Citizen Brief

Engaging Older Adults with Complex Health and Social Needs, and Their Caregivers, to Improve Hospital-to-home Transitions in Ontario

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McMaster University | HEALTH FORUM

EVIDENCE >> INSIGHT >> ACTION

The McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence, as well as citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 14-16 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. A citizen panel can be used to elicit the values that citizens feel should inform future decisions about an issue, as well as to 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 to serve as the basis for discussions by the citizen panel on engaging older adults with complex health and social needs, and their caregivers, to improve hospital-to-home transitions. This brief includes information on this topic, including what is known about:

- the underlying problem;
- three possible elements of an approach to address the problem; and
- potential barriers and facilitators to implement these elements.

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?

Several factors make it hard for older adults with complex health and social needs (and their caregivers) to become involved in their own care during the transition from hospital to home, including:

- many older adults have a wide range of complex health and social needs that make hospital-to-home transitions complex and risky;
- caregivers often feel unprepared to support hospital-to-home transitions;
- the health system in Ontario is not currently designed to support older adults with complex health and social needs to be involved in their care during hospital-to-home transitions; and
- bringing about system changes takes time, resources and commitment from many players.

What do we know about elements of a potentially comprehensive approach for addressing the problem?

- **Element 1:** Enabling older adults and their caregivers to play a role in their own care during hospital-to-home transitions
  - Strategies to develop self-management skills are effective when individuals have only one health condition to manage. Discharge tools co-designed with patients can help hospital-to-home transitions.
- **Element 2:** Enabling providers to improve the quality of hospital-to-home transitions
  - Several strategies seem effective to improve transitions, including strategies that are used: early in the hospital admission; during the hospital stay and transition process; close to time of discharge; and after discharge.
- **Element 3:** Enabling decision-makers to make small yet rapid changes to improve the quality of hospital-to-home transitions
  - This element focuses on an approach called "rapid-learning systems." Decision-makers have found that creating rapid-learning systems require action within seven areas (including engaging patients and caregivers in decision-making about how best to improve programs, services and policies).

What implementation considerations need to be kept in mind?

- Perhaps the biggest barriers are:
  - behaviours and attitudes among some providers, which are not favourable to engaging older adults and caregivers, and
  - the many siloes in the system making it difficult to improve hospital-to-home transitions.
- One of the biggest windows of opportunity is that the health system in Ontario is increasingly putting patients and rapid learning and improvement at its centre.

Questions for the citizen panel

>> We want to hear your views about the problem, three elements of a potentially comprehensive approach to addressing it, and how to address barriers to moving forward.

Box 1: Questions for citizens

Questions related to the problem

- Looking back over a hospital-to-home transition you or your loved one experienced:
  - What were your experiences **at the hospital** that positively or negatively affected the transition?
  - What were your experiences **back home** that positively or negatively affected the transition?
  - What were the **decisions** made by you or by someone else that positively or negatively affected the transition?
- Are you aware of the **health reforms underway** in Ontario that could affect hospital-to-home transitions?
  - If so, how do you think the reforms could change the transition that you or your loved one experienced?

Box 1: Questions for citizens (cont'd)

Questions related to the elements of a potentially comprehensive approach to address the problem

- Element 1 – Enabling older adults and their caregivers to play a role in their own care during hospital-to-home transitions
  - What role would you (and your caregiver) like to play in your own care during hospital-to-home transitions?
  - What supports would enable you (and your caregiver) to play that role?
- Element 2 – Enabling providers to improve the quality of hospital-to-home transitions
  - What could providers do individually, and as a team, to improve the quality of hospital-to-home transitions?
  - What role would you (and your caregiver) like to play in this process?
  - What supports would enable you (and your caregiver) to play that role?
- Element 3 – Enabling decision-makers to make small yet rapid changes to improve the quality of hospital-to-home transitions
  - What could decision-makers do to improve the quality of hospital-to-home transitions?
  - What role would you (and your caregiver) like to play in this process?
  - What supports would enable you (and your caregiver) to play that role?
  - How will we know if hospital-to-home transitions have improved?

Question related to implementation considerations

- What could be the biggest challenges to implementing a new approach to hospital-to-home transition?
  - How could we address these challenges proactively?
- What other changes could facilitate the implementation of this new approach?

Box 2: Glossary

Caregiver

An individual who provides ongoing care and assistance, without pay, for a family member or a friend in need of support due to physical, cognitive or mental health conditions. In addition to family members or significant others, friends, neighbours, or members of a faith community may be caregivers. Caregivers are increasingly recognized as 'care partners' and members of the 'care team'.

Chronic condition

A health problem requiring ongoing management over a period of years or decades (for example, arthritis, asthma, cancer, depression, dementia, diabetes and heart disease).(3)

Engagement

Patients, caregivers and professionals working in active partnership to improve health. You can be engaged at various levels: in your own care, in the organizations that deliver care, and in policymaking.(6)

Health

"A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."(7)

Home

Your usual place of residence, which may include a personal residence, a retirement home, an assisted-living facility or a shelter.(1)

Home and community care

Services to help people live as independently as possible in their home. Home and community care can be delivered by various organizations (for example, community support services), professionals (for example, nurses, social workers, dietitians), and personal support workers.

Box 2: Glossary (cont'd)

Hospital-to-home transition

The process of supporting patients who are being discharged from hospital and are moving back home. The aim is to help patients to manage their health and care, and also support all members of the care team (including the patients and caregivers) to work together to deliver home and community care.

Integrated care

Care that addresses both the health and social needs of individuals, and that is provided in a seamless and coordinated way across providers, organizations and sectors.

Mental health condition

A wide range of conditions that affect people's mood, thinking and behaviour (for example, anxiety, depression, and Alzheimer's and other dementias).

Social determinants of health

Many factors can have an influence on your health, including your genetics and lifestyle choices, but also where you were born, grow, live, work and age.(4) The social determinants of health refer to the social and economic factors influencing your health,(5) such as:

- health and social services (for example, access to hospital-to-home transitional care, home and community care, and primary care);
- Indigenous status;
- disability;
- education;
- employment and working conditions;
- early childhood development;
- ethnocultural background;
- food insecurity;
- gender;
- housing;
- income and income distribution;
- social exclusion;
- social safety network; and
- unemployment and job security.

Hospital-to-home transitions can be particularly stressful and risky for older adults with complex health and social needs, and for their caregivers.

The context: Why is improving hospital-to-home transitions a high priority?

Going home from the hospital can be both an exciting and stressful time for patients and their caregivers. They are leaving their hospital-based care team (which may include doctors, nurses, physiotherapists, mental health workers, dietitians and volunteers). They will need to establish new routines to manage their own health and care. This may include using a new medication or treatment, or working with a different care team.(8)

This transition can be particularly stressful for older adults with complex health and social needs (and for their caregivers too). It is increasingly common for older adults to have multiple chronic conditions. Many are also living with mental health conditions (anxiety, depression, and Alzheimer's and other dementias). These older adults are at increased risk for poor quality of life and poor health outcomes, particularly when they are transitioning from hospital to home.(9) They will typically receive fragmented care from multiple care providers who often lack a common system for coordination and communication.(10; 11)

In addition, many older adults with complex health needs live in complex social circumstances. They may be financially insecure, lonely, geographically isolated, live in

inadequate and unaffordable housing, have limited ability to use health information, and may be unaware of care and other supportive services in their community.(12) All these factors may negatively affect their transition from hospital to home.

There is still limited research evidence on the most effective ways to support hospital-to-home transitions for older adults with complex health and social needs.(10) Quality transitions from hospital to home result in a number of positive outcomes, including:

- reduced length of stay at the hospital;(13)
- reduced hospital readmissions;(13-15)
- increased use of primary-care services that could help to prevent health problems;(14)
- reduced use of unnecessary home-care services;(14)
- reduced admission to long-term care homes;(16) and
- better health outcomes and quality of life.(17)

Unfortunately, hospital-to-home transitions are often poorly planned and supported. These situations pose serious safety risks to older adults, lead to complications and hospital readmissions, and put an added strain on older adults, their caregivers and the entire health system.(18; 19)

Improving hospital-to-home transitions is a high priority for the Ontario government. In 2019, the government announced major health-system reforms. One key element of these reforms is the creation of Ontario Health Teams in which all healthcare providers offering care to a defined population of patients will work as one coordinated team. The reforms aim to break down the silos in the system (such as those that exist between specialty care, primary care, and home and community care), provide more integrated care, and improve care transitions.(2; 20; 21)

As the province moves towards these new reforms, there is a unique opportunity to seek input on how to improve the quality of hospital-to-home transitions for older adults with complex health and social needs (and their caregivers). It is also an opportunity to explore how older adults and their caregivers could be engaged more meaningfully during hospital-to-home transitions.(22)

The complex health needs of older adults are often intertwined with complex social needs.

The problem: Why is it challenging to engage older adults with complex health and social needs (and their caregivers) during hospital-to-home transitions?

We identified four factors that make it hard for older adults with complex health and social needs (and their caregivers) to become involved in their own care during the transition from hospital to home:

1) many older adults have a wide range of complex health and social needs that make hospital-to-home transitions complex and risky;
2) caregivers often feel unprepared to support hospital-to-home transitions;
3) the health system in Ontario is not currently designed to support older adults with complex health and social needs to be involved in their care during hospital-to-home transitions; and
4) bringing about system changes takes time, resources and commitment from many players, including older adults, family caregivers, providers, organizations and the system as a whole.

Many older adults have a wide range of complex health and social needs that make hospital-to-home transitions complex and risky

Many older adults have a wide range of complex health needs (both physical and mental). For example, older adults are more likely to have complex health needs associated with multiple chronic conditions.(23) Across the country, approximately 29% of Canadians are living with one chronic condition, but 15% have two chronic conditions, and 7% have three or more chronic conditions. Living with multiple chronic conditions is something that is more likely to affect older adults. In Ontario, 43% of adults over the age of 65 have two or more chronic conditions.(3) Older adults with multiple chronic conditions (compared to those without multiple chronic conditions) report lower levels of health-related quality of life, and have higher levels of disability, mortality and caregiver burden.(24)

But the complex health needs of older adults are often intertwined with complex social needs. Unmet social needs put these individuals at greater risk for poor health outcomes.(25; 26) These older adults may:

- lack social support;
- be lonely;
- be geographically isolated;
- be financially insecure;
- live in inadequate and unaffordable housing;
- have limited access to transportation;
- lack access to affordable, nutritious food;
- have limited access to health and social services (or may not seek these services when in need);
- have limited access to services that are linguistically and culturally sensitive; or
- have marginalized identities that put them at greater risk for discrimination and being excluded.(27)

Addressing the wide range of health and social needs of older adults is challenging. A recent Canadian study examined the experiences of community-dwelling older adults, family caregivers and healthcare providers about managing multiple chronic conditions.(28)

The study revealed the large gap between the needs of older adults (and the needs of their caregivers) and the ability of health and social systems to meet these needs. The care experiences were described as "piecemeal and fragmented with little focus on the person and family as a whole."(28) Efforts to improve the situation will likely hinge on how well transitions are managed in the system, given the complex health and social needs of many older adults.

This resonates with international studies examining older adults' experiences of adapting to daily life after going back home from hospital.(29) Studies revealed that older adults often experienced an insecure or unsafe transition, and had difficulty settling into their new situation at home (Table 1).

Table 1. Older adults' experiences of adapting to daily life after going back home from hospital (29)

Challenges	Examples of challenges
Experiencing an insecure and unsafe transition	• Lacking information about their health situation, treatment and/or care • Experiencing a rushed discharge • Being confused about medication and how to take their medications • Not being engaged in their own care • Not being engaged in decisions about their own life • Not understanding the information being provided to them (or not explained well) • Lacking coordination and communication between the different providers (which may lead to errors in treatment and other adverse events) • Conflicting opinions between providers • Not having all their medication reviewed by the care team
Having difficulty settling into a new situation at home	• Being dependent on additional help from others • Losing independence • Home not being prepared (for example, lack of specialized equipment and assistive devices) • Having problems performing daily activities • Not receiving care according to needs • Not feeling ready to go home (or not feeling confident to go home) • Having to change care team (and managing appointments) disrupted efforts to get back to their daily routines • Feeling lonely and isolated • Feeling depressed and experiencing no meaning in life

Caregivers often feel unprepared to support hospital-to-home transitions

More than eight million Canadians provide care to a family member or friend with a long-term health condition (most commonly cancer) or aging-related needs. Older adults with multiple chronic conditions have greater care needs and rely more heavily on their caregivers compared with those with a single chronic condition.(3; 30) As a report from the Canadian Medical Association pointed out: "Much of the burden of continuing care falls on caregivers."(31)

Caregivers play many important roles during hospital-to-home transitions, including:

- helping the care team identify the health and social needs of older adults (and the needs of the caregivers who will be providing care at home) before being discharged from hospital;
- taking notes, asking questions, and advocating for older adults while in hospital;
- providing emotional support;
- accompanying older adults to medical appointments;
- reporting or managing side effects;
- giving medication;
- keeping track of medicines, test results and papers;
- providing physical care (for example, feeding, dressing and bathing);
- coordinating care and services;
- keeping family and friends informed; and
- making legal and financial arrangements.

Despite their crucial role, caregivers often feel unprepared to provide care at home. They often receive little guidance and coaching from healthcare providers.(32) This aligns with findings from a recent Canadian study which concluded that caregivers viewed supporting their loved ones with managing multiple chronic conditions as "overwhelming, draining and complicated" and "being split into pieces."(28)

In addition to the perceived lack of preparedness, caregivers often lack access to practical, social, emotional, and financial support that can affect hospital-to-home transitions.(30; 32) A report by Health Quality Ontario revealed that more than one in four individuals receiving care at home were relying on a caregiver who experienced "continued distress,

anger or depression in relation to their caregiving role."(33) Caregivers of older adults with multiple chronic conditions and Alzheimer's disease are known to experience very complex and distressing transitions. Studies have shown that they must take on complex, new roles and responsibilities, must deal with responsive behaviours/personal expressions associated with dementia, and often feel isolated.(34-36)

This lack of support can have a negative impact on the physical and mental health of caregivers, their personal and professional lives, and the quality of care that they provide during hospital-to-home transitions. As reported by a discussion forum of Canada's leading cancer, mental health and caregiver groups: "Failure to recognize, acknowledge and support family caregivers heightens their risk of becoming 'collateral casualties' of the illness, compromises their health, reduces the efficacy of the help they can provide to their relatives, and increases costs to the health and social service systems."(37)

The health system in Ontario is not currently designed to support older adults with complex health and social needs to be involved in their care during hospital-to-home transitions

Several system-level factors make it more difficult to support older adults with complex health and social needs during hospital-to-home transitions. In Table 2, we describe several important health-system challenges related to:

- governance arrangements (who can make what types of decisions);
- financial arrangements (how money flows from taxpayers to government to organizations and professionals); and
- delivery arrangements (how care is organized).

Table 2. Summary of system-level challenges

Challenge	Example/description of the challenge
Governance arrangements (who can make what types of decisions)	**Jurisdictional complexity** • Decision-making authority for addressing the many health and social needs of older adults often spans a wide range of government departments and different levels of governments (for example, municipal, provincial and federal). This contributes to care delivery in siloes. **Lack of data about hospital-to-home transitions** • There is a lack of data to understand what happens to older adults with complex health and social needs (and their caregivers) after being discharged (and beyond hospital readmissions). • Much of the data being collected are about providers and not about patient-reported experiences and outcomes, caregivers, or about the broader social determinants of health. In addition, current data systems are not connected to each other across different areas of the health and social systems. • Data about patient experiences is not routinely collected.
Financial arrangements (how money flows from taxpayers to government to organizations and professionals)	**Older adults and their caregivers may face an additional financial burden during hospital-to-home transitions** • Older adults and their caregivers may have to pay out-of-pocket for additional home- and community-care supports (such as rehabilitation, therapy, a home-care nurse), which may not be available in their region. • Informal and family caregivers often lose out on earning income and use their retirement savings to support caregiving. It is estimated that there are more than two million unpaid caregivers in Canada (38; 39) and the estimated economic value to the health and social systems of their contributions is in the range of $25 billion per year.(40) Financial support for caregivers remains limited. **How doctors are paid is not conducive to support integrated and comprehensive care** • Most doctors are paid for each separate service they provide, which is not conducive to supporting integrated care for patients with complex health and social needs, and may promote fragmentation in the system.(41) **How hospitals are funded is not conducive to support the patients back in the community** • Current funding models for hospitals in Ontario do not create incentives to support patients in the community. **The home- and community-care sector is underfunded** • Due to limited funding, home- and community-care resources are very limited and have restrictive eligibility criteria.(42) • Home and community care is funded separately from hospital care. When hospitals save money for shorter lengths of stay, it may increase the costs for the home- and community-care sector.

Challenge	Example/description of the challenge
	Financial burden on the broader health system • High-needs users have a significant financial impact on the health system in Ontario (which means those with the highest healthcare spending, but not necessarily with multiple chronic health conditions). • It is estimated that 1% of the population accounts for 33% of healthcare costs, and 5% accounts for 66% of healthcare costs.(43) • This illustrates how important it is to find more cost-effective ways to provide the care needed to older adults who have complex needs.
Delivery arrangements (how care is organized)	**Older adults with complex needs are not always identified when being admitted and before being discharged from hospital** • Delirium and depression among older adults admitted to hospitals is often unrecognized and untreated. And even when they are recognized, they often go untreated.(44) This may lead to poor quality of life and increased use of health services. **Older adults with complex health and social needs (and their caregivers) are not always engaged meaningfully in planning their transition back home** • There are often organizational pressures to discharge patients rapidly (resulting in limited capacity to meaningfully engage patients and caregivers in conversations about hospital-to-home transitions). • Hospital discharge is often planned around a single problem (usually a physical problem), as opposed to considering the wide range of health and social needs a person may be experiencing. • Providers rarely engage older adults and their caregivers in decisions about their care. The barriers that are the most cited are: time constraints; providers thinking that it is not necessary given the patient's situation; patients not expecting to be engaged or being afraid to upset their providers; and providers lacking the skills to engage their patients in decisions about their own care.(45) The lack of meaningful engagement can result in unmet needs once home.(46) • It is difficult for providers and organizations (for example, home and community care) to develop comprehensive and customized packages of care and services based on older adults' complex needs and their ability to pay. **The health system is not currently designed to provide integrated care for people with complex health and social needs at home** • Older adults with multiple chronic conditions often receive care that is fragmented.(47) For instance, a patient with diabetes, multiple sclerosis and emphysema may need to seek care from different doctors for each condition. These doctors may be in different settings and may not effectively communicate with each other,(41) which increases the risks of medical errors, poor communication with patients (and across providers), and poor care coordination.(48)

Challenge	Example/description of the challenge
	• Standard 15-minute appointments are not sufficient for patients with multiple chronic conditions and complex needs, limiting the provision of optimal care and support for self-management.(49) • There are many silos in the system: silos between those providing health care and social care; silos between different sectors (for example, between hospital care, primary care, specialty care, and home and community care); and even silos within each sector (for example, silos between organizations providing home and community care). **Older adults and caregivers are often not provided with adequate information to enable them to engage in their own health and their own care after transitioning to their own home** • Older adults and caregivers have limited access to their health information, and when they do have access, it is difficult to understand and use. • Older adults and their caregivers often receive conflicting information (particularly those who are managing multiple chronic conditions and receiving care from many different providers in different settings). • Older adults and caregivers are often unaware of the home and community care available to them.

Bringing about system changes take time, resources and commitment from many players

There have been some promising steps taken by the government, healthcare organizations, researchers, professionals and many others to improve hospital-to-home transitions. However, major system changes take time, resources, and commitment from many players (including older adults, caregivers, providers, organizations and the system, as a whole).

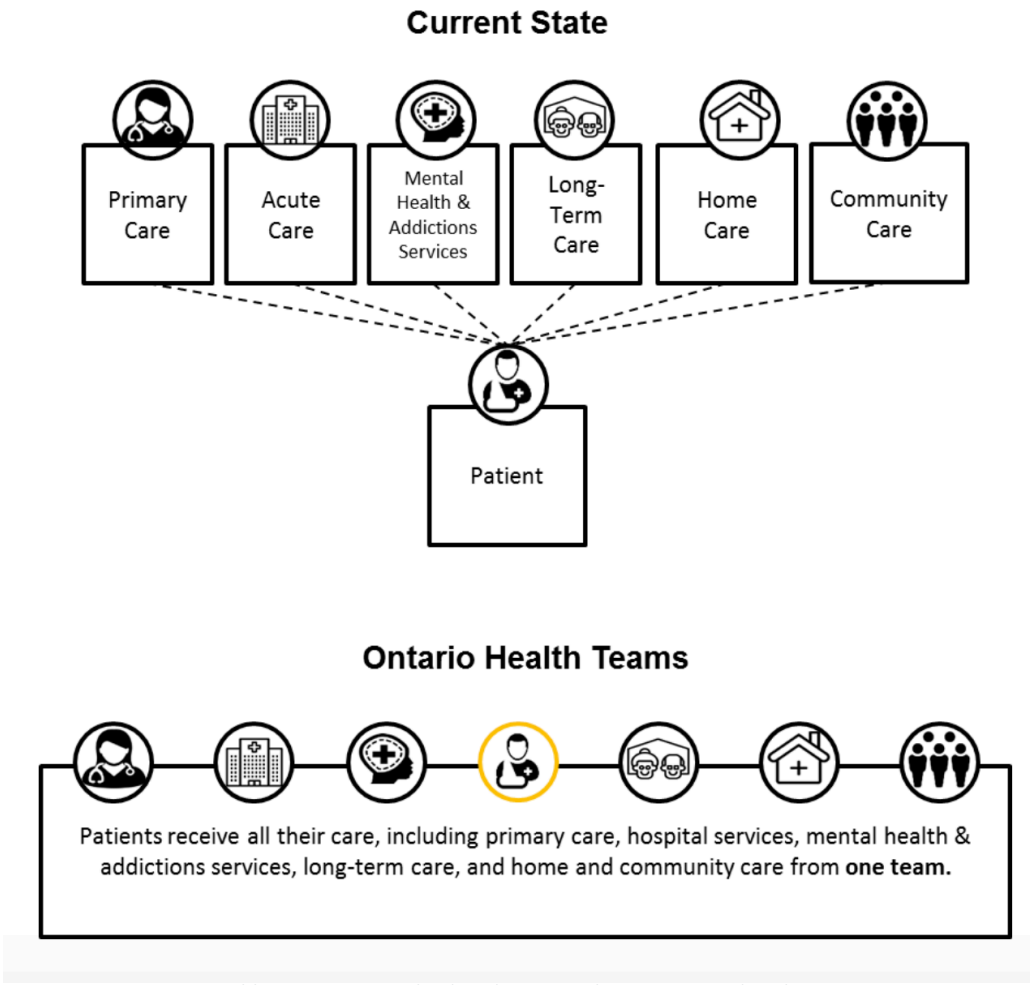
Below, we briefly describe three initiatives that are currently underway and that may have a significant impact on hospital-to-home transitions: 1) major health reforms that are reshaping how care is organized and delivered in Ontario; 2) initiatives by Health Quality Ontario to develop quality standards in hospital-to-home transitions; and 3) an example of a promising model of hospital-to-home transition as part of a study conducted in Ontario.

While the initiatives described below are promising and have the potential to fundamentally change for the better how patients (including older adults) transition from hospital to home, each is complex and requires several components to go right in order for them to achieve their goals for patients. As such, many Ontarians may not experience improvements for some time.

Major health reforms in Ontario

Improving hospital-to-home transitions is a high priority for the Ontario government. In 2019, the government announced a major health-system reform, which includes two key changes: 1) the creation of Ontario Health Teams in which all healthcare providers will work as one coordinated team; and 2) the creation of Ontario Health, a central organization that will oversee and coordinate all provincial agencies and specialized provincial programs (see Figure 1 and Box 3). The reforms aim to break down silos in the system, provide more integrated care, and improve care transitions.(2; 20; 21)

Figure 1. Creation of the Ontario Health Teams



Source : http://health.gov.on.ca/en/pro/programs/connectedcare/oht/default.aspx

Box 3: The reforms underway in Ontario (2)

Creation of Ontario Health Teams

- Healthcare providers will work as one coordinated team (called Ontario Health Teams). They will provide the following services:
  - primary care;
  - hospital care;
  - rehabilitative care;
  - home and community care;
  - residential long-term care; and
  - mental health and addiction care.
- Each patient's Ontario Health Team will:
  - know their health history;
  - be aware of healthcare services in their area;
  - help them navigate the system 24/7;
  - ensure their referrals get to the right place;
  - receive and share health records with patients, such as test results; and
  - provide them with digital options, such as online access to health records and virtual care.

Creation of Ontario Health

- A single agency – Ontario Health – will have the mandate to oversee healthcare delivery, improve clinical guidance and provide support for providers to offer better care. Some provincial agencies will gradually transition to the new agency, including:
  - Cancer Care Ontario;
  - Health Quality Ontario;
  - eHealth Ontario;
  - Trillium Gift of Life Network;
  - Health Shared Services Ontario;
  - HealthForceOntario Marketing and Recruitment Agency; and
  - 14 Local Health Integration Networks.

Initiatives led by Health Quality Ontario

Health Quality Ontario, the provincial organization supporting the quality of healthcare, is leading several projects to improve hospital-to-home transitions, including:

- a Patient Conversation Guide with questions patients can ask their care team as they get ready to leave the hospital;(8)
- a tool (the Patient Oriented Discharge Summary – PODS) co-developed with patients to help patients and caregivers better manage their care after leaving the hospital, which is being implemented in 27 hospitals across Ontario;(50) and
- developing quality standards for hospital-to-home transitions.(1)

The 'quality standards' being developed by Health Quality Ontario focus on hospital-to-home transitions for people of all ages (not just older adults with complex health and social needs).(1) This work is being done in collaboration with healthcare providers, patients, citizens and caregivers across the province. These quality standards are 10 short statements (Box 4). These statements should:

- help patients and caregivers know what to expect from hospital-to-home transitions;
- help providers know what care they should be offering (based on evidence and expert consensus); and
- help organizations evaluate and improve their performance.

Box 4: Quality statements for hospital-to-home transitions proposed by Health Quality Ontario (1)

1. Information-sharing on admission

"When people are admitted to hospital, the hospital notifies their primary care and home and community care providers soon after admission via real-time electronic notification. The community-based providers then share all relevant information with the admitting team in a timely manner."

2. Comprehensive assessment

"People receive a comprehensive assessment of their current and evolving health care and social support needs. This assessment is started early upon admission, and updated regularly throughout the hospital stay, to inform the transition plan and optimize the transition process."

3. Patient, family and caregiver involvement in transition planning

"People transitioning from hospital to home are involved in transition planning and developing a written transition plan. If people consent to include them in their circle of care, family members and caregivers are also involved."

4. Patient, family and caregiver education, training and support

"People transitioning from hospital to home, and their families and caregivers, have the information and support they need to manage their health after the hospital stay. Before transitioning from hospital to home, they are offered education and training to manage their health care needs at home, including guidance on medications and medical equipment."

5. Transition plans

"People transitioning from hospital to home are given a written transition plan (which can reside fully within the discharge summary), developed by and agreed upon in partnership with the patient, any involved caregivers, the hospital team, and the home and community care team, before leaving hospital. Transition plans are shared with primary care and home and community care providers within 48 hours of discharge."

Box 4 (cont'd): Quality statements for hospital-to-home transitions proposed by Health Quality Ontario (1)

6. Coordinated transitions

"People admitted to hospital have a named health care professional who is responsible for timely transition planning, coordination, and communication. Before people leave hospital, this person ensures an effective transfer of transition plans and information related to people's care."

7. Medication review and support

"People transitioning from hospital to home have medication reviews on admission, before returning home, and once they are home. These reviews include information regarding medication reconciliation, adherence, and optimization, as well as how to use their medications and how to access their medications in the community. People's ability to afford out-of-pocket medication costs are considered, and options are provided for those unable to afford these costs."

8. Coordinated follow-up medical care

"People transitioning from hospital to home have follow-up medical care with their primary care provider and/or a medical specialist coordinated and booked before leaving hospital. People with no primary care provider are provided with assistance to find one."

9. Appropriate and timely support for home and community care

"People transitioning from hospital to home are assessed for the type, amount, and appropriate timing of home care and community services they and their caregivers need. These services are arranged before people leave hospital and are in place when they return home."

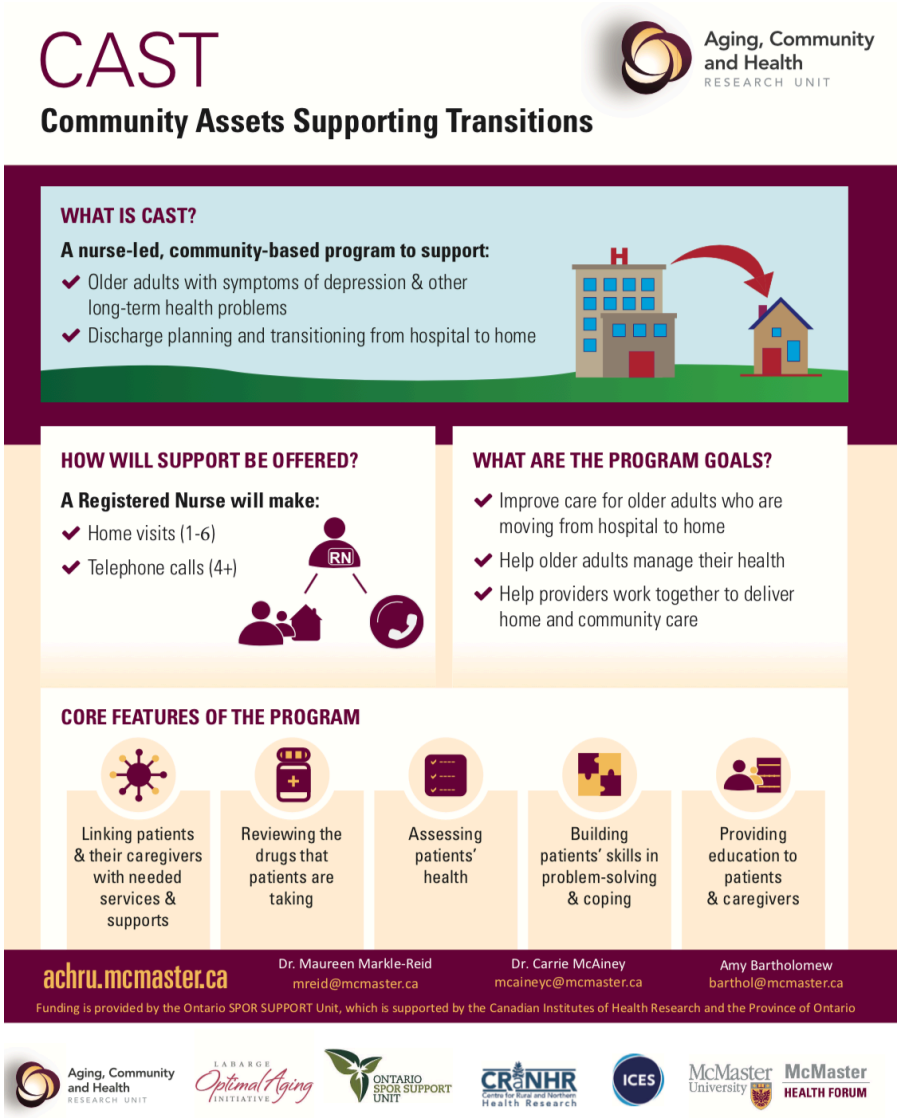
10. Out-of-pocket costs and limits of funded services

"People transitioning from hospital to home have their ability to pay for any out-of-pocket health care costs assessed by the health care team, and alternatives for unaffordable costs are considered in transition plans. The health care team explains to people what publicly funded services are available to them and what services they will need to pay for."

Example of a promising hospital-to-home transitional care model

One example is the model developed by the Community Assets Supporting Transitions (CAST) study. The study aims to determine the effects, implementation and costs of a hospital-to-home support program for older adults with multiple chronic conditions and depressive symptoms. This nurse-led model includes home visits, telephone follow-up, and nurse-led care coordination over a period of six months (see Figure 2). The researchers are working side-by-side with patients, caregivers and providers from three communities in Ontario (Burlington, Hamilton and Sudbury) to tailor the model to each community.(51)

Figure 2. The Community Assets Supporting Transitions (CAST) study



Source: Aging, Community and Health Research Unit (52)

We have identified three elements of an approach to address the problem for which we are seeking your input.

Elements of an approach to address the problem

>> To promote discussion about the pros and cons of potential solutions, we have selected three elements of an approach to engaging older adults and their caregivers to improve hospital-to-home transitions

Many approaches could be selected as a starting point for discussion. We have selected the following three elements of an approach for which we are seeking public input:

1. enabling older adults and their caregivers to play a role in their own care during hospital-to-home transitions;
2. enabling providers to improve the quality of hospital-to-home transitions; and
3. enabling decision-makers to make small yet rapid changes to improve the quality of hospital-to-home transitions.

These elements should not be considered separately. Instead, each should be considered as contributing to a potentially comprehensive approach to addressing the problem. New elements could also emerge during the Citizen Panel discussions.

To inform the discussion about these elements, the next section presents what is known about each element based on the best available research evidence. Box 5 summarizes how the research evidence has been identified, selected and synthesized for each element.

Box 5: Identification, selection and synthesis of research evidence presented in this brief

- Whenever possible, we describe what is known about each element based on systematic reviews.
- A systematic review is a summary of all the studies looking at a specific topic.
- A systematic review uses very rigorous methods to identify, select and appraise the quality of all the studies, and to summarize the key findings from these studies.
- A systematic review gives a much more complete and reliable picture of the key research findings, as opposed to looking at just a few individual studies.
- We identified systematic reviews in Health Systems Evidence (**www.healthsystemsevidence.org**). Health Systems Evidence is the world's most comprehensive database of research evidence on health systems.
- A systematic review was included if it was relevant to one of the elements covered in the brief.
- We then summarized the key findings from all the relevant systematic reviews.

Element 1 – Enabling older adults and their caregivers to play a role in their own care during hospital-to-home transitions

Overview

This element aims to identify effective strategies to enable older adults with complex health and social needs (and their caregivers) to play a role in their own care during hospital-to-home transitions. These might include:

- strategies to empower older adults and caregivers to feel confident to take part in planning the hospital-to-home transition with the care team, and also confident to support care at home;
- strategies to provide concrete tools to enable older adults and their caregivers to engage in conversations about hospital-to-home transitions (for example, the Patient Conversation Guide being developed by Health Quality Ontario) or provide them with clear instructions to know how to manage at home once discharged (for example, the Patient-Oriented Discharge Summary [PODS] used in 27 hospitals across Ontario); and
- strategies to develop the skills of older adults and their caregivers to manager their own health and care (known as 'self-management' skills).

Evidence to consider

There are many systematic reviews examining various self-management interventions. However, these reviews generally focus on self-management for single conditions (for example, diabetes or cardiovascular diseases). While reviews of self-management for single conditions are important, they do not address the complexity involved with self-management for older adults with multiple chronic health conditions. Only one review focused specifically on older adults with multiple chronic conditions and found mixed results about the effectiveness of self-management.(53)

We also found two other relevant reviews: 1) a review identifying the types of knowledge, attitudes, skills, behaviours and assets that caregivers need to feel empowered;(32) and 2) a review that found that discharge tools co-designed with patients can help hospital-to-home transitions.(54)

We present a more detailed summary of the evidence in Table 3.

Table 3. Types of activities that could be included in element 1

Area of focus	Types of activities
Strategies to empower caregivers	• A recent rapid synthesis identified many examples of the types of knowledge, attitudes, skills, behaviours and assets that caregivers need to feel empowered: ○ **knowledge** (for example: understanding the patient's condition and medical history, knowing how to manage specific conditions, understanding the process of transition, knowing what community services are available, understanding the health system and roles of the different providers); ○ **attitudes** (for example, self-efficacy, self-esteem, positive attitudes towards the patients, resiliency, and affirmation); ○ **skills** (for example, skills in providing personal care, note-taking skills, coping skills, advocacy skills, problem-solving skills); ○ **behaviours** (for example: encouraging social participation, making house adaptations, making lifestyle adaptations); and ○ **assets** (for example, ensuring the home is close to services, and having access to benefits that could lessen the financial burden).(32)
Strategies to provide discharge tools	• One systematic review examined the effectiveness of discharge tools that are developed for patients.(54) The review found that: ○ the use of discharge tools with media and visual aids improved patient understanding of instructions; and ○ involving patients in the design and delivery of discharge tools also improved patient understanding of instructions. • No systematic review examined the Patient-Oriented Discharge Summary currently being implemented in Ontario, but recent evaluations have found that: ○ 93% of patients reported understanding their medications upon discharge and 85% reported understanding what to do if concerned; ○ 98% of patients and 86% of providers found the tool useful and would recommend its use; and ○ 4% reduction in 30-day hospital readmission rate during the period that the tool was implemented.(50)
Strategies to develop self-management skills	• We found one systematic review examining the effectiveness of patient-oriented interventions for managing multiple chronic conditions.(53) These included educational interventions and support for self-management (for example, supporting self-management with focus on diet and physical activity, or group-based support programs for people with multiple chronic conditions). The review revealed mixed findings, but overall interventions that are not linked to healthcare delivery are less effective. • Other reviews found that the following self-management interventions were beneficial (but they focused on self-management for single conditions):

	○ patient education; ○ family interventions; ○ information and communication technology (for example, home telehealth and telemonitoring); ○ home-based support; and ○ interventions aimed at supporting appropriate medicine use by patients.(3)

Questions to consider

- What role would you (and your caregiver) like to play in your own care during hospital-to-home transitions?
- What supports would enable you (and your caregiver) to play that role?

Element 2 – Enabling providers to improve the quality of hospital-to-home transitions

Overview

This element focuses on identifying strategies to enable individual providers (or providers working as a team) to improve the quality of hospital-to-home transitions. These might include:

- strategies designed to support providers to improve the quality of hospital-to-home transitions;
- strategies to help providers to proactively identify older adults with complex health and social needs in their community using available data and other means (in order to reach out to them before they are hospitalized); and
- strategies to engage older adults and caregivers as advisors to healthcare organizations to improve the quality of hospital-to-home transitions.

Evidence to consider

We identified a report by Health Quality Ontario providing an overview of systematic reviews about strategies designed to improve the quality of hospital-to-home transitions.(55) The report identified a series of strategies that are supported by strong research evidence, and others that appear to be promising. These strategies can be used at different moments during the hospital-to-home transition, such as:

- early in the hospital admission;
- during the hospital stay and transition process;
- close to time of discharge; and
- after discharge.

We also found a systematic review examining strategies to engage patients in patient advisory councils or committees to co-design programs and services.(56) The review found limited research evidence, but did find that some of these strategies could be promising.

We present a more detailed summary of the evidence in Table 4.

Table 4. Types of activities that could be included in element 2

Area of focus		Types of activities
Strategies designed to improve the quality of hospital-to-home transitions	Early in the hospital admission	• Three strategies that are effective early in the hospital admission: ○ performing medication reconciliation on admission; ○ assessing patient risk of readmission; and ○ assessing health literacy.(55) • One promising strategy: ○ notifying primary care and community providers of patient admission to hospital (and start coordinating the care plan) using e-notifications.(55)
	During the hospital stay and transition process	• Two strategies providers can use that are effective during hospital stay and transition process: ○ using 'teach back' to build patient and caregiver capacities; and ○ using visual tools to help patients and caregivers to communicate.(55)
	Close to time of discharge	• Two strategies for providers that are effective close to time of discharge: ○ ensuring personal clinician-to-clinician information transfer; and ○ performing medication reconciliation at discharge. (55) • One promising strategy: ○ scheduling primary-care visit before leaving hospital.(55)
	After discharge	• Four promising strategies after discharge: ○ identifying one lead to perform medication reconciliation in the community; ○ ensuring discharge summary available to primary-care providers within 48 hours; ○ conducting follow-up within 48 hours of transition to home; and ○ designating a person in the community to support non-clinical needs immediately after hospital discharge.(55)
Strategies to help providers to proactively identify older adults with complex health and social needs		• No systematic reviews found.
Strategies to engage older adults and caregivers as advisors to healthcare organizations		• One systematic review examining strategies to engage patients in patient advisory councils or committees to co-design programs and services found a limited body of research evidence. However, some of these strategies appeared promising, such as: ○ engaging patients as advisors in the design of public health interventions to improve clinical outcomes; and ○ engaging patients as advisors to help healthcare planning efforts and identify priorities.(56)

Questions to consider

- What could providers do individually, and as a team, to improve the quality of hospital-to-home transitions?
- What role would you (and your caregiver) like to play in this process?
- What supports would enable you (and your caregiver) to play that role?

Element 3 – Enabling decision-makers to make small yet rapid changes to improve the quality of hospital-to-home transitions

Overview

Most health systems have not been set up to learn and improve rapidly. Instead, they often go through large-scale reforms over an extended period of time. Since it is unlikely we get all changes right from the beginning, such large-scale reforms are not optimal.

This element focuses on an approach called "rapid-learning systems". Decision-makers would be able to make small yet rapid changes to improve the quality of hospital-to-home transitions for older adults with complex health and social needs. Decision-makers at all levels (from those working in local organizations delivering care to those working in the government) could try new approaches, rapidly evaluate them in 'real time,' and quickly adjust the approach when necessary.

Evidence to consider

The most relevant evidence for element 3 comes from two recent rapid syntheses produced by the McMaster Health Forum. One focused on creating a rapid-learning health system in Ontario,(57) and the other on creating a rapid-learning health system in Canada.(58)

Decision-makers have found these types of changes require action within seven areas:

1) engaging patients and caregivers in decision-making about how best to improve programs, services and policies;
2) collecting and sharing data (for example, data about older adults with complex health and social needs throughout hospital-to-home transitions);
3) ensuring organizations (for example, independent agencies, researchers working at academic hospitals) in the system are able to produce research in a timely way (for example, research about effective models of hospital-to-home transitions);
4) supporting patients, caregivers, providers and policymakers to use data and research to inform their decisions;
5) ensuring that all parts of the system are aligned, such as who can make what decisions, how money flows and how the systems is organized (for example, a system in which the funding is attached to the patient, or a system with clear quality standards like those drafted by Health Quality Ontario);
6) creating a culture that supports small yet rapid improvements; and

7) fostering the skills needed by all individuals involved in hospital-to-home transitions to take these actions.

Questions to consider

- What could decision-makers do to improve the quality of hospital-to-home transitions?
- What role would you (and your caregiver) like to play in this process?
- What supports would enable you (and your caregiver) to play that role?
- How will we know if the quality of hospital-to-home transitions have improved?

Implementation considerations

We will face some barriers if we try to implement the three elements discussed above. These barriers may be related to different groups (for example, patients, the general public, health professionals), to specific organizations delivering care (for example, hospitals), or to specific aspects of a health system (for example, how care is financed). Some of these barriers could be overcome. However, other barriers could be so important that we would need to reconsider whether we should pursue some elements. Potential barriers to implementing the elements are summarized in Table 5.

Table 5: Potential barriers to implementing the elements

Element	Description of potential barriers
Element 1 – Enabling older adults and their caregivers to play a role in their own care during hospital-to-home transitions	• Some older adults and their caregivers may not want to be engaged (particularly those with complex health and social needs). • Some older adults and their caregivers may not have the capacity to play an active role in their own care (for example, some caregivers are already overburdened, have limited resources, or are struggling with complex and conflicting advice and instructions). • Some individuals may perceive that a focus on self-management means that their providers are abandoning them. • Some providers may be reluctant (or lack the skills) to empower and engage older adults and caregivers.
Element 2 – Enabling providers to improve the quality of hospital-to-home transitions	• Many providers and care teams may not have the same capacity to deploy all the strategies designed to improve the quality of hospital-to-home transitions. • Older adults with complex health and social needs (and their caregivers) may be experiencing compassion fatigue and additional health concerns, and thus are unable to engage in informing providers about how transitional care quality could be improved designing programs and services. • Some older adults and their caregivers may not want to be engaged advisors, or may not have the capacity to be engaged as advisors (particularly those with complex health and social needs). • Some providers may be reluctant (or lack the skills) to meaningfully engage older adults and caregivers in designing programs and services.

Element 3 – Enabling decision-makers to make small yet rapid changes to improve the quality of hospital-to-home transitions	• Making changes in the system (even small and rapid changes) may be perceived as challenging. • Older adults with complex health and social needs (and their caregivers) may be experiencing compassion fatigue and additional health concerns, and thus are unable to engage in designing programs, services and policies. • Some decision-makers may be reluctant (or lack the skills) to meaningfully engage older adults and caregivers in designing programs, services and policies. • The many silos in the system could make it difficult to improve the quality of hospital-to-home transitions.

Some factors could also facilitate (or help) the implementation of the three elements discussed previously. Sometimes, there may be a window of opportunity, a period of time during which there is a chance to do something. A window of opportunity could open as a result of a recent event that was highly publicized in the media, a crisis, a new technology emerging, a change in public opinion, or an upcoming election. Factors that may help implementing these elements are summarized in Table 6.

Table 6: Potential factors that could help implementing the elements

Element	Description of potential facilitators

Element 1 – Enabling older adults and their caregivers to play a role in their own care during hospital-to-home transitions	• Several organizations are trying to empower patients and caregivers, for example:
	  ○ the conversation guide about hospital-to-home transitions by Health Quality Ontario;(8) and
	  ○ the McMaster Optimal Aging Portal is a website offering direct and easy access to evidence-based information about how to stay healthy, active and engaged, and how to manage our health conditions, as we grow older (https://www.mcmasteroptimalaging.org/).

Element 2 – Enabling providers to improve the quality of hospital-to-home transitions	• Several non-governmental organizations are leading initiatives to improve the quality of hospital-to-home transitions: ○ The Aging, Community and Health Research Unit is a collaborative research group working together with older adults with multiple chronic conditions and their family caregivers to promote optimal aging at home.(59) Their studies (for example, Community Assets

	Supporting Transitions) actively engage patients as partners in the research.(51) ○ The Canadian Foundation for Healthcare Improvement is leading a project (Bridge-to-Home) with 16 organizations across seven provinces to improve the quality of care, as well patient and caregiver experiences of care, during hospital-to-home transitions.(60) ○ The Registered Nurses' Association of Ontario will update its practice guideline on transitions in care in the coming year.(17) The guideline will assist nurses to become more comfortable, confident and competent when caring for clients undergoing care transitions. ○ Other initiatives could also inspire ways to improve the quality of-care transitions for older adults with complex health and social needs. For example, Behavioural Supports Ontario recently published a checklist that can be used by care teams to support complex transitions from hospital and community into long-term care.(61)
Element 3 – Enabling decision-makers to make small yet rapid changes to improve the quality of hospital-to-home transitions	• The health system in Ontario is increasingly putting patients and rapid learning and improvement at its centre. • There are many mechanisms to support patient and family engagement in the province: ○ Patient and Family Advisory Councils (PFACs) or their equivalent (for example, Ontario Citizens' Council; Patient and Caregiver Advisory Table for Home and Community Care) help to set direction for the system (or for organizations). ○ Health Quality Ontario is leading several initiatives on patient engagement in quality improvement (for example, patient-engagement tools and resources, and Patient, Family and Public Advisors Council).

Questions to consider

- What could be the biggest challenges to implement a new approach to hospital-to-home transition?
  - How could we address these challenges proactively?
- What other changes could facilitate the implementation of this new approach?

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Merit review

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