may include making patients feel valued, family inclusion and cultural support in care decision-making, having Indigenous staff in hospitals and enhancing access to primary care and specialist services.(65)	No	5/9 (AMSTAR rating from McMaster Health Forum)	2017	No	• Identifying implementation considerations
	Indigenous health services can reduce healthcare costs for low income families, providing transportation to and from appointments and involving Indigenous community members in identifying and addressing care needs.(66)	No	5/9 (AMSTAR rating from McMaster Health Forum)	Published September 2016	No	• Selecting an option for addressing the problem

Sub-element (and search strategy used)	'Best'* available evidence syntheses to inform decision-making about the components	Living status	Quality	Last year literature searched	Availability of GRADE profile	Type of policy question addressed
are high quality and two are moderate quality) and one synthesis being planned	Anti-racist education and training post-licensure can consist of a wide range of topics, including white privilege, discrimination and unconscious bias, but the modality and the curricular content is not always clearly delineated.(68)	No	2/9 (AMSTAR rating from McMaster Health Forum)	October 2020	No	• Selecting an option for addressing the problem
	Greater clarity is needed on cultural safety related concepts along with more intentional engagement of Indigenous peoples in the development of cultural safety training programs.(67)	No	2/9 (AMSTAR rating from McMaster Health Forum)	May 2020	No	• Identifying implementation considerations
	A scoping review will examine key elements of cultural safety interventions to improve healthcare for Indigenous peoples.(92) [Protocol]	n/a	n/a	n/a	n/a	• Selecting an option for addressing the problem

*'Note: 'best' is defined as most up-to-date (i.e., literature searched within the last five years), highest quality and transparently presented evidence syntheses (i.e., a medium or high AMSTAR score)

Appendix 7: Jurisdictional scan of promising examples of working as an ally

Focus	Examples

Supporting reconciliation with Indigenous peoples	• The United Nations (UN) Declaration on the Rights of Indigenous Peoples was adopted by the UN General Assembly in September 2007 and establishes a universal framework of minimum standards regarding the survival, dignity and well-being of Indigenous Peoples around the world
	  ○ The United Nations Declaration on the Rights of Indigenous Peoples Act (2021) provides a framework to advance the implementation of the UN Declaration in Canada at the federal level by preparing and implementing an action plan that includes specific measures to achieve the Declaration's objectives
	  ○ The Action Plan was published in June 2023 and includes 181 measures to reflect the priorities identified by First Nations, Inuit and Métis
	• The Truth and Reconciliation Commission of Canada produced a Report in 2015 with 94 calls to action in order to redress the legacy of residential schools and advance reconciliation in Canada
	  ○ Calls to action 18 to 24 focused on health systems
	  ▪ 18. "We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties."
	  ▪ 19. "We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services."
	  ▪ 20. "In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples."
	  ▪ 21. "We call upon the federal government to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority."
	  ▪ 22. "We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients."
	  ▪ 23. "We call upon all levels of government to: 1) increase the number of Aboriginal professionals working in the health-care field; 2) ensure the retention of Aboriginal health-care providers in Aboriginal communities; 3) provide cultural competency training for all healthcare professionals."
	  ▪ 24. "We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism."
	• The Steering Committee on Canada's Archives responded to the Report of the Truth and Reconciliation Commission Taskforce by undertaking several activities, including:
	  ○ a review of archival policies across Canada
	  ○ a survey (Canada-wide) of professionals to identify barriers to reconciliation practices
	  ○ dialogue and collaboration with representatives from First Nations, Inuit and Métis communities
	  ○ development of a reconciliation framework with the primary objective of building relationships grounded in the principles of respect, reciprocity, relevance and responsibility
	• On the fifth anniversary of the Truth and Reconciliation final report, the Minister of Crown-Indigenous Relations at the time, Hon. Carolyn Bennett, indicated that 80% of the calls to action that involved the Government of Canada had been completed, are at early stages of progress or were well underway, including:

Focus	Examples
	○ launching a National Inquiry into Missing and Murdered Indigenous Women and Girls ○ collaborating with Indigenous peoples to reform the child and family services system and to promote Indigenous languages ○ working to implement the United Nations Declaration on the Rights of Indigenous Peoples ○ working to amend the Oath of Citizenship to include references to the Aboriginal and treaty rights of First Nations, Inuit and Métis peoples • The National Collaborating Centre for Indigenous Health is supporting health-system renewal and health equity through knowledge translation and exchange (many resources are directly relevant to reconciliation, Indigenous-governed health systems and anti-Indigenous racism) • The National Consortium for Indigenous Medical Education is advancing Indigenous medical education and leadership in healthcare • The Canadian Medical Association convened a Guiding Circle in September 2022 made up of 16 First Nations, Inuit and Métis leaders and experts to help the CMA to identify areas of focus for their work on Indigenous health ○ On 13 June 2023, the CMA announced the beginning of an apology process for the harms caused to Indigenous Peoples as a meaningful step towards reconciliation • The Canadian Institutes for Health Research adopted an action plan for stepping up its efforts to build the research evidence that is critical for improving the health status of First Nations, Inuit and Métis peoples ○ The Institute of Indigenous Peoples' Health and the Institute of Health Services and Policy Research are both positioned to advanced the research agenda relevant to element 3 • Several pan-Canadian health organizations have launched efforts to support reconciliation, including: ○ Canadian Institute for Health Information ○ Canadian Partnership Against Cancer ○ Healthcare Excellence Canada ○ Mental Health Commission of Canada • Several Canadian universities have launched efforts to support reconciliation, including: ○ dedicated resources for the enrollment and mentorship of Indigenous students (e.g., UBC adopted a Indigenous Strategic Plan and Université Laval adopted several initiatives to promote access to and success of Indigenous students in academic programs) ○ creation of new Indigenous research institutes and research chairs to promote research for, by and with Indigenous peoples (e.g., Ongomiizwin – Indigenous Institute of Health and Healing at the University of Manitoba or the Indigenous Health Learning Lodge at McMaster University) • Several organizations have developed educational resources and toolkit to learn how to become an ally to Indigenous peoples (e.g., Laurentian University and Queen's University) • In June 2023, a bill was presented by the Quebec government to establish the cultural safety approach within the provincial health system
Supporting Indigenous-governed health systems	• The First Nations Health Authority designs, manages and funds the delivery of health programs for First Nations in British Columbia • The Southern Chiefs' Organization (SCO) represents 34 First Nations in southern Manitoba to promote and assist First Nations members advancing their goals and defending Treaty and Aboriginal rights ○ In June 2022, the SCO announced that it was working with provincial and federal governments to establish its own health authority in Manitoba • The First Nations Health & Social Secretariat of Manitoba works with Indigenous Peoples in the province to participate in planning and development of the health system and health policies • The Indigenous Primary Health Care Council published a framework on Indigenous health-system transformations to strengthen and grow Indigenous health programs and services in the context of Ontario Health Teams • Aboriginal Health Access Centres in Ontario provide aboriginal people with access to doctors, social workers, dieticians, traditional healers and mental health professionals to meet their health needs • The Maamwesying Ontario Health Team works to provide a range of health services that are accessible, culturally safe and holistic for their First Nations community members

Focus	Examples
	• Tajikeimik is a health and wellness organization in Nova Scotia that has been created to lead health transformation for Mi'kmaw communities and address gaps in health services
Addressing anti-Indigenous racism in health systems	• The Rise Above Racism campaign brings to the forefront the issue of anti-Indigenous racism within health systems in Canada, is calling organizations to become allies and offers educational resources • Anti-Indigenous racism, cultural safety and humility training curriculum: o San'yas Anti-Racism Indigenous Cultural Safety Training (British Columbia) o Indigenous Primary Health Care Council (Ontario) o Cultural safety resources from the National Collaborating Centre for Indigenous Health • Accreditation requirements developed for health services providers, including administrators: o Accreditation for Indigenous Health and Social Services (Accreditation Canada) o British Columbia Cultural Safety and Humility Standard (Health Standards Organization) o Community Accreditation and Quality Improvement program (BC First Nations Health Authority) • Efforts are being made to integrate culturally safe care in acute care settings and traditional approaches to health: o Turtle Lodge (International Center of Excellence in Indigenous Education and Wellness) o First Nations, Inuit and Métis Community Advisory Panel (Unity Health Toronto) • Process to report racism and discrimination o First Nation Health Ombudsperson's Office (Saskatchewan)

Appendix 8: Citizen-engagement assets that could be leveraged to enable citizen co-led transformations (with some groups already focused on health-system transformation, some working around the edges of transformation, and others not yet engaged in transformation)

Jurisdiction	Examples of existing structures and processes	**Potential focus of engagement** (i.e., designing the vision, executing the vision, ensuring accountability for achieving the vision)
Federal/Pan-Canadian	Accreditation Canada's patient surveyors	**Executing the vision** Patient surveyors have extensive, first-hand knowledge of the health system and are willing to volunteer their time to help health organizations improve on an ongoing basis
	Canadian Medical Association's Patient Voice	**Designing the vision** The 15-member group offers ideas on how to make Canadians healthier and contribute to a vibrant medical profession, highlights emerging issues, and provides insights into the best ways for the CMA and physicians to engage with patients
	Evidence Commission Citizen Leadership Group	**Designing the vision** A group of citizen leaders and leaders of citizen-serving NGOs striving to put evidence at the centre of everyday life
	Imagine Canada	**Designing and executing the vision** A group committed to an ongoing process of becoming a more equity-driven, inclusive, transformative and provocative player within and for the social good sector
	Jack.org	**Designing the vision** A charity empowering young leaders to improve mental health across Canada
	Patient Advisors Network	**Designing and executing the vision** A network of patients who are committed to improving healthcare as partners and advisors across Canada
	SE Health Wiser Advisors	**Designing and executing the vision** A program developed to bring together people with lived experience (e.g., clients, caregivers, family members, patients) to work with SE Health to improve healthcare and make social impact
	Patients for Accountable Healthcare	**Ensuring accountability** A coalition of patients, patient advocates and supporters aiming to keep health-system leaders focused on following through on achieving real change
British Columbia	BC Health Care Matters	**Designing the vision** A grassroots patient advocacy group campaigning for timely access to a family doctor for every resident of British Columbia
	Patient Voices Network	**Designing and executing the vision** A network of patients, families and caregivers working together with healthcare partners to improve B.C.'s health system
Alberta	Imagine Citizens Network	**Designing and executing the vision** A network of people and community-oriented partners that creates pathways to bring citizen voices to drive health-system transformation
	Patient and Family Advisors in the Strategic Clinical Networks	**Designing and executing the vision** Patient and Family Advisors committed to sharing their knowledge, perspectives and time as part of Strategic Clinical Networks committees
	Virtual Patient Engagement Network	**Designing and executing the vision** A platform that connects patients, families and caregivers with people and teams working to improve primary care
Saskatchewan	Patient and Family Advisor Program	**Designing and executing the vision and ensuring accountability**

Jurisdiction	Examples of existing structures and processes	**Potential focus of engagement** (i.e., designing the vision, executing the vision, ensuring accountability for achieving the vision)
		A program to engage patients and families in the development, implementation and evaluation of health-system policies and programs
Manitoba	Shared Health's Patient and Family Advisor Network	**Designing the vision** A network of members of the public, patients, family members and caregivers sharing their experiences and suggestions on a range of projects and health-system issues
Ontario	Minister's Patient and Family Advisory Council	**Designing a vision** A council advising the Ontario government on key healthcare priorities that have an impact on patient care and experiences, driving meaningful changes to provincial programs and policies, and helping inform healthcare planning
	Patient and Family Advisors Network	**Designing and executing the vision** A virtual network for anyone who uses healthcare services in Ontario and wants to build a better system
	Patient Ombudsman	**Ensuring accountability** The Patient Ombudsman receives, responds to and helps resolve complaints from current or former patients (or their caregivers) about their care or experiences with public hospitals, long-term care homes and home and community care support-services organizations
Quebec	Centre of Excellence on Partnership with Patients and the Public	**Designing and executing the vision** A centre dedicated to public and patient partnership to improve health and health systems
	Health and Welfare Commissioner's Consultation Forum	**Designing the vision and ensuring accountability** A deliberative forum of 18 citizens and nine experts providing their point of view on various questions submitted by the Health and Welfare Commissioner during its work (including appraising health-system performance)
	Institut du Nouveau Monde	**Designing the vision** An independent and non-partisan organization dedicated to increasing citizen participation in democratic life (including on health-system issues)
New Brunswick	The Patients Voices Network, led by the New Brunswick Health Council	**Designing the vision** A forum that allows citizens to share their experiences and voice their opinions on specific components of the health system
Nova Scotia	Engage Nova Scotia	**Designing the vision** An independent non-profit organization engaging citizens in conversation, visioning and storytelling to improve quality of life for all
Prince Edward Island	Health PEI Volunteer Patient and Family Partners	**Designing and executing the vision** Patient and family partners will support Health PEI in many ways including sharing their stories, participating on quality-improvement teams, and working on short-term quality-improvement projects
Newfoundland and Labrador	Patient Partners at Quality of Care NL	**Designing the vision** Patients and members of the public providing insights on the work done by Quality of Care NL to improve the health system
Yukon	None identified	
Northwest Territories	None identified	
Nunavut	None identified	

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