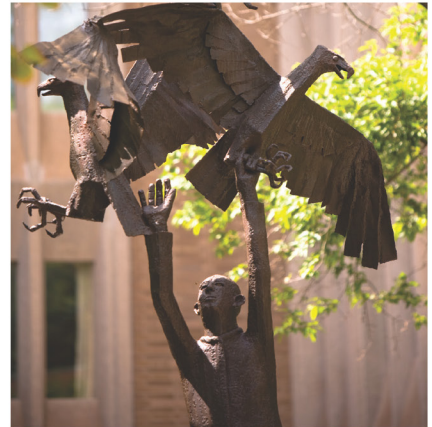




## CITIZEN BRIEF



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



18-19-20 AUGUST 2015



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 brief

This brief was produced by the McMaster Health Forum and the Centre for Rural and Northern Health Research (CRaNHR) to serve as the basis for discussions by three citizen panels about engaging communities in setting priorities for home and community care in northeastern Ontario. This brief includes information on this topic, including what is known about:

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

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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# Key Messages

## **What's the problem?**

Planning for the future home and community care needs of older adults in northeastern Ontario is challenging because:

- the needs of older adults vary widely, especially with a growing number living with multiple chronic health conditions;
- delivering home and community care in northeastern Ontario is challenging (e.g., vast rural/remote/northern communities, shortage of health workforce; the need to provide care that meet the needs of culturally- and linguistically-diverse populations); and
- planning for and implementing the home and community care we need takes time, resources and commitment from many organizations.

## **What do we know about three options for addressing the problem?**

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

- The top 10 criteria that are generally used by policymakers to guide resource allocation decisions in the health sector are: equity/fairness; effectiveness; cost-effectiveness; stakeholder interests and pressures; strength of evidence; safety; mission and mandate of health system; organizational capacity; patient-family reported outcomes; and need.
- There is a lack of research evidence to determine which public-engagement mechanisms are the most effective and how public views might be integrated with other factors when making resource-allocation decisions.

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

- Cultural safety education for healthcare professionals and culturally appropriate health education for patients have been found to be effective at meeting patient needs.
- There is a lack of evidence about the effectiveness of interventions to improve cultural safety skills in healthcare for Aboriginal populations (e.g., educating and training healthcare professionals, developing culturally specific health programs, and recruiting an Aboriginal healthcare workforce), but they seem promising.

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

- Providing patient education, family-oriented interventions, home telehealth and e- health/information technology have been found to improve patient and caregiver knowledge and health outcomes.

## **What implementation considerations need to be kept in mind?**

- Barriers to implementing these options might include the difficulty for patients and individuals in rural/remote/northern communities to have their voice heard, as well as the shortage of healthcare workforce.
- Facilitators to implementing these options might include recent efforts by the provincial government and regional actors who are committed to advancing the transformation of the home and community care system, and the desire of patients to play a more active role in their own care.



There is a need to spark a public conversation about the home and community care needs in northeastern Ontario.

## **The context:** Why is planning for the future home and community care needs in northeastern Ontario a high priority?

>> Helping older adults to be healthy and live at home and in the community for as long as possible is a top priority for the health system.

The need to plan for the future home and community care needs of older adults has attracted a lot of attention, in part because:

- **we have an aging population** (in the next two decades, the number of Ontarians aged 65 or older is expected to double, those 85 and older to quadruple, and those 100 and older to triple);(16)
- **older adults want to live in their homes and in their communities for as long as possible** (a recent survey indicated that 63% of Canadians selected home and community care for older adults as a top priority);(17)



- **older adults increasingly have complex care needs** (it is estimated that 43% of adults over the age of 65 have two or more chronic health conditions);(18) and
- **there are growing calls to transform the health system to ensure that people receive the right care, at the right time and at the right place** (the Ontario Ministry of Health and Long Term Care's Patients First: Action Plan for Health Care includes priorities for improving patient experience and ensuring a system that is patient- and family-centred).(8)

While these issues are present across Ontario, the North East region faces some important challenges of its own. This vast geographic region is home to more than 565,000 people spread across an estimated 400,000 km<sup>2</sup>. The region is culturally and linguistically diverse with a large number of Francophones (23% of the population) and Aboriginal Peoples (10% of the population). Those aged 65 or older comprise 18% of the population, compared to the lower provincial average of 14.6%. All these factors contribute to very specific challenges for planning for home and community care services in the region (see Box 1 below for a brief description of the system in the region).

This brief was prepared to support the discussion by a series of citizen panels about setting priorities for home and community care in northeastern Ontario. The input from the citizen panels will help to inform the 2016-2019 strategic plan of the North East Community Care Access Centre (the organization that connects people with the care they need, at home and in their communities).

## Glossary

### Aboriginal Peoples

The first inhabitants of Canada, which include First Nations, Inuit and Métis peoples.

### Chronic health condition

A health problem requiring ongoing management over a period of years or decades (e.g., asthma, cancer, depression, diabetes and heart disease).(2)

### Home and community care

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.”(9) Home and community care is delivered by various healthcare organizations (e.g., community support services), professionals (e.g., nurses, social workers, dietitians), personal support workers, and unpaid caregivers (e.g., family members, friends and volunteers).

### Remote communities

Communities without year-round road access, or which rely on a third party (e.g., train, ferry, airplane) for transportation to a larger centre.(11)

### Rural communities

Communities with a population of less than 30,000 that are more than 30 minutes away in travel time from communities with more than 30,000 people.(11)

### Unpaid caregiver

An individual who is providing unpaid and ongoing care or social support to a family member, neighbour or friend who is in need due to physical, cognitive or mental health conditions.(14)

### **Box 1 >> Health system in northeastern Ontario**

- Medical care provided in hospitals and by physicians is fully covered by Ontario's publicly funded health system.
- The federal government has responsibility for delivery of health services for Aboriginal people on reserves, and the provincial government provides additional services.
- Care and support provided by other healthcare professionals such as nurses, physiotherapists, occupational therapists, personal support workers, and dietitians are typically not covered by the health system unless provided in a hospital or long-term care setting, or in the community through the Community Care Access Centre, Community Health Centres, Family Health Teams, Nurse Practitioner-Led Clinics, and other designated clinics.
- Other healthcare and community services such as prescription drug coverage, community support services, and long-term care homes receive partial public coverage in Ontario, which requires citizens to pay for the uncovered portion on their own or through private insurance.
- One Local Health Integration Network (LHIN) has responsibility for the planning and funding of healthcare in the region, and for ensuring that the different parts of the health system in the region work together.
  - The North East LHIN works with le Réseau du mieux-être francophone du Nord de l'Ontario, a planning entity providing advice on how to engage the Francophone population and on the planning and implementation of services in French.
  - The North East LHIN established a Local Aboriginal Health Committee that meets on a regular basis and advises on the health planning priorities in general within Aboriginal/First Nation/Métis communities.
    - 75 Aboriginal health partners are involved in the planning and delivery of care to the region's Aboriginal population.
- One Community Care Access Centre (CCAC) has responsibility for connecting people with the care they need at home and in their communities.
- 69 not-for-profit community support services (CSS) agencies funded by the North East LHIN provide services to support community-dwelling people in the region (most of which are older adults). Assistance provided includes personal support (e.g., for household tasks), assisted living, Meals on Wheels, transportation, and respite and adult day programs.(12)
- Six Health Links (Algoma East, Greater Sudbury, North Cochrane, Sault Ste. Marie, Temiskaming and Timmins) mobilize the delivery of integrated care for those with complex needs within their communities.





People who have multiple chronic health conditions have complex care needs that are difficult to meet in a coordinated way, especially in rural, remote and northern settings.

## **The problem:** Why is planning for the future home and community care needs in northeastern Ontario challenging?

>> Planning for the future home and community care needs in the region is challenging because many factors affecting patients and families, healthcare providers and the health system must be considered.

In this section, we highlight some factors that contribute to the problem and that require careful consideration.

## A new generation of older adults

Future home and community care for older adults will need to take into account that, in general, older adults (and their informal/family caregivers):

- are more comfortable with technology;
- have different expectations for the health system (i.e., they expect a system that engages them actively in their own care, but also engages them in planning home and community care services to meet their needs); and
- are increasingly expecting culturally-sensitive care (i.e., care that can be adapted to their values, beliefs and preferences) in the official language of their choice.(19)

These new realities pose challenges and opportunities for how to adapt our existing system. For example, progress towards implementing technology in the healthcare system has been slow.(20) Expectations among older adults for a system that prioritizes home and community care,(17) and that emphasizes flexibility and choice will also require significant changes (namely, a move away from care being provided in hospitals and long-term care homes).

Lastly, barriers to care due to cultural and language differences can occur if home and community care is not culturally sensitive. First Nations, urban Aboriginal and Métis populations are growing and now account for approximately 10% of the population of the North East region.(21) As for Francophones, they comprise approximately 23% of the total population in the region.(22) This situation raises the question of how to deliver culturally sensitive care to address the specific needs of these populations. This is particularly important since cultural and linguistic barriers may limit access to needed care, but also may lead to isolation, dependency and poverty.(17;23)

## A growing number of older adults with multiple chronic health conditions

Chronic health conditions are a significant and growing challenge in the province. In 2009, it was estimated that 24% of Ontarians had two or more chronic health conditions, which represents a 40% increase since 2003.(24) The most common chronic health conditions in the province are osteoarthritis and other arthritis, hypertension, asthma, depression, diabetes and cancer.(24) Other health conditions, like dementia, can also have an important impact on future home and community care in the region. Dementia is a serious condition that is estimated to rise substantially with the aging population. It is estimated that 35% of people over the age of 85 have dementia, and there are strong risk factors for dementia in the region.(25)

People living with multiple chronic health conditions are more likely to experience the following consequences:

- disabilities;
- poor quality of life;
- greater social isolation;
- high healthcare utilization;
- high out-of-pocket costs; and
- increased patient and family burden.(26)

This situation has a significant impact on the health system as well, since those with multiple chronic health conditions are high users of healthcare services. It is estimated that two out of every three dollars spent on healthcare goes to those living with multiple chronic health conditions.(27) A Canadian study also estimated that patients with three or more chronic health conditions (while representing only 4% of the Canadian population) use 9-10% of family physician and specialist consultations, 16% of nurse consultations, and 23% of overnight stays in hospitals.(28)

Many groups are particularly affected by the burden of chronic health conditions.

- **Older adults:** 43% of Ontarians over the age of 65 are living with two or more chronic health conditions, and the risks grow steadily with age.(26;28)
- **Women:** 14% of Canadian women have two or more chronic health conditions as compared to 11% of men (across all age groups).(28)
- **Vulnerable populations:** The problem is particularly affecting the most vulnerable in our society (e.g., people with limited education, low incomes and/or socially and geographically isolated).(28) Residents of rural, remote and northern communities often experience poorer health, greater poverty and higher mortality rates than urban populations.(29;30) The poorest Canadians are almost three times as likely as the highest-income Canadians to have multiple chronic health conditions.(28)
- **Aboriginal Peoples:** Aboriginal Peoples are greatly affected by the burden of chronic health conditions and often at a younger age than non-Aboriginal populations. In Aboriginal communities, it is estimated that 45% of people over the age of 65 report fair/poor health, and 69% have activity limitations.(31) Aboriginal Peoples consistently score lower on measures of health and well-being, and experience rates of lower life expectancy and higher mortality than non-Aboriginal populations. These poorer health outcomes stem from a unique set of inter-related factors, including: the fact that a high proportion of Aboriginal Peoples live in rural, remote and northern communities, which can exacerbate their vulnerability; inequitable access to adequate income, education and

health care; and a colonial relationship with the government that has resulted in historical trauma and disruptions to Aboriginal lifeways.(32)

- **Francophone minorities:** Some recent studies have also demonstrated several health disparities between Canada's Francophone minorities and Anglophone majority populations (i.e. those residing outside of Québec).(33-35) Francophone minorities experience higher rates of obesity,(36) have a more inactive lifestyle, make unhealthy dietary choices, and have poorer self-rated mental health.(37-39) Furthermore, Francophone minorities across Canada tend to be older, with lower education levels, more likely to be unemployed, and more likely to live in a rural area. All these factors may exacerbate a sense of vulnerability and increase the risk of developing chronic health conditions.

## Current programs and services can lack coordination, and may not completely meet the needs and preferences of older adults in rural, remote and northern settings

Coordinating the range of home and community care needed by older adults is challenging. This challenge can be exacerbated by various factors, including: it is difficult to deliver coordinated care to people with multiple chronic health conditions; the region is characterized by vast rural/remote/northern communities; there is a lack of healthcare workforce in the region; and it is difficult to deliver care that meets the needs of culturally and linguistically diverse populations. These challenges are further explored below.

### *Providing coordinated care to people with multiple chronic health conditions*

This is particularly difficult for those living with multiple chronic health conditions who often require care from many providers in different settings, resulting in care that is fragmented.(40) For instance, a patient with diabetes, arthritis and dementia may need to seek care from a different doctor for each condition, in addition to a primary care professional who could coordinate their overall care. These various healthcare professionals may be in different settings and may not effectively communicate with each other.(41;42) The same patient also likely requires care provided in their home, help with transportation to and from appointments, perhaps help with preparing meals, as well as help with maintaining their home. The patient may also benefit from other community supports like community day programs and Meals on Wheels. While many of these supports may be available within a community, they are not always provided in a coordinated way, resulting in gaps between what is needed and provided.

*A shortage of healthcare professionals*

The North East region is very large, stretching over 400,000 km<sup>2</sup>. The distance between communities and the uneven distribution of the North East population have significant impacts on the availability and delivery of home and community care services. Many communities in the North East region are facing a shortage of healthcare professionals (e.g., physicians, specialists, dietitians, physiotherapists and more), and some communities do not even have primary-care providers. For example, in Moosonee (a town approximately 19 kilometres south of James Bay), the care coordinator at the Community Care Access Centre completes the care plan with a patient, but also carries out the care plan. The care coordinator must provide direct front-line care, as there is no other professional to deliver care.

This shortage of healthcare workforce, particularly in remote communities, results in sporadic and inconsistent care, long wait times, and a lack of services to follow up with patients in their home or in the community.<sup>(43)</sup> In addition, the healthcare workforce (e.g., physicians, nurses and others) often remain in these communities for only a brief period of time, which has a negative effect on the continuity and quality of care for patients. Thus, patients and families in the region often have to settle for less than those living in an urban community as there just are not enough healthcare professionals to meet their home and community care needs.

Another related challenge is the lack of financial and practical support, as well as a lack of training for certain types of healthcare professionals in the North East region. This issue seems particularly salient for personal support workers who provide a great deal of home and community care services (including care such as changing wound dressings and administering medication, and practical support such as bathing, preparing meals and other housework). This situation may lead to poor and sometimes unsafe working conditions for these healthcare professionals.

For healthcare needs that cannot be met within their community, residents must travel – in some cases long distances – to receive necessary care. However, many residents in northeastern Ontario are geographically isolated. For example, car travel may not be possible within the North East Community Care Access Centre are because the provincial highway system does not extend above the 50<sup>th</sup> parallel. In addition, the vast majority of the North East region has no municipal infrastructure to support residents, such as public transit. The limited availability of appropriate transportation in some communities, poor roads, and inclement weather conditions may worsen this challenge.<sup>(11)</sup> Families are often forced to place their older family members prematurely into a long-term care facility, outside of their communities, as the care is just not available locally.

*Providing coordinated care that meets the needs of culturally and linguistically diverse populations*

Northeastern Ontario is culturally and linguistically diverse with large Aboriginal and Francophone populations. The challenges of delivering home and community care to Aboriginal populations are exacerbated by several factors. First, Aboriginal healthcare occurs across federal, provincial and First Nations jurisdictions. Aboriginal Health Access Centres and Friendship Centres all provide services to older Aboriginal adults. Providing home and community care services to Aboriginal Peoples requires increased administrative efforts to align policies and necessitates significant interactions with federally mandated care providers. Since multiple policy levels and organizations may be considered providers of home and community care in Aboriginal communities, there is a perception that some organizations (including the CCAC) may have considered the duplication of service as a rationale for not engaging Aboriginal communities.

Second, there is a lack of expertise to deliver home and community care in Aboriginal communities. It has been argued that there is a lack of dedicated Aboriginal expertise and policy input at the level of the CCAC in terms of need, engagement and service provision. In addition, those providing front-line care are often perceived as having little to no training in Aboriginal values, culture or tradition. This can create communication problems and misunderstandings among Aboriginal Peoples toward home and community care providers. There is a need for relationship building between the North East CCAC and various Aboriginal healthcare organizations.

Third, there is also a lack of specific services that are culturally sensitive, trauma-based and dedicated to Aboriginal values. There is a need for recognition of emotional trauma in older adults from Aboriginal communities. These older adults need to be able to tell their stories (e.g., the trauma of experiencing residential schools) as a first step toward improved self-care.

There are also challenges in delivering culturally and linguistically sensitive care in Francophone communities. The French Language Services Act mandates that all government-funded services in northeastern Ontario be provided in both official languages. Providing home and community care in both official languages may lead to better quality of care and better communication, especially with an older population that is more at ease in their first language. It may also lead to care that is more patient and family-centred. However, the recruitment and retention of skilled bilingual healthcare professionals across the region has proven to be challenging. In a context where older adults often have multiple chronic health conditions and require care from multiple providers, the Francophone population often lacks continuity of care in French.



## Unpaid caregivers need support

Unpaid caregivers are extremely important in home and community care. In 2012, it was estimated that 8.1 million Canadians provided care to a family member or friend with a long-term health condition (most commonly cancer) or aging-related needs.(44) As a report from the Canadian Medical Association pointed out: “Much of the burden of continuing care falls on [unpaid] caregivers. More than one million employed people aged 45-64 provide informal care to seniors with long-term conditions or disabilities and 80% of home care to seniors is provided by [unpaid] caregivers [in Canada].”(45)

The many roles that unpaid caregivers play are crucial and include any or all of the following:(46)

- providing emotional support;
- accompanying patients to medical appointments;
- reporting or managing side effects;
- giving medicines;
- keeping track of medicines, test results and papers;
- providing physical care (e.g., feeding, dressing and bathing);
- coordinating care;
- keeping family and friends informed; and
- making legal and financial arrangements.

Despite their crucial roles in supporting the health of older adults, practical, social, emotional, informational and financial support for unpaid caregivers is lacking or inconsistently available across the province.(47) This lack of support can have a negative impact on the physical and mental health of unpaid caregivers, on their personal and professional lives, as well as on the quality of care that they provide.(48)

## The financial burden for the health system, patients and their caregivers can be high

An aging population will result in more people living with chronic conditions, which is very expensive for taxpayers. Analyses of high-needs users of the health system in Ontario (which means those with the highest healthcare spending but not necessarily with multiple chronic health conditions) have found that:

- 1% of the population accounts for 33% of healthcare costs;
- 5% accounts for 66% of healthcare costs;(27) and

- the estimated burden of chronic health conditions in Ontario amounts to just over 55% of total direct and indirect healthcare costs, and this is expected to rise.(49)

Therefore, it is increasingly important to find better ways to provide the care needed for those who have complex needs.

There is also significant financial burden for patients and their unpaid caregivers. Many often have to pay for additional home and community supports that are needed beyond what the North East Community Care Access Centre and local community support services can provide, such as rehabilitation therapy, nursing care, other types of home care, and transportation to medical appointments. Some turn to private insurance to pay for these services, but 20-30% of citizens do not have supplemental or employer insurance.(19) Also, low-income older adults spend close to 60% of their income on housing and food, resulting in many not being able to pay for transportation or needed home and community care. These findings are likely a key reason that a poll conducted by the Canadian Medical Association found that two-thirds of Canadians reported that they could not afford home or institutional care.(17)

## Planning for and implementing the home and community care system we will need takes time, resources and commitment from many players

There have been some promising steps taken by several organizations and governments at all levels to meet the future home and community care needs in the North East region and in the province. However, efforts of this kind take time, resources and commitment from many players to bring about change. Box 2 provides a list of a few recent initiatives.



## **Box 2 >> A few recent initiatives**

### ***Provincial initiatives***

- The provincial government released various reports and strategies in recent years to strengthen home and community care both for the general population and specifically for older adults. The most recent are:
  - Bringing Care Home: Report of the Expert Group on Home and Community Care;(3)
  - Patients First: Action Plan for Health Care; (8) and
  - Patients First: A Roadmap to Strengthen Home and Community Care.(10)
- Behavioural Supports Ontario – an initiative to enhance the healthcare services of older adults across Ontario, their families and caregivers, who live and cope with dementia, mental illness, and addictions.

### ***Regional initiatives***

- The North East LHIN's Integrated Health Service Plan, 2013-2016 highlights several key priorities, including aging at home, 'home first', and targeting the needs of culturally diverse population groups.
- The North East LHIN commissioned in 2014 an analysis of the North East Community Care Access Centre to ensure it is able to meet the current and future needs at home or in community, while remaining financially sustainable.
- Six Health Links (Algoma East, Greater Sudbury, North Cochrane, Sault Ste. Marie, Temiskaming and Timmins) have been launched in the region to mobilize the delivery of integrated care for those with complex needs.(13) Health Links are also designed to support local patient-care networks that are led by a coordinating partner, and to coordinate and optimize access to needed services.
- Home and community supports provided by CCAC and CSS agencies are moving to a model of collaborative care coordination based on a client's level of need.(15)
- The North East CCAC recently launched an innovative technological project (the Telehomecare Program) allowing clients with chronic obstructive pulmonary disease (COPD) and congestive heart failure to have symptoms monitored remotely.
- Other new services that are delivered by the North East CCAC are mental health and addiction nursing, rapid response nursing, palliative nurse practitioners, physiotherapy reform, and coordination of assisted living and adult day care.
- The North East CCAC has created [NorthEasthealthline.ca](http://NorthEasthealthline.ca), with the support of the North East LHIN, a website to help people find home and community care services they need close to home.
- The North Shore Tribal Council has developed a promising model for First Nations' home and community care that crosses federal and provincial jurisdictions.



We have selected three options (among many) for which we are seeking public input.

## **Options:** How can we address the problem?

>> To promote discussion about the pros and cons of potential solutions, we have selected three options for meeting the future home and community care needs in northeastern Ontario

Many options could be selected as a starting point for discussion. We have selected three options (among many) for which we are seeking public input:

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.

The three options do not have to be considered separately. They could be pursued together or in sequence. New options could also emerge during the discussions.

In the following sections, we examine what is known about the pros and cons for each option, by summarizing the findings of systematic reviews of the research literature. A systematic review is a summary of all the studies addressing a clearly formulated question. The authors use systematic and explicit methods to identify, select and evaluate the quality of the studies, and to summarize the findings from the included studies.

Not all systematic reviews are of high quality. We present the findings from systematic reviews along with an appraisal of the quality of each review.

- High-quality reviews: conclusions drawn from these reviews can be applied with a high degree of confidence.
- Medium-quality reviews: conclusions drawn from these reviews can be applied with a medium degree of confidence.
- Low-quality reviews: conclusions drawn from these reviews can be applied with a low degree of confidence.

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

The North East LHIN has recently completed a comprehensive survey of what Northerners want when it comes to home and community care.<sup>(50)</sup> The results were very clear: people want more access to services. The North East CCAC runs a large number of home and community care services. In a context of scarce resources, increasing access to one type of service may require reducing access to another type of service. Thus, very difficult decisions must be made.

This first option aims to identify which home and community care services are the most important to people in northeastern Ontario, and to allocate resources accordingly. This option may include:

- 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.

We found a recent and medium-quality systematic review examining criteria often used to guide resource allocation decisions in the health sector.<sup>(51)</sup> The top 10 most frequently mentioned criteria were:

- **equity/fairness** (e.g., what will be the impact of these decisions on equity of access to home and community care?);

- **effectiveness** (e.g., what do we know about the effectiveness of these home and community care services?);
- **cost-effectiveness** (e.g., what are the relative costs and effects of these services?);
- **stakeholder interests and pressures** (e.g., are there any groups advocating for certain services?);
- **strength of evidence** (e.g., are the decisions based on robust research evidence?);
- **safety** (e.g., are these services safe?);
- **mission and mandate of health system** (e.g., are these services aligned with the mandate of the health system?);
- **organizational requirements and capacity** (e.g., does the health system have the capacity to implement these services?);
- **patient-family reported outcomes** (e.g., what do we know from patients and families about the effects of these services?); and
- **need** (e.g., do these services meet the needs of our patients, families and communities?).

We also found an older and medium-quality systematic review examining how members of the public can be involved in defining priorities in the health sector.<sup>(52)</sup> The review reveals that policymakers increasingly recognize the benefits of consulting the public using various mechanisms. Traditional mechanisms to consult the public continue to predominate (e.g., publicity in newspapers, hotlines/1-800 numbers, focus groups, public hearings, town-hall meetings). However, there is a growing interest in more deliberative approaches to engage the public in a dialogue to explore the different facets of the problem and find solutions together (i.e., citizen panels and juries, consensus conferences). There is a lack of research evidence to determine which public-engagement mechanisms are the most effective. In addition, it is unclear how public views might be integrated with other decision inputs when making resource-allocation decisions.



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

An important role played by the Community Care Access Centres (CCACs) is helping patients and their families as they transition from one care setting to another (e.g., from home to hospital, from hospital to home, from home or hospital to long term care, from home to palliative hospice). The CCACs also provides help those in home to transition on to other community services such as assisted living, meals on wheels, transportation programs, and Alzheimers society services. Given that transitions are among the most difficult journeys to manage within the health system, it is important to find ways to better meet the needs of patients and families through these difficult times. This may be particularly challenging to support patients and families with 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:

- 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 and active offer of French language services to Francophone populations.

One way to improve transitions in care could be to introduce ‘health system navigators’ (also known as ‘transition coaches’). A health system navigator is a person who helps patients and families to access services, guides them through the health system, and helps them overcome barriers they may face. Many people could play this role, including healthcare professionals, trained volunteers or peers (e.g., people from the same culture or community). Navigation programs can also be delivered online. Health system navigators have knowledge about local services and the broader health system. They also have the capacity to adapt to the changing (and complex) needs of patients and families. They provide constant guidance to patients and families independently of the location of care. Health system navigation programs have often focused on people with cancer. However, a few recent programs have been established to support specific underserved populations or cultural groups.(53)

We found a recent and medium-quality review that examined navigator models relevant for older adults who must manage chronic health conditions. The authors found benefits for integrated and coordinated care guided by a navigator, using a variety of interventions such as care plans and treatment goals. A care plan is an agreement between you and your healthcare providers to help you manage your health on a day-to-day basis, with clear and achievable goals. The authors also found that health system navigators could improve satisfaction for both patients and healthcare providers, as well as improve the patients' quality-of-life and functionality.(54)

It is also important to ensure that transitions in care reflect the cultural and linguistic needs of patients and families. Developing culturally safe care for older adults can occur through training healthcare professionals and changing organizational environments to ensure that they can provide appropriate care to patients with diverse values and beliefs, as well as different cultural and language needs. Approaches to teach cultural safety can range from very simple 'culture-facts' with do's and don'ts to increasing cultural self-awareness and intercultural communication skills. Cultural safety training is aimed at more system-level interventions to adapt care processes to the needs of different communities.

## Glossary

### Cultural safety education

Education to develop the skills of healthcare professionals in order to help them communicate with a patient in that patient's social political, linguistic, economic and spiritual realm.(7)

### Self-management

"An individual's ability to manage the symptoms, treatment, physical, psychosocial, and lifestyle changes inherent in living with a chronic condition."(1) It empowers patients and prepares them to manage their health and healthcare.(4-6) It is sometimes referred to as 'self-care.'

We found two recent and high-quality systematic reviews examining the effectiveness of cultural safety education for healthcare professionals. The first review showed some support for cultural safety education for health professionals. These findings are tentative however, as the quality of the evidence was low and more research evidence is needed. In addition, there was no clear consensus on the core components of educational programs to teach cultural safety skills.(55)

The second review examines the effectiveness of interventions to improve cultural competency in healthcare for Aboriginal populations in Canada and other countries (i.e., Australia, New Zealand and the United States). The review identified different types of interventions such as educating and training healthcare professionals, developing culturally specific health programs, and recruiting an Aboriginal healthcare workforce. Overall, there was a lack of evidence about the effectiveness of

such interventions. However, such interventions seem promising to improve healthcare professionals' confidence, as well as patients' satisfaction with and access to healthcare.(56)

We also found a recent and high-quality systematic review examining the effectiveness of culturally appropriate health education for people in ethnic minorities with Type 2 diabetes. The review revealed that culturally appropriate health education has short- to medium-term effects on glycemic control and on knowledge of diabetes and healthy lifestyles.(57)

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

This option aims to better engage patients, families and communities in the care delivery process (and thus help to fill gaps in services). This option might include:

- 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.

Approaches that support and prepare older adults to manage their health and care generally focus on improving “an individual's ability to manage the symptoms, treatment, physical, psychosocial, and lifestyle changes inherent in living with a chronic condition.”(58) The most relevant reviews that we identified related to this type of approach found that:

- **patient education** (e.g., teaching sessions, group discussion and written materials) for people with long-term conditions increases physical functioning, illness knowledge and the patients' beliefs in their own ability to manage their health;(59)
- **family-oriented interventions** (e.g., by providing education and skills related to chronic health conditions and to address family functioning) improve physical and mental health outcomes in patients and caregivers;(60)
- **home telehealth** (that is, delivering health-related services and information via telecommunications technologies while the patient is at home) has been found to be acceptable to patients and providers,(61) reduce re-hospitalization and length-of-stay in hospital,(61) and improve health outcomes for specific chronic diseases such as diabetes;(62) and
- **e-health/information technology** interventions in general have had positive effects on supporting individuals in managing their own health and care.(61;63-65)

**Table 1. Summary of what is known about the three options**

<b>Option 1 – Increasing access to highly valued services and reducing the provision of less highly valued services</b>
<b>What is known about option 1</b>
<ul style="list-style-type: none"> <li>• A recent and medium-quality review identified the top 10 most frequently mentioned criteria to guide resource-allocation decisions in the health sector: equity/fairness; effectiveness; cost-effectiveness; stakeholder interests and pressures; strength of evidence; safety; mission and mandate of health system; organizational requirements and capacity; patient-family reported outcomes; and need.(51)</li> <li>• An older and medium-quality review examined how members of the public can be involved in defining priorities in the health sector.(52) <ul style="list-style-type: none"> <li>○ policymakers increasingly recognize the benefits of consulting the public;</li> <li>○ traditional mechanisms to engage the public continue to predominate, but there is a growing interest in more deliberative approaches; and</li> <li>○ there is a lack of research evidence to determine which public-engagement mechanisms are the most effective, and how public views might be integrated with other decision inputs when making resource-allocation decisions.</li> </ul> </li> </ul>
<b>Option 2 – Better meeting needs during transitions in care, and among Aboriginal and Francophone groups</b>
<b>What is known about option 2</b>
<ul style="list-style-type: none"> <li>• Health system navigators appear promising to provide integrated and coordinated care, using a variety of interventions such as care plans and treatment goals.(54)</li> <li>• A recent and high-quality review showed some support for cultural safety education for health professionals, but there is no clear consensus on the core components of educational programs to teach cultural safety skills.(55)</li> <li>• A recent and high-quality review found a lack of evidence about the effectiveness of interventions to improve cultural competency in healthcare for Aboriginal populations (e.g., educating and training healthcare professionals, developing culturally specific health programs, and recruiting an Aboriginal healthcare workforce), but they seem promising to improve healthcare professionals' confidence as well as patients' satisfaction with and access to healthcare.(56)</li> <li>• A recent and high-quality review found that culturally appropriate health education has short- to medium-term effects on glycemic control, and on knowledge of diabetes and healthy lifestyles.(57)</li> </ul>
<b>Option 3 – Better engaging patients, families and communities into the care delivery process</b>
<b>What is known about option 3</b>
<ul style="list-style-type: none"> <li>• Several reviews evaluating approaches to help older adults manage their own care found that: <ul style="list-style-type: none"> <li>○ patient education for people with long-term conditions increases physical functioning, illness knowledge and the patients' beliefs in their own ability to manage their health;(59)</li> <li>○ family-oriented interventions improve physical and mental health outcomes in patients and caregivers;(60)</li> <li>○ home telehealth has been found to be acceptable to patients and providers,(61) reduce re-hospitalization and length-of-stay in hospital,(61) and improve health outcomes for specific chronic health conditions such as diabetes;(62) and</li> <li>○ e-health/information technology interventions in general have had positive effects on supporting individuals to manage their own health and care.(61;63-65)</li> </ul> </li> </ul>

## Implementation considerations

It is important to consider what barriers we may face if we implement the proposed options. These barriers may affect different groups (e.g., patients, citizens, healthcare providers), different healthcare organizations or the health system. While some barriers could be overcome, others could be so substantial that they force us to re-evaluate whether we should pursue that option.

The implementation of each of the three options could also be influenced by the ability to take advantage of potential facilitators. A facilitator could be a recent event that was highly publicized in the media, a crisis, a change in public opinion, the publication of a new report, or an upcoming election. Such events can facilitate the implementation of an option.

A list of potential barriers and windows of opportunity for implementing the three options is provided below. This table is provided to spur reflection about some of the considerations that may influence choices about an optimal way forward. We have identified the barriers and windows of opportunity from a range of sources (not just the research literature) and we have not rank ordered them in any way.

**Table 2. Summary of barriers and facilitators for moving forward**

<b>Option 1 – Increasing access to highly valued services and reducing the provision of less highly valued services</b>	
<b>Barriers</b>	<b>Facilitators</b>
<ul style="list-style-type: none"><li>• The public may be reluctant to recommend reducing the provision of some home and community care services that are publicly funded (e.g., due to a lack of interest or perceived lack of skills to do this at the level of specific services).</li><li>• Patients and individuals in rural/remote/northern communities may have difficulties getting their voice heard.</li><li>• Communities in northeastern Ontario can be very different from one another:<ul style="list-style-type: none"><li>○ it may be difficult to define priorities that will align with the needs and preferences of all communities; and</li><li>○ it may be hard to identify where the leadership is in each community and who to talk to.</li></ul></li></ul>	<ul style="list-style-type: none"><li>• There is widespread motivation from the government and others to seek public input on health priorities.</li><li>• Systems like the <a href="#">interRAI Home Care Assessment System</a> are increasingly used to better understand people's specific needs and preferences.</li><li>• The Ontario government is committed to advancing the transformation of the home and community care system to ensure that it is aligned with the needs and preferences of the client and family,(3) and recently released a new plan to improve and expand home and community care over the next three years.(10)</li></ul>

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

Barriers	Facilitators
<ul style="list-style-type: none"> <li>• Health system navigators may have limited capacity to encourage cooperation (particularly when they are peer navigators).(53)</li> <li>• The current lack of human resources may be a barrier to the provision of home and community care aligned with cultural and linguistic needs/preferences.</li> <li>• Health-system leaders may still face challenges in aligning federal and provincial policies to meet the home and community care needs of First Nations populations.</li> <li>• Aboriginal and Francophone groups in rural/remote/northern communities may have difficulty getting their voice heard (e.g., a lack of representation on boards of healthcare organizations).</li> <li>• There is a lack of training and misconceptions regarding Aboriginal culture, health, and preferred modes of service delivery.</li> <li>• In smaller communities, the lack of privacy may discourage help-seeking (e.g., the nurse is so-and-so's aunt).</li> </ul>	<ul style="list-style-type: none"> <li>• Meeting the needs of culturally diverse population groups has been identified as one of the four priorities in the North East Local Health Integrated Network's 2013-2016 Integrated Health Services Plan.</li> <li>• Research demonstrating the impacts of cultural competency/sensitivity/safety training is in its infancy and is difficult to compare and draw conclusions from because each intervention can be quite distinct. Yet many studies are showing promising results. Despite the relatively small amount of evidence accumulated to date, major professional organizations in Canada have mandates to include cultural safety training for health professionals, and many medical schools in Canada have incorporated cultural safety for Aboriginal populations into their curriculum (e.g., the Northern Ontario School of Medicine of Laurentian University and Lakehead University, McMaster University, etc.).</li> <li>• In the past few years many models of cultural safety training have emerged that could be adapted or used – in other words, resources to support this are available (including some from Northern Ontario). For example, recently the North East LHIN has supported worker training in Cultural Safety for the care of First Nations, Inuit and Métis people.</li> </ul>

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

Barriers	Facilitators
<ul style="list-style-type: none"> <li>• Many patients may be socially and geographically isolated, thus without potential support from their family and community to fill the gaps in services.</li> <li>• Some unpaid caregivers have frail health themselves, which complicates the reliability of caregiving and help in the home when formal services are not available.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients increasingly want to play an active role in their own care.</li> <li>• Patients and families may be better supported through the increased use of technology (e.g., by helping to manage care and connect individuals facing similar challenges to help prevent social isolation).</li> </ul>



## Questions for the citizen panel

>> We want to hear your views about the problem, the three options for addressing it, and how we can move forward.

This brief was prepared to stimulate the discussion during the citizen panels. The views, experiences and knowledge of citizens can make a great contribution in finding viable solutions to the problem.

More specifically, the panels will provide an opportunity to explore the questions outlined in Box 3. Although we will be looking for common ground during these discussions, the goal of these panels is not to reach consensus, but to gather a range of perspectives on this topic.



### **Box 3 >> Questions for the citizen panels**

What has been your experience with home and community care in the region (as a patient and/or caregiver)?

What are the key challenges in providing home and community care in the region?

What are the home and community care needs in the region?

What are your views about the three proposed options?

>> **Option 1:** increasing access to highly valued services and reducing the provision of less highly valued services;

>> **Option 2:** better meeting needs during transitions in care, and among Aboriginal and Francophone groups; and

>> **Option 3:** better engaging patients, families and communities in the care delivery process.

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## Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the citizen brief. The funder played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the citizen brief.

## Merit review

The citizen brief was reviewed by a small number of citizens, other stakeholders, policymakers and researchers in order to ensure its relevance and rigour.

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