

Panel Summary

Engaging older adults with complex health and social needs, and their caregivers, to improve hospital-to-home transitions in Ontario

15 November 2019



HEALTH FORUM

EVIDENCE >> INSIGHT >> ACTION

Engaging older adults with complex health and social needs, and their caregivers, to improve hospital-to-home transitions in Ontario

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 and systematically elicited 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 views 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 summary

On the 15th of November 2019, the McMaster Health Forum convened a citizen panel on engaging older adults with complex health and social needs, and their caregivers, to improve hospital-to-home transitions in Ontario. This summary highlights the views and experiences of panel participants about:

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

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

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Summary of the panel

During the deliberation about the problem, panellists were asked to share what they perceived as the biggest challenges about engaging older adults with complex health and social needs (and their caregivers) to improve hospital-to-home transitions in Ontario. They focused on four challenges: 1) despite some positive experiences, hospital-to-home transitions have been generally described as stressful and risky; 2) the hospital-to-home transition process is fuelled by assumptions; 3) care needs and decisional needs are hard to identify (and address); and 4) there is skepticism towards large-scale reforms to improve hospital-to-home transitions.

In discussing the elements of a potentially comprehensive approach to address the problem, panellists expressed the need for: greater patient and caregiver empowerment (**element 1**) with accessible and personalized information supports (particularly for those with limited health literacy levels or different cultural considerations); information from comprehensive assessments to identify the health and social needs (and also consider illness trajectories); greater collaboration (with providers and peers); and concrete tools to hold providers accountable. Panellists indicated that to enable providers to improve hospital-to-home transitions (**element 2**), there was a need for: improved collaboration between patients, caregivers, and providers, as well as between caregivers and their peers); a way to prioritize this issue so that providers can engage in conversations with patients and caregivers, and comprehensive care needs and decisional needs assessment; and proactively providing health promotion, prevention and maintenance support, rather than responding reactively when individuals become very unwell. Lastly, panellists emphasized the need to enable decision-makers (**element 3**) with: a solid strategy for scale-up and spread of an innovative hospital-to-home transition model; the necessary infrastructure to support those who will implement the model across the province; accountability mechanisms (for example, complaint systems, audit and feedback and public reporting); and a culture of innovation (the system must learn from its successes and failures).

Panellists identified the limited resources (both human and financial) as one of the biggest barriers for improving hospital-to-home transitions for those with complex health and social needs. They also had doubts about the system's capacity to scale up and spread a commonly agreed upon transitional-care model that would be able to break down the silos (within the health system, and across the relevant sectors). In discussing potential strategies to move forward, panellists emphasized the need to convene a dialogue with provider organizations (both from the public not-for-profit and private sectors), government policymakers from all the relevant sectors, representatives of older adults with complex needs, and representatives of caregivers to find solutions to this collective problem.



“I was overwhelmed prior to transition and did not know what to ask.”

Discussing the problem:

What are the most important challenges to engaging older adults with complex health and social needs (and their caregivers) during hospital-to-home transitions?

During the deliberation about the problem, panellists were asked to share what they perceived to be the main challenges to engaging older adults with complex health and social needs (and their caregivers) during hospital-to-home transitions. To do so, they were asked to look back over a hospital-to-home transition they (or a loved one) experienced and identify experiences at the hospital and back home that affected the transition (both positive and negative experiences). They were also asked about decisions made by them (or by someone

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else) that positively or negatively affected the transition. Lastly, they reflected on the health reforms underway in Ontario and how these could affect hospital-to-home transitions.

Panellists individually and collectively focused on four challenges in particular:

- 1) despite some positive experiences, hospital-to-home transitions have been generally described as stressful and risky;
- 2) the hospital-to-home transition process is fuelled by assumptions;
- 3) care needs and decisional needs are hard to identify (and address); and
- 4) there is skepticism towards large-scale reforms to improve hospital-to-home transitions.

We review each of these challenges in turn below.

Despite some positive experiences, hospital-to-home transitions have been generally described as stressful and risky

Some panellists discussed some positive experiences in relation to hospital-to-home transitions. Yet, panellists generally had the impression that hospital-to-home transitions were stressful and risky. They generally felt left to their own devices to manage their own care (or the care of their loved one), to coordinate care and to navigate the health and social systems.

Panellists identified six key areas that contributed to the stress and risks associated with hospital-to-home transitions:

- 1) not having community-based providers assigned to follow up with them after being discharged from hospital;
- 2) not having access to information to manage their health and care;
- 3) not having a comprehensive assessment before being discharged and at home;
- 4) not being engaged meaningfully in planning hospital-to-home transitions;
- 5) not receiving timely follow-up; and
- 6) not all sectors have the same capacity to support hospital-to-home transitions.

Not having community-based providers assigned to follow up with them after being discharged

Some panellists emphasized that they highly valued the various providers who were assigned to their case at the point of transition (including nurses, occupational therapists, physical therapists, dietitians, social workers and others). One panellist particularly appreciated her

experience when she met the entire multidisciplinary care team to ensure she received consistent information and a clear plan for the transition back home (as opposed to having individual meetings with each provider).

Yet, some panellists had the impression that the hospital-to-home transition is often dependent on individual providers who are able to go above and beyond what is expected from them. Most panellists indicated lacking an identified care coordinator at the hospital and back in the community who would know their entire medical record in and out, whose job was to ask about their health and social needs, and then makes sure that referrals to services are made to align with these needs. One panellist indicated that, based on his personal experience, the care coordinator who has been assigned to him at the point of transition is not the one providing services, therefore the home-care providers need to connect with the (indirect) care coordinator (or their administrator) who can change the plan of care for additional supports. This gave the impression that the care coordinator lacked the authority to properly arrange all the support needed (and to make things happen).

Not having access to information to manage their health and care

For those who had positive transition experiences, one aspect they noted aided in this positive impression was having a clearly detailed and outlined guide for what to expect at every step of the transition process, both while in the hospital and then while at home. One panellist appreciated receiving in advance printed material to properly prepare for his elective procedures and to prepare for his return home (for example, the guide for patients and their loved ones developed by the Regional Cardiac Care Centre at St. Mary's General Hospital in Kitchener describing the heart surgery, how to prepare for the surgery, the day of the surgery, what to expect after the surgery and what to expect when going back home).

Conversely, those who had negative experiences frequently commented that they did not know what was going on with their health and care, what to expect next when they returned home from hospital, and whom they should ask for help. They hoped to get access to personalized information support about their current health and care (since many older adults and caregivers have different levels of health literacy and other cultural considerations), personalized information support about their illness trajectory and anticipating future care needs (for example, lacking information about the trajectories of cognitive decline in Alzheimer's disease can affect the ability of older adults and caregivers to plan for future home and community care), as well as information to help them navigate the health system

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(for example, what programs and services are publicly available, what are the criteria for eligibility for these programs and services, and what other services that are not publicly funded may be available).

Panellists pointed out that you don't know what you don't know. One panellist indicated that she would have never thought that finding a way to be safely transported back home after discharge would be so challenging: "I didn't know that transportation would be an issue [to go back home] until it was an issue." A second panellist highlighted that no information was provided to her about the need for supportive equipment and home modifications (for example, the need to install assistive technologies) to facilitate her return back home. She did not know she needed certain types of equipment before returning home, and then she didn't know how to access and afford the equipment.

Panellists expressed that providers should be proactive in pointing older adults and caregivers in the right direction to access information, but they should also recognize when directing them to information isn't enough (due to the older adults' conditions). One panellist was surprised her loved one was handed a list of references and agencies to call before being discharged, without proactively identifying and addressing barriers to accessing these services. "She lived alone and they gave her a list of agencies for her to call, but she could not get out of bed for a glass of water let alone calling agencies."

Not having a comprehensive assessment before being discharged and at home

A panellist with a positive experience outlined that he had a comprehensive assessment prior to, and immediately after, the transition home. This assessment outlined to him and the providers what was needed and where extra assistance could and should be provided.

Conversely, those with negative experiences were generally sent home without a comprehensive assessment, or without being asked specific questions about their other health and social needs. A few panellists indicated that the care team in the hospital tended to focus on the one problem for which they were hospitalized, without a clear understanding of the complex health and social challenges that they were dealing with back home. Thus, there was no plan put in place to address the complex health and social needs.

One panellist recalled her experience of being discharged after an outpatient surgery. The care team never asked questions about her diabetes and other conditions and, once back home,

she experienced severe hypoglycaemia. Without her husband's swift intervention, she is convinced that she would have died. A second panellist provided the example of her mother who was prematurely discharged without proper assessment of the home environment. She was unable to walk up and down stairs and thus unable to function in her home environment. Within 48 hours of discharge she fell due to mobility issues and became very dehydrated, and thus she was readmitted to hospital.

Not being engaged meaningfully in planning hospital-to-home transitions

A few panellists indicated that they appreciated being engaged meaningfully in planning of their hospital-to-home transition. This generally meant having the opportunity to have time to digest the information provided to them, ask questions, and be provided with choices.

However, panellists generally felt that older adults and caregivers were rarely meaningfully engaged. Some pointed out that the shortage of hospital staff undermined their engagement in meaningful conversations (and planning) about hospital-to-home transition. As one panellist said: "attentive care was not possible."

Others indicated that when they were provided with so-called 'choices', they felt that these were not viable choices. For example, one panellist indicated being provided with the choice of going home (but with limited home support) or to an inpatient rehabilitation hospital. However, there was no guarantee where that hospital would be. This panellist preferred to go back home because he feared being sent to a rehabilitation hospital far away from his community and his social support network. This resonated with another panellist who indicated that patients in rural, remote and northern areas are often transferred to care facilities that are hours away from their homes/families as part of the hospital-to-home transition process

Some panellists who acted as caregivers to an older adult with complex needs revealed difficulties in engaging with (and receiving support from) providers. One panellist was under the impression that hospital staff tended not to check in on patients as often when family was at the bedside. A second panellist worried that providers were not sharing important information with caregivers (even if the older adults did not have the cognitive ability to understand). Lastly, some caregivers felt they could not have frank and open discussion about the burden they experienced: "If caregivers talk about stress, it comes across as complaining and there tends to be a guilt trip put on them for complaining."

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Not receiving timely follow-up

Few panellists indicated receiving timely follow-up after returning home. Panellists generally felt that this issue was exacerbated by breakdowns in communication and information sharing between patients, caregivers, care coordinators and care providers. As one panellist said: “I was told at discharge by the CCAC [Community Care Access Centre] that all the services would be ready when I got home. It took almost two weeks for them to call to ask if I needed anything.” This resonated with a second panellist who said: “The person in the hospital filled out the form and only put two home visits with no rehab. The visiting nurse knew that it was not enough and it took more than a week for that nurse to arrange with those ‘with authority’ to properly arrange the required rehab.”

One panellist spoke about the risks associated with the lack of timely follow-up (which is particularly critical in a context where patients do not have social support at home). He gave the example of a neighbour who was discharged from hospital back home. He found his neighbour, who was living alone, face down in the apartment several hours after being discharged. If he had not decided to pay an impromptu visit to his neighbour, the latter would have probably been found dead.

Not all sectors have the same capacity to support hospital-to-home transitions

Some panellists perceived that hospital-to-home transitions may be better managed in some sectors than others. Those who experienced hospital-to-home transition for surgical care (for example, cardiac surgery, orthopedic surgery), cancer care or palliative care described receiving more support during the process. In contrast, some panellists who have been hospitalized for acute or chronic problems experienced transitions that were more rushed: “[The care team] set up home care before we left, which included assessments at the house. What they provided was not overly helpful until [my loved one] became palliative and then things at home really improved in terms of the equipment and the care provided.” Thus, some panellists perceived that some ‘silos’ in the health system may be better at supporting hospital-to-home transitions.

The hospital-to-home transition process is fuelled by assumptions

Panellists pointed out that the hospital-to-home transition process is generally fuelled by assumptions made by providers, older adults and caregivers, including:

- assumptions that older adults who are discharged will have support from family or friends back home, when in fact for some their support network is compromised (no siblings, family members, or friends who can take care of them, long-distance caregivers, or having to rely on involuntary caregivers such as neighbours or former spouse);
- assumptions that older adults will be able to access the right amount of services to meet their individual needs;
- assumptions that the care plan will be implemented once back home (and that care providers will be doing what they were supposed to do or what they said they would do, and work in collaboration with other providers to meet the needs of older adults);
- assumptions about responsibility and accountability (and that all older adults will have a designated care coordinator who is actively seeking to implement the care plan);
- assumptions that older adults will be able to manage their health and care (for example, going back home may provide older adults with a false sense of security and control);
- assumptions that all older adults are capable of making their own decisions, whereas some may experience cognitive challenges that impair decision-making;
- assumptions that older adults and their caregivers would understand all the

Box 1: Key features of the citizen panel

The citizen panel about engaging older adults with complex health and social needs, and their caregivers, to improve hospital-to-home transitions in Ontario had the following 11 features:

it addressed a high-priority issue in Ontario;

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

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- assumptions that older adults will be truthful in disclosing the level of support that they have at home (or lack thereof), or have the capacity to do so (for those with cognitive impairment).

Care needs and decisional needs are hard to identify (and address)

Panellists were then asked to identify the decisions made by themselves (or by someone else) that positively or negatively affected their transition from hospital to home. They generally struggled with this question, which reflected that:

- older adults and caregivers may not have a clear picture of their health conditions and their care needs, and thus may be unable to identify the decisions that they should make;
- hospitalization can be physically and mentally overwhelming, and thus supports are needed to enable patients and caregivers to make decisions about their care (as one panellist said, “I was overwhelmed prior to transition and did not know what to ask”);
- healthcare providers rarely engage older adults and caregivers in shared decision-making during the planning of hospital-to-home transitions (thus it was unclear for patients and caregivers that they

Box 2: Profile of panel participants

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants:

- **How many participants?**
12
- **Where were they from?**
Burks Falls (1), Curve Lake (1), Elliot Lake (1), Mississauga (1), Oakville (1), Orleans (1), Puslinch (1), Sarnia (1) and Toronto (4)
- **How old were they?**
45-64 (3), and 65 and older (9)
- **Were they men, or women?**
men (3) and women (9)
- **What was their perspective?** Older adults with complex needs (7 out of 8), and caregivers of older adults with complex needs (3 out of 4)
- **What was the educational level of participants?**
8% completed elementary school, 25% completed high school, 25% completed community college, and 42% completed a bachelor’s degree/post-graduate training or professional degree
- **What was the work status of participants?** 8% working full-time, 83% retired, and 8% disabled
- **What was the income level of participants?**
17% earned less than \$20,000, 25% between \$20,000 and \$40,000, 17% between \$60,000 and \$80,000, 25% more than \$80,000, and 17% preferred not to answer
- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panel

- could play a role in making actual decisions); and
- older adults and caregivers may not feel empowered to make their care needs known to providers (thus, they often don't know when or how to speak up, to ask questions and clarifications, and to ask for help).

There is skepticism towards large-scale reforms to improve hospital-to-home transitions

Panellists were asked whether or not they were aware of the health reforms underway in Ontario that could affect hospital-to-home transitions (notably the creation of the new Ontario Health Teams). Most panellists were not aware of such reforms and how it would affect the care they currently receive (or may seek).

They also expressed skepticism about the capacity to make large-scale system changes to improve hospital-to-home transitions for older adults with complex health and social needs. This skepticism was fuelled by three factors:

- a general distrust in government reforms (as one panellist said, “It’s the government. They are always changing and wasting money and not improving anything. Nothing ever gets done.”);
- the perceived difficulty of bridging silos across providers, across settings (for example, acute care, primary care, home and community care, long-term care), and across sectors and levels of governments (municipal, provincial/territorial, and federal); and
- scarce resources (both human and financial) that limit the capacity to scale up and spread innovative models of hospital-to-home transitions.

Regarding the latter point, panellists recognized that there are innovative models of hospital-to-home transitions being pilot tested (such as the Community Assets Supporting Transitions study presented in the citizen brief). However, some panellists doubted that we could scale up and spread these innovations across the province. For instance, given the critical nursing shortage in rural and northern communities of Ontario, nurse-led hospital-to-home transition models may not be feasible. As one panellist said: “There is nothing in the document that is not a good idea, but I have a hard time seeing how they can happen.”

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“There is a huge problem in this province with a looming deficit. (...) We need to be realistic and not expect that we can throw money and get more providers.”

Discussing the elements:

How can we address the problem?

After discussing the challenges that together constitute the problem, participants were invited to reflect on three elements (among many) of an approach to engaging older adults with complex health and social needs (and their caregivers) to improve hospital-to-home transitions in Ontario:

- 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.

Panellists were reminded that the three elements can be pursued together or in sequence. A description of these elements, along with a summary of the research evidence about them, was provided in the citizen brief that was circulated to participants before the event. Whenever possible, we describe areas of common ground and differences of opinions among panellists and (where possible) identify the values underlying different positions.

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

The discussion about the first element focused on identifying 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. As outlined in the citizen brief, this could 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 used in 27 hospitals across Ontario); and
- strategies to develop the skills of older adults and their caregivers to manage their own health and care (known as ‘self-management’ skills).

During the discussion about their roles and the supports needed to play these roles, seven values-related themes emerged (see Box 3). The first value-related theme emerging from the deliberation was ‘engagement’. Panellists generally agreed that older adults with complex needs and their caregivers have a right to be engaged in decisions that will affect their lives (including treatment decisions and decisions related to hospital-to-home transitions).

However, participants talked about a wide range of ‘engagement’: no engagement, collaboration, partnership and advocacy. On one end of the spectrum, some older adults and their caregivers may not be capable or confident to engage in their own health and care. For instance, some may not have the cognitive or physical capacity to understand or use the instructions provided to them, or some caregivers may not be capable of (or comfortable) implementing the new care plan back home. Most panellists indicated that older adults and caregivers should be collaborators or partners within the care team. On the other end of the spectrum, many panellists saw their role as advocates in defending the rights of older adults with complex needs (and their caregivers) to ensure they receive optimal care.

The second value-related theme was empowerment. Panellists generally agreed about the need to empower older adults and caregivers to take part in decisions related to their health

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and care. To enable this, care providers should value shared decision-making, and older adults and caregivers should have access to trustworthy information allowing them to make the right decisions about their health and care. As one panellist said: “I need to get an advance copy of [a guide describing] what it would look like. I like to ruminate and then have an opportunity to sit down and interrogate the care team. I may not be able to receive the information when I’m sedated.” This shows how empowerment is intimately linked with the first value-related theme: there can’t be meaningful engagement if there is no empowerment.

The third and fourth values-related themes were holistic, and person- and family-centred. Panellists wanted to help develop holistic transition plans that considered the wide range of health and social needs of older adults, as well as those of caregivers. As one panellist said: “As a caregiver, I’m quite happy to get instructions about what to do and how to do it . . . but there needs to be an element that considers myself as a caregiver. [The transition plan must] consider my ability to do what you’re asking me to do.”

The fifth value-related theme was adaptability. The transition plan (and the information support about the transition plan) must be adaptable and tailored to the care needs and decisional needs of older adults and their caregivers. Panellists were reluctant to receive large, generic phonebook-style guides that may be hard to navigate and use given their specific conditions. Panellists emphasized that older adults and caregivers have varying levels of health literacy and different cultural considerations, and thus information supports should be adapted to diverse needs (whether these are websites, mobile applications, or helplines).

Box 3: Key messages about element 1

What are the values-related themes that emerged during the discussion?

- engagement
- empowerment
- holistic
- person- and family-centred
- adaptability
- collaboration
- accountability

The sixth value-related theme was collaboration, particularly with providers and peers. Panellists expected greater collaboration with both groups to answer their pressing questions in a timely fashion (for example, a contact person who could have small one-minute discussions), as opposed to being directed to the emergency department. Some panellists

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envisioned a much greater role from peers who could help them navigate the program and services available, share their own experiences, and provide support and mentorship to caregivers. One panellist said: “[Peers can] teach you what they have learned along the way [as caregivers], sometimes the hard way.” A second panellist went further: “Peer support may be about other things than care, it’s care for me [as a caregiver].”

The seventh value-related theme was accountability. Several panellists indicated the need to be equipped with concrete tools (for example, a checklist detailing the entire transition process, or proper mechanisms and key contacts if things do not go as planned) to hold providers accountable if things do not go as planned. One panellist explained how she developed her own checklists to monitor the hospital-to-home transition process, along with the home and community care required by her loved one.

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

The discussion about the second element focused on identifying strategies to enable individual providers (or providers working as a team) to improve the quality of hospital-to-home transitions, as well as discussing what role older adults and caregivers could play in this process. As outlined in the citizen brief, this could 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.

Box 4: Key messages about element 2

What are the values-related themes that emerged during the discussion?

- collaboration (between patients, caregivers and providers, as well as between caregivers and their peers)
- proactive
- realistic
- openness
- accountability

There were five value-related themes that emerged during the discussion about element 2 (see Box 4). The first values-related theme that emerged was collaboration (between patients, caregivers and providers, as well as between caregivers and their peers). A few panellists indicated that there was a pervasive “us versus them” mentality between providers and patients/families in the health system, which was not conducive to collaborative care. There was a need to address this perception in order to enable providers to improve hospital-to-home transitions.

The second value-related theme was proactivity. Panellists indicated that providers should be proactive in offering health promotion, prevention and maintenance support, rather than responding reactively when individuals become very unwell. Proactive support appeared essential, given the complexity of health and social needs of older adults, but also the concern that these individuals may be socially isolated and may not proactively seek care. As one

panellist said: “We have a decent system in dental health. They are sending postcards every six months. They are not waiting for your teeth to fall out.” Panellists recommended a similar approach be adopted across health and social systems.

The third value-related theme was having realistic expectations about what providers can do to improve hospital-to-home transitions. Panellists generally agreed that there are not enough publicly funded services to meet people’s needs, and a shortage of providers may be one factor contributing to this problem. While some called for greater public funding to increase the number of providers, others argued that it was not a realistic solution. One panellist insisted that we needed to find solutions within the confine of existing (yet scarce) resources: “There is a huge problem in this province with a looming deficit. (...) We need to be realistic and not expect that we can throw money and get more providers.” Thus, they called for new models of care that could prioritize this issue and allow providers to engage in conversations with patients and caregivers, provide individual coaching, or engage in quality-improvement efforts).

The fourth value-related theme was openness. Panellists acknowledged that relevant patient information needed to be easily accessible to all providers, including personal-support workers. They indicated that personal-support workers were in a unique situation with regular contact with older adults and caregivers. If they were better informed about the complex health and social needs of older adults, they could proactively raise red flags with home- and community-care providers. Personal-support workers could play a key role in care coordination and communication across providers.

The fifth value-related theme was accountability. Panellists believed that there should be a mechanism to support providers (and provider organizations) to better monitor the hospital-to-home transition process. As one panellist said: “There should be a way for professionals to follow-up with you. Is everything going as planned? Do you need additional help?”

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

The discussion around element 3 focused 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.

As outlined in the citizen brief, 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.

While panellists grappled a bit more to define a role for themselves in a rapid-learning system, some panellists indicated that it was an approach that made “common sense.” Four values-related themes emerged during the discussion about element 3 (see Box 5).

Box 5: Key messages about element 3

What are the values-related themes that emerged during the discussion?

- person- and family-centred
- innovation
- openness
- accountability

The first value-related theme that emerged was person- and family-centred. A rapid-learning system should be guided by the needs and priorities of patients and caregivers. As one panellist said: “Patients should point out what needs to be fixed. And then, [health-system leaders should] ask those most affected to see if it has been fixed.”

The second value-related theme was innovation. Several panellists hoped that innovative models of hospital-to-home transitions could be adopted more rapidly across the province. They favored an incremental approach (“let’s divide things up, roll things up sequentially, and learn along the way”). In order to address potential regional inequities in the adoption of innovative models, they suggested that a central provincial agency should develop a team of trainers who are not bound geographically and could support the adoption of the innovation across the province. And while they supported innovation, they were clear that it didn’t mean a complete overhaul of the current system: “Don’t re-invent the wheel. Don’t fix what is not broken.”

The third value-related theme was openness. In order to support a rapid-learning system, there was a need for greater openness in sharing successes and failures. They pointed out that the learning process is not strictly about sharing best practices, it is also about sharing failures and learning from those. However, some panellists indicated that there was a “fear of failure” among health-system leaders, which may be exacerbated by increased public and media scrutiny. This fear may nurture a lack of transparency and candor among health-system leaders when initiatives do not achieve their objectives (and thus not allowing us to collectively learn from failures).

The fourth value-related theme was accountability. Panellists discussed the importance of accountability in three ways: 1) those who are accountable/responsible to bring about change should have the necessary authority to make the change happen; 2) there needs to be clear communication mechanisms in place to inform the public (for example, public reporting mechanisms) about the changes and to help them monitor progress (“The community should be considered as equal partners. Inform us of what’s going on, how we can take part in this process, and how can I let you know if this isn’t working.”); and 3) you need a set of indicators to monitor progress (for example, hospital readmission rates, perception of seamless transition, perceived health status, patient/caregiver satisfaction and provider satisfaction).



“I want my mother to feel important and be important in the system.”

Discussing implementation considerations:

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

After discussing the three elements of a potentially comprehensive approach for addressing the problem, participants examined potential challenges and facilitators for moving forward.

Panellists identified the limited resources (both human and financial) as one of the biggest barriers for improving hospital-to-home transitions for those with complex health and social needs. Although panellists had mixed views about whether increasing healthcare budgets would translate to more staff and improved hospital-to-home transitions, they also had doubts about the system's capacity to scale up and spread a commonly agree upon model. Regarding the latter point, they also noted the following challenges:

- there may be resistance from providers to changing how things are being done (behavioural, attitudinal and cultural barriers to change);
- some providers seem unable to work to their full scope of practice due to work overload (and some may not have the authority required to make the change happen); and

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- there are many silos in the health system that are hard to break down (which is illustrated by the lack of interprofessional collaboration), but also across the relevant sectors (silos that may be reinforced by competing priorities that may be hard to reconcile).

In discussing potential strategies to move forward, panellists emphasized the need to convene a dialogue with provider organizations (from the public sector, not-for-profit sector, and private sector), government policymakers from all the relevant sectors, and representatives of older adults with complex needs and caregivers. Such dialogue could help to proactively address some of the challenges listed above (for example, identifying a backbone organization to support the implementation, spread and scale-up of new models of care delivery), and find solutions to our collective problem. As one panellist concluded, these types of initiatives can be a good reminder that the health and social systems are working with and for the people: “I want my mother to feel important and be important in the system.”

Engaging older adults with complex health and social needs, and their caregivers,
to improve hospital-to-home transitions in Ontario

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