



## Topic Overview

### Citizen Panels and Stakeholder Dialogue

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

The McMaster Health Forum convened two citizen panels on the subject of optimizing patient and family transitions from cancer treatment to primary- and community-care supports in Canada convened on 2 & 9 March 2018, followed by a stakeholder dialogue on the same subject convened on 27 March 2018, that was informed by the insights captured at the panels. The panels and dialogue were organized with the support of the Canadian Partnership Against Cancer. The panels brought together a total of 22 citizens from across Canada, and the dialogue brought together 21 participants – 6 policymakers, 7 managers (several of whom are also health professionals), 1 researcher and 7 stakeholders – from across Canada to examine the problem, elements of a potentially comprehensive approach for addressing it and key implementation considerations.

### Insights from citizens about the problem

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.

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*The views expressed in the panel summary are the views of panel participants and should not be taken to represent the views of the Canadian Partnership Against Cancer, or the authors of the panel summary.*



**A total of 22 citizens from across the country gather during McMaster Health Forum citizen panels on 2 March 2018 (Hamilton) and 9 March 2018 (Quebec City).**

*Photos include participants and McMaster Health Forum staff.*

## **Insights from citizens about the elements**

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).

## **Insights from citizens about the implementation considerations**

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.



A total of twenty-one participants drawn from government and from health, professional and research organizations gather during a McMaster Health Forum stakeholder dialogue on 27 March 2018.

*Photos include participants and McMaster Health Forum staff.*

## Stakeholders' deliberation about the problem

Dialogue participants generally agreed that the four features of the problem as outlined in the evidence brief are a helpful framing, however, they collectively suggested that five issues related to the problem warranted more attention, including that: 1) many of the difficulties survivors face when trying to get help for symptoms they experience after treatment are not specific to cancer, but common across the health system; 2) the range of supports that survivors may need after cancer treatment are often not proactively identified at important junctures in a patient's cancer journey by health professionals in their care team; 3) the expectations placed on primary-care teams to provide survivorship care may be unrealistic given that not all will have the ability (e.g., because lack of time and/or training) to provide the full range of supports needed; 4) limited information about available services and how to access them for survivors, family members and health professionals makes it challenging for them to make informed decisions; and 5) the lack of long-term health-system planning needs to be addressed given anticipated increases in the prevalence of cancer and in cancer survival.

## Stakeholders' deliberation about an approach

Dialogue participants expressed support for three main strategies to improve the survivorship experience as identified in the evidence brief: 1) provide training and information tools to help health professionals to better support survivors and families transitioning after cancer treatment; 2) align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community; and 3) provide survivors and families with reliable information and tools that can enable them to better manage their transition from treatment to survivorship.

Participants particularly emphasized the importance of having appropriate psychosocial and other supports available across the cancer journey.

## Stakeholders' deliberation about next steps (short-term)

Overall, in discussing how to move forward with these elements, participants agreed there is a need to balance a focus on short-term achievable goals with addressing harder-to-change elements that require long-term political commitments. The short-term achievable goals and next steps discussed included: 1) identifying and learning from successful survivorship models implemented across the country, including those outside of cancer care, and supporting the adoption of successful elements in health systems across Canada; 2) increasing awareness, availability and integration of existing community, cancer-system, and virtual resources to enable survivors, families and health professionals to better manage the transition from treatment to survivorship; and 3) supporting health professionals in identifying survivors having difficulty in transition (e.g., through risk-stratified discharge planning and follow-up care pathways).

## Stakeholders' deliberation about next steps (long-term)

The harder-to-change elements identified by participants included addressing broader structural issues that exist in provincial and territorial health systems more generally (e.g., enhancing timely access to primary care as well as to comprehensive and affordable home and community care), developing national standards of care for cancer which include long-term survivorship care, and changing funding models to incorporate care associated with transitions, including supports that are typically delivered in the community (e.g., psychosocial services and physiotherapy). Pursuing significant changes to funding and remuneration models was recognized as the most challenging element to address as change will require sustained political will and leadership. Participants also emphasized that models of survivorship care need to reflect the values and culture of the communities in which they are delivered.

## Panels and dialogue deliverables

To learn more about this topic, consult our complete [set of products](#), which include: the citizen brief that was presented to citizens before the panels, the evidence brief that was presented to dialogue participants before the dialogue, the summary of the panel, the summary of the dialogue, and the video interviews with dialogue participants.

Products addressing other topics are also available on our website [www.mcmasterforum.org](http://www.mcmasterforum.org). Click on 'Find evidence>Products' in the menu.