Panel Summary

Enhancing Equitable Access to Assistive Technologies in Canada

7 April, 21 April & 5 May 2017

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For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at regional/provincial levels and at national levels, the Forum harnesses information, convenes stakeholders and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions and communicate the rationale for actions effectively.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-16 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. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

About this summary

On April 7 (Ontario), April 21 (Edmonton) and May 5 (Moncton) 2017, the McMaster Health Forum convened citizen panels on how to enhance equitable access to assistive technologies in Canada. The purpose of the panels was to guide the efforts of policymakers, managers and professional leaders who make decisions about our health systems. This summary highlights the views and experiences of panel participants about:

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

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

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Summary of the panel

Panel participants identified seven challenges related to enhancing equitable access to assistive technologies in Canada: 1) assistive technologies do not seem to be fairly allocated; 2) access to assistive technologies is complicated and often not focused on needs of the individual; 3) many face challenges in paying for needed assistive technologies and/or engaging with the private sector to identify and purchase what they need; 4) there is a lack of an integrated approach to delivery of assistive technologies as part of larger care pathways and packages of care; 5) stigma associated with needing an assistive technology; 6) caregiver burden and challenges in getting appropriate supports; and 7) the lack of integration of assistive technologies into infrastructure.

Participants were supportive of information and education provision to help them make decisions about which assistive technologies they need and how to access them (element 1), emphasizing that information needs to be reliable and provided through a central point of contact. To help citizens get the most out of publicly funded programs (element 2), participants stressed the need for equitable access regardless of ability to pay. Participants emphasized the need to ensure access to assistive technologies that help people meet basic needs for daily living, and to all of the 50 priority assistive technologies identified by the World Health Organization, as well as supporting groups that face a disproportionate burden (e.g., people with disabilities, mental health conditions and chronic disease). For supporting access to needed assistive technologies that are not covered by public programs (element 3), participants recognized the need for collaboration between the health system and other sectors, with a focus on the private sector (e.g., insurance companies) and voluntary sector (e.g., charities). Across the elements, two values-related themes emerged with some consistency: 1) collaboration (to coordinate access to needed assistive technologies and between the health system and other sectors to support consistency across the country); and 2) equity (to ensure that all of those in need of assistive technologies have access regardless of ability to pay).

When discussing the potential barriers and facilitators to moving forward, participants identified collaboration between the health system and other sectors as a challenge, yet central to supporting streamlined access to programs and services offering assistive technologies across Canada. Despite this, participants thought there was an opportunity for coordination and collaboration given the potential for cost-savings to the health system through greater efficiency. Within the health system, participants identified having occupational therapists work within primary-care teams as key to supporting system navigation.

> “A lot of people don’t know where to go [for assistive technologies], so they go without.”

Discussing the problem: What are the most important challenges to enhancing equitable access to assistive technologies?

Panel participants agreed that the need for assistive technologies is increasing. Participants shared their experiences (or those of a family member or someone to whom they provide care) with a variety of programs and services offering assistive technologies. They individually and collectively focused on seven challenges:

- assistive technologies do not seem to be fairly allocated;
- access to assistive technologies is complicated and often not focused on needs of the individual;
- many face challenges in paying for needed assistive technologies and/or engaging with the private sector to identify and purchase what they need;
- there is a lack of an integrated approach to delivery of assistive technologies as part of larger care pathways and packages of care;
- stigma associated with needing an assistive technology;
- caregiver burden and challenges in getting appropriate supports; and
- the lack of integration of assistive technologies into infrastructure.

Most of these themes emerged across all three of the panels held in Edmonton, Hamilton and Moncton. However, the theme related to stigma only emerged in the Moncton panel and the theme related to lack of integration with existing infrastructure only emerged during Edmonton and Moncton panels. We note this below, and also highlight specific examples from panels in the other themes were shared.

Assistive technologies do not seem to be fairly allocated

Participants identified several reasons for why assistive technologies seem to not be fairly allocated. First, most agreed that differences in assistive-technologies programs and services within and between provinces means that Canadians are treated differently based on where they live, especially those in remote communities.

Participants also identified the variability in publicly funded lists of assistive technologies as a reason for unfair allocation. In particular, many participants emphasized how some assistive technologies are central to living (e.g., continuous positive airway pressure (CPAP) machines), but are not publicly funded or only partially funded in some jurisdictions. As a result, many indicated that those with limited financial means often are unable to access needed technologies.

Box 1: Key features of the citizen panels

The citizen panels about enhancing equitable access to assistive technologies in Canada had the following 11 features:

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

Finally, eligibility criteria for assistive technologies was also identified across all three panels as an important factor that contributes to unfair allocation of assistive technologies. For example, some participants pointed out that eligibility criteria are most often focused on older adults and those living with a disability. This means that others in need of assistive technologies, such as those living with invisible disabilities, are not able to access needed assistive technologies because they are not accounted for in eligibility criteria. Some participants specifically discussed not being able to access publicly funded assistive technologies because they did not meet the age criteria, despite having a need for the technology.

Access to assistive technologies is complicated and often not focused on needs of the individual

Adding to the challenge of assistive technologies not being fairly allocated, many participants expressed frustration with the complicated processes required for accessing assistive technologies, and that the focus is not on the needs of the individual. For example, in emphasizing how complicated and frustrating it can be to access the technologies they need, participants in the Hamilton panel all agreed with one participant who stated that "a lot of people don't know where to go, so they go without."

Based on their experiences, participants provided several examples for why access is complicated and not focused on the needs of individuals. First, participants discussed challenges with eligibility assessments for programs. Many expressed frustration with the rigid classification of disability into 'boxes,' that allocation does not take into account the spectrum of need within these boxes, and that many people do not fit well into just one box or any box at all. As a result, participants indicated that this type of rigid approach makes it very hard for those in need to identify where to go when their needs are not accurately reflected in program criteria.

Participants in all the panels also identified system navigation as a main concern. In particular, participants agreed that access to assistive technologies is fragmented, and there are many access points in the health system. Many indicated that this makes it hard to know where to go to access publicly funded assistive technologies, and others noted that it is very complicated for those with complex and/or multiple conditions (i.e., those fitting in multiple eligibility 'boxes'). For example, some participants noted that while there are many programs that provide assistive technologies (e.g., federal programs, publicly funded provincial programs, municipal programs, charitable organizations, private insurance and employment-based benefits), the landscape is very complicated from a user perspective. Adding to this, it was noted that there is a lack of coordination between agencies and inconsistencies between them in terms of what and how much is covered. Moreover, participants expressed significant frustration related to the lack of information to support system navigation across this complicated landscape of programs.

Lastly, some participants described the process of accessing assistive technologies as bureaucratic and provided examples of having to routinely ‘prove’ disability to qualify for supports, even though they had a permanent disability. For example, in the Hamilton panel, a participant with a congenital amputation and a participant with a permanent colostomy described having to routinely provide proof of their disability despite each having a permanent disability. Expressing frustration about this situation, one participant questioned “how many times do I have to prove that I have a disability to someone at the government?”

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?**
  15 (Edmonton); 12 (Moncton); 10 (Hamilton)
- **Where were they from?**
  Participants came from Alberta, Ontario, Nova Scotia and New Brunswick
- **How old were they?**
  25-34 (3), 35-49 (4), 50-64 (7), 65-74 (14), and 75 and older (8)
- **Were they men, or women?**
  Men (19) and women (18)
- **Were they living in urban, suburban or rural settings?**
  Urban (20), suburban (9) and rural (8)
- **How many have used assistive technologies?**
  Sought or are currently using assistive technologies (21)
  Currently providing care to a family member or friend who has sought or is currently using assistive technologies (14)
  Have never sought or used assistive technologies (16)
- **What was the income level of participants?**
  11% earned less than $20,000, 11% between $20,000 and $34,999, 30% between $35,000 and $49,999, 27% between $50,000 and $79,999, 19% more than $80,000, and 3% preferred not to answer
- **How were they recruited?**
  Participants were selected based on explicit criteria from the AskingCanadians™ panel

Many face challenges in paying for needed assistive technologies and/or engaging with the private sector to identify and purchase what they need

An additional challenge to accessing needed assistive technologies that are not publicly financed is high out-of-pocket costs. Some participants discussed going without needed assistive technologies because the costs are prohibitive. Other participants discussed challenges that pharmacies experience in stocking needed supplies because of the high purchasing costs. One participant cited having to drive to multiple pharmacies in order to get the technology they needed.

Some participants also expressed challenges with approved vendors not supplying the specific technology that they need. The lack of choice in vendors was also identified as making it difficult to get the most suitable assistive technologies, which relates back to the issue of rigid approaches and not taking into account the spectrum of need within eligibility 'boxes.'

Finally, several participants discussed the role of charitable organizations in providing assistive technologies that are not publicly financed. Specifically, participants were concerned with the sustainability of charities providing assistive technologies in areas they thought should be the government's responsibility.

There is a lack of an integrated approach to delivery of assistive technologies as part of larger care pathways and packages of care

A broader challenge identified by most participants extends beyond accessing assistive technologies and relates to the health and social systems in which they are delivered. Participants recognized the role of family physicians as gatekeepers to programs and services offering assistive technologies. However, some discussed challenges in accessing needed assistive technologies for those that do not have a primary-care provider, as well as those who cannot access one in a timely manner. In addition, participants were concerned with the burden placed on primary-care providers to be able to accurately direct patients to the variety of programs and services offering assistive technologies.

Along with issues identified with primary care, many participants also discussed a lack of timely access to specialty care. For example, wait times for orthopedic surgeons was cited by several as a barrier to access, and some participants discussed not being able to work for an extended period during the wait for surgery. Others identified a lack of sensitivity in the health system to addressing urgent issues, especially as access to some assistive technologies is contingent on assessments from specialists.

The final broader health-system challenge raised by some participants related to what were seen as inefficiencies in the system. Examples of inefficiencies that participants experienced ranged from duplication of laboratory work and lack of information sharing between healthcare providers. These inefficiencies were viewed as adding to fragmented care and many participants thought these challenges could be addressed through better sharing of medical information using technology (i.e., electronic health records and personal health records).

Stigma associated with needing an assistive technology

During the panel in Moncton, participants discussed the stigma associated with assistive technologies, either as users or as caregivers trying to encourage someone to use assistive technologies. Examples of stigmatization associated with assistive technologies included wearing hearing aids, using a CPAP machine for sleep apnea, and a range of mobility devices (e.g., walkers and wheelchairs). In describing their experience with using a CPAP machine, one participant shared that “the long-term effects are dramatic, but I travel for work. I don’t take it with me because of the stigma. I feel terrible by the end of the week because I don’t have it. There’s a mouth device but it’s not covered, and this clunky machine is a hassle. The assistive technologies have advanced, but it’s not readily available [in my province].”

Caregiver burden and challenges in getting appropriate supports

Several of the participants indicated that they were currently caregivers and mentioned the lack of supports available to them. Some of them discussed restrictions to their employment, either only working part-time or not able to work at all because of the significant time required for their role as a caregiver. In addition, some participants expressed difficulties with finding and maintaining appropriate supports in the home. For example, some noted the need to extend supports beyond cleaning and maintenance and having personal support workers engage with the client to improve socialization and engagement within the community.

The lack of integration of assistive technologies into infrastructure

A few participants in the Edmonton and Moncton panels expressed frustration with the variability of accessibility standards and inaccessible public spaces (e.g., building codes and accessibility requirements). The variability in standards poses challenges even when participants have been able to access needed assistive technologies. One participant in the Edmonton panel summarized the challenge as, “my own independence is limited by inaccessible environments.”

Building on the challenges presented by the variability of accessibility standards, a few participants also discussed difficulties with using assistive technologies outside, particularly during the winter. Specific examples included lack of maintenance of sidewalks and ramps, which leaves people housebound.

Discussing the elements of an approach to address the problem

After discussing their views and experiences related to the problem, participants were asked to reflect on three elements of a potentially comprehensive approach to enhancing equitable access to assistive technologies in Canada:

1) informing citizens, caregivers and healthcare providers to help them make decisions about which assistive technologies they need and how to access them;
2) helping citizens get the most out of publicly funded programs; and
3) supporting citizens to access needed assistive technologies that are not covered by public programs.

Several values-related themes emerged during the discussion about these elements, with two emerging with consistency across the elements:

- collaboration (to coordinate access to needed assistive technologies and between the health system and other sectors to support consistency across the country); and
- equity (to ensure that all of those in need of assistive technologies have access regardless of ability to pay).

We describe below these two values as they relate to the three elements, along with other values that emerged during the deliberations.

Element 1 – Informing citizens, caregivers and healthcare providers to help them make decisions about which assistive technologies they need and how to access them

The discussion about the first element focused on supporting information and education provision for citizens, caregivers and healthcare providers. As described in the citizen brief, this approach could include:

- providing information or education through:
  - logical community points of contact (e.g., family physician or nurse, home- and community-care coordinators or other healthcare providers), and/or
  - a reliable and trusted online source usable by those who could make direct use of assistive technologies (including families and caregivers);
- including questions/prompts about the need for assistive technologies in decision aids that support care planning and purchasing of assistive technologies (either through government or private sources); and
- providing system navigators for those with complex needs, and equipping the navigators with the knowledge and skills needed to identify and support access to assistive technologies for those who could benefit from them.

Four values-related themes emerged during the discussion about element 1 across all three panels. The first value related to empowering patients and caregivers to make evidence-informed decisions through access to reliable information about programs and services offering assistive technologies. Participants expressed preferences for access to reliable information, which focused on having a central point of contact to help with system navigation. Participants also emphasized the need to provide information in accessible language that is easy to understand. In particular, suggestions were made for a centralized and trusted website with prompts to guide individuals to appropriate resources. Participants also suggested low-tech options for those that are not comfortable with technology, which included a centralized telephone service that would guide individuals to the appropriate resources.

The remaining three values related to how to proceed with implementing the components of element 1. Two of the values raised by participants related to collaboration. The first dealt with collaboration among patients, providers and organizations within the health system to ensure more coordinated access to needed assistive technologies (and care more generally). Participants thought this could be facilitated through better information sharing (e.g., electronic health records and patient-held records), and information and educational supports for providers (e.g., to enhance their awareness of programs and services offering assistive technologies). As an example, some participants suggested an expanded role for the Canadian Broadcast Corporation in radio programming providing education on assistive technologies for older adults.

The second value related to collaboration was between the health system and other sectors. Specifically, participants suggested enhancing awareness of and access to all programs that provide access to assistive technologies, ranging from publicly funded programs to those provided by charitable organizations.

Box 3: Key messages about informing citizens, caregivers and healthcare providers to help them make decisions about which assistive technologies they need and how to access them (element 1)

Four values-related themes emerged during the discussion about element 1 across all three panels.

- Empowerment (of patients and caregivers in making decisions)
- Collaboration among patients, providers and organizations within the health system
- Collaboration between the health system and other sectors
- Trusting relationships (between patients and their primary-care providers)

The final value related to the implementation of element 1 was the need to build trusting relationships between patients and their primary-care providers. This relationship was seen as extremely important by participants given the role of primary-care providers in identifying the need for assistive technologies and facilitating access to programs and services.

Element 2 – Helping citizens get the most out of publicly funded programs

The discussion about the second element focused on publicly funded programs and helping citizens to get the most out of them. As outlined in the citizen brief, this could include:

- providing public funding based on need for different types of assistive technologies (e.g., for those that improve physical and mental health, mobility, social connectedness, safety, leisure and activities of daily living), which could be done through:
  - giving funding based on need, and/or
  - controlled budgets that allow the individual to buy the products they need;
- streamlining existing government approaches that provide access to assistive technologies (e.g., tax deductions); and
- establishing transparent and flexible criteria to define what technologies are covered.

Five values-related themes emerged during the discussion about element 2 across all three panels. The most prominent value that emerged was related to equity, given that participants consistently emphasized the need to ensure that all of those in need of assistive technologies have access regardless of ability to pay. Preferences for how to implement equitable access centred on:

- ensuring access to assistive technologies that help people meet basic needs for daily living, with an emphasis on those that support communication and mobility;
- enhancing access to all of the 50 priority assistive technologies identified by the World Health Organization; and
- addressing the persistent inequitable access to technologies (and needed care more generally) that several groups seem to consistently face, including people with disabilities, mental health conditions, and chronic disease, as well as those who are homeless or marginally housed.

Box 4: Key messages about helping citizens get the most out of publicly funded programs (element 2)

Five values-related themes emerged during the discussion about element 2 across all three panels.

- Equity and fairness (in access to assistive technologies)
- Manageable per capita costs (as an outcome to prioritize)
- Ensuring excellent health outcomes (through prevention of additional health issues)
- Flexibility and adaptability (of services)
- Collaboration between the health system and other sectors

The remaining four values related to how to improve outcomes and ways to proceed with implementing components of this element. For outcomes, participants emphasized the need to focus on managing per capita costs and ensuring excellent health outcomes. In relation to prioritizing manageable per capita costs for the system, many participants indicated that whatever funding is available should be used to address the needs of those who could benefit from assistive technologies the most. For ensuring excellent health outcomes, many participants highlighted the role of assistive technologies in prevention of additional health issues. This was seen as not only saving resources for the health system in the long term (which relates to managing per capita costs), but also keeping people healthier by allowing them to age in place through enhanced access to assistive technologies. Several also pointed to the need to focus on using low-cost assistive technologies (e.g., grab bars and shower stools) to prevent injuries that require much more intensive care (e.g., through hospitalization and more intensive home and community care for longer periods of time).

Values-related ways to proceed with implementing components of this element that were emphasized by participants include ensuring flexibility and adaptability of services, and collaboration between the health system and other sectors. Ensuring flexibility and adaptability was seen as essential given that programs are often not able to address the unique needs of individuals. However, most participants also agreed that selecting from a list of preapproved vendors for assistive technologies was appropriate as it serves to protect the consumer as well as the government. Some also saw this as a way of ensuring that approvals are made in a timely fashion since assessments would only have to focus on eligibility of the individual and not the proposed vendor.

Lastly, collaboration between the health system and other sectors was identified as being important for supporting consistency in what is provided across the country, and for streamlining access to programs that provide people with needed assistive technologies. Some participants indicated that streamlining should include efficient and timely approval processes for assistive technologies, as well as a greater role for the federal government as a steward for supporting consistency and streamlined access.

Element 3 – Supporting citizens to access needed assistive technologies that are not covered by public programs

Box 5: Key messages about supporting citizens to access needed assistive technologies that are not covered by public programs (element 3)

Four values-related themes emerged during the discussion about element 3 across all three panels.

- Collaboration between the health system and other sectors
- Accountability
- Manageable per capita costs
- Equity and fairness

The discussion focused to a lesser extent on the third element, which focused on supporting citizens and caregivers to access assistive technologies that are not currently covered by public programs. As described in the citizen brief, this approach could include:

- using cost-sharing mechanisms, which could involve one or more of:
    - sliding-scale payments with the amount paid through insurance or out-of-pocket determined by an individual's ability to pay,
    - flat-rate user fees, or
    - full private payment (either from insurance coverage or out-of-pocket payment);
- enhancing supports for people with disabilities to participate in the workforce, by enhancing the scope of coverage for assistive technologies through employment-based insurance as well as through non-profit and charity programs; and
- streamlining regulatory approval processes for technologies to be brought to markets across the country.

Four values-related themes emerged during the discussion about element 3 across all of the panels. First, participants identified the need for collaboration between the health system and other sectors, with a focus on the private sector (e.g., insurance companies) and voluntary sector (e.g., charities). Specifically, information sharing across these sectors was identified as central to streamlining access to assistive technologies. Participants suggested that organizations within these sectors could undergo an approval process with approved organizations being able to access patient information and share information. Second, accountability was emphasized as a value to ensure that pricing of assistive technologies is kept affordable. For example, participants indicated that holding vendors accountable for the pricing of assistive technologies and maintaining reasonable expectations for profit would help to lower insurance premiums. Related to this, the third value emphasized was to keep per capita costs manageable, with some mentioning the role of bulk purchasing to help bring down costs. Finally, equity and fairness was identified as important in relation to cost-sharing mechanisms used. Specifically, many participants pointed to the need to prevent those in need from not accessing technologies because of inability to pay.

Discussing implementation considerations: What are the potential barriers and facilitators to implement these elements?

In discussing the three elements, participants identified potential barriers and facilitators to enhancing equitable access to assistive technologies in Canada. Although participants were supportive of the approaches discussed in the three elements, they also recognized some challenges to implementation. The main challenge identified pertained to collaboration between the health system and other sectors. While collaboration was identified as central to supporting consistency and streamlining access to programs across the country, participants recognized that communication and coordination across a large number of agencies would be challenging. Despite this, participants felt there was an opportunity to improve communication and coordination, given the potential for cost-savings to the health system through a more coordinated approach to the delivery of assistive technologies. In addition, participants identified occupational therapists as key facilitators to supporting system navigation and collaboration among patients, providers and organizations within the health system. Given this, participants felt there was an opportunity to more consistently embed occupational therapists within interprofessional primary-care teams.

Acknowledgments

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the panel summary, and that they had final decision-making authority about what appeared in the panel summary.

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