Evidence Brief

Scaling Up Shared Decision-making in Home and Community Care in Canada

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McMaster Health Forum
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KEY MESSAGES

What's the problem?
- Challenges associated with scaling up shared decision-making (SDM) in home and community care can include:
  - complex decisions about home and community care are increasingly being made, but older adults are rarely meaningfully engaged in these decisions;
  - there is confusion between identifying the care needs and identifying the decisional needs of older adults;
  - little focus has been placed on how provider organizations and government policymakers could help to meet the decisional needs of older adults; and
  - system-level factors make it difficult to meet older adults' decisional needs.

What do we know about three groupings of decisional needs?
- Grouping 1 – Decisional needs that provider organizations could help meet
  - Provider organizations could help to meet certain decisional needs of older adults in relation to home and community care, such as: who can I turn to in order to understand where and how I can get care and support; where can I find the help I need in order to make complex decisions; or what can I expect between frequency and intensity of care and support.
- Grouping 2 – Decisional needs that government health policymakers could help meet
  - Government health policymakers could help to meet certain decisional needs of older adults in relation to home and community care, such as: how can I or my caregiver have a say in the future direction of home and community care; how can I access additional care beyond what is publicly funded; or how can I know that the care being provided to people like me is adequate.
- Grouping 3 – Decisional needs that government policymakers from other sectors could help meet
  - Government policymakers from other sectors (e.g., finance, housing and transportation) can help to meet certain decisional needs of older adults in relation to home and community care, such as: what type of housing can enable me to receive an appropriate level of home and community care; what type of nutritional support can I access; what type of transportation can I access; or what types of financial support are available.

What is known about scaling-up strategies?
- We found seven systematic reviews and one systematic review in progress examining what is known about scaling-up strategies in health and social systems, as well as one rapid synthesis examining the rapid-learning health system approach (as a lens through which scaling-up strategies could be designed). There is a limited body of synthesized research evidence examining the effectiveness of scaling-up strategies, along with a lack of consensus about metrics for scaling up. Most of the literature examined the conceptual and theoretical underpinnings of scale-up and spread strategies, dissected the steps of scale-up and spread processes, or identified potential barriers and facilitators.
- While many barriers to scaling up SDM in home and community care may exist at the level of patients, providers, provider organizations and systems, perhaps the biggest barrier lies in policymakers' long history of failing to scale up health innovations in Canada.
- Windows of opportunity for scaling up SDM in home and community care might include several governments in Canada leading reforms and initiatives where home and community care and SDM are both front and centre. Many assets related to SDM and citizen and patient engagement more broadly (e.g., expertise, decision-support tools, training programs and infrastructure) can be leveraged to take advantage of these windows of opportunity.

REPORT

Home and community care is a part of the continuum of healthcare that is highly valued by Canadians. In a 2016 survey of 1,000 adult Canadians, 81% said that aging at home with access to healthcare is important.(1) In 2012, 2.2 million Canadians received home care, and seniors (those aged 65+) represented 40% of this total.(2) This number will increase as the population ages, capacity pressures grow in the acute care and long-term care sectors, and new technologies facilitate access to and delivery of health and social services at home and in the community.

In an effort to better meet older adults' needs for home and community care, federal, provincial and territorial governments have made significant investments in this sector. For example, federal, provincial and territorial governments agreed to a Common Statement of Principles on Shared Health Priorities after the 2017 federal budget announcement of about $6 billion being allocated over 10 years to support home- and community-care programs.(3; 4) Provincial and territorial governments have also boosted investments to strengthen and expand home and community care, the most recent examples being the Government of Ontario announcing an additional $155 million in 2019,(5) and the Government of Quebec announcing an additional $1.5 billion over the next five years.(6)

The growing needs for and options in home and community care will translate into more decisions, and more types of decisions, being made by older adults. These decisions can be complex and significantly affect their health and well-being, and they can range from decisions about treatment options to decisions about housing options.

Shared decision-making (SDM) is a collaborative process whereby health and social care providers support individuals in making decisions informed by the best available evidence and what matters most to them.(7) While research evidence shows that SDM leads to better care experiences and health outcomes for patients and better performance metrics for the health system (e.g., better use of healthcare dollars),(8-11) most Canadians do not experience SDM, and even fewer older adults experience it.(12)

Promising SDM tools and training programs have been developed to help home- and community-care teams support older adults, including their families and

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Box 1: Background to the evidence brief

This evidence brief mobilizes both global and local research evidence about a problem (the challenges in scaling up shared decision-making), three groupings of decisional needs that could be the focus of scaling-up efforts, and key implementation considerations related to scaling up. Whenever possible, the evidence brief summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review 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. The 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 the evidence brief involved five steps:
- convening a Steering Committee comprised of representatives from the partner organizations (including the Canada Research Chair in Shared Decision Making and Knowledge Translation and the McMaster Health Forum);
- developing and refining the terms of reference for an evidence brief, particularly the framing of the problem and groupings of decisional needs, in consultation with the Steering Committee and a number of key informants, and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
- identifying, selecting, appraising and synthesizing relevant research evidence about the problem, groupings of decisional needs, and implementation considerations;
- drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence; and
- finalizing the evidence brief based on the input of several merit reviewers.

The evidence brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants' views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. A second goal of the stakeholder dialogue is to generate action by those who participate in the dialogue and by those who review the dialogue summary and the video interviews with dialogue participants.

caregivers. These tools and programs have typically addressed how home- and community-care teams can help older adults make decisions about care options (e.g., testing and treatment decisions). However, little is known about how provider organizations and government policymakers can also help to meet a complementary set of decisional needs of older adults. For example, older adults may have decision needs like: 1) what balance between frequency of visits and continuity of provider can be accommodated; 2) how can I know that the care being provided to people like me is adequate; and 3) what type of housing will enable me to receive an appropriate level of home and community care.

Moreover, SDM tools and programs have often been implemented as part of local pilot projects and not scaled up to benefit as many Canadians as possible. As provincial and territorial health systems increasingly focus on improving care experiences and health outcomes in the home- and community-care sector,(13) while keeping per capita costs manageable and providers satisfied, there will be a growing imperative to expand SDM to meet the full range of older adults' decisional needs and to ensure that SDM is actively offered to and supported for all of those who can benefit from it.

Aim of the evidence brief

This evidence brief aims to inform deliberations that could help scale up SDM to address the pressing and diverse decisional needs of older adults in relation to home and community care in Canada. In doing so, it mobilizes the best available evidence to identify:
1) the challenges in scaling up shared decision-making;
2) the top decisional needs of older adults (including their families and caregivers) that could be the focus of scaling-up efforts (with a specific focus on those that provider organizations and government policymakers could help to meet); and
3) key implementation considerations related to scaling-up efforts.

As explained in Box 1, the evidence brief does not contain recommendations. Moving from evidence to recommendations would have required the authors to introduce their own values and preferences. Instead, the intent is for this evidence brief to inform deliberations

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Box 2: Equity considerations

A problem may disproportionately affect some groups in society. The benefits, harms and costs of options to address the problem may vary across groups. Implementation considerations may also vary across groups.

One way to identify groups warranting particular attention is to use "PROGRESS," which is an acronym formed by the first letters of the following eight ways that can be used to describe groups†:
- place of residence (e.g., rural and remote populations);
- race/ethnicity/culture (e.g., First Nations and Inuit populations, immigrant populations and linguistic minority populations);
- occupation or labour-market experiences more generally (e.g., those in "precarious work" arrangements);
- gender;
- religion;
- educational level (e.g., health literacy);
- socio-economic status (e.g., economically disadvantaged populations); and
- social capital/social exclusion.

The evidence brief explores equity considerations from two angles:
- populations (specifically equity issues arising from home and community care delivered to linguistically or ethnoculturally diverse populations); and
- geography (specifically equity issues arising from home and community care delivered in urban versus rural and remote areas).

Many other groups warrant serious consideration as well, and a similar approach could be adopted for any of them.

† The PROGRESS framework was developed by Tim Evans and Hilary Brown (Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. *Injury Control and Safety Promotion* 2003;10(1-2): 11–12). It is being tested by the Cochrane Collaboration Health Equity Field as a means of evaluating the impact of interventions on health equity.

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where participants in a stakeholder dialogue will themselves decide what actions are needed based on the available evidence, their own experiential knowledge, and insights arising through the deliberations.

To draw attention to equity considerations, the evidence brief also focuses on two groups that were identified by the Steering Committee and key informants. Specifically, when considering the challenges in scaling up SDM, the evidence brief explores equity considerations from two angles: 1) populations (specifically equity issues

arising from home and community care delivered to linguistically or ethnoculturally diverse populations); and 2) geography (specifically equity issues arising from home and community care delivered in urban versus rural and remote areas). Scaling up SDM may pose particular equity challenges for both (see Box 2). Many other groups warrant serious consideration as well, and a similar approach could be adopted for any of them.

Key definitions

This evidence brief uses several key terms that need to be defined and in some cases described. The terms and their definitions and descriptions are outlined in Table 1.

Table 1: Key definitions

Term	Definition and description

Decisional needs	● Decisional needs refer to a "deficit that can adversely affect the quality of a decision (informed, match most valued features) and require tailored decision support."(14)
	● The Ottawa Decision Support Framework identifies six factors that may affect decisional needs:
	  o the decision (i.e., the type of decision, the number of options, the degree of risk and uncertainty, the seriousness of outcomes, and whether it is irrevocable);
	  o decisional conflict (i.e., uncertainty about a course of action);
	  o knowledge (about the problem, options and outcomes) and expectations (probability of outcomes of each option);
	  o values;
	  o support and resources (including others' opinions, pressure, role in SDM, experience, self-efficacy, motivation, skills, and external support); and
	  o personal and clinical characteristics (of those involved in the decision-making process).(15)

Home and community care	● Home and community care refers to an array of publicly and privately funded services to help people receive "care at home, rather than in a hospital or long-term care facility, and to live as independently as possible in the community."(16) ● Home and community care is delivered by various health and social care organizations (e.g., third-party contractors paid by provincial or regional health authorities), professionals (e.g., nurses, dietitians and social workers), other types of health workers (e.g., personal-support workers), and unpaid caregivers (e.g., family members, friends and volunteers). ● From a programmatic perspective, home care can include: 1) professional services to assess clients' needs (e.g., nursing care, physiotherapy, occupational therapy, respiratory therapy, speech-language therapy, and social work); 2) services by care coordinators (i.e., a trained health professional in charge of coordinating a patient's care delivery from multiple providers); 3) services by system navigators (i.e., a trained professional, trained volunteer or peer who helps patients and families in need of home and community care to access services, guides them through the health and social system, and helps them overcome barriers they may face; 4) personal-support services to help clients with daily care (e.g., bathing, dressing, eating and personal hygiene); 5) homemaking services (e.g., cleaning, planning and preparing meals, caring for children); and 6) end-of-life care with in-home visits and respite care.(17) ● Community care can include: 1) adult day programs; 2) supportive housing (e.g., personal support, homemaking); 3) retirement homes (e.g., personal support, homemaking services, social and recreational opportunities); and 4) transportation services. Other examples could include community and residential hospice services such as counselling and support groups, exercise and falls-prevention programs, and assistive-devices programs (e.g., enteral feeding supplies, insulin pumps and supplies for diabetics).(17)
Shared decision-making	● Shared decision making (SDM) is a collaborative process whereby a third party (e.g., a physician or social worker) supports individuals in making decisions that are informed by the best available research evidence and by what matters to them.(4) ● Much SDM takes place through interaction between older adults, families, caregivers and the home- and community-care team, and can significantly affect older adults' care trajectory and well-being.(12) ● Various SDM models exist, including: o the Three-Talk model, which highlights three phases of SDM: 1) team talk (work together,

	describe choices, offer support, and ask about goals); 2) option talk (discuss alternatives using risk communication principles); and 3) decision talk (get to informed preferences, make preference-based decisions); (18) and
	
	    ○ the Interprofessional Shared Decision Making (IP-SDM) model which highlights the contextual influences at the individual level, influences at the systemic or organizational level, and influences at the broader policy or social level.(19)
	
	● While there are variations across SDM models, they usually have three key elements in common:
	    ○ recognizing and acknowledging that a decision is required;
	    ○ knowing and understanding the best available evidence relevant to the decision; and
	    ○ incorporating the patient's values and preferences into the decision.(20)
	
	● Interventions for increasing the use of SDM by providers can target: providers only (e.g., training); (21) patients only (e.g., giving them a decision aid, which is a pamphlet explaining options and inviting them to think about their values and preferences);(21) both providers and patients (e.g., training plus a decision aid);(21) provider organizations; and government policymakers, both in the health sector and in other sectors.(19)
	
	● Systematic reviews found that SDM can:
	    ○ improve the care experiences and health outcomes of individuals;(8; 10)
	    ○ keep per capita costs manageable;(11) and
	    ○ maintain provider satisfaction.(9)
	
	● Research evidence examining tools used to support SDM have also shown benefits. For example, systematic reviews found that decision aids can:
	    ○ help patients to be better informed with more realistic expectations;(22)
	    ○ clarify their values and activity in decision-making;(22)
	    ○ reduce the overuse of unnecessary and ineffective care options;(22)
	    ○ increase the uptake of effective care options;(22) and
	    ○ reduce harms and increase client safety.(8)
	
	● Few studies have examined SDM in the context of home and community care. Two randomized controlled trials of SDM training and decision aids in home care were conducted in select communities.(23; 24) Findings revealed that:
	    ○ older adults and caregivers were more engaged in decisions about whether to stay at home or move elsewhere and about end-of-life care plans;(25)
	    ○ older adults and caregivers were able to play the role they wanted in the decision-making process;(26) and
	    ○ online decision-support interventions to support older adults to live independently at home were perceived as acceptable and helpful.(27)
	
	● SDM is considered a best practice in obtaining informed consent, fundamental to patient/family-centred care, and considered by many to be an ethical imperative.(28)

Policymakers	● Policymaker refers to a wide range of people who are involved in making policies and policy decisions (e.g., senior civil servants and elected officials), as well as those in programmatic roles within governments.
Scaling up	● Scaling up refers to deliberate efforts to tackle "the infrastructural problems (across an organization, locality, or health system) that arise during full scale implementation."(29) Scaling-up strategies aim to "increase the impact of successfully tested health innovations so as to benefit more people and to foster policy and program development on a lasting basis."(30) We use the term here to mean ensuring that SDM is actively offered to and supported for all of those who can benefit from it.
Spreading	● Spread refers to "replicating an initiative somewhere else."(30)

THE PROBLEM

In this section, we describe four challenges in scaling up SDM in home and community care:

1) complex decisions about home and community care are increasingly being made, but older adults are rarely meaningfully engaged in these decisions;
2) there is confusion between identifying the care needs and identifying the decisional needs of older adults;
3) little focus has been placed on how provider organizations and government policymakers could help to meet the decisional needs of older adults; and
4) system-level factors make it difficult to meet older adults' decisional needs.

We describe each of these challenges in turn below based on data and evidence we identified from our searches, as well as from insights we identified through the key-informant interviews that we conducted during the preparation of this evidence brief.

Complex decisions about home and community care are increasingly being made, but older adults are rarely meaningfully engaged in these decisions

Helping older adults to live at home and in their community for as long as possible is a top priority in Canada. The need to take action to strengthen home and community care has become more pressing given that:

- in 2015, for the first time, there were more persons aged 65 years and older in Canada (which is the definition we use for older adults) than children aged 0 to 14 years;(31)
- the proportion of adults over the age of 80 is expected to grow from 28% of Canadians in 2012 to 32% in 2036;(31)
- the older people get, the more likely they are to accumulate health problems (e.g., chronic diseases, reduced mobility, and disability);(31)
- most older adults express a preference to stay at home for as long as possible, in a secure and autonomous way;(1) and
- older adults are increasingly confident that new technology-based systems and services can be used to enhance their health and well-being, and support independent living.(32)

In their continued efforts to provide optimal home and community care to older adults, federal, provincial and territorial governments have committed significant investments. For instance, as noted above, the 2017 federal budget included $6 billion over 10 years in support of home-care programs.(3) Bilateral agreements with provincial and territorial governments target federal investments in at least one of four action areas:

1) spreading and scaling up evidence-based models of home and community care that are more integrated and connected with primary healthcare;
2) enhancing access to palliative and end-of-life care at home or in hospices;
3) increasing support for caregivers; and
4) enhancing home-care infrastructures (e.g., digital connectivity, remote monitoring technology and facilities for community-based service delivery).(4)

> **Box 3: Mobilizing research evidence about the problem**
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> The available research evidence about the problem was sought from a range of published and 'grey' research literature sources. Published literature that provided a comparative dimension to an understanding of the problem was sought using three health services research 'hedges' in MedLine, namely those for appropriateness, processes and outcomes of care (which increase the chances of us identifying administrative database studies and community surveys). Published literature that provided insights into alternative ways of framing the problem was sought using a fourth hedge in MedLine, namely the one for qualitative research. Grey literature was sought by reviewing the websites of a number of domestic and international organizations, such as the Canada Research Chair on Shared Decision Making and Knowledge Translation, the Canadian Home Care Association, and the Ottawa Hospital Research Institute.
>
> Priority was given to research evidence that was published more recently, that was locally applicable (in the sense of having been conducted in Canada), and that took equity considerations into account.

The investments being made by federal, provincial and territorial governments in home and community care will ultimately translate into more older adults living at home,(3) and hence into more decisions being made in relation to home and community care. These decisions may pertain to both health and social care, and include care planning (e.g., testing and treatment), paid and unpaid services, finances, housing transportation, and other issues that could affect their health and well-being.(33-35)

For example, a recent project by Health Quality Ontario identified 52 decision points that could affect hospital-to-home transitions.(36) This means that someone transitioning back home from hospital (which is quite common for older adults) may face 52 moments when a choice must be made. These 52 decisions points were grouped into six categories: 1) decisions about care in the hospital; 2) decisions about the hospital-discharge planning and process; 3) decisions about timely service and logistic support after discharge; 4) decisions about home care and medical care in the community; 5) decisions about the uncovered costs and limits of funded services; and 6) decisions about coordination of medical follow-up.(37)

These decisions are complex and call for more and 'better' SDM. However, research evidence reveals that a large proportion of older adults and their caregivers are not formally engaged in their decisions about their own health and well-being. In a 2018 survey of 1,591 Canadians (of whom 939 had received health services in the previous year), only 36% of older adults said they were often presented with choices, and only 35% were often asked what mattered to them.(12)

Systematic reviews on barriers to the uptake of SDM tend to focus on barriers at the level of patients and providers. The most frequent barriers cited by patients and providers are:
- time constraints;
- providers thinking that it is not necessary (or applicable) given the characteristics of the patient or the clinical situation;
- patients not expecting to participate in SDM; and
- provider lacking the skills to engage their patients in SDM.(38; 39)

There is confusion between identifying the care needs and identifying the decisional needs of older adults

Home and community care is typically focused on responding to the tangible (and sometimes pressing) 'care needs' of older adults. Identifying care needs can be done through individual assessments (sometimes called comprehensive geriatric assessments) that aim to identify the "medical, psychosocial, and functional limitations of a frail older person in order to develop a coordinated plan to maximize overall health with aging."(40) These individual assessments will focus on multiple issues, including the individual's physical, cognitive, affective, social, financial, environmental and spiritual issues that influence an older adult's health and well-being.(40) For example, the "Système de mesure de l'autonomie fonctionnelle" (SMAF) used in Quebec and the Resident Assessment Instrument – Home Care (RAI-HC) commonly used in other Canadian provinces and territories are examples of assessment tools used to guide comprehensive planning of home and community care for older adults.(41) Care needs can also be identified through community- or population-level needs assessments, which may lead to defining priorities and allocating resources that will improve health and reduce health inequities.(42)

These individual and population assessments are important to identify the care needs of older adults (as individuals or as groups) and can provide critical information that could help to inform decisions made by older adults, their caregivers and the care team. For example, care assessments can help to better understand older adults' state of health and possible trajectories (as best as possible), and thus help to frame decisions. In addition, comprehensive geriatric assessments can help to understand how different care options could allow older adults to remain in their homes longer.

However, these assessments do not explicitly identify the 'decisional needs' of older adults in relation to home and community care. Decisional needs refer to a "deficit that can adversely affect the quality of a decision

(informed, match most valued features) and require tailored decision support."(14) As noted in the top row of Table 1 and as depicted in the upper left box in Figure 1, the Ottawa Decision Support Framework – an evidence-informed framework that has been extensively used to guide the development and evaluation of decision aids and other decision support tools – identifies six factors that can influence decisional needs.(15) Identifying decisional needs can be done during a decisional needs assessment, which is a '360-degree' assessment of all decisions facing an individual where multiple options need to be deliberated.(43) Decisional needs assessments can help to identify and prioritize the 'cascade' of complex and inter-related decisions facing an individual and that may involve multiple stakeholders.(43) This is particularly relevant for older adults, since they may have a wide range of complex health needs (e.g., older adults with multimorbidity and co-occurring mental health conditions) and social needs (e.g., older adults who lack social support; who are lonely, geographically isolated, or financially insecure; or who are living in inadequate and unaffordable housing).

Assessing the decisional needs of older adults (and their caregivers) is needed in order to develop effective decision supports, which is the second component of the Ottawa Decision Support Framework (see the lower box in Figure 1).(15) Decision supports may include counselling, decision tools and coaching.(15)

Lastly, the Ottawa Decision Support Framework asserts that decisional needs, which are ideally enabled with decision supports, will affect decision quality, which will in turn affect actions (or behaviours) as well as impacts (e.g., health outcomes, emotions like regret and blame, and the appropriate use and costs of services).(15)

Figure 1: Ottawa Decision Support Framework (adapted from O'Connor, 2006 (15))
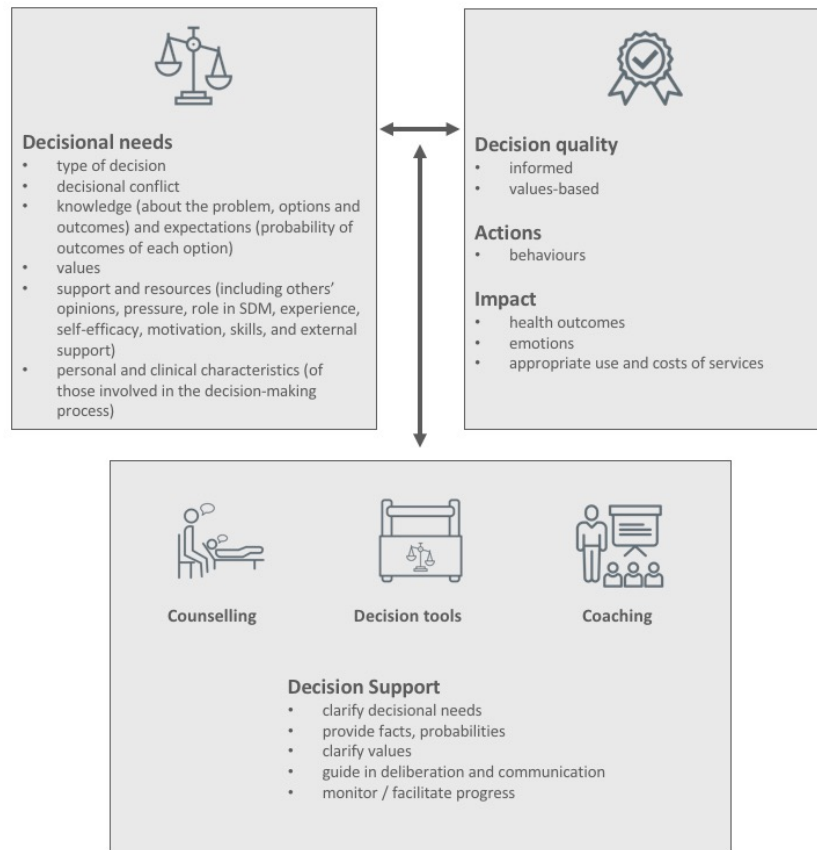
Little focus has been placed on how provider organizations and government policymakers could help to meet the decisional needs of older adults

Most SDM models have focused on the decisional needs that can be met by the care team. However, older adults are facing many complex decisions in relation to home and community care that go beyond the traditional testing and treatment decisions. For example, a recent systematic review of factors influencing housing decisions among frail older adults identified at total of 88 factors, of which 71 seem to influence decisions.(35) Those findings illustrate that many decisional needs could be met by provider organizations, government health policymakers, as well as government policymakers from other sectors (e.g., community and social services, financial protection, housing, nutrition, transportation, and even public safety and justice).

System-level factors make it difficult to meet older adults' decisional needs

A variety of features of existing governance, financial and delivery arrangements within health and social systems in Canada may also limit our capacity to meet the decisional needs of older adults in relation to home and community care. We summarize key examples of system-level challenges in Table 2.

Table 2: **Overview of key system-level factors that make it difficult to meet the decisional needs of older adults in relation to home and community care**

Health-system building blocks	Challenge	Description of the challenge
Governance arrangements *(who can make what types of decisions)*	What is "home and community care" varies across jurisdictions	● It is challenging and often confusing when it comes to defining and distinguishing the different type of home-care and community-care services. These services vary across jurisdictions, which could include: short-term and long-term care based on need; complement and supplement independent living, assisted living or residential care services (including end of life care); or home-based services that would otherwise require hospital admission. ● For example, in Alberta, "continuing care services", is used as an umbrella term which fits other services such as rehabilitative care and adult day programs. In Ontario, home care can include: 1) professional services to assess clients' needs (e.g., nursing care, physiotherapy, occupational therapy, respiratory therapy, speech-language therapy, and social work); 2) personal-support services to help clients with daily care (e.g., bathing, dressing, eating, personal hygiene); 3) homemaking services (e.g., cleaning, planning and preparing meals, caring for children); and 4) end-of-life care with in-home visits and respite care.(13) Community-care programs can include: 1) adult day programs; 2) supportive housing (e.g., personal support, homemaking); 3) retirement homes (e.g., personal support, homemaking services, social and recreational opportunities); and 4) transportation services. Other examples could include community and residential hospice services such as counselling and support groups, exercise and falls-prevention programs, and Assistive Devices Program (e.g., enteral feeding supplies, insulin pumps and supplies for diabetics).(13) ● How providers define (or understand the scope of) "home and community care" will frame the options that are offered to older adults and their caregivers (for which decisions are required). This may lead to intrinsic systemic biases in SDM in home and community care.
	Jurisdictional complexity	● The decisional needs of older adults in relation to home and community care often span a wide range of government sectors (e.g., health, community and social services, financial protection, housing and transportation) and different governments levels (e.g., municipal, provincial/territorial and federal). ● Addressing the decisional needs of older adults may require whole-of-government approaches, at all levels, which may be difficult to achieve given the current jurisdictional complexity (e.g., home care/extra-mural program under

		the Department of Health and long-term care facilities/home support under the Department of Social Development are separate entities in New Brunswick).
	Accountability mechanisms are not focused on addressing decisional needs	● Current accountability mechanisms for government health policymakers are focused on improving access to care and clinical performance (not addressing the decisional needs of older adults).
Financial arrangements *(how money flows through the system)*	The patchwork of publicly and privately funded services poses a challenge	● The patchwork of publicly and privately covered services poses a challenge to meet the decisional needs of older adults in relation to home and community care. ● The availability of publicly funded services vary across and within jurisdictions, thus affecting the options that older adults can deliberate about. ● How "home and community care" is defined may set expectations that some providers are unable to meet due to uneven resource allocation.
	Lack of investments to support system-wide access to SDM	● A lack of investment and support has hindered system-wide access to SDM for most Canadians, including meeting the decisional needs of older adults in relation to home and community care (with the exception of local pilot projects).

Delivery arrangements *(how care is organized to reach those who need it)*	Home and community care is a fragmented sector	● Home and community care is a fragmented sector, both horizontally (across parts of the health system) and vertically (across 'layers' in the health system and across jurisdictions).
		  ○ There are multiple layers of decision-making (each with specific decisional needs).
		● Home and community care is delivered by various health and social care organizations (e.g., third-party contractors paid by provincial or regional health authorities), professionals (e.g., nurses, dietitians and social workers), other types of health workers (e.g., personal-support workers), and unpaid caregivers (e.g., family members, friends and volunteers).
		  ○ Care coordination remains challenging, and it is difficult to connect all the providers and engage with all the other sectors.

	There is no standardized tool being used to identify decisional needs	● While standardized and evidence-based tools exist to document the care needs of older adults (e.g., interRAI-HC), no such tool exists yet to identify the decisional needs of older adults in relation to home and community care (which makes the identification of decisional needs complex and inconsistent).
	Differential access to telehealth limits capacity to provide decision support in rural and remote areas	● Many factors may influence patients' access and use of telehealth services (including concerns over technology, service changes, and privacy; ease-of-use; knowledge of the benefits of telehealth; access to care; and cost).(44) Some areas in Canada (e.g., rural and remote areas) face particular challenges with IT infrastructures required for telehealth services.(45) Addressing these challenges will likely be needed to operationalize SDM and provide online decision supports (e.g., counselling, coaching and decision tools) across the country.

Additional equity-related observations about the problem

An important element of the problem that requires further discussion is how the problem may disproportionately affect certain groups or communities. With respect to scaling up SDM in home and community care, many groups warrant particular attention. However, as noted above, this evidence brief explores equity considerations from two angles: populations (specifically older adults from ethnoculturally and linguistically diverse populations) and geography (specifically older adults living in urban versus rural and remote areas).

The findings from a recent cross-sectional survey about SDM experienced by Canadians facing health-related decisions raise important equity concerns.(12) The survey revealed that older adults, particularly those receiving

home care, were less likely to be engaged in health-related decisions than individuals from lower age groups. In addition, "non-white people" and people living in rural areas were also less involved in health-related decisions. Living in the province of Quebec was also associated with less SDM compared to living in other provinces (which, according to the study authors, could be partly explained by the disparities in initiatives to support SDM across the country, and that SDM has evolved mostly in English-speaking jurisdictions).(12) The authors pointed out that: "These results call for increased consideration of vulnerable populations, who would most benefit from engaging in shared decision making. Shared decision making is an opportunity to decrease inequities, but we have to ensure that its implementation does not increase them instead."(12)

These findings resonate with research evidence indicating that patients can face ethnocultural and linguistic challenges in SDM. Indeed, ethnocultural background may influence values and norms regarding various dimensions of care, such as the patient's and family's perspectives on a range of issues – health, suffering, death and dying; advance care planning; home and community; the use of Western medicine; the role of informal/family caregiving; information and prognosis disclosure – and influence the ability or desire of patients to engage in SDM. The multicultural makeup of Canada necessitates the development of SDM models that can help to meet the decisional needs of culturally and linguistically diverse older adult populations in relation to home and community care. The challenges to meet their decisional needs can also be exacerbated by broader policies and social contexts (e.g., providing home- and community-care services to Indigenous peoples requires increased administrative efforts to align policies across federal and provincial/territorial areas of jurisdiction and necessitates significant interactions with federally mandated care providers; providing home- and community-care services to francophone communities in minority situations). However, certain policies could mitigate these challenges. For example, with respect to francophone communities in minority situations, the French-language services legislation that has been passed in some jurisdictions could help support older adults seeking home- and community-care services in French. In addition, under Section 41 of the Official Languages Act, the Government of Canada has the mandate to enhance the vitality of official-language minority communities, which translates into policies and programs such as the Official Languages Health Program, which recently launched a call for proposals to improve access to home and community care in the minority language (among other priorities).(46)

The findings from the recent cross-sectional survey also raise important equity concerns for older adults living in urban versus rural and remote areas.(12) It calls for a better understanding of how decisional needs may vary due to where an older adult lives (e.g., urban versus rural and remote areas), and how the rural versus urban context may affect capacity to meet the decisional needs of older adults in relation to home and community care (e.g., the basket of home- and community-care services may not be the same in rural versus urban areas, the 'care dynamic' may be quite different in rural versus urban areas, and the capacity of provider organizations to provide decision support may vary between rural versus urban areas).

THREE GROUPINGS OF DECISIONAL NEEDS

Many approaches could be selected as a starting point for deliberations about older adults' decisional needs related to home and community care in Canada. In this section, we focus on identifying a potentially comprehensive list of such decisional needs and specifically those that take us beyond the traditional decisions related to testing and treatments that can be met by a care team (see Box 4).

To facilitate discussion, we have categorized the decisional needs into three groupings:
1) decisional needs that provider organizations could help meet;
2) decisional needs that government health policymakers could help meet; and
3) decisional needs that government policymakers from other sectors could help meet.

The three groupings are presented separately to foster deliberations about the relative importance of decision needs both within and across groupings.

> **Box 4: Identifying the three groupings of decisional needs**
>
> The three groupings of decisional needs were developed and refined through a four-stage process:
> - a consultation with the Steering Committee;
> - a consultation with key informants who were interviewed during the development of this evidence brief;
> - a scan of systematic reviews and primary studies examining the decisional needs of older adults, families and caregivers in relation to home and community care; and
> - a scan of repositories of decision-support tools (e.g., repository of patient decision aids managed by the Ottawa Hospital Research Institute; Decision Box managed by Laval University).

Grouping 1 – Decisional needs that provider organizations could help meet

Provider organizations could help to meet certain decisional needs of older adults in relation to home and community care.
- Who can I turn to in order to get care and support?
  - e.g., many types of health workers depending on my needs
- Who can I turn to in order to help me make complex decisions?
  - e.g., peers
  - e.g., virtual support groups and forums
  - e.g., professionals trained in SDM
  - e.g., individuals with particular expertise in certain types of decision aids
- What balance between frequency and intensity of care and support can be accommodated?
- What balance between frequency of visits and continuity of provider can be accommodated?
  - e.g., choosing more frequent visits with a larger number of providers versus less frequent visits by a small number of providers who are well known to the patient
- How can care and support be made more linguistically and culturally appropriate?
- What types of services could be proactively offered to me when I have contact with the health system for other reasons (i.e., what are sometimes called 'in-reach services')?
  - e.g., screening services that have been selected based on my identified risk factors
- What types of outreach services could be offered to me if I do not have contact with one or more parts of the health system for some time?
  - e.g., a call or visit by a physician, nurse or other health worker from my primary-care provider's office
- How can I share my health information with providers?
  - e.g., adding a provider to my digital 'circle of care'
  - e.g., remote digital monitoring
  - e.g., recording symptoms and other details
  - e.g., completing brief surveys of care experiences or health outcomes
- How can I play a greater role in managing my own health and care?

- o e.g., access to a patient portal that contains my test results
- o e.g., access to a portal with information about optimal-aging practices
- What can my goals for care be?
  - o e.g., maintaining quality of life versus living long enough to participate in a major family event
- What wishes, beliefs and values should I communicate with my care providers and substitute decision-makers?
- What steps should I take to ensure my wishes, beliefs and values are acted upon by my care providers and substitute decision-makers?
- How can I share my experiences/insights to improve services?
  - o e.g., use a formal complaints process
  - o e.g., contact 'user' committees comprised of older adults receiving services and their families and caregivers
- Who can advocate for me?
  - o e.g., informal/family caregiver
  - o e.g., substitute decision-maker
  - o e.g., peers
  - o e.g., Patient Ombudsman or equivalent (if one exists in the organization or health system)

Grouping 2 – Decisional needs that government health policymakers could help meet

Government health policymakers (typically those at the provincial and territorial level given their responsibility for most health system-related decisions) could help to meet certain decisional needs of older adults in relation to home and community care.
- How can I or my family member or caregiver have a say in the future direction of home and community care?
  - o e.g., patient and family advisory councils
- How can I access additional care beyond what is publicly funded?
- How can I be informed of all services available across the full continuum of care, whether those services are publicly or privately funded?
  - o e.g., website describing publicly funded home care and support options
  - o e.g., website describing privately funded home care and support options
- How can I know that the care being provided to people like me is adequate?
  - o e.g., website with indicators about the quadruple-aim metrics of all provider organizations
  - o e.g., website with indicators about the quality and safety of home and community care
  - o e.g., website with indicators that capture equity in the delivery of home and community care
- How can I know that the health workers providing care to me meet the requirements of their profession?
  - o e.g., website with status of all types of health workers
- How can I share my experiences/insights to improve health policies, programs and services?
  - o e.g., contact Patient Ombudsman
  - o e.g., contact appeal and review board
- Who can advocate for me?
  - o e.g., informal/family caregiver
  - o e.g., substitute decision-maker
  - o e.g., peers
  - o e.g., service providers
  - o e.g., Patient Ombudsman

Grouping 3 – Decisional needs that government policymakers from other sectors could help meet

Government policymakers from other sectors (again, typically those at the provincial and territorial level) could help to meet certain decisional needs of older adults in relation to home and community care.
- What type of housing will enable me to receive an appropriate level of home and community care?
  - e.g., adjust my home
  - e.g., move to alternative forms of housing, ranging from supportive housing to a long-term care home
- What type of nutritional support can I access?
  - e.g., meals on wheels
  - e.g., food banks
  - e.g., drop-in centres offering meals
- What type of transportation can I access?
  - e.g., continue driving own vehicle
  - e.g., drive rental vehicles or use a car-sharing program when needed
  - e.g., use a ride-sharing company like Uber
  - e.g., use regular public transit
  - e.g., use public transit services specific to people with special needs
- What are my financial options to support me now (and in the future if my need changes), and on what terms?
  - e.g., out-of-pocket expenses
  - e.g., subsidized services
  - e.g., tax credits
- What types of financial support are available to me now and could be in future if my needs change, and on what terms?
- What types of information from different sectors can I choose to combine in order to better tailor supports to my needs?
  - e.g., health, housing, nutrition and transportation
- How can I share my experiences/insights to improve policies, programs and services?
  - e.g., contact Patient Ombudsman
  - e.g., contact appeal review board
- Who can advocate for me?
  - e.g., informal/family caregiver
  - e.g., substitute decision-maker
  - e.g., peers
  - e.g., Patient Ombudsman

SCALING-UP STRATEGIES

Over the years, promising SDM tools and training programs have been developed to help care teams support older adults, including their families and caregivers. However, SDM has often been implemented as part of local pilot projects and not scaled up to benefit as many Canadians as possible.

The aim of this section is fourfold: 1) examining what is known about scaling-up strategies based on findings from systematic reviews; 2) identifying potential barriers to scaling up SDM in home and community care in Canada; 3) identifying potential windows of opportunity for scaling up SDM in home and community care in Canada; and 4) using the ongoing health-system reforms in Ontario as an illustrative case to explore how SDM could be scaled up.

What is known (from systematic reviews) about scaling-up strategies

We present the findings from systematic reviews along with an appraisal of whether their methodological quality (using the AMSTAR tool) (47) is high (scores of 8 or higher out of a possible 11), medium (scores of 4-7) or low (scores less than 4) (see the appendix for more details about the quality-appraisal process). We also highlight whether they were conducted recently, which we define as the search being conducted within the last five years.

In total, we identified seven systematic reviews (29; 30; 48-52) and one systematic review in progress (53) about scaling-up strategies, as well as one rapid synthesis about the rapid-learning system approach that was deemed relevant.(13)

Below we group the key findings from these reviews into three domains: 1) the limited body of synthesized research evidence examining the effectiveness of scaling-up strategies; 2) the different models of scaling-up strategies; and 3) the different 'lenses' that can inform scaling-up strategies.

The limited body of synthesized research evidence about the effectiveness of scaling-up strategies may be explained by: 1) poor reporting and lack of rigor in primary studies; 2) confusion between the innovation to be scaled up and strategies to scale it up; 3) under-reporting of harms and failures; and 4) the limited applicability of findings to high-income countries, to home and community care, or to initiatives being scaled up across many sectors.(30; 50; 54) Related to the first of these four explanations, we also noted a lack of consensus about the metrics to assess the effectiveness of scaling-up strategies.(50) This point echoes recent concerns about potentially negative consequences of initiatives to scale up SDM at a national level if limitations in

> **Box 5: Mobilizing research evidence about scaling-up strategies**
>
> The available research evidence about scaling-up strategies was sought primarily from Health Systems Evidence (www.healthsystemsevidence.org), which is a continuously updated database containing more than 7,800 systematic reviews and more than 2,700 economic evaluations of delivery, financial and governance arrangements within health systems. The reviews and economic evaluations were identified by searching the database for reviews addressing features of scaling-up strategies.
>
> The authors' conclusions were extracted from the reviews whenever possible. Some reviews contained no studies despite an exhaustive search (i.e., they were 'empty' reviews), while others concluded that there was substantial uncertainty about the strategy based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the reviews' quality, the local applicability of the reviews' findings, equity considerations, and relevance to the issue. (See the appendix for a complete description of these assessments.)
>
> Being aware of what is not known can be as important as being aware of what is known. When faced with an empty review, substantial uncertainty, or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an option could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a review that was published many years ago, an updating of the review could be commissioned if time allows.
>
> No additional research evidence was sought beyond what was included in the systematic review. Those interested in pursuing a particular strategy may want to search for a more detailed description of the strategy or for additional research evidence about the strategy.

defining and measuring SDM are not addressed.(55) Researchers recently emphasized the need to have "prespecified definitions of desired outcomes, offer guidance on the tools used to measure SDM in the multitude of contexts in which it occurs, evaluate the impact of SDM policy initiatives over time, review that impact at regular intervals, and revise SDM measurement tools as needed."(55)

Nonetheless, the current body of synthesized research evidence indicates that promising scaling-up strategies require action on five fronts: 1) infrastructure (e.g., digital health tools that can support SDM); 2) governance arrangements (e.g., policies that support SDM); 3) financial arrangements (e.g., changing payment mechanisms to reward SDM); 4) human resources (e.g., training providers in SDM and accommodating the changing roles of providers with respect to SDM); and 5) patient and public engagement (e.g., in co-designing scaling-up strategies).(30; 50; 54)

The available research evidence also revealed different models for scaling up and spreading SDM (51), notably:
- initiative-specific spread efforts (e.g., often with a unidirectional 'push' to spread sites, focused on one initiative/practice, and with resources often externally provided);
- collaboratives or exchanges that support the scale up or spread of multiple initiatives within a specific topic area (e.g., often with a bidirectional exchange of information/ideas, topically related efforts, and opt-in participation); and
- scale-up or spread efforts being embedded across a system (e.g., aligning activities with system priorities, sharing infrastructure in spread sites, and establishing clear boundaries for spread).(51)

Lastly, systematic reviews revealed that different theoretical lenses can inform scaling-up and spread strategies:
- implementation science, which takes a mechanical, structured and phased approach to developing, replicating and evaluating an intervention in multiple sites;
- complexity science, which encourages a flexible and adaptive approach to change in a dynamic, self-organizing system; and
- social science approaches, which consider why people act in the way they do, especially the organizational and wider social forces that shape and constrain people's actions.(29)

Certain lenses may be more appropriate in certain contexts. For example, the review authors suggested that "the larger, more ambitious, and more politically contested the spread challenge, the more ecological and social practice perspectives will need to supplement (or replace) 'mechanical' efforts to replicate an intervention."(29)

A summary of the key findings from the synthesized research evidence is provided in Table 3. For those who want to know more about the systematic reviews contained in Table 3 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in the appendix.

Table 3: Summary of key findings from systematic reviews relevant to scaling-up strategies

Category of finding	Summary of key findings
Benefits	- No evaluations of benefits of scaling-up strategies were explicitly identified in included systematic reviews.
Potential harms	- No evaluations of potential harm of scaling-up strategies were explicitly identified in included systematic reviews.
Costs and/or cost-effectiveness in relation to the status quo	- One old and medium-quality review revealed that the costs of scaling up an intervention are specific to the type of intervention and its particular setting.(48) The review also identified four principles to determine the costs of interventions: 　○ calculate separate unit costs for urban and rural populations; 　○ identify economies and diseconomies of scale, and separate the fixed and variable components of the costs; 　○ assess availability and capacity of health human resources; and 　○ include administrative costs, which can constitute a significant proportion of scale-up costs in the short run.(48)

Category of finding	Summary of key findings
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	• One recent medium-quality review found a limited body of research evidence about the effectiveness of scaling-up strategies in primary care. The review also revealed that there is minimal consensus about the metrics of scaling up needed to assess the effectiveness of scaling-up strategies.(50) Only one study used a model to assess the impact of a scaling-up strategy: the "Reach, Effectiveness, Adoption, Implementation and Maintenance" (RE-AIM) model.(50) • One review in progress is examining the effectiveness of strategies to scale up social-welfare interventions (i.e., interventions to provide care, support and protection to children or adults at risk of, or with needs arising from, mental illness, disability, age and poverty).(53)

Key elements of the policy option if it was tried elsewhere	• One recent medium-quality review revealed that scaling-up strategies in primary care usually had one or more of the following components (in order of frequency as reported by the studies):(50)
	  o components related to human resources (e.g., policymakers/managers, providers, external medical consultants and community healthcare workers);
	  o components related to healthcare infrastructure (e.g., new buildings, linkages between different clinical sites); and
	  o components related to changes in policy/regulation; those related to financing (e.g., paying bonuses to healthcare workers).
	• One recent medium-quality review examined available strategies to scale up and spread clinical and administrative practices across large health systems (with a focus on "hard-to-engage" sites).(51) The review revealed four key phases of large scale-up or spread process:
	  o test and pilot (with innovators);
	  o test and spread (with early adopters);
	  o mass broadcast (with early and late majority); and
	  o re-personalize (with late adopters/hard-to-reach).(51)
	• The same review revealed three models to describe the organization or infrastructure of spread efforts:
	  o spread efforts that embedded scale-up or spread within a system of care (e.g., activities align with system priorities, shared infrastructures in spread sites, and clear boundaries for spread);
	  o collaboratives or exchanges to support the spread of multiple initiatives within a specific topic area (e.g., bidirectional exchange of information/ideas, topically related efforts, and opt-in participation); and
	  o initiative-specific spread efforts (e.g., unidirectional 'push' to spread sites, focused to one initiative/practice, and resources often external).(51)
	• One recent medium-quality review identified three theoretical lenses that have been used to inform spread and scale-up strategies:
	  o implementation science, which takes a mechanical, structured and phased approach to developing, replicating, and evaluating an intervention in multiple sites;
	  o complexity science, which encourages a flexible and adaptive approach to change in a dynamic, self-organizing system; and
	  o social science approaches, which consider why people act in the way they do, especially the organizational and wider social forces that shape and constrain people's actions.(29)
	• The same review concludes that all three approaches may be used in combination to tackle the challenges of spread and scale-up (from small to large magnitude changes), and can offer insights to front-line teams about how and why particular change efforts are effective or not.(29)
	• One medium-quality review identified eight frameworks for scaling up public-health interventions (the majority being focused on low- and middle-income countries), as well as key success factors for scaling up:
	  o developing a monitoring and evaluation strategy;
	  o modelling costs and economic factors associated with various intervention approaches;
	  o engaging a diverse group of intervention implementers and members of the targeted community through participation;
	  o designing a contextually appropriate scale-up strategy;
	  o actively finding and using research evidence;
	  o the presence of infrastructure to support implementation;
	  o strong leadership, advocacy and political will; and
	  o designing a comprehensive scaling-up strategy.(30)
	• One low-quality review revealed 16 stages of the innovation and scale-up process: 1) identify the

Category of finding	Summary of key findings

	problem; 2) develop the innovation; 3) design the pilot test; 4) pilot test; 5) evaluate the pilot test; 6) decide to implement; 7) plan the implementation; 8) implement; 9) evaluate the implementation; 10) test for extensibility; 11) decide to scale up; 12) plan the scale-up; 13) scale up; 14) evaluate the scale-up; 15) monitor the scale-up; and 16) institutionalize.(49)
	• One older low-quality review examined how governments can coordinate large system transformations and focused on five themes: leadership; monitoring and reporting; historical context; physician engagement; and patient and family engagement. Facilitators for each of these five include:
	  ○ implementing transparent transformation efforts, creating a central coordinating body that is isolated from political influence, and clearly articulating the goals of the change;
	  ○ budgeting for IT systems, establishing independent oversight of measurement and reporting, and offering rewards and sanctions for achievement of measures;
	  ○ consideration of historical context and careful assessment of readiness for transformation, and storing and reporting information on past change measures;
	  ○ significant physician engagement in the change process by working with educational institutions and regulatory bodies; and
	  ○ significant engagement of patients and families in governance and advisory mechanisms for healthcare institutions and bodies, and collecting information on patient wishes through surveys.(52)

Stakeholders' views and experience	• One recent medium-quality review examined the characteristics of hard-to-engage sites in large-magnitude scale and spread efforts.(51) While hard-to-engage sites appear to have different needs, they may have:
	  ○ low bandwidth or limited resources;
	  ○ local innovations or homegrown solutions already in place that present competition for the innovation; and
	  ○ competing priorities that do not overlap with the priorities of the spread initiative.
	• The same review also identified potential benefits of engaging hard-to-engage sites:
	  ○ a healthy skepticism can lead to collaboration and potential innovation improvement;
	  ○ hard-won engagement that is slow to come may be more durable in the long term; and
	  ○ low-performing sites can sometimes be easier to engage since their priorities are in alignment with a spread initiative's goals.(51)
	• One low-quality review revealed that the uptake of innovation depends on the innovation aligning with the interests of three critical stakeholder groups (innovators, end users and the decision-makers) and is also influenced by three broader contexts (social and physical environment, the health system, and the regulatory, political and economic environment).(49)

The learning health system approach has been identified as a 'complex system' lens through which scaling-up and spread efforts could be developed and operationalized.(29; 51) Greenhalgh et al indicated that: "A learning health system is characterised by participatory culture, distributed leadership, engaged patients, shared and evidence based decision making, transparent assessment of outcomes, and use of information and technology for continuous learning. Innovation, improvement, spread and scale-up will all occur more readily in such a system."(29)

This seems particularly relevant since most Canadian health systems have both a health system and a research system that are increasingly putting patients and rapid learning and improvement at their centre. The CIHR Institute of Health Services and Policy Research and the Canadian Health Services and Policy Research Alliance commissioned the production of a rapid synthesis to serve as a jumping off point for their efforts to support the creation of rapid-learning health systems across Canada.(13) The rapid synthesis was meant to start a conversation about how the framework and concepts can be adapted, piloted and iteratively revised within and across Canadian jurisdictions. While the findings are too detailed to report on here, three high-level points are noteworthy:
• patient engagement (including SDM) is a key characteristic of a rapid-learning health system;(13)

- the list of assets to support the development of rapid-learning provincial and territorial health systems is remarkably rich, both for most health systems as a whole and elderly populations within the health systems specifically, even in many small jurisdictions;(13) and
- home and community care has been or will be the focus of sustained efforts to create rapid-learning health systems in some jurisdictions.(13)

In Table 4, we provide a more detailed description of the four features of rapid-learning health systems, including the seven characteristics associated with them and examples of activities for each characteristic.

Table 4: Characteristics of rapid-learning health systems (RLHS) (table reproduced with permission from Lavis et al. 2018)(13)

Category	Characteristic	Examples

Patient-centred	**Engaged patients:** Systems are anchored on patient needs, perspectives and aspirations (at all levels) and focused on improving their care experiences and health at manageable per capita costs and with positive provider experiences	1) Set and regularly adjust patient-relevant targets for rapid learning and improvement (e.g., improvements to a particular type of patient experience or in a particular health outcome)
		2) Engage patients, families and citizens in:
		  a) their own health (e.g., goal setting; self-management and living well with conditions; access to personal health information, including test results)
		  b) their own care (e.g., shared decision-making; use of patient decision aids)
		  c) the organizations that deliver care (e.g., patient-experience surveys; co-design of programs and services; membership of quality-improvement committees and advisory councils)
		  d) the organizations that oversee the professionals and other organizations in the system (e.g., professional regulatory bodies; quality-improvement bodies; ombudsman; and complaint processes)
		  e) policymaking (e.g., committees making decisions about which services and drugs are covered; government advisory councils that set direction for (parts of) the system; patient storytelling to kick off key meetings; citizen panels to elicit citizen values)
		  f) research (e.g., engaging patients as research partners; eliciting patients' input on research priorities)
		3) Build patient/citizen capacity to engage in all of the above

Data and evidence driven	**Digital capture, linkage and timely sharing of relevant data**: Systems capture, link and share (with individuals at all levels) data (from real-life, not ideal conditions) about patient experiences (with services, transitions and longitudinally) and provider engagement alongside data about other process indicators (e.g., clinical encounters and costs) and outcome indicators (e.g., health status)	1) Data infrastructure (e.g., interoperable electronic health records; immunization or condition-specific registries; privacy policies that enable data sharing) 2) Capacity to capture patient-reported experiences (for both services and transitions), clinical encounters, outcomes and costs 3) Capacity to capture longitudinal data across time and settings 4) Capacity to link data about health, healthcare, social care and the social determinants of health 5) Capacity to analyze data (e.g., staff and resources) 6) Capacity to share 'local' data (alone and against relevant comparators) – in both patient- and provider-friendly formats and in a timely way – at the point of care, for providers and practices (e.g., audit and feedback), and through a centralized platform (to support patient decision-making and provider, organization and system-wide rapid learning and improvement)
	Timely production of research evidence: Systems produce, synthesize, curate and share (with individuals at all levels) research about	1) Distributed capacity to produce and share research (including evaluations) in a timely way 2) Distributed research ethics infrastructure that can support rapid-cycle evaluations 3) Capacity to synthesize research evidence in a timely way

Category	Characteristic	Examples
	problems, improvement options and implementation considerations	4) One-stop shops for local evaluations and pre-appraised syntheses 5) Capacity to access, adapt and apply research evidence 6) Incentives and requirements for research groups to collaborate with one another, with patients, and with decision-makers **Note that for Indigenous peoples, this row would ideally be re-conceptualized to include traditional knowledge**

System supported	**Appropriate decision supports**: Systems support informed decision-making at all levels with appropriate data, evidence, and decision-making frameworks	1) Decision supports at all levels – self-management, clinical encounter, program, organization, regional health authority and government – such as:
		  a) patient-targeted evidence-based resources
		  b) patient decision aids
		  c) patient goal-setting supports
		  d) clinical practice guidelines
		  e) clinical decision support systems (including those embedded in electronic health records)
		  f) quality standards
		  g) care pathways
		  h) health technology assessments
		  i) descriptions of how the health system works

	Aligned governance, financial and delivery arrangements: Systems adjust who can make what decisions (e.g., about joint learning priorities), how money flows and how the systems are organized and aligned to support rapid learning and improvement at all levels	1) Centralized coordination of efforts to adapt a RLHS approach, incrementally join up assets and fill gaps, and periodically update the status of assets and gaps 2) Mandates for preparing, sharing and reporting on quality-improvement plans 3) Mandates for accreditation 4) Funding and remuneration models that have the potential to incentivize rapid learning and improvement (e.g., focused on patient-reported outcome measures, some bundled-care funding models) 5) Value-based innovation-procurement model 6) Funding and active support to spread effective practices across sites 7) Standards for provincial expert groups to involve patients, a methodologist, use existing data and evidence to inform and justify their recommendations 8) Mechanisms to jointly set rapid-learning and improvement priorities 9) Mechanisms to identify and share the 'reproducible building blocks' of a RLHS
Culture and competencies enabled	**Culture of rapid learning and improvement**: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability	1) Explicit mechanisms to develop a culture of teamwork, collaboration and adaptability in all operations, to develop and maintain trusted relationships with the full range of partners needed to support rapid learning and improvement, and to acknowledge, learn from and move on from 'failure'
	Competencies for rapid learning and improvement: Systems are rapidly improved by teams at all levels who have the competencies needed to identify and characterize problems, design data- and evidence-informed approaches (and learn from other comparable programs, organizations, regions, and sub-regional communities about proven approaches), implement these approaches, monitor their	1) Public reporting on rapid learning and improvement 2) Distributed competencies for rapid learning and improvement (e.g., data and research literacy, co-design, scaling up, leadership) 3) In-house capacity for supporting rapid learning and improvement 4) Centralized specialized expertise in supporting rapid learning and improvement 5) Rapid-learning infrastructure (e.g., learning collaboratives)

Category	Characteristic	Examples
	implementation, evaluate their impact, make further adjustments as needed, sustain proven approaches locally, and support their spread widely	

Potential barriers to scaling up SDM in home and community care in Canada

A number of barriers might hinder scaling up SDM in home and community care in Canada, and these barriers need to be factored into any decision about whether and how to pursue any given scaling-up strategy (Table 5). These potential barriers could exist at the levels of patients/individuals, providers, provider organizations and systems. These barriers may also affect the capacity to address the three groupings of decisional needs discussed earlier. Perhaps the biggest barrier lies in policymakers' long history of failing to scale up health innovations in Canada. The 2015 report of the federal Advisory Panel on Healthcare Innovation noted that most health systems lack the ability to scale up and spread innovation and that common barriers include:(56)

- lack of meaningful patient engagement;
- outmoded human resource models;
- system fragmentation;
- inadequate health data and information-management capacity;
- lack of effective deployment of digital technology;
- barriers for entrepreneurs;
- a risk-averse culture; and
- inadequate focus on understanding and optimizing innovation.

Table 5:   Potential barriers to scaling up SDM in Canada

Levels	Grouping 1 – Decisional needs that provider organizations could help meet	Grouping 2 - Decisional needs that government health policymakers could help meet	Grouping 3 - Decisional needs that government policymakers from other sectors could help meet
Patient/ individual	• Patients/individuals may face many barriers to SDM, such as their and their providers' time constraints, their providers thinking that SDM is not necessary or applicable (given the characteristics of the patient or the clinical situation), them not expecting to participate in SDM, and their providers lacking the skills to engage them in SDM) (38; 39)	• Same as the first bullet in grouping 1 • Patients/individuals may face decision-support systems and functions that are not sufficiently oriented to meeting their decisional needs (13) • Patients/individuals may not be meaningfully engaged in prioritizing what 'needles to move' in care experiences and health outcomes for patients/individuals like them and hence in the broader context for SDM (13)	• Same as the first bullet in grouping 1 • Patients/individuals may not have access to decision-support systems (e.g., decision aids or decision coaches) in other sectors to meet the full range of their decisional needs • Patients/individuals may not be meaningfully engaged in system changes in other sectors and hence in the broader context for SDM • Patients/individuals may not be able to access all relevant information because integrating data across sectors for public-service improvement may: 1) raise concerns among members of the public about privacy risks; 2) be pursued in an ad hoc

			rather than sustained way; and 3) be particularly complex in areas of shared federal and provincial jurisdiction (31)
Provider	• Providers may face many of the same barriers to SDM as those listed above for patients • Providers may be hesitant to engage in scaling-up initiatives when: 1) financial arrangements have already left them feeling overstretched and then aren't adjusted to accommodate SDM; 2) it takes them beyond their perceived service-delivery mandate; and 3) their own decision needs (and how they intersect with patients' decisional needs) haven't been addressed	• Same as the first and second bullets in grouping 1	• Same as the first and second bullets in grouping 1 • Providers may also be hesitant to engage in scaling-up initiatives when the challenges in coordinating providers from different sectors haven't been addressed
Provider organization	• Provider organizations may be hesitant to engage in scaling-up initiatives when their own decisional needs (and how they intersect with patients' decisional needs) haven't been addressed • Provider organizations may lack timely access to the types of linked data about care experiences (with services, transitions and longitudinally) and health outcomes that are needed to support SDM (13) • Small and/or remote provider organizations may not have the necessary competencies (or partners with the necessary competencies) to scale up SDM initiatives (e.g., analyze and share relevant local data, conduct relevant research or contextualize decision supports)	• Same as the first bullet in grouping 1	• Same as the first bullet in grouping 1 • Provider organizations may also be hesitant to engage in scaling-up initiatives when the challenges in coordinating provider organizations from different sectors haven't been addressed
System	• Policymakers have not yet created a culture of SDM in home and community care	• Same as the first bullet in grouping 1 • Policymakers may lack timely access to the types of linked data that are needed to support SDM (13) • Policymakers may be hesitant to engage in scaling-up initiatives when their own decisional needs (and how they intersect with patients' decisional needs) haven't been addressed • Policymakers may not have	• Same as bullets 1-4 in grouping 2 • Policymakers from across sectors (and across the country) may find it challenging to adopt a common vision, model and metrics for SDM and to coordinate their scale-up efforts

| | | the necessary competencies (or partners with the necessary competencies) to scale up SDM initiatives (e.g., implementation science)
• Policymakers have a long history of failing to scale up health innovations in Canada – "a country of perpetual pilot projects" (57) – and SDM may be no exception | |

Potential windows of opportunity for scaling up SDM in home and community care in Canada

On the other hand, a number of potential windows of opportunity could be capitalized upon (Table 5), which also need to be factored into any decision about whether and how to scale up SDM in home and community care. Notable windows of opportunity include several governments in Canada leading reforms and initiatives where home and community care and SDM are both front and centre. Many assets related to SDM and to patient and public engagement more broadly (e.g., expertise, decision-support tools, training programs and infrastructure) can be leveraged to take advantage of such windows of opportunity.

Table 5: Potential windows of opportunity for scaling up SDM

Type	Grouping 1 – Decisional needs that provider organizations could help meet	Grouping 2 - Decisional needs that government health policymakers could help meet	Grouping 3 - Decisional needs that government policymakers from other sectors could help meet
General	• The home- and community-care sector has been or will be the focus of sustained efforts to create rapid-learning health systems in some Canadian jurisdictions, which could support scaling up SDM.(13) • Under the leadership of the Canadian Home Care Association, more than 350 stakeholders across Canada have agreed on a set of 'harmonized principles'.(58) These principles emphasize that engaging clients and caregivers as partners in care and require that care options be presented and potential consequences of decisions be discussed in light of what matters most to them. They also stress that effective decision support is needed to maximize the value of care options and achieve goal-concordant care. The harmonized principles could help to develop a common vision for scaling up SDM in home and community care. • The newly elected federal government may keep similar priorities to before the election (e.g., patient and public engagement, home and community care, the Canadian Institutes of Health Research's Strategy for Patient-Oriented Research, including its national networks and provincial SPOR SUPPORT Units) which may create a favourable climate to scaling up SDM. • Scaling-up efforts could build on some of the models that broaden the perspective of SDM beyond the patient-provider interaction. One notable example is the Interprofessional Shared Decision Making (IP-SDM) Model,(19) which addresses three levels in the healthcare system: the individual-, organizational-, and broader policy and social contextual-levels. As noted above, the model describes the SDM process (i.e., identifying decisions, discussing options, values, feasibility, and reaching consensus) in conjunction with the key actors in the SDM process (i.e., individuals and family, care teams) and broader environmental influences (i.e., policies, provider organizations, governments or health authorities).(26) However, the IP-SDM model has not yet been operationalized to address how provider organizations and government policymakers could help to meet the decisional needs of older adults.		
Specific to a grouping	• Some provider organizations are planning	• Several federally funded pan-Canadian health organizations develop competencies and use	• Whole-of-government

	to scale up SDM (e.g., Centre intégré universitaire de santé et de services sociaux de la Capitale-Nationale in Quebec City).
	• Some provider organizations are taking part in the SPRINT Implementation Collaboratives by the Canadian Home Care Association, which: 1) is designed for home and community service providers to implement leading practices and test innovative approaches; and 2) supports 11 teams across Canada to adapt and implement a leading practice in interdisciplinary communication, collaborative care planning and SDM within an integrated palliative care model.(59)
		an array of other approaches to support scaling up and spread in select areas. For example, the Canadian Foundation for Healthcare Improvement and the Canadian Patient Safety Institute support the spread of healthcare innovations and increases in patient safety, respectively (and the former has supported learning collaboratives in a number of areas).(13)
		• Some health systems in Canada have created system-wide clinical networks to support the scale up and spread of innovation,(13; 60) such as Alberta's 16 strategic clinical networks that have a mandate to scale up effective clinical practices to the provincial level, and the strategic clinical networks being developed in New Brunswick.
		• Many organizations are building the competencies needed for rapid learning and improvement (e.g., Ontario's Rapid-Improvement Support and Exchange, B.C. Academic Health Sciences Network, Canadian Health Services and Policy Research Alliance's Learning Health System Working Group).
		• Organizations like the Canadian Institute for Health Information could play a critical role to support timely access to data that could be used to monitor progress in scaling up SDM (e.g., standardized health and functional information through interRAI-Home Care).
		• Canada has remarkable assets in terms of SDM (and patient and public engagement more broadly) in both health systems and research systems:
		  o expertise, tools and training programs in patient engagement (including SDM) could be leveraged and connected (e.g., Canada Research Chair in Shared Decision Making and Knowledge Translation; Patient Decision Aids Research Group at the Ottawa Hospital Research Institute; and Decision Box program at Université Laval);
		  o organizations providing patient-targeted decision aids (e.g., Seniors BC), system-navigation resources (e.g., Office of the Seniors Advocate), and care-planning supports (e.g., Advanced Care Planning Initiative) relevant to older adults; and
		  o patient-led organizations advocating greater patient engagement at all levels of health systems (e.g., Patient Advisors Network, Patients Canada, Patients for Patient Safety Canada, and Imagine Citizens).(13)
			approaches are increasingly being used to work across portfolio boundaries to achieve a shared goal and an integrated government response to pressing health and social issues (and thus could facilitate the engagement of policymakers from across sectors).
			• There are growing demands for the development of policies that address older adults' holistic and multifaceted needs, which require comprehensive approaches (including data integration across sectors for public service improvement).(31)

Case example: Current health-system reforms in Ontario

As one example of a provincial health system that is increasingly putting patients and rapid learning and improvement at its centre, the Government of Ontario has introduced Ontario Health Teams (OHTs), which will become clinically and fiscally accountable for delivering a full and coordinated continuum of care to a defined population. OHTs will need to learn and improve rapidly in:

1) designing each of eight OHT building blocks, four of which are of particular relevance here:
   - patient partnership and community engagement, which includes implementing the Patient Declaration of Values for Ontario,
   - improving patient care and experience, which includes health literacy support, SDM, and patient-reported experience and outcome measures,
   - digital health, which includes a patient portal, digital health tools, and e-consultations, and
   - performance measurement, quality improvement, and continuous learning; and
2) harnessing these building blocks to achieve specific targets related to the care experiences and health outcomes for their year 1 priority populations (e.g., older adults with frailty) and eventually for their entire attributed population.(61)

The explicit attention given to SDM and to the many supports needed to scale up SDM provide a unique window of opportunity for scaling up SDM in this province. Moreover, Rapid-Improvement Support and Exchange (www.OHTrise.org) and other members of the OHT Central Program of Supports are well placed to support such scale-up.

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APPENDIX

The following table provides detailed information about the systematic reviews identified for scaling-up strategies. Each row in the table corresponds to a particular systematic review. The focus of the review is described in the first column. Key findings from the review are listed in the second column, while the third column records the last year the literature was searched as part of the review.

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 systematic reviews 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.

The last three columns convey information about the utility of the review in terms of local applicability, applicability concerning prioritized groups, and issue applicability. The third-from-last column notes the proportion of studies that were conducted in Canada, while the second-from-last column shows the proportion of studies included in the review that deal explicitly with one of the prioritized groups. The last column indicates the review's issue applicability in terms of the proportion of studies focused on shared decision-making.

All of the information provided in the appendix table was taken into account by the evidence brief's authors in compiling Table 4 in the main text of the brief.

Appendix 1: Systematic reviews relevant to scaling-up strategies

Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on scaling up SDM interventions
Identifying effective strategies for scaling up evidence-based practices in primary care (50)	This review included 14 studies in order to identify and examine effective strategies for scaling up evidence-based practices in primary care. Most of the included studies were conducted in middle-income countries (n=6), followed by low-income countries (n=5) and high-income countries (n=3). Most of the evidence-based practices were focused on preventing or treating infectious diseases, such as HIV, tuberculosis, and malaria (n=8). The other practices were focused on child care (n=4), depression (n=1), and optimal aging of seniors (n=1). Most of the studies were before-and-after with no control (n=8), followed by non-randomized controlled trials (n=4), randomized controlled trials (n=1), and controlled before and after (n=1). Components of scaling-up strategies mentioned in the studies were, in order of frequency, those relating to human resources, those relating to healthcare infrastructure, those relating to changes in policy and regulation, and those relating to financing. Eight studies mentioned several components of a multifaceted scaling-up strategy, while five studies only mentioned one component. Six studies reported on scaling up evidence-based practices across different settings in a phased manner, and eight studies did not mention whether the scaling up was horizontal or vertical. Five studies reported on scaling-up process outcomes. Three studies reported on the coverage of targeted units, one study reported on costs, and two studies reported on other process measures. One study quantitatively reported successful coverage. Nine studies qualitatively reported successful coverage, two studies reported that scaling up did not succeed, and two were unclear. With regards to the main outcomes of studies, six quantitatively reported a favourable impact and three quantitatively reported no impact. Four qualitatively reported a favourable impact, and one study did not report enough information about the impact. This review is limited by the small number of included studies, as well as because a majority of these studies were undertaken in low- and middle-income countries that focused on the ability of evidence-based practices to tackle infectious diseases. Thus, the results are not generalizable to broad populations. It is also noted that there were vast inconsistencies in the reporting of scaling up, and the necessary components of such interventions. This review also resulted in limited measurable evidence.	2018	4/9 (AMSTAR rating provided by McMaster Health Forum)	Not reported in detail	0	14/14

	In conclusion, this review identified strategies for scaling up evidence-based practices in primary-care settings. However, it is uncertain whether any of these strategies are effective due to limitations in outcome reporting. Further research should be directed towards achieving consensus on the metrics of scaling up that are needed to assess the scaling up of evidence-based practices in primary care.					
Examine strategies available to scale up and spread clinical and administrative practices across healthcare systems (51)	This review examined 52 studies in order to examine strategies available to scale up and spread clinical and administrative practices across healthcare systems. The included studies discussed spread strategies for hard-to-engage sites (n=7), described hard-to-engage sites but did not discuss specific strategies (n=11), and discussed spread strategies in more general terms (n=37). Within the included publications, three macro models were identified to describe the organization of spread efforts. The first model embedded scale-up interventions within a system of care (n=29), the second involved collaborations or exchanges aimed to support the spread of multiple initiatives within a specific topic area (n=14), and the third involved initiative-specific spread efforts (n=9). Preconditions to consider in large-magnitude scale-up were identified to be ensuring initiators gather information on who will need to be involved at each site, and ensuring goals are aligned with everyone involved in all aspects and in all phases of the scale-up. When working with hard-to-engage sites, it is important to consider that these sites often have limited resources and competing priorities that do not overlap with the priorities of the scale-up initiative. Due to the variation in needs of these sites, it is important to use a flexible, tailored approach with each site. Data limitations of this review prevented the use of statistical tests to determine publication bias. However, it is likely that publication bias is present as unsuccessful scaling-up efforts are unlikely to be published. In summary, this review recommends that future work in implementing scale-up or spread efforts should include the following: i)taking time to understand the salient factors before engaging sites, and determining if there are existing networks that could be leveraged; ii) when organizing a spread or scale-up effort, the various infrastructure models that could be used and what impacts they may have should be considered; and iii) Identifying potential challenges or characteristics of sites that make them hard-to-engage and tailoring efforts appropriately.	2018	4/9 (AMSTAR rating provided by McMaster Health Forum)	Not reported in detail	0	52/52
Identifying different ways scale-up interventions can be approached (29)	This rapid review included 11 articles in order to identify different ways scaling-up interventions can be approached. This review identified three different approaches to spread and scale-up innovation and improvement. The first approach is an implementation science approach. This approach focuses on evidence-based interventions in practice and provides concrete, planned approaches to the delivery and study of spread and scale-up interventions. The implementation science approach measures improvement quantitatively using metrics, and qualitatively using a systematic approach to	Not reported	6/10 (AMSTAR rating provided by McMaster Health Forum)	Not reported in detail	0	11/11

	exploring processes and mechanisms. Ultimately, success is measured through replication of a particular service model or approach across multiple contexts. The second approach is the complexity science approach. This approach focussed on the evolving and emergent properties of systems. This approach emphasizes the system's need for adaptive change at interacting levels. This approach's preferred method for achieving spread and scale up includes gaining an understanding of the case's historical, socio-political, and organizational context, and deriving creative ways to accomplish the goals. This approach measures improvement using a case study approach and success by analyzing how the intervention was adapted or abandoned. The third approach is the social science approach. The focus of this approach is the social study of individuals, groups and organizations. This approach analyses patterns of social behaviour and interaction, beliefs and values, and routines. This approach involves developing and applying theories of how individuals' actions are influenced by various factors. This approach measures improvement using interview-based methods, and measures success of the intervention using informed and justified explanations about human behaviour. In summary, the identified approaches can inform the design and implementation of spread and scale-up interventions.					
Examining government's role in coordinating large-scale health-system transformations (52)	This systematic realist review and evidence synthesis drew from both the published literature and current practice regarding large systems transformation generally. The authors identified a lack of literature on large system transformation at the macro level, but were able to identify five evidence-based themes which were validated and modified during two rounds of merit review with international experts. The review found that large system transformation in healthcare systems requires both top-down leadership that is passionately committed to change, as well as distributed leadership and engagement of personnel at all levels of the system. Recommendations for action in this area include facilitating communication and visibility of the transformation efforts by working with those who have a history of leadership in the area, providing a central coordinating body for the change initiative that is isolated from political influence and change, and clearly articulating the goals of the change. The review found that measurement and reporting on progress toward short and long-term goals is critical for achieving effective and sustainable large system transformations. Recommendations for action in this area include providing resources including IT systems for collecting and reporting on measures, establishing independent oversight of measurement development, reporting and interpretation, and offering equitably distributed rewards and sanctions for the measures. The review found that consideration and acknowledgment of historical context will help avoid unnecessary pitfalls and increase buy-in and support from stakeholders. Recommendations for action in this area include carefully assessing organizational readiness for transformation, and storing and reporting information about past change efforts, especially efforts that were unsuccessful.	Not reported	3/9 (AMSTAR rating provided by McMaster Health Forum)	Not reported in detail	Not reported in detail	Not reported in detail

	The review found that large system transformation in healthcare systems relies on significant physician engagement in the change process. Recommendations for action in this area include working with educational institutions and regulatory bodies to modify initial and continuing training curricula to provide skills and roles that are consistent with transformational efforts, engaging physicians and other health professionals in policy development, and providing funding, regulations, and incentives for physician engagement. The review found that large system transformation that aims to increase patient-centredness requires significant engagement of patients and families in the change process. Recommendations for action in this area include setting up independent governance and advisory mechanisms for healthcare institutions and bodies at the provincial, regional and local levels, ensuring the right players are involved in the change process through adequate funding and compensation, and collecting information on patients' wishes through robust surveys or other data-collection methods, while being careful to ensure that patient engagement is not reduced to patient-satisfaction surveys alone.				
Synthesizing research on frameworks to scaling up public-health interventions and identifying enablers/barriers to scaling up (30)	This narrative review included 24 studies exploring existing frameworks to scaling up public-health interventions into policy and practice as well as the respective enablers and barriers of implementing such frameworks. Of the 24 included studies, eight described frameworks for scaling up. While seven of the frameworks were aimed towards scaling up in low- and middle-income countries, this review argued that such frameworks were as equally applicable in high-income country settings due to comparable goals in advancing population health. The following characteristics were commonly shared across frameworks: 1) utilizing research evidence to determine factors which may influence strategies in scaling up; 2) identifying the specific intervention features being scaled up (i.e., effectiveness, acceptability, outreach); 3) pinpointing and supporting key implementers of change; 4) identifying a suitable approach in delivering the intervention; 5) tailoring the scaling-up approach towards the traits of the targeted community; 6) considering socio-political factors; and 7) evaluating and monitoring approaches towards scaling up. Primary factors identified as enablers of scaling up public-health interventions include: 1) developing a monitoring and evaluation strategy; 2) modelling costs and economic factors associated with various intervention approaches; 3) engaging a diverse group of intervention implementers and members of the targeted community through participation; 4) designing a contextually appropriate scale-up strategy; 5) actively finding and using research evidence; 6) the presence of infrastructure to support implementation; 7) strong leadership, advocacy and political will; and 8) designing a comprehensive scaling-up strategy. Barriers gleaned from this review are converse to the identified enablers and mainly include: 1) failing to develop approaches relevant to community contexts; 2) costs and economic considerations; 3) limited human resources; 4) resistance in adopting new interventions due to limited organization capacity and community resources; staff turnover and recruitment; and 5) weak political will.	2013	4/9 (AMSTAR rating provided by McMaster Health Forum)	1/24	0	0

	The findings of this review further suggest that the implementation of a successful strategy is not dependent on the number of components involved or the levels of a system it aims to target. Individual components within complex strategies must be comprehensible and adoptable by implementers and communities in order to efficaciously scale up interventions. Limitations of this review include publication/selection bias and the exclusion of literature which did not use terms such as 'scaling up' or 'scalability'.				
Identifying factors which influence cost projections for scaling-up interventions (48)	This review included 37 studies exploring factors which influence the cost of scaling up health-service interventions, with a specific exploration of costs across rural and urban settings. This review further involved a discussion on costs associated with varying forms of interventions and degrees of coverage.

From this review, the following considerations in estimating costs were identified: 1) cost of transportation, supervision and training professionals; 2) availability of resources and strength of existing infrastructure; 3) availability of trained and qualified health professionals; and 4) average cost of treatment per patient as well as marginal costs of scaling up. Management strategies such as strong multi-level communication, ongoing quality assurance and building administrative capacity were also noted as key considerations. In settings lacking administrative structure and networks necessary for the implementation of an intervention, setting up the appropriate infrastructure may incur additional expenses. As such, leveraging existing under-utilized interventions, bulk purchasing intervention supplies, and undertaking a gradual approach towards meeting scale-up targets may be beneficial in maximizing efficiency and curtailing high costs.

The findings of this review suggest that the cost of scaling-up interventions is considerably greater in rural and remote regions in comparison to urban settings due to geographical barriers, limitations in infrastructure, staffing shortages, greater marginal costs and higher average cost of treatment per patient. Implementing alternative strategies, such as mobile services or educational awareness campaigns, may offer a more economically sustainable route towards scaling up interventions while also increasing service demand in rural and remote communities.

Authors of the review were unable to calculate concrete cost projections due to variability in intervention settings and extent of coverage. However, the authors noted the following similarities across studies on guidelines to determine total cost projections: 1) estimating average costs for both urban and rural areas; 2) determining extent of coverage and fixed costs for all program features; 3) evaluating availability of human resources and infrastructure capacity; and 4) calculating management costs associated with scaling up.

Limitations of this study include inadequate data related to scaling-up costs for health services interventions. | 2002 | 5/10 (AMSTAR rating provided by McMaster Health Forum) | 1/10 | 0 | 0 |
| Identifying stages of intervention implementation and describing a tool to assist | This review included 69 studies that described common stages of innovation in order to develop the Note to Tail Tool (NTT), an instrument aimed to assist stakeholders in identifying barriers and solutions when scaling up single- or multi-component healthcare interventions. Objectives of the NTT also include guiding innovation teams in identifying the stage of process at which their intervention currently exists, pinpointing stakeholder concerns at particular stages, and addressing contextual barriers. | Not reported | 2/9 (AMSTAR rating provided by McMaster | 2/9 | 0 | 0 |

scaling-up efforts (49)	The following stages of developing an intervention were identified: 1) problem identification; 2) intervention development; 3) designing and piloting a test; 4) pilot test; 5) assessing the pilot test; 6) decision to implement design; 7) implementation-strategy planning; 8) implementation stage; 9) assessing the implementation; 10) testing in different settings to ensure consistent positive outcomes; 11) decision to expand and extend intervention; 12) scaling-up strategy planning; 13) scale-up stage; 14) evaluating the scale-up; 15) monitoring scale-up; and 16) institutionalize change. Factors which influence the scaling up of an intervention include: 1) characteristics of the intervention; 2) interest of stakeholders, such as researchers, end users, and decision-makers; 3) social and physical setting where the intervention will be scaled up; 4) the health system unit targeted by the intervention; and 5) political and economic landscape. Authors of this review emphasize the importance of collaboration between end users, decision-makers and researchers, as well as undertaking a participatory approach, in designing and implementing interventions. Limitations of this review include lack of empirical evidence and the use of a narrow search strategy centred around the term 'scale up'.		Health Forum)			
Evaluating the effectiveness of various approaches in scaling up social-service interventions (53)	This protocol aims to evaluate the effectiveness of various approaches in scaling up social-welfare interventions. The primary outcome measure assessed by this protocol includes the extent by which an intervention was implemented in accordance to plan. Secondary outcomes include evaluating process of uptake, integration of proposed interventions into existing systems or practices, sustainability, effectiveness, acceptability, the degree by which the intervention addresses the problem, feasibility of implementation, and associated costs. Authors of this protocol note several challenges in addressing the irregular and non-uniform uptake of social-system interventions across geographical locations, including poor training, limited support and prevalent attitudes towards the use of research evidence in practice. The following strategies towards scaling up were identified by the studies discussed in this protocol: 1) collaboration between fields of research and practice; 2) engaging stakeholders in decision-making processes; 3) resource allocation; 4) capacity building; 5) restructuring existing systems; 6) quality appraisal and evaluation; 7) collaboration between key organizations; and 8) modifying intervention to meet contextual factors. Conducting an ongoing evaluation of implemented interventions is further emphasized in identifying and addressing barriers towards scaling up.	N/A	Not available for this type of document	N/A	N/A	N/A