Dialogue Summary

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

12 December 2019

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McMaster Health Forum
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Citation
> Gauvin FP, Lavis JN, Légaré F, Plourde K. Dialogue summary: Scaling up shared decision-making in home and community care in Canada. Hamilton: McMaster Health Forum, 12 December 2019.

Dialogue
> The stakeholder dialogue about scaling up shared decision-making in home and community care in Canada was held on 12 December 2019 at the McMaster Health Forum in Hamilton, Ontario.

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SUMMARY OF THE DIALOGUE

The deliberation about the problem initially focused on whether we are at a critical juncture to scale up shared decision-making (SDM) in home and community care in Canada. Participants indicated that many jurisdictions across the country have been introducing innovations (or are in the midst of health-system transformations) that put SDM front and centre. In addition to the features of the problem articulated in the evidence brief, participants highlighted four additional challenges: 1) the need to address systemic and cultural barriers to SDM in home and community care (e.g., home- and community-care services are not publicly insured through the Canada Health Act; remuneration issues); 2) the lack of indicators focusing on SDM metrics (as opposed to access and cost-containment metrics which are the prime focus of policymakers); 3) the lack of professionals to broker conversations about the wide range of decisional needs of older adults and caregivers; and 4) the potentially conflicting expectations towards the SDM model in home and community care.

The deliberation then shifted to 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. The deliberation started with the need to clarify what is a 'decisional need.' Some participants indicated that a decisional need should not be defined negatively as a 'deficit' (as presented in the evidence brief), but re-framed positively as supporting older adults and caregivers to define their goals, explore options, and make choices when they are at a crossroad. The deliberation then moved to providing input about the three groupings of decisional needs: decisional needs that provider organizations could help support (grouping 1); decisional needs that government health policymakers could help support (grouping 2); and decisional needs that government policymakers from other sectors could help support (grouping 3). Some participants indicated these groupings of questions should be in the back of the mind of those designing home- and community-care services. Others suggested re-framing some of the decisional needs around quality of life-related choices.

In deliberating about possibly effective strategies to scale up SDM in home and community care in Canada, participants identified several strategies, including a manageable set of simple-to-use decision aids covering the full spectrum of groupings of decisional needs: governance arrangements (e.g., accountability agreements, accreditation and other processes that include metrics related to supporting SDM and/or patient/caregiver experiences with SDM); financial arrangements (e.g., adjusting payment mechanisms and incentives to support SDM); delivery arrangements (e.g., digital tools to support context-specific SDM, and decision-support coaches available to providers); and system-wide reforms that shift the focus and culture of providers towards improving quality of life and supporting decision-making that enhances quality of life. Participants also identified several implementation enablers, such as: learning and improvement collaboratives focused on SDM; incorporating SDM in broader learning and improvement initiatives like strategic clinical networks; and examining how we could develop a new narrative about SDM in home and community care that could resonate in a more macro way with the big policy issues (e.g., debt, hallway medicine, and integration of care).

Participants prioritized several actions as part of a first step towards scaling up SMD in home and community care in Canada, including: leveraging current reforms in each jurisdiction as well as pan-Canadian initiatives (e.g., quality-improvement collaboratives, and practice-based learning networks); and creating compelling narratives about SDM in home and community care that will resonate at all levels (e.g., re-framing SDM in home and community care in order to attach it to priorities on the government agenda and to core societal values such as informed consent, medical aid in dying, or pharmacare). These actions revealed the need for collective efforts and 'joint advocacy' in order to scale up SDM in home and community care in Canada.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

The deliberation about the problem initially focused on whether we are at a critical juncture to scale up shared decision-making (SDM) in home and community care in Canada. Dialogue participants indicated that many jurisdictions across the country have been introducing innovations (or are in the midst of health-system transformations) that put SDM front and centre. For example, improving patient care and experience (including shared decision-making) has been identified as one of the eight building blocks of the new Ontario Health Teams that are being established across the province.

In addition, several pan-Canadian organizations are leading collaboratives relevant to SDM in home and community care, including the Canadian Home Care Association, the Canadian Patient Safety Institute, and the Canadian Foundation for Healthcare Improvement. That being said, one participant emphasized that we have been late in scaling up SDM and such a change has been necessary for a long time: "We're 20 years behind the critical juncture." Another participant shared their optimism that, given the various initiatives happening right now, scale up of SDM in home and community care is possible across the country: "We're not starting at 'ground zero'."

The deliberation then turned to the most pressing challenges confronting the scale up of SDM in home and community care in Canada. In addition to the features of the problem articulated in the evidence brief, participants highlighted four additional challenges:
- the need to address systemic and cultural barriers to SDM in home and community care;
- the lack of indicators focusing on SDM metrics;
- the lack of professionals to broker conversations about the wide range of decisional needs of older adults and caregivers; and
- the potentially conflicting expectations towards the SDM model in home and community care.

The need to address systemic and cultural barriers to SDM in home and community care

Several participants initiated the deliberations by pointing out systemic and cultural barriers to scaling up SDM in home and community care in Canada, notably:
1) home and community care is a complex patchwork of programs and services;
2) home- and community-care services are not publicly insured through the Canada Health Act;

Box 1: Background to the stakeholder dialogue

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

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

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

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3) privacy legislation constrains who holds information about patients and who has the ability to act on it;
4) a disconnect exists between the health sector and the broader human-services sector that is needed to help older adults live at home for as long as possible;
5) remuneration issues create disincentives for providers to engage older adults and caregivers in conversations about their decisional needs;
6) little attention is given to SDM at the provider and policy level (e.g., access to care and cost-containment have been the predominant lenses applied); and
7) a lack of culture of patient engagement in general, and particularly in the case of older adults.

Regarding the fourth point (about the lack of connection between health and broader human services), one participant noted: "We want to help people live at home. We can do that from a healthcare perspective. But there is a disconnect with all the other areas and services necessary to [support their non-medical decisional needs]. What matters most to patients and caregivers is often these other non-medical [decisional] needs." And regarding the last point (about the lack of a supportive culture) another participant observed: "We don't have a culture of older adults expecting to be engaged in decisions about them. We often turn to the family even if the older adult is sitting there." A second participant went further: "Our system is about mitigating all risk. How do we get out of our societal value of over protecting our elderly [and thus not allowing them to make choices]."

The lack of indicators focusing on SDM metrics

Several dialogue participants emphasized that access-to-care and cost-containment metrics are the prime focus of policymakers. A few participants illustrated this point with the 2017 federal, provincial and territorial (F/P/T) agreement to improve access to mental health and addiction services, as well as to home and community care. As part of the agreement, F/P/T health ministers agreed to work with the Canadian Institute for Health Information to develop 12 common indicators to measure pan-Canadian progress on improving access to care. These indicators are also the focus of the Priority Health Innovation Challenge supported by a coalition of leading Canadian healthcare organizations. However, some participants expressed concern that none of the indicators relate to SDM, and that the way they were formulated may actually stifle innovation: "If you look at the framing of these indicators, they are considered as a barometer to identify problems. But does it stifle innovation?"

Some participants stressed that there could be some mistrust at the policy level regarding the types and range of decisions that patients could make. Given that policymakers are focused on cost-containment, they may be concerned that greater SDM may lead to "patients mak[ing] crazy decisions" that could jeopardize public finances. This focus on cost-containment was also seen as influencing providers who are inclined to "play by the rules [and thus] don't engage. They don't have time and there are no choices." Participants contradicted that perspective and emphasized that SDM was in fact a way to reduce the overuse of ineffective options.

Thus, several participants called for greater efforts to develop and support the uptake of SDM metrics, which was key to value-based care: "The framework of SDM is a terrific one. [But] one of the key problems is [that we are trying] to do two things at once: [consider] all the social determinants that are relevant to their care and the population-based metrics in order to create a value-based equation that you could feed into a business model."

The lack of professionals to broker conversations about the wide range of decisional needs of older adults and caregivers

Dialogue participants pointed out the lack of professionals to broker conversations about the wide range of decisional needs of older adults and caregivers. More specifically, they pointed out that there is:
1) a general lack of understanding of SDM among professionals;
2) a lack of professionals who are familiar with the broad array of human resource services within a community;

3) a lack of professionals with a dedicated role to support the decisional needs of older adults and caregivers (e.g., decision coaches or decision navigators); and
4) a lack of professionals who are familiar with the realities of rural and remote communities, and thus able to support the decisional needs of older adults in these communities (which is particularly salient when patients are receiving care in urban centres and then transitioning back home).

Regarding the first point (about understanding), one participant commented: "I don't think front-line providers understand shared decision-making. Telling somebody and working collaboratively with somebody is different."

The potentially conflicting expectations about SDM for home and community care

Dialogue participants then mentioned that there may be conflicting expectations towards SDM in home and community care between (and among) the various stakeholders, in part due to: 1) the complex business model of home and community care; 2) a disconnect between patients and providers; and 3) the complex terminologies being used.

A few participants focused on the complex 'business model' of home and community care: "Home and community care drives me crazy. It's a part of healthcare, which drives me crazy, [but it's also] about life care . . . how people live their lives. This sector has an interesting business model, with outsourcing services, etc., that is different from the hospital sector. How do you work in that business model? [There is] very limited conversation about the model of care that must be put in place. We need to force these conversations."

Others emphasized the disconnect between patients and providers towards SDM in home and community care, and the lack of common ground: ". . . what the clients believe as necessary and we as managers believe is necessary. We need to find common ground." A second participant indicated that patients often struggle with the role they should be playing in the decisions about their own health and care: "The toll, from the caregiver perspective, is that we assume that you're going to tell us [what to do]. You're trying to make us a 'we', but we struggle with that."

A few participants indicated that the conflicting expectations may also be exacerbated by the complex terminology being used, including SDM, collaborative decision-making, home and community care, or decisional needs (which will be further discussed in the next section). As one participant noted: "Shared decision-making doesn't mean anything when I'm in the trenches [as a patient or caregiver]. How you tell the story, this is the big deal for the patients and caregivers." Different terminologies could be used across the country, which may constitute a barrier in the way of scaling up SDM in home and community care in Canada. As another participant noted, there may be a need to do a jurisdictional scan to map the terminologies being used and then try to find which terms would resonate the most. "[It may be] useful to look at the various provinces given that the legislations and terminologies may be different. [It may be] worthwhile exploring different terms. Once the terms are clarified, they can be socialized."

DELIBERATION ABOUT THREE GROUPINGS OF DECISIONAL NEEDS

Participants then focused on identifying a potentially comprehensive list of decisional needs, and specifically those that take us beyond the traditional decisions related to testing and treatments and that can be met by a care team. To facilitate discussion, the evidence brief proposed three groupings of decisional needs:
1) decisional needs that provider organizations could help support;
2) decisional needs that government health policymakers could help support; and
3) decisional needs that government policymakers from other sectors could help support.

Before jumping into the deliberation about the three groupings, several participants emphasized the need to first clarify what is a 'decisional need.' They indicated struggling with the definition provided in the evidence brief, which stated that a decisional need refers to a 'deficit' that can affect the quality of a decision and required tailored decision support. Those participants particularly struggled with using 'deficit' as a starting point, as opposed to framing it more positively as a way to empower individuals, support them when they are

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at a crossroad and must make a choice, and help them make more informed decisions. A few other participants indicated that the word 'deficit' may create confusion as people may think it refers strictly to individuals having a cognitive deficit and thus are not capable or competent to make decisions. "They'll think about the capacity to make decisions. The cognitive ability, consent, etc. Perhaps we could call it 'decisional-support needs' and to frame this positively in the definition."

In the remaining section, we present the key themes that emerged when participants deliberated about each of the three groupings of decisional needs.

Grouping 1 – Decisional needs that provider organizations could help support

The deliberation about the first grouping focused on the decisional needs that provider organizations could help support.

Several participants emphasized that, in addition to the list in the evidence brief, the following decision points were important to consider.
- What are my options to support me during hospital-to-home transitions?
- What are my options to ensure my safety?
- What are my options to access palliative care, end-of-life care, and medical aid in dying?
- What are my options to support me if I have cognitive impairments?
- What are my options to ensure that all my providers are proactively informed about my health- and social-related decisional needs?
- What are my options for whom I can share my information with (e.g., regulated health and social-care providers, human-services professionals, personal-support workers, etc.)?
- What are my options to access home and community care (i.e., the 'entry points')?
- What are my options to hold people accountable if something happens to me?
- What are my options to be supported in my activities of daily living (including transportation, food security, yardwork, snow shovelling)?
- What are my options to support me if I relocate to another jurisdiction?

As participants deliberated about the first grouping of decisional needs, they pointed out that:
- some of the 'decision points' are triggered by healthcare events;
- it is important to ensure that there are options and "there is really a choice" to be made;
- try to formulate the decisional needs around core societal values such as 'quality of life;' and
- try to formulate the decisional needs within a timeframe (e.g., when do you need to have this decision being made).

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

The deliberation about the second grouping focused on decisional needs that government health policymakers could help support. Four key themes emerged from this deliberation:
- policymakers must be able to know what home- and community-care options are currently publicly available;
- the list of decisional needs raises the question about what we (as a society) are prepared to offer in terms of options for each decision point listed above;
- the list of decisional needs has implications in terms of funding-arrangement options to allow people to have access to additional services (e.g., tax implications); and
- the people we serve are not homogenous and will likely have different decisional needs.

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

Dialogue participants discussed to a lesser extent the decisional needs that government policymakers from other sectors could help support. The discussion mostly focused on the needs to bring all the different sectors together, and perhaps leveraging community-based initiatives to achieve this.

Considering the full array of decisional needs

When considering the full array of decisional needs listed in the evidence brief, several participants indicated that it was innovative to move beyond the clients' and providers' perspectives: "We usually assess the decisional needs at the level of clients, caregivers and providers. This is innovative to look at the decisional needs at higher levels." They also emphasized the following points:

- identifying decisional needs is challenging ("people are not good at identifying, out of thin air, their decisional needs") and this means that it will require deep reflection from provider organizations and policymakers to understand the clients' decisional needs and options;
- there is a need to train providers, provider organizations and policymakers to conduct decisional-needs assessments;
- decisional needs should be formulated in a way that supports social justice and not reinforce inequities (e.g., having the possibility to choose providers may in some cases nurture a systemic bias towards some providers with specific ethnocultural backgrounds);
- the lists of decisional needs should not be too 'boxy' and cluster the decisional needs in a way that may be hard to adapt to different circumstances ("we need to look at the whole person before answering all the questions");
- these groupings of decisional needs should be in the back of the mind of those designing home- and community-care services; and
- there is a need for SDM metrics allowing us to determine the progress in supporting those decisional needs.

DELIBERATION ABOUT SCALING-UP STRATEGIES

Dialogue participants then discussed strategies to scale up SDM in home and community care in Canada. Three key themes emerged from the discussion: 1) there are preconditions before being able to scale up SDM; 2) there is a need for scaling-up strategies aimed at policy and organizational decisions that are supportive of SDM; and 3) some implementation enablers could facilitate the scaling up of SDM.

Preconditions for scaling up SDM

Participants initially discussed some of the preconditions for scaling up SDM in home and community care in Canada. They emphasized the importance of having a manageable set of easy-to-use decision aids that: 1) cover the full spectrum of groupings of decisional needs covered in the evidence brief; 2) can be easily contextualized to local realities; and 3) can be used by individuals, with providers, or both.

Regarding the first point, several participants highlighted the need to equip older adults and caregivers with decision aids (and algorithms) to help them identify decision points and then discuss their values, preferences and goals of care (e.g., the Goals of Care Designations in Alberta that guide healthcare teams about the general focus of patients' care, and where they might want that care). As one participant said: "People may have an intuitive knowledge of their values and preferences, but never thought about them explicitly."

Several participants indicated that patient decision aids are rarely co-designed with patients. While co-designing decision aids may be resource intensive, it was identified as a precondition for the successful scaling up of SDM. "Co-design work is slow and requires commitment, but I'm a believer." Some participants pointed out current co-design initiatives happening in Alberta to facilitate conversations around safety, as well as relevant co-design initiatives in Australia.

Nonetheless, a few participants suggested that providing decision aids may be a necessary precondition, but was not sufficient for scaling up SDM. Several participants indicated that it was necessary to address systemic issues, as well as perceptions among providers, managers, policymakers and other stakeholders. "Providing tools won't be enough. We need to influence perceptions."

Policy and organizational decisions

Participants also pointed out the need to adapt governance, financial and delivery arrangements to be supportive of SDM.

In terms of governance arrangements, they pointed out the need to have legislation or policies that are supportive of SDM, notably: 1) accountability agreements, accreditation and other processes that include metrics related to supporting SDM and/or patient/caregiver experiences with decision-making (as part of quadruple-aim metrics of improving care experiences and health outcomes at manageable per capita costs and with positive provider experiences); 2) clinical standards to which the providers are held accountable ("engaging in SDM could become part of your competencies in your licensure"); and 3) policies that remove barriers to SDM (e.g., adjusting privacy legislation so relevant information is available to providers supporting SDM). Several participants highlighted the key role of governments and regulatory colleges in achieving this. One challenge identified was the need to align governance arrangements with other sectors beyond health, as well as across all levels of governments (municipal, provincial, territorial and federal).

In terms of financial arrangements, they indicated the need to have funding and payment mechanisms to support SDM, notably: 1) a single funding envelope across health and social services (and possibly broader human) services; and 2) financial incentives to specifically support early adoption of SDM.

In terms of delivery arrangements, they pointed out several strategies that could support SDM, notably: 1) digital tools to support context-specific SDM; 2) training providers in SDM (and in the preparatory stages and re-visiting stages as well); 3) decision-support coaches available to providers; and 4) clear point-of-contact for decision support.

Lastly, some participants called for system-wide reforms that shift the focus and culture of providers towards improving quality-of-life choices and supporting decision-making that enhances quality of life (and towards putting risk management in appropriate perspective and being flexible about how decisional needs are met, particularly in rural and remote communities). One participant highlighted that system-wide reforms may need to be grounded in declaration of principles, like the Patient Declaration of Values for Ontario, which serves as a compass for providers and provider organizations. "It's explicit in it [the need for SDM], and the obligation of OHTs [Ontario Health Teams] to operationalize it."

Implementation enablers

Participants then turned to enablers to the successful scaling up of SDM in home and community care in Canada. They individually and collectively focused on four types of implementation enablers: 1) leveraging learning and improvement collaboratives; 2) developing a new narrative to align SDM with the big policy issues; 3) engaging patients; and 4) building an evidence trail.

The first enabler was leveraging learning and improvement collaboratives focused on SDM, but also incorporating SDM in broader learning and improvement initiatives. One participant pointed out the

SPRINT Implementation Collaboratives led by the Canadian Home Care Association, which is designed for home- and community-service providers to implement leading practices and test innovative approaches (including SDM). Other participants mentioned broader learning and improvement collaboratives, including: Alberta's Strategic Clinical Networks, which focus on various areas of healthcare (such as seniors health), or the implementation collaboratives and open innovation challenges led by the Canadian Foundation for Healthcare Improvement.

The second enabler was developing a new narrative to align SDM with the big policy issues, which could help to give it more visibility and bring it on the governmental agenda. Several participants pointed out the need to capitalize on the current government priorities to push this further on the agenda. "If we could leverage those (e.g., patient- and family-centred care, aging in place, life care, hospital-to-home transitions, and the economic imperative), they are all trying to sell the same goals." A few participants wondered whether it would be more effective to take SDM out of the realm of home and community care to facilitate the scaling up. "Let's use it as a rallying call."

The third enabler was leveraging the various public- and patient-engagement initiatives across the country (individual patient advisors, partners and advocates, along with organizations supporting them such as the Centre of Excellence for Partnership with Patients and the Public), which could help bring the issue of SDM into the public domain. As one participant indicated: "I'm a fan to bring this in the public domain. The lowest-hanging fruits are the patient advocates." A second participant went further. "Put these decisions in the people's hands. Use this as a pull strategy, (and let) seniors take it on. There is a desire to be supported in decision-making. They realize it. Let's put it in the hands of others who can mobilize organically."

The fourth enabler was to develop an evidence trail to document what is known about the decisional needs of older adults, providers, provider organizations, and policymakers from health and other sectors. Currently there is a limited body of research evidence about decisional needs, most of which focuses on the decisional needs of patients and providers.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

In the deliberations about next steps, participants outlined what they would bring back to their respective constituencies and how their suggestions could work to advance the proposed solutions. Many participants indicated that the time is ripe for scaling up SDM in home and community care in Canada, even if the model needed to be refined. "We don't need to make it perfect. Let's make it happen." It resonated with another participant who said: "It's time to rise to the occasion."

Together, participants prioritized the following actions:
- exploring how to leverage current reforms and initiatives in each jurisdiction (e.g., using the Rapid-Improvement Support and Exchange to embed SDM in the new Ontario Health Teams; integrate SDM in Alberta's Seniors Health Strategic Clinical Network or the Dementia Strategy and Action Plan);
- exploring how to leverage pan-Canadian initiatives to scale up and spread SDM in home and community care across the country including,
  - leverage quality-improvement collaboratives and open innovation challenges (including those funded by the Canadian Patient Safety Institute, the Canadian Home Care Association, the Canadian Foundation for Healthcare Improvement, or Health Canada),
  - leverage practice-based learning networks to help bridge the gaps between communities, funders, policymakers, and other stakeholders across the country, and
  - promote greater leadership from the federal government given its roles around the care of seniors;
- creating compelling narratives about SDM in home and community care that will resonate with providers and policymakers, such as,
  - at the policy level: (re)frame SDM in home and community care in order to attach it to priorities on the government agenda and to core societal values, and

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- o at the provider level: emphasize how the core values of SDM are shared by providers and that they have a responsibility to go in that direction;
- developing commonly agreed-upon and transparent standards to articulate "what people can expect" from provider organizations; and
- creating opportunities for intensifying training in SDM in home and community care, and leveraging initiatives by regulatory colleges like the College of Family Physician of Canada's Outcomes of Training project to embed SDM in the curriculum of students, the scope of practice and the philosophy of care.

Regarding the third point (compelling narratives at the policy level), one participant noted: "It is about 'life care', it could address hallway medicine, it could support the integration of care, it could improve the quality of care, it could ensure that health and social care is grounded in patients' values and preferences, it could improve patient and caregiver satisfaction, it could support self-management and person-centred care, it could help to determine more appropriate health and social care to match the needs of patients and caregivers, it could reduce wasteful public spending, and it could support informed consent, as well as medical aid in dying and pharmacare."

These actions revealed the need for collective efforts and 'joint advocacy' in order to scale up SDM in home and community care in Canada. As one participant said: "We will need an entire ecosystem to make this happen. And we must [encourage] healthy competitive processes."