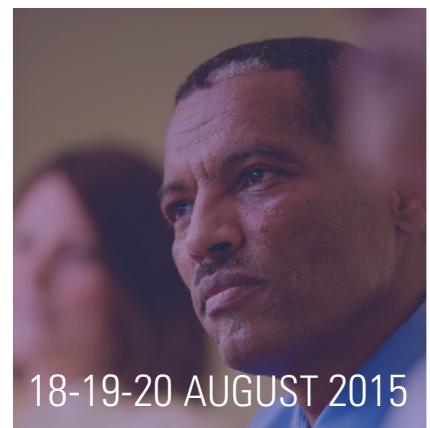


ENGAGING COMMUNITIES
IN SETTING PRIORITIES FOR
HOME AND COMMUNITY CARE
IN NORTHEASTERN ONTARIO

influential thinkers and doers
leading hub
action local
best available evidence



EVIDENCE >> INSIGHT >> ACTION

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-14 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the view of others. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

About this summary

Over the last year, significant effort has been put into understanding and improving the provision of home and community care across Ontario. The Ministry of Health and Long-Term Care, informed by the “Bringing Care Home” report, released “Patients First: A Roadmap to Strengthen Home and Community Care,” which describes a plan to transform home and community care in the province. The North East Local Health Integration Network took a close look at the public’s views about ways to improve the work of the North East Community Care Access Centre (North East CCAC), which is the organization that connects people with the care they need, at home and in their communities. More recently, the North East CCAC partnered with the McMaster Health Forum and the Centre for Rural and Northern Health Research (CRaNHR) to convene three additional citizen panels to engage communities in setting priorities for home and community care in northeastern Ontario. Separate panels were convened for: 1) Aboriginal community members; 2) Francophone community members; and 3) mainstream community members. The purpose of the panels was to inform the development of a strategic plan for the North East CCAC for the period 2016-19.

This panel summary highlights the views and experiences of panel participants about:

- the underlying problem;
- three possible options to address the problem; and
- potential barriers and facilitators to implement these options.

The citizen panels did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

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Summary of the panel

Participants discussed challenges related to planning for future home and community care needs in northeastern Ontario. During the deliberations, the following eight challenges were raised: 1) realities of older adults' lives; 2) desire for holistic care; 3) increasingly complex care needs emerging at a younger age; 4) geographic isolation; 5) cultural and linguistic diversity; 6) fragmentation of current programs; 7) personal support workers' needs for support and training; and 8) informal/family caregivers' need for support.

Participants reflected on three options (among many) for addressing home and community care in northeastern Ontario: 1) increasing access to highly valued services and reducing the provision of less highly valued services; 2) better meeting needs during transitions in care, and among Aboriginal and Francophone groups; and 3) better engaging patients, families and communities in the care delivery process. Several values-related themes emerged during the discussion about these options, with three emerging with some consistency: 1) equity/fairness (e.g., striving for equity across northeastern communities and between northern and southern Ontario, recognizing that vulnerable older adults may require additional support); 2) cultural and linguistic sensitivity (making sure that care is attuned to the diverse needs of Aboriginal and Francophone groups, ensuring the cultural and linguistic competence of health-system navigators); and 3) empowerment (engaging frontline organizations, community organizations and associations, supporting self-management so that older adults and their informal/family caregivers can play an active role in their care).

When turning to potential barriers to address home and community care needs in northeastern Ontario, participants identified three sets of barriers to moving forward: 1) the specific needs of northerners do not seem to be a priority for provincial and federal governments; 2) organizations and their boards appear to operate in silos; and 3) fragmentation in the health system limits capacity for care coordination, information sharing and intersectoral collaboration. Participants then turned to the factors that could facilitate efforts to improve home and community care in northeastern Ontario. They encouraged health-system leaders and stakeholders to be innovative and creative. They also proposed key strategies to bring about change, with the strategies targeting patients and informal/family caregivers, providers, healthcare organizations and the health system more broadly.



“In the north, no one realizes how isolated you really are here.”

Discussing the problem: What are the most important challenges to planning for the future home and community care needs in northeastern Ontario?

Panel participants began by reviewing the findings from the pre-circulated citizen brief, which highlighted what is known about the underlying problem – shortfalls in the planning and delivery of home and community care in northeastern Ontario – and its causes. They individually and collectively focused on eight challenges in particular:

- realities of older adults’ lives;
- desire for holistic care;
- increasingly complex care needs emerging at a younger age;
- geographic isolation;
- cultural and linguistic diversity;
- fragmentation of current programs;
- personal support workers’ needs for support and training; and
- informal/family caregivers’ need for support.

We review each of these challenges in turn on page 3.

Realities of older adults' lives

Discussions initially focused on the perception that we have a 'new' generation of older adults, which may pose both challenges and opportunities for how to adapt our existing system. Participants emphasized that we are slowly transitioning to this new generation, but that older adults are not fully comfortable with technologies (and many do not even have access to the internet, particularly if they're in remote communities), are not empowered to be more actively engaged in their care, and are rarely advocating to have access to culturally sensitive care in the language of their choice.

Several participants noted that older adults often become increasingly vulnerable as they age and develop more complex health conditions, and this vulnerability can include limits in their physical and cognitive capacities to use technologies and to advocate for themselves. One participant emphasized that this vulnerability raises bigger challenges among deferential older adults: "My parents didn't question their physicians. That group of seniors don't question and don't ask.... It complicates the problem because we're coming up with technological solutions that to some seniors aren't solutions. We're trying to design a [home and community care system] for seniors who will be there 20 years from now, but what about the people who are seniors now?"



Other participants elaborated specifically on the tendency of healthcare organizations and governmental agencies to push for technological solutions and to disseminate health-related information exclusively online, which may not be adapted to the current generation of older adults (and their informal/family caregivers). As one participant said: “There was an information fair with the CCAC. I wanted information about existing programs and services, and I was told ‘*ah, there’s plenty on the computer!*’ In the evening, I have no time! Or if I have time, I’m too exhausted.” This reflected the need to proactively provide information to older adults and their informal/family caregivers, rather than simply providing greater access via online resources that must be thoroughly searched by them.

Desire for holistic care

Participants then discussed that it remains difficult to provide the holistic care that older adults and their informal/family caregivers want and need. For instance, many participants in the three panels described the difficulty of obtaining care for people with dementia. As one participant mentioned: “The CCAC doesn’t seem to have a dementia care strategy. We were offered four hours per week respite care, but my mother needed 24/7 care. We believed that the healthcare system was going to

Box 1 >> Key features of the citizen panels

The citizen panels about engaging communities in setting priorities for home and community care in northeastern Ontario had the following 11 features:

1. they addressed a high-priority issue in Ontario;
2. they provided an opportunity to discuss different features of the problem;
3. they provided an opportunity to discuss three options for addressing the problem;
4. they provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. they provided an opportunity to talk about who might do what differently;
6. they were informed by a pre-circulated, plain-language brief;
7. they involved a facilitator and co-facilitators to assist with the discussions;
8. they brought together citizens affected by the problem or by future decisions related to the problem;
9. they aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. they aimed for open and frank discussions that will preserve the anonymity of participants; and
11. they aimed to find both common ground and differences of opinions.

take care of our needs as we aged. There has to be a more honest communication about what our own personal responsibility is in our healthcare as we age. What does the system expect of us as we age? There are lots of people who can't afford what the system requires."

Participants then discussed the multiple stressors in their lives (e.g., living on a low income or in poverty, living in crowded and unsafe housing, etc.). As many participants noted, the system rarely looks at health in a holistic way, which includes looking at the social determinants of health. One participant told a story of an older adult with diabetes living in the community who couldn't afford the oil to heat her house during the winter. She was hospitalized and her foot was amputated because of severe frostbite. She was then discharged and sent back home, without proper follow-up and without addressing the root causes of the problem.

Safe and affordable housing was a recurring theme during the panel discussions. As a participant from the Aboriginal panel pointed out: "We can't provide [home and community care] without heat in the house, if there is no running water, if there is mould in the house, if you can't get through doorways with wheelchairs, or can't have another ramp on that house because it was destroyed. If you want people to live at home and receive home care, the bigger picture of housing needs to be looked at."

Increasingly complex care needs emerging at a younger age

Several participants in the Aboriginal panel expressed concerns that many people have complex care needs (and multiple chronic health conditions) at a younger age. As one participant indicated: "They might not be old chronologically, but their illnesses make them aged. The 45-55-year-olds [can] have more complex care than the 80-year-olds."

Several participants emphasized the trauma of experiencing residential schools. "Residential school survivors have had their spirits broken. They don't know how to be parents, how to hug their children, or say I love you." This may explain why the burden of chronic health conditions seems to be affecting people at a younger age in these communities.

Participants in the other two panels also emphasized that the needs of people requiring home and community care are evolving, but are rarely re-assessed. As one participant from the Francophone panel pointed out: "The CCAC does not come often to re-assess. They did not come for two and a half years [and] my husband's needs have changed since the early days. I know they are stressed and overworked, but we are the ones who suffer in the end." In the same vein, several participants expressed concerns that healthcare professionals

often have very limited time to spend with older patients, which made it impossible to address their various care needs (particularly for those with multiple chronic health conditions).

Geographic isolation

The burden of geographic isolation in many communities of northeastern Ontario was a recurring theme in all three panels. For example, one participant noted: “There are no transport routes in West Nipissing. Monitoring the elderly becomes difficult.” Participants suggested that geographic isolation led to several problems in terms of access to home and community care, and especially during transitions in care. As one participant said: “[there is a] lack of services within a reasonable distance.” A second participant went further: “In the north, no one realizes how isolated you really are here.”

Several participants pointed out that people may be transported by ambulance or air ambulance for specialized care in Sudbury, but they are then left to their own devices once they are discharged. As one participant noted: “My roommate in the hospital was flown down from Hearst. When she was released, she had to find her own way back. (...) [Providing transportation back home] is just common sense, and unfortunately there is not a lot of common sense.” Others emphasized the significant out-of-pocket expenses for those living in rural, remote and northern areas.

Participants expressed frustration with the very narrow eligibility criteria and limited scope of existing programs to address geographic isolation. For instance, to be eligible under the Northern Health Travel Grants, people must drive at least 100 km one-way to access a medical specialist or approved healthcare facility that are not available locally. However, there is a deductible of 100 kilometres on your trip. Therefore, if someone drives 102 km, the program reimburses only 2 km. One participant indicated that the lack of formal support to address geographic isolation can have serious consequences, especially for those with low incomes: “Those on low incomes [may] have to make three different trips to different cities, sometimes even have to pay dinners and hotel rooms for [informal/family] caregivers who must accompany them. [Because of that] people are often skipping appointments. We caregivers live with the illness, the financial stress, constantly worry for the other - we worry about what we will be able to put on their plates tomorrow. It’s exhausting.”

Some participants pointed out that a degree of disparity in access to, or availability of, healthcare facilities and services may be understandable given the reality of northeastern

Ontario (“we cannot be perfect everywhere” as one participant said), but that we should aim to have a least some minimum standards of services everywhere.

Other participants advocated for using the Ontario Telemedicine Network more extensively (and to actively offer the service) to deliver care to people in northeastern Ontario. “When you’re sick, travelling is no gift. Why not use the OTN [Ontario Telemedicine Network]? My husband is exhausted after a trip. We started to do that more often [using the OTN], but it was me who had to organize it.”

Cultural and linguistic diversity

The challenge of addressing cultural and linguistic diversity was a recurring theme in the panel discussions, particularly in the Aboriginal and Francophone panels.

Participants in the Aboriginal panel generally emphasized the “lack of cultural understanding of outsiders coming into the communities,” despite the slow and gradual efforts made by some organizations. As one participant said: “The healthcare system represents authority and it’s a very sterile environment. The staff doesn’t understand the culture.” This was exacerbated by a lack of cultural safety training of healthcare professionals, their lack of capacity to speak in Aboriginal languages (including the lack of interpreter services readily available), the lack of recognition of “traditional healing as an option of care,” and the lack of culturally sensitive incentives to support the uptake of prevention interventions (e.g., “if we offered chainsaws to our diabetes clinics, instead of fruit baskets, we would have more men there.”)

The role of traditional healers in home and community care was discussed at length. Several issues were raised, including the shortage of funds to bring in traditional healers, the constraints of some organizations working with a “pre-approved list of traditional healers” who are covered (thus limiting the capacity of people to choose their traditional healer), the difficulty of ensuring continuity of care since traditional “healers come and go”, and the challenge of integrating traditional healing with Western medicine. One participant observed: “Some elders are afraid to tell Western professionals that they’ve seen a traditional healer. There would be no communication between the two. They don’t tell you that they are taking traditional medicine. There has to be a system that the traditional healer is giving care on a consistent basis and there is communication between the two.”

Francophone panellists also expressed concern about the lack of linguistically sensitive care in the region. While welcoming the North East CCAC’s recent designation to work towards actively offering French services as part of their French language implementation plans,

most participants in the Francophone panel identified challenges in receiving care in French in northeastern Ontario. Participants were skeptical about the capacity and sometimes willingness of healthcare organizations in their region to offer French services: “They automatically showed me the form in English. When I asked for a French form, I was told ‘oh, we have it somewhere but will have to dig it up.’”

Francophone participants discussed at length the important consequences of not being able to access care in French. One participant remembered his sister, who was battling cancer, telling him, “what is most difficult when you’re sick is not to be able to be sick in your own language.” Several participants claimed that when seeking care for an illness, patients and their informal/family caregivers are in a vulnerable position. “When you’re sick, especially if it’s an emergency, you become more obedient towards healthcare professionals [and do not advocate for French services].” This seems to be particularly true for older adults suffering from Alzheimer’s disease and other dementias. “One would say that it is a return to childhood. He is perfectly bilingual, but his native language is French”.

A few participants also questioned the willingness of healthcare organizations to address the needs of culturally diverse population groups, and to meaningfully engage them in the organization of home and community care in the region. “Sometimes, they avoid putting a Francophone on administrative committees to avoid having to do more work, or they put them on these committees to look good, but this person should keep it shut [i.e., avoid talking].”

Fragmentation of current programs

The issue of fragmentation was a recurrent theme across all three panels. Participants generally agreed that home and community care is highly fragmented at three levels: delivery arrangements, funding arrangements and governance arrangements.

Delivery arrangements

Participants highlighted the difficulty of navigating the home and community care system, and knowing who could provide needed services. As one participant noted, it can be difficult to get information about where to go for what: “Good luck trying to navigate it.” This was exacerbated by the mosaic of providers involved in home and community care and the complexity of information communicated to the public. “The language is insufferable – medical terms and CCAC terms, it’s indecipherable.” Several participants felt that they were not adequately supported to navigate the system. “Primary-care physicians need a lot of education too because they just give you pamphlets and you’re on your own.”

The communication gap between healthcare providers and CCAC providers was also a recurrent theme, particularly when discussing the growing burden of multimorbidity. Some participants expressed a need for greater communication and continuity in care between CCAC service providers. Participants explained that they had to retell their stories each time to a new personal support worker (PSW). One Francophone participant noted in the 2.5 years she had been receiving CCAC services, she has interacted with 38 different PSWs. Many participants agreed that it brought more stress (rather than relief/respice) to accept a new stranger in their home each week.

Some participants also suggested that there might be information and communication gaps regarding community needs in the region, and that the CCAC seems to be uniquely positioned to bridge such gaps. As one participant noted: “They are the source of all information. They’re the ones that should say, *‘this is where the needs are in our community.’*” Thus, several participants urged the CCAC to take a leadership role to provide the information to appropriate parties (e.g., Ministry of Health and Long-Term Care and other healthcare organizations) so a better picture of community needs is available. Panel participants also sought reassurance that all levels of the CCAC (from front line to decision-making administrators) were communicating with each other about the needs of individuals and communities.

Funding arrangements

The issue of fragmentation was also discussed in terms of funding arrangements for home and community care. Some participants expressed concern that the funding wasn’t ‘attached’ to individual patients who had to navigate the system and receive home and community care from multiple providers. As one participant in the Francophone panel said: “We have monumental silos [that should be broken down], without creating new castles. In the education system, the solution was to attach funding to each student. The problem is

that we have patients who are at home, and the different organizations have not received the money that should go to these people.”

Governance arrangements

Turning to governance arrangements, participants suggested that sometimes the administration of home and community care is top-heavy, with numerous agencies providing support in the community, each with its own governance structure. The Aboriginal panel pointed out more specifically the complexity involved in aligning the various levels of governance to provide optimal home and community care in Aboriginal communities. One Aboriginal participant suggested that “[the system] needs to be more mindful, as First Nations communities are caught between federal and provincial funding.” Another Aboriginal participant noted that First Nations communities are always having to ask for permission from federal services to access the full range of home and community care, which causes delays and unnecessary barriers to care.

Personal support workers’ needs for support and training

The discussion then shifted to the role of personal support workers and their needs for support and training. Several participants highlighted that the lack of support was exacerbated by the lack of role recognition. “It’s so important that the infrastructure not forget about the people who are coming in to help people in their homes. They deserve some real credit. If we forget that side of it, there’s going to be a real issue because there aren’t going to be enough of them and they’re not going to be well-qualified.”

While many participants recognized that personal support workers are involved in providing a spectrum of care (and may be trained and not trained in specific forms of care), they suggested that many personal support workers are not qualified to provide care to patients with complex care needs (e.g., older adults with multimorbidity and polypharmacy, older adults with dementia, etc.). Yet, these participants noted, some organizations are running initiatives to bridge this gap, such as the Alzheimer Society, which provides training in dementia care for personal support workers who work for the society. As one participant pointed out: “There is a right way to communicate to those suffering from dementia to avoid any problem.”

Several participants were concerned about the shortage of personal support workers in the region, and many pointed out the increasing number of job openings that were never filled. They suggested that the shortage may be caused by poor working conditions and stressful work environments, which may translate into fewer qualified people joining the profession.

For some participants, the shortage of personal support workers, combined with poor care coordination, made continuity of care impossible. Several participants mentioned being exhausted by the dozens of personal support workers who could come to their home. This required the informal/family caregiver to spend a significant amount of time writing a detailed plan for the personal support workers, to make sure that they knew what needed to be done. This planning significantly increased the caregivers' level of stress.

Informal/family caregivers' need for support

The emotional, financial and physical burden of informal/family caregivers was another recurring theme during the panel discussions. Five dimensions of this challenge emerged with some consistency during the discussions: 1) caregivers may be reluctant to seek care and ask for help (e.g., being afraid that “if they ask for help, they're not living up to what's expected of them”); 2) there is a lack of access to respite care; 3) a large part of the caregivers' burden is the challenge of coordinating care provided by strangers coming into their home (e.g., as one participant said, “it's not the patient who exhausts us, it's the coordination”); 4) some caregivers may be forced into taking on tasks that are in some way inappropriate (e.g., more clinical tasks); and 5) violence is common in caregiving experiences.

On the issue of violence, which is often a neglected topic of discussion, a few participants noted that while providing unpaid care to a loved one can be a rewarding and empowering experience, it can sometimes be marked by extreme stress that results in violence or harm to others (towards caregivers, but sometimes also towards patients). Several participants pointed out that the stress – and related discomfort, frustration, burn-out and anger – and resulting violence may be exacerbated when additional care and respite support are not available to both patients and their caregivers, and by certain health conditions such as Alzheimer's disease and other dementias. One participant said that home and community care providers have a key role to play in preventing both the stress and the violence that can follow from it, as well as the premature institutionalization, negative health outcomes and higher costs that can arise when violence is noted and the root causes not addressed.



“We need systematically collected data about community needs.”

Discussing the options:

How can we address the problem?

After discussing the challenges related to planning for future home and community care needs in northeastern Ontario, participants were invited to reflect on three options (among many) for moving forward:

- 1) increasing access to highly valued services and reducing the provision of less highly valued services;
- 2) better meeting needs during transitions in care, and among Aboriginal and Francophone groups; and
- 3) better engaging patients, families and communities in the care delivery process.

Several values-related themes emerged during the discussion about these options, with three emerging with some consistency: 1) equity/fairness (e.g., striving for equity across northeastern communities and between northern and southern Ontario, recognizing that vulnerable older adults may require additional support); 2) cultural and linguistic sensitivity (making sure that care is attuned to the diverse needs of Aboriginal and Francophone groups, ensuring the cultural and linguistic competence of health-system navigators); and 3) empowerment (engaging frontline organizations, community organizations and associations, supporting self-management so that older adults and their informal/family caregivers can

play an active role in their care). We review the themes that emerged for each option in more detail below.

Option 1 – Increasing access to highly valued services and reducing the provision of less highly valued services

The discussion about the first option focused on finding ways to support the North East CCAC in identifying which home and community care services are the most important to people in northeastern Ontario, and allocating resources accordingly. This option may include (but is not limited to):

- developing a list of criteria to help guide resource-allocation decisions; and
- creating mechanisms to regularly engage community members to define priorities and make resource-allocation decisions.

Seven values-related themes emerged during the discussion that were identified as being important for guiding priority-setting and resource-allocation decisions regarding home and community care:

- attuned to patient and community needs;
- flexibility;
- equity;
- stability;
- security;
- based on evidence, including cost-effectiveness;
- cultural and linguistic sensitivity.

Box 2: Key messages about option 1

Seven values-related themes emerged during the discussion about option 1:

- attuned to patient and community needs;
- flexibility
- equity;
- stability;
- security
- based on evidence, including cost-effectiveness; and
- cultural and linguistic sensitivity.

While a few participants saw the value of creating community forums in the north, participants generally focused on two distinct approaches:

- leveraging and empowering frontline healthcare organizations, community organizations and associations that can communicate community needs to the CCAC; and
- leveraging existing data (e.g., epidemiology data) that is collected by frontline agencies in order to have a better portrait of community needs.

McMaster Health Forum

Participants generally supported the idea of developing a list of criteria to help guide resource-allocation decisions. As one participant pointed out, this could help with making difficult decisions and with moving away from historically-based resource allocation that may not be effective, and to really focus on the needs of northeastern patients and communities. “We’ve been doing something for a long time and people are used to it [and some think] we shouldn’t change it because people will be upset – [but] we need a robust discussion on what needs to be let go of.” However, several participants emphasized that such criteria must be flexible enough to accommodate the specific needs that patients and communities may have. As one participant said: “We’re different from Parry Sound, from Wiky [Wikwemikong], etc.” Other participants emphasized that patients’ needs may change rapidly, which further requires greater flexibility. Equity was another key values-related theme that emerged. Participants generally agreed that equity (across northeastern communities, but also between northern and southern Ontario) should be an important value to consider when defining priorities and making resource-allocation decisions. A few participants argued that we replace *equity* with equality in terms of northern and southern Ontario, but others pointed out that “equality is not possible because the north is very geographically broad and communities very distant from each other.”

The need for stability was also identified as an important values-related theme during the discussion. “The stability of individual care providers and agencies in relation to that client [is crucial]. Today we see a person and tomorrow it’s someone different. We need continuity, we need stability *vis-à-vis* who sees the client.”

Security was also brought to the fore during panel discussions. Some emphasize the need to provide a safe environment to patients, caregivers and care providers. Others mentioned that care providers often decline to provide important interventions that could be done at home for security reasons. One participant said: “We see cases of palliative care patients at the ER where patients are denied medication if they do not want to stay at the hospital. So, if they do not want to stay in the hospital to die, he or she must suffer for their last hours. It is not necessary to die in a hospital setting. Security is exaggerated. The patient should not be in pain if he or she wants to die at home.” A second participant pointed out the need for flexibility in how we conceive security: “We want security for our older adults, but people can live with a different definition of ‘security.’ We must come to a point where we know what works for the client.”

A few participants mentioned the need to ensure that the best available research evidence informs priority-setting and resource-allocation decisions. This would ensure that the North East CCAC invests resources in home and community care interventions that are proven to

be cost-effective. “[We need to have] people look at the research that’s already been done.... Policymakers should get together with the people who have done the research before they start implementing things.”

Cultural and linguistic sensitivity was another values-related theme that emerged during the panel discussions. Some participants emphasized the need to assess the potential impact of priority-setting and resource-allocation decisions on Aboriginal and Francophone communities before the decisions are finalized.

The discussions also addressed potential mechanisms to regularly engage community members to define priorities and make resource-allocation decisions. The Aboriginal panel emphasized the importance of in-person community engagement in the priority-setting process. Participants suggested that the mechanisms need to be tailored based on an understanding of Aboriginal culture and historical context, a perspective rooted in empathy, and an orientation that recognizes the full spectrum of service delivery (e.g., from home care to long-term care).

While a few participants saw the value of creating community forums in the north (e.g., Cochrane and Kapuskasing), participants generally focused on two distinct approaches to community engagement. Some participants emphasized the need to leverage and empower frontline healthcare organizations, community organizations and associations (e.g., Fédération des aînés et des retraités francophones de l’Ontario) to have a better understanding of community needs. As one participant said: “The CCAC should integrate itself with the frontline agencies and there should be [a]quarterly reporting system to the CCAC,” which could ensure decision-makers are aware of what is happening at the front-line and vice-versa. A second participant indicated that this should also be done at the provincial level: “We need to ensure effective communication between the Ministry of Health [and Long-Term Care] and its bodies and smaller, non-affiliated bodies at the community level.”

A second proposed approach to community engagement involved better leveraging existing data (e.g., epidemiology data and data about the broader social determinants of health) that are collected by frontline agencies, in order to have a better portrait of community needs. “We need systematically collected data about community needs.” Some members of the Aboriginal panel pointed out existing initiatives from the First Nations Information Governance Centre, which serves as the permanent home of the First Nations Regional Longitudinal Health Survey. While not directly linked to home and community care needs, this initiative could serve as an example for a comprehensive information system that collects home and community care data for the diverse communities in northeastern

Ontario. Participants indicated that this would be an invaluable information system to guide priority-setting and resource-allocation decisions.

Option 2 – Better meeting needs during transitions in care, and among Aboriginal and Francophone groups

The discussion about the second option focused on helping patients and their families as they transition from one care setting to another, and to do so while addressing their specific cultural and linguistic needs. This option aims to develop strategies to better meet the needs of patients and families during transitions in care, with a specific focus on Aboriginal and Francophone groups. This option might include (but is not limited to):

- supporting the development of health-system navigators;
- supporting the recruitment and retention of Aboriginal and Francophone healthcare professionals in the region and supporting the cultural safety education of these professionals and the staff and administration in their organizations; and
- developing a program offering culturally appropriate health education for Aboriginal and Francophone groups, continuing to regularly engage Aboriginal and Francophone community members in designing home and community care services, and supporting the implementation of (and actively offering) French language services to Francophone populations.

Three values-related themes were identified as being important for helping patients and their families as they transition from one care setting to another:

- excellent patient and family experience (to improve transitions in care, health-system leaders must fully understand the realities of northerners);
- attuned to the diversity of needs of Aboriginal and Francophone groups (health-system navigators should be culturally and linguistically competent); and
- expertise (health-system navigators must be knowledgeable).

Some participants questioned the role of the CCACs during transitions of care as presented in the evidence brief. Some participants understood (and experienced) the mandate of the CCACs more as ‘brokers’ of services aiming to connect people (‘to place people’), rather than helping them to navigate the system.

Several participants suggested that health-system leaders may not be as sensitive to, or familiar with, the reality of most northerners as they could be, particularly in the context of transitions of care. Some participants suggested implementing ‘shadowing’ interventions for health-system leaders (similar to the TV series *Undercover Boss*) to better understand the realities and practical challenges facing patients and informal/family caregivers during transitions in care. Health-system leaders could ‘shadow’ home and community care providers, as well as patients and informal/family caregivers, to learn from their experiences and adapt/improve existing programs and services (or develop new ones if necessary).

Participants generally supported the idea of bolstering health-system navigator efforts, a role that is slowly emerging in some care settings. As one participant noted: “Some folks are coming from small communities, they are oblivious to the system.” To be effective, participants suggested that health-system navigators must be familiar with the intricacies of the health system and be culturally and linguistically competent. “I

Box 3: Key messages about option 2

Three values-related themes emerged during the discussion about option 2:

- excellent patient and family experience (to improve transitions in care, health-system leaders must fully understand the realities of northerners);
- attuned to the diversity of needs of Aboriginal and Francophone groups (health-system navigators should be culturally and linguistically competent); and
- expertise (health-system navigators must be knowledgeable).

Participants suggested the implementation of ‘shadowing’ interventions for health-system leaders to better understand the realities and practical challenges facing patients and informal/family caregivers during transitions in care.

Participants generally supported the idea of bolstering health-system navigator efforts.

was around when the first [system] navigator was hired. No one knew her, she didn't speak [First Nations] language, but she was our navigator? People who make these decisions have to take this into consideration. Navigators are a good idea, but they have to be connected to people and functional.”

The deliberation then shifted to who would be best positioned to be health-system navigators. Some emphasized the need to leverage existing and retired nurses to play the role of health-system navigators since they are extremely knowledgeable and have the ability to advise, while others argued that such nurses are in short supply. Others suggested leveraging volunteers and community organizations, but some emphasized that “the health system needs real professionals to run it, not volunteers.”

Option 3 – Better engaging patients, families and communities in the care delivery process

The discussion about the third option focused on finding ways to better engage patients, families and communities in the care delivery process (and thus help to fill gaps in services). This option might include (but is not limited to):

- supporting patients to manage their own health and care (known as ‘self-management’); and
- improving communications between unpaid caregivers and healthcare organizations to better integrate them into the delivery of care of their loved ones.

Six values-related themes were identified as being important for better engaging patients, families and communities in the care delivery process:

- autonomy (self-management can support older adults and their informal/family caregivers to stay active and healthy at home and in the community for as long as possible);
- empowerment (self-management can support older adults and their informal/family caregivers to play an active role in their care);
- privacy (may constitute a barrier to engaging informal/family caregivers);
- fairness (vulnerable older adults may require additional support);
- partnership (self-management should rely on a true partnership between patients, informal/family caregivers and healthcare professionals); and
- trust and mutual respect (a pre-requisite to engaging patients, families and communities).

Participants initially discussed the positive impacts that self-management interventions could have on older adults and their informal/family caregivers, including increasing their autonomy and empowering them to play an active role in their care (which are the first two values in the above list). As one participant said: “When someone gets sick, he/she loses control over their personal life. [Self-management] is based on a weekly action. Each week, we create an action plan and work to achieve it. It’s a little thing that helps a lot.” Ultimately, self-management interventions could help to break down stereotypes and change public attitudes towards older adults. “It could tackle ageism and give a meaningful role to older adults.”

Despite the potential benefits of self-management, several participants pointed out that it was challenging to engage patients, families, and communities in the delivery of care. Some participants emphasized that many older adults cherish their privacy (the third theme in the list) and are often reluctant to share information regarding their health conditions with informal/family caregivers. In other circumstances, healthcare professionals refuse to include informal/family caregivers in the conversation for privacy reasons. “The CCAC often does not consult caregivers, and patients often do not have the capacity to make decisions, or prefer to hide their need from the CCAC.” Privacy was thus perceived as a serious obstacle to

Box 4: Key messages about option 3

Six values-related themes emerged during the discussion about option 3:

- autonomy (self-management can support older adults and their informal/family caregivers to stay active and healthy at home and in the community for as long as possible);
- empowerment (self-management can support older adults and their informal/family caregivers to play an active role in their care);
- privacy (may constitute a barrier to engaging informal/family caregivers);
- fairness (vulnerable older adults may require additional support);
- partnership (self-management should rely on a true partnership between patients, informal/family caregivers and healthcare professionals); and
- trust and mutual respect (a pre-requisite to engaging patients, families and communities).

Despite the potential benefits of self-management, several participants pointed out that it was challenging to engage patients, families, and communities in the delivery of care (e.g., privacy concerns, personal and environmental conditions that are not favourable, and need for trust and mutual respect between all care partners).

the optimal delivery of home and community care. As one participant said: “Sometimes, ill people do not understand what is going on and the caretaker is a better resource for information.” A second participant said: “My father insisted on going into the doctor’s [office] alone. My family doesn’t know how sick he is – this creates a burden. There needs to be a special type of consent so the caretakers have information too.” Participants generally agreed that it was essential that informal/family caregivers be fully engaged, but some worried about relying on potentially ineffective and legally cumbersome mechanisms to formalize this relationship (e.g., the Power of Attorney for Personal Care).

A few participants suggested that fairness may mean that vulnerable older adults be given additional support. These participants expressed concern that self-management may only be viable for certain patients. As one participant said, self-management depends on personal and environmental conditions: “It can be useful, but in some situations, where people don’t have support or resources, case management is needed before self-management can be considered.” Those with limited literacy skills, and those who may be unable to advocate for themselves, may require additional support.

Several participants expressed interest in interventions that would establish effective and meaningful partnerships between patients, informal/family caregivers, and healthcare professionals (the fifth theme in the list). All these actors should be active partners, or ‘part of the same team.’ However, some participants noted that trust and mutual respect (the sixth theme), which they considered to be pre-conditions for such partnerships, are often lacking or difficult to achieve. One participant from the Aboriginal panel emphasized the need to establish cultural awareness training so that healthcare professionals are equipped to promote and support self-management: “The people don’t show that they’re engaged in their health, because their spirit is broken. They don’t show the emotions that they want to be involved in self-management. But it’s because their spirit is broken. It’s very hard to gain their trust because they’re so broken. Providers that are not of First Nations’ descent, they don’t understand that. Cultural-awareness training is so important. Providers have to understand that in their approach to self-management.”



“Every community will know what works best for them.”

Discussing the implementation considerations:

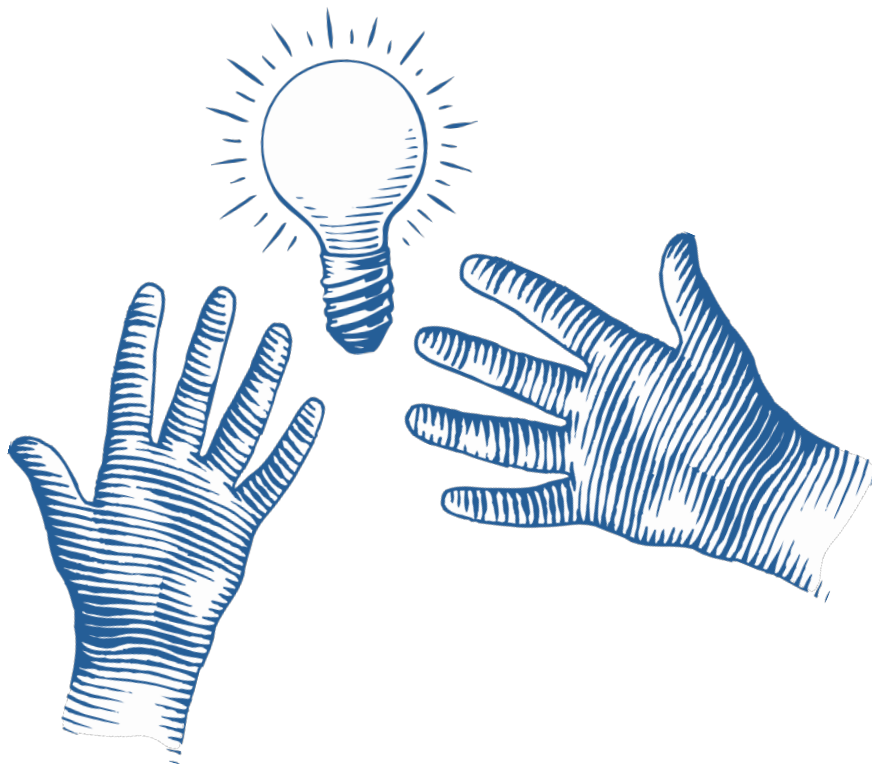
What are the potential barriers and facilitators to implementing these options?

After discussing the three options (among potentially many) for improving home and community care in northeastern Ontario, participants examined potential barriers and facilitators to moving forward.

Participants generally perceived three sets of challenges to moving forward: 1) the specific needs of northerners do not seem to be a priority for provincial and federal governments; 2) organizations and their boards appear to operate in silos; and 3) fragmentation in the health system limits capacity for care coordination, information sharing and intersectoral collaboration. A few participants emphasized that provincial and federal governments do not seem to prioritize the specific needs of northerners, which may be exacerbated by a lack of understanding of their realities. As one participant said: “We are an afterthought [in the north].” Several participants also perceived the home and community care system as characterized by multiple siloed administrative bodies, each with its own board and governance structure. Related to this, a few participants suggested that fragmentation in the health system is a barrier to effective care coordination for patients and informal/family caregivers, information sharing across providers (but also between providers and patients),

and to intersectoral collaboration to address the full scope of social determinants of health (e.g., income, housing, food security, etc.). Several participants emphasized that it is essential to have a holistic approach to ensure that older adults can be healthy and live at home and in the community for as long as possible. One participant summarized the importance of such a holistic approach in this way: “[We need to] build a system that’s well connected and integrated so issues in other areas like criminal justice, child services, etc. can be addressed so that the health system isn’t burdened in the end.”

Participants then turned to the factors that could facilitate efforts to improve home and community care in northeastern Ontario. They encouraged health-system leaders and stakeholders to be innovative and creative. But to achieve this, participants suggested that it is essential to engage communities as active partners and to ensure that solutions are aligned with their values, needs and preferences. As one participant said: “Every community will know what works best for them.... Come to these communities to see the suffering with your own eyes. Then be creative to find ways to fix it.” Participants also proposed key strategies to bring about change in home and community care in the region. Some of these strategies target patients and informal/family caregivers, while others target healthcare providers, healthcare organizations or the health system more broadly (see Box 5). Such strategies could guide the efforts of health-system leaders and stakeholders to meet future home and community care needs in northeastern Ontario.



Box 5: Specific strategies to bring about change

Patient/caregiver-targeted strategies

- Information and education provision to support self-management
- Personal support interventions, with a focus on increasing access to respite care for informal/family caregivers and implementing violence-prevention interventions
- Interventions to facilitate communication and decision-making, with a focus on interventions to alleviate the burden of care coordination currently placed on the shoulders of informal/family caregivers
- Health-system navigation efforts (that are culturally and linguistically sensitive) to support patients and caregivers

Provider-targeted strategies

- Educational interventions to enhance the cultural-safety skills and competence of healthcare providers
- Educational interventions for personal support workers to enhance their skills and competence in caring for patients with complex care needs (e.g., Alzheimer's and other dementias, multimorbidity and polypharmacy)

Organization/system-targeted strategies

- Developing a comprehensive strategy to support informal/family caregivers, including a full review of current financial assistance plans to support those who are geographically isolated (e.g., Northern Health Travel Grants)
- Supporting organizations to ensure that they are fully equipped to actively offer services that are culturally and linguistically sensitive (e.g., interpreter services and forms readily available in the patient's or caregiver's language)
- Reviewing current arrangements to ensure that funding is attached to individual patients (i.e., the funding 'travels' with them)
- Implementing 'shadowing' interventions to allow health-system leaders to better understand the realities and practical challenges facing patients and informal/family caregivers during transitions in care
- Creating mechanisms to regularly assess and monitor community needs (e.g., community forums, mechanisms to engage with frontline organizations, and a comprehensive information system to collect data about community needs)
- Investing in efforts to develop a strategy to promote a holistic vision of home and community care and to develop intersectoral actions supporting such a vision

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Conflict of interest

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