

# Panels Summary

Optimizing Patient and Family Transitions from  
Cancer Treatment to Primary- and Community-  
care Supports in Canada

2 & 9 March 2018



**EVIDENCE >> INSIGHT >> ACTION**



## 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

The McMaster Health Forum convened two citizen panels on how to improve the experiences of cancer survivors as they transition from the end of their cancer treatment to primary and community care supports in Canada. The panels were held on March 2 and 9 in Ontario and Quebec, with citizens from across 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 panellists 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 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 panels**

Panellists identified seven challenges related to improving the transition experience for cancer survivors in Canada after they complete their cancer treatment: 1) limited coordination and integration between cancer treatment and primary- and community-care supports; 2) limitations in information and communication technology infrastructure create challenges for those who receive and provide care; 3) a siloed approach to care, which means that the range of concerns faced by cancer survivors and their families are not always identified and addressed; 4) limited involvement of survivors and their families in identifying their care needs and types of supports they may require after cancer treatment; 5) access to supports from primary and community care is not consistent for everyone; 6) the transitions phase of the cancer journey is hard to define; and 7) lack of clarity and comfort with the terms used to refer to survivorship.

In discussing the elements of a comprehensive approach to address the problem, panellists were supportive of building trusting relationships and collaboration between survivors, health professionals and organizations within the system. Family physicians were identified as the main point of contact for transitions after treatment, but it was emphasized that survivors should have the full range of supports (for example, specialist, rehabilitation and psychological) available to them to ensure that family physicians are equipped to consult and refer to the appropriate supports. Panellists highlighted the need for equal access to supports for all regardless of ability to pay. When panellists discussed issues related to ways to improve the transition process after cancer treatment, they suggested the need to be empowered to make evidence-informed decisions, supported by access to reliable information and education supports (for example, a trusted website or telephone line, system navigators, volunteers or peer-to-peer support services).

When discussing the potential barriers and facilitators to improving the transition process, panellists identified the lack of funding as the most fundamental obstacle, highlighting the need for funding of programs and services to support their transitions, as well as pharmacare funding for supportive-care drugs to manage late and long-term effects of cancer treatment. Despite this, panellists thought there was an opportunity to improve coordination and integration by learning from other areas that are working well within the health system. The growing public awareness of cancer survivorship was also viewed as an opportunity to engage survivors and their families in the transition process.



“Patients [transitioning from cancer care] don’t know what they need, but I don’t think the family physician knows either.”

## **Discussing the problem:** What are the most important challenges to improving transition experiences for cancer survivors in Canada?

Panellists reviewed the findings from the pre-circulated citizen brief, which highlighted what is known about the problem. They individually and collectively focused on seven challenges:

- limited coordination and integration between cancer treatment and primary- and community-care supports;
- limitations in information and communication technology infrastructure create challenges for those who receive and provide care;
- a siloed approach to care, which means that the range of concerns faced by cancer survivors and their families are not always identified and addressed;
- limited involvement of survivors and their families in identifying their care needs and types of supports they may require after completing cancer treatment;
- access to supports from primary and community care is not consistent for everyone;
- the transition phase of the cancer journey is hard to define; and
- lack of clarity and comfort with the terms used to refer to survivorship.

## Limited coordination and integration between cancer treatment and primary- and community-care supports

The deliberation initially focused on the limited coordination and integration after completing cancer treatment and transitioning to primary- and community-care supports.

Many panellists agreed that there are significant challenges in communication between the various health professionals involved in cancer-care transitions. A number of communication challenges were cited between specialists (for example, oncologists and radiologists) and between specialists and family physicians during the transition period.

Panellists described how the lack of communication between health professionals affected their ability to ensure coordinated follow-up care in terms of knowing what types of supports are needed and what is available. One panellist described the challenge of communication between their oncologist and family physician in follow-up care, and the risk for survivors who are not proactive during the transition period: “I had to go to my family physician to order the scans and I took a copy [from my oncologist] to give to her because she didn’t know. I had to go seek it out to tell her what I needed.”

### Box 1: Key features of the citizen panels

The citizen panels on improving transition experiences for cancer survivors 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 of a comprehensive approach 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.

As a result of the limited coordination and integration post cancer treatment, many expressed concerns that there is too much reliance on survivors and their families to find their own way in the health system. Panellists gave many examples of having to coordinate care between health professionals and settings, as well as a need to become experts in navigating the system in order to integrate the different components of their care.

## Limitations in information and communication technology infrastructure create challenges for those who receive and provide care

While deliberating on the challenges to the coordination between health professionals and sectors, the majority of panellists cited limitations in information and communication technology infrastructure as one of the main barriers. Many panellists expressed frustration with the long-standing difficulties with implementing electronic health records, which would facilitate information exchange to support seamless transition and ensure that health professionals have timely, up-to-date information.

A number of panellists had professional experiences and described successful electronic information-sharing systems in other fields (for example, police and armed forces). They expressed frustration as to why such robust infrastructures can exist in some social policy domains to share sensitive data, but are not yet widely adopted in healthcare, which has similar types of privacy and security concerns.

## A siloed approach means that the range of concerns faced by cancer survivors and their families are not always identified and addressed

The majority of panellists shared experiences with the late and long-term effects of cancer treatment, such as psychological (for example, anxiety and depression) and physical (for example, dealing with scars and intimacy issues). Some panellists described feelings of isolation after cancer treatment and that the siloed approach (lack of communication and integration of care across health professionals and sectors) limited their ability to get

appropriate supports. Other panellists highlighted that the siloed approach in cancer care limits learning from other systems and cited this as a lost opportunity for efficiencies. Panellists also noted that many of the survivorship programs (for example, those offered in cancer centres and by charitable organizations) are working in isolation from each other, and that there is a need for a core program, one that teaches the basics and can be built on based on individual needs.

## Limited involvement of survivors and their families in identifying their care needs and types of supports they may require after completing cancer treatment

When discussing the transition period, panellists highlighted that this phase of the cancer journey is different for everyone. As a result, the package of supports for transitions needs to be customized based on the individual. Panellists noted that this is challenging or impossible without meaningful engagement of survivors and their families to identify these needs.

Some panellists raised the lack of follow-up after cancer treatment and that they

### **Box 2: Profile of panellists**

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 panellists:

- **How many panellists?**  
10 (Hamilton panel); 12 (Quebec City panel)
- **Where were they from?**  
Panellists came from British Columbia, Manitoba, Ontario, Quebec and Newfoundland and Labrador
- **How old were they?**  
35-49 (1), 50-64 (9), 65 and older (12)
- **Were they men, or women?**  
Men (11) and women (11)
- **Were they living in urban, suburban or rural settings?**  
Urban (13), suburban (7) and rural (2)
- **What type of non-metastatic cancer?**  
All panellists had completed cancer treatment for: breast cancer (7); colorectal cancer (1); prostate cancer (6); melanoma (6); or hematological cancer (2)
- **What was the income level of panellists?** 5% earned less than \$20,000, 23% between \$20,000 and \$34,999, 18% between \$35,000 and \$49,999, 27% between \$50,000 and \$79,999, and 9% more than \$80,000
- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panel

\* Recruitment attempted to ensure representation from cancer survivors who have completed treatment within the past three years with non-metastatic cancer (breast, colorectal cancer, prostate cancer, melanoma or hematological) and aimed for balance in terms of gender, age, socioeconomic status, ethnocultural background and location of residence (e.g., urban, rural and northern).

were not aware of their options in terms of programs and services post-treatment. One panellist summarized the challenge as, “they [survivors] are either confused or they don’t know where to go. When you get cancer, you have lost control.”

## Access to supports from primary and community care is not consistent for everyone

In deliberating on the range of primary- and community-care supports for transitions in cancer care, many panellists noted the variations in the available supports based on where they lived. Those living in rural and remote areas in particular, discussed challenges in accessing necessary supports. One panellist described restrictions to accessing needed services based on boundaries, saying that “services are not arranged around needs or efficiency, they are arranged around borders.”

## The transitions phase of the cancer journey is hard to define

Some panellists discussed challenges with defining the transition period, saying that it is not well understood by health professionals or survivors and their families. They suggested that in order to understand the transition period of the cancer journey, there needs to be a clear understanding of the entire journey, from diagnosis through treatment and beyond.

In thinking of the cancer journey, many panellists gave examples of circumstances and interactions with health professionals during initial diagnosis. It was felt that the diagnosis phase set the tone for the entire cancer journey, including the transition period. One panellist described a bad experience with their family physician (for example, significant delays in prescribing needed tests) which affected trust, and had a serious impact on their relationship with their family physician as they transitioned back to primary care after cancer treatment ended.

## Lack of clarity and comfort with terms used to refer to survivorship

The majority of panellists expressed discomfort with the terms used to refer to the survivorship phase of the cancer journey. The Hamilton panellists in particular did not like the term ‘moving on’ and felt it was not the right phrase to use. One panellist in reference to the term said, “it sounds like ‘get over it.’” This was not an issue in the Quebec City

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panel as the term used in French is the equivalent of ‘transition’. Panellists in both the panels did not like the term survivor and felt it defined them by their cancer diagnosis, which was a reminder of the trauma of the experience.

The Quebec panellists highlighted that the transition period was often influenced by the perceptions of others regarding the ‘size’ of their cancer (for example, cancer type and severity). Panellists found that comparisons in cancer type influenced their comfort with terms used to describe survivorship, as well as willingness to seek supports during transitions (for example, perceptions that some cancers are more severe than others and those with less severe cancers might be more hesitant to seek support).



"Services are not arranged around needs or efficiency, they are arranged around borders."

## **Discussing the elements:** How can we address the problem?

After discussing their views and experiences related to the problem, panellists were asked to reflect on three elements of a potentially comprehensive approach to improving transition experiences of cancer survivors in Canada:

- 1) support, train and provide organizational and system supports that enable health professionals to identify and engage survivors and families who will be transitioning after cancer treatment;
- 2) make sure funding flows appropriately to the organizations and professionals that need to support survivors and families in the transitions; and
- 3) help survivors and families learn how to manage the transition process after cancer treatment.

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 to panellists in the citizen brief that was circulated before the event.

## **Element 1** – Support, train and provide organizational and system supports that enable health professionals to identify and engage survivors and families who will be transitioning after cancer treatment

The discussion about the first element focused on ways to support health professionals to identify and help those who will be transitioning after cancer treatment. As outlined in the citizen brief, this could include strategies such as:

- engaging survivors and their families in decision-making about transition plans after cancer treatment;
- equipping health professionals and teams to identify and address the full range of survivor and family needs (for example, best-practice guidelines, professional training programs and educational opportunities); and
- creating the systems and processes to support the two bullets listed above (for example, patient-held medical records and nurse navigators).

Three main values-related themes emerged during the deliberations about element 1 across both panels: 1) building trusting relationships between survivors, health professionals and organizations within the health system; 2) facilitating collaboration among survivors, health professionals and organizations within the health system; and 3) the efficiency of the transition process. The first two values-related themes of trust and collaboration were intertwined, and panellists identified the need for health professionals to play an advisory role to introduce the concept of post-treatment realities and the supports that may be needed. Family physicians were identified as the main point of contact for transitions, but it was emphasized that survivors should have the full range of supports (for example, specialist, rehabilitation and psychological) available to them to ensure that family physicians are equipped to consult and refer to the appropriate supports. Preferences also included the use of a navigator who would provide reliable information and a central point of contact to help with system navigation.

In terms of trusting relationships between survivors and organizations within the system, panellists recognized the role of charitable organizations in providing supports during transition, and the need to ensure that access to supports was consistent across the cancer-care continuum.

The third values-related theme focused on the efficiency of the transition process. Panellists emphasized the need to strengthen the information communication technology infrastructure. Electronic health record systems were identified as essential to supporting transitions through efficiencies in sharing of patient information between health professionals. Panellists emphasized that this needs to be central to achieve efficient coordination and integration between cancer treatment and primary- and community-care supports.

**Box 3: Key messages about supporting health professionals to identify and help those who will be transitioning after primary cancer treatment (element 1)**

Three values-related themes emerged during the discussion about element 1 across both panels.

- Trusting relationships between survivors, health professionals and organizations within the system
- Collaboration among survivors, health professionals and organizations within the system
- Efficiency of the transition process, with a particular focus on the flow of information

## **Element 2** – Make sure money flows appropriately to the organizations and professionals that need to support survivors and families in the transition

The discussion focused to a lesser extent on the second element, the flow of money to organizations and professionals to support transitions. As outlined in the citizen brief, this could include:

- funding primary- and community-care organizations;
- paying health professionals involved in delivering support services for survivors and families;
- purchasing programs and services to support survivors and families through the transition after cancer treatment (for example, making changes to public-insurance plans); and
- removing potential disincentives for survivors and families that can influence whether and how they access needed primary- and community-care supports (for example, out-of-pocket payments).

It should be noted that panellists in both panels found this element most challenging during the deliberations, both in terms of the complexity of health systems and in terms of understanding the evidence.

Four values-related themes emerged during the deliberation about element 2 across the two panels. The most prominent value that emerged was related to equity, as panellists emphasized the need for consistency to ensure that all of those in need of supports had access regardless of ability to pay. Panellists in both panels emphasized that there is significant variability within and between provinces in terms of the resources available (for

### **Box 4: Key messages about ensuring the flow of funds to organizations and health professionals to support transitions (element 2)**

Four values-related themes emerged during the discussion about element 2 across both panels.

- Equity considerations to ensure that all survivors have access to services regardless of ability to pay
- Transparency and accountability in terms of funding organizations and remunerating health professionals
- Decision-making based on data and evidence in terms of the scope and nature of public-insurance plans
- Centralization versus decentralization of funding arrangements

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example, range of health professionals, programs and services, and what is covered under public-insurance plans). Preferences included improving access to personal-support workers, and that access should be integrated and equal across provinces. Panellists also discussed this in terms of ensuring equity in access for other aspects of their care, including cancer drugs. Parking costs were also raised as a disincentive to accessing needed survivorship programs and services.

The remaining three values-related themes focused on how to proceed with implementing components of this element. In making changes to funding organizations and remunerating health professionals, panellists highlighted the role of transparency and accountability and expressed concern over the feasibility of increasing costs to the health system. This was particularly salient in the Quebec context where the remuneration of physicians has been a highly debated topic in the media. Panellists also emphasized that decision-making should be based on data and evidence in terms of the scope and nature of public-insurance plans. When discussing scarcity of resources and funding arrangements, panellists felt that the needs of survivors should be prioritized before exploring the feasibility of expanding supports to family members.

There were divergent views with regards to centralization versus decentralization of funding arrangements, that is whether the funding should flow to one organization to provide oversight and care, or whether there should be distributed funding that would be based on survivor need. Some panellists thought that centralization could support greater accountability and efficiency of the health system. Other panellists expressed concerns over loss of control over specific services available locally.

## **Element 3** – Help survivors and families learn how to manage the transition process after cancer treatment

The deliberations of the third element focused on helping survivors and their families to manage the transition process after cancer treatment. As outlined in the citizen brief, this could include:

- ensuring information and education supports are available (for example, tailored informational and educational resources);
- supporting survivors with self-management skills;
- engaging survivors and their families as advisors in program and service planning; and
- engaging survivors in system monitoring and feedback to promote person-centred continuous quality improvement.

Two main values-related themes emerged during the discussion about element 3 across both panels. The first related to empowering survivors to make evidence-informed decisions supported by access to reliable information and education resources. Preferences about how to access reliable information focused on having a central access point (for example, a trusted website or a telephone line for those who do not have computer access). Moreover, panellists emphasized key groups that can play an important role in the provision of information, education and self-management, which included:

- system navigators, which links closely with element 1;
- volunteers (for example, survivors); and
- peer-to-peer support services.

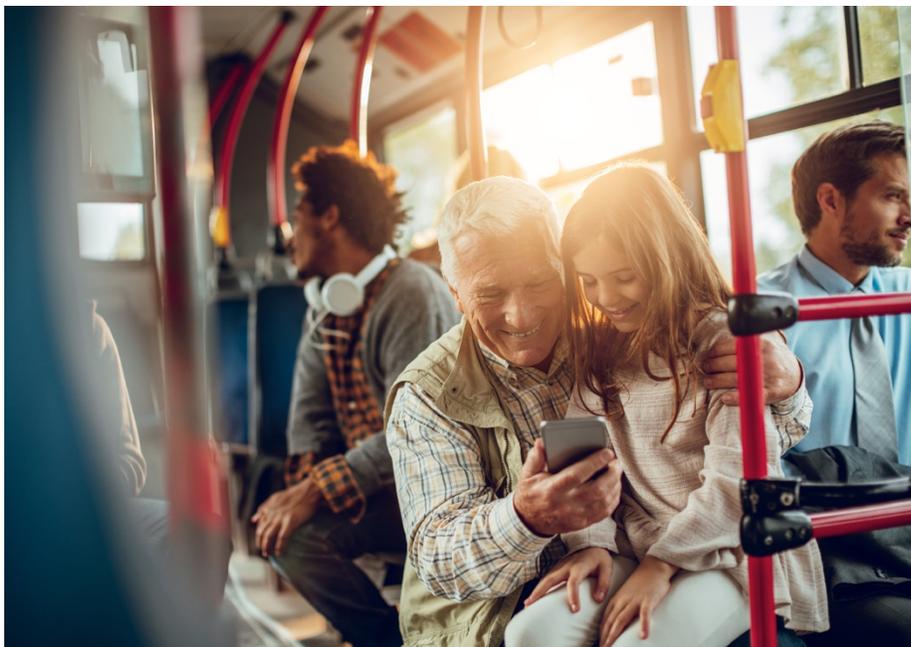
### **Box 5: Key messages about helping survivors and families learn how to manage transitions (element 3)**

Two values-related themes emerged during the discussion about element 3 across both panels.

- Empowerment to make evidence-informed decisions through access to reliable information and education supports to optimize the transition from cancer treatment to primary and community care
- Collaboration among survivors, health professionals and organizations within the health system to provide reliable information and education supports for transitions

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The second values-related theme related to enhancing collaboration and communication among survivors, health professionals and organizations within the health system, to better enable the sharing of reliable information and education supports for transitions. Related to this, preferences for implementing the element focused on the role of a case manager or ‘dispatcher’ who would facilitate the coordination between the survivor and other parts of the health system to obtain necessary information and education supports. In terms of where the case manager should be located (for example, cancer-care system or primary and community care) it was felt that the professional should be situated within the family physician’s office.



“There are more people surviving cancer and there is a real need for supports.”

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

In deliberating on the three elements, panellists identified potential barriers and facilitators to improving transition experiences of cancer survivors in Canada. The discussion generally focused on the lack of funding and political will as the most fundamental obstacle for improving transition experiences. Funding was seen as the most significant barrier both in terms of the funding needed for programs and services to support transitions, as well as pharmacare funding for supportive-care drugs to manage late and long-term effects of cancer treatment.

Despite this, panellists thought there was an opportunity to improve coordination and integration between cancer care and primary- and community-care supports. One panellist suggested learning from other areas within the health system, saying that “no need to reinvent the wheel, we need to find out what is working in other areas and apply it to cancer.” Panellists also felt that the stigma of being labelled a cancer patient has changed and it is no longer considered a death sentence. Panellists cited the growing public awareness as an opportunity to engage survivors and their families in the transition process.

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